

**Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (with CD)**

Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care  
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# UNEQUAL TREATMENT

CONFRONTING RACIAL AND ETHNIC  
DISPARITIES IN HEALTH CARE

Brian D. Smedley, Adrienne Y. Stith, and  
Alan R. Nelson, Editors

Committee on Understanding and Eliminating  
Racial and Ethnic Disparities in Health Care

Board on Health Sciences Policy

INSTITUTE OF MEDICINE  
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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **HAROLD C. SOX**, Editor, *Annals of Internal Medicine*, Philadelphia, PA, appointed by the Institute of Medicine, and **ELAINE L. LARSON**, Professor of Pharmaceutical & Therapeutic Research, Columbia University School of Nursing, New York, NY. Appointed by the NRC's Report Review Committee, these individuals were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.





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Data from focus group discussions involving racial and ethnic minority healthcare consumers and healthcare providers helped to put a “human face” on the problem of disparities in care. The committee extends its gratitude to the many individuals who participated in these focus group discussions and shared their experiences, which included both positive as well as negative experiences in healthcare systems. These focus groups were convened and conducted by Westat, Inc., and a summary of the major themes is presented in Appendix D. Tim Edgar and Meredith Grady of Westat deserve special thanks for their work to convene these groups and provide a synthesis of the data.

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## Summary

### ABSTRACT

*Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients. Consistent with the charge, the study committee focused part of its analysis on the clinical encounter itself, and found evidence that stereotyping, biases, and uncertainty on the part of healthcare providers can all contribute to unequal treatment. The conditions in which many clinical encounters take place—characterized by high time pressure, cognitive complexity, and pressures for cost-containment—may enhance the likelihood that these processes will result in care poorly matched to minority patients' needs. Minorities may experience a range of other barriers to accessing care, even when insured at the same level as whites, including barriers of language, geography, and cultural familiarity. Further, financial and institutional arrangements of health systems, as well as the legal, regulatory, and policy environment in which they operate, may have disparate and negative effects on minorities' ability to attain quality care.*

*A comprehensive, multi-level strategy is needed to eliminate these disparities. Broad sectors—including healthcare providers, their patients, payors, health plan purchasers, and society at large—should be made aware of the healthcare gap between racial and ethnic groups in the United States. Health systems should*

*base decisions about resource allocation on published clinical guidelines, insure that physician financial incentives do not disproportionately burden or restrict minority patients' access to care, and take other steps to improve access—including the provision of interpretation services, where community need exists. Economic incentives should be considered for practices that improve provider-patient communication and trust, and reward appropriate screening, preventive, and evidence-based clinical care. In addition, payment systems should avoid fragmentation of health plans along socioeconomic lines.*

*The healthcare workforce and its ability to deliver quality care for racial and ethnic minorities can be improved substantially by increasing the proportion of underrepresented U.S. racial and ethnic minorities among health professionals. In addition, both patients and providers can benefit from education. Patients can benefit from culturally appropriate education programs to improve their knowledge of how to access care and their ability to participate in clinical-decision making. The greater burden of education, however, lies with providers. Cross-cultural curricula should be integrated early into the training of future healthcare providers, and practical, case-based, rigorously evaluated training should persist through practitioner continuing education programs. Finally, collection, reporting, and monitoring of patient care data by health plans and federal and state payors should be encouraged as a means to assess progress in eliminating disparities, to evaluate intervention efforts, and to assess potential civil rights violations.*

Looking gaunt but determined, 59-year-old Robert Tools was introduced on August 21, 2001, as a medical miracle—the first surviving recipient of a fully implantable artificial heart. At a news conference, Tools spoke with emotion about his second chance at life and the quality of his care. His physicians looked on with obvious affection, grateful and honored to have extended Tools' life. Mr. Tools has since lost his battle for life, but will be remembered as a hero for undergoing an experimental technology and paving the way for other patients to undergo the procedure. Moreover, the fact that Tools was African American and his doctors were white seemed, for most Americans, to symbolize the irrelevance of race in 2001. According to two recent polls, a significant majority of Americans believe that blacks like Tools receive the same quality of healthcare as whites (Lillie-Blanton et al., 2000; Morin, 2001).

Behind these perceptions, however, lies a sharply contrasting reality. A large body of published research reveals that racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than are white Americans. Relative to whites, African Americans—and in some cases, Hispanics—are less likely to receive appropriate cardiac medication (e.g., Herholz et al., 1996)

or to undergo coronary artery bypass surgery (e.g., Ayanian et al., 1993; Hannan et al., 1999; Johnson et al., 1993; Petersen et al., 2002), are less likely to receive peritoneal dialysis and kidney transplantation (e.g., Epstein et al., 2000; Barker-Cummings et al., 1995; Gaylin et al., 1993), and are likely to receive a lower quality of basic clinical services (Ayanian et al., 1999) such as intensive care (Williams et al., 1995), even when variations in such factors as insurance status, income, age, co-morbid conditions, and symptom expression are taken into account. Significantly, these differences are associated with greater mortality among African-American patients (Peterson et al., 1997; Bach et al., 1999).

### STUDY CHARGE AND COMMITTEE ASSUMPTIONS

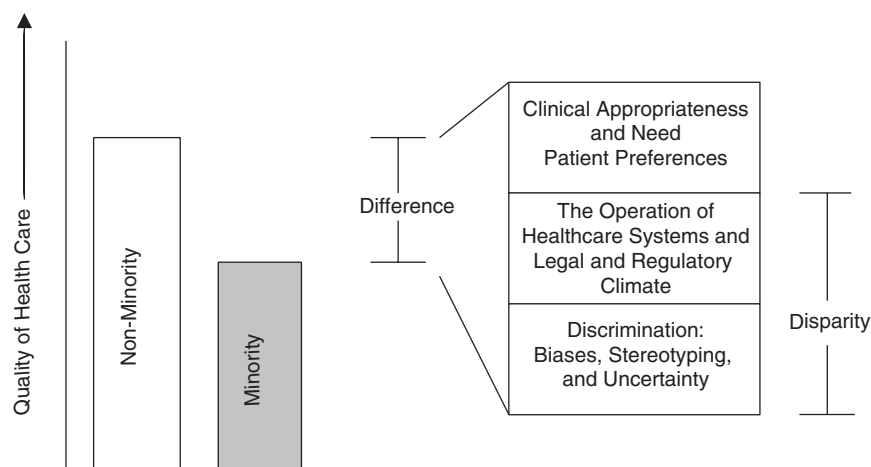
These disparities prompted Congress to request an Institute of Medicine (IOM) study to assess differences in the kinds and quality of health-care received by U.S. racial and ethnic minorities and non-minorities. Specifically, Congress requested that the IOM:

- Assess the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage);
- Evaluate potential sources of racial and ethnic disparities in health-care, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels; and,
- Provide recommendations regarding interventions to eliminate healthcare disparities.

This Executive Summary presents only abbreviated versions of the study committee's findings and recommendations. For the full findings and recommendations, and a more extensive justification of each, the reader is referred to the committee report. Below, findings and recommendations are preceded by text summarizing the evidence base from which they are drawn. For purposes of clarity, some findings and recommendations are presented in a different sequence than they appear in the full report; however, their numeric designation remains the same.

### Defining Racial and Ethnic Healthcare Disparities

The study committee defines *disparities* in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access-



**FIGURE S-1** Differences, disparities, and discrimination: Populations with equal access to healthcare. SOURCE: Gomes and McGuire, 2001.

related factors or clinical needs, preferences,<sup>1</sup> and appropriateness of intervention (Figure S-1). The committee's analysis is focused at two levels: 1) the operation of healthcare systems and the legal and regulatory climate in which health systems function; and 2) discrimination at the individual, patient-provider level. Discrimination, as the committee uses the term, refers to differences in care that result from biases, prejudices, stereotyping, and uncertainty in clinical communication and decision-making. It should be emphasized that these definitions are not legal definitions. Different sources of federal, state and international law define discrimination in varying ways, with some focusing on intent and others emphasizing disparate impact.

<sup>1</sup>The committee defines patient *preferences* as patients' choices regarding healthcare that are based on a full and accurate understanding of treatment options. As discussed in Chapter 3 of this report, patients' understanding of treatment options is often shaped by the quality and content of provider-patient communication, which in turn may be influenced by factors correlated with patients' and providers' race, ethnicity, and culture. Patient preferences that are not based on a full and accurate understanding of treatment options may therefore be a source of racial and ethnic disparities in care. The committee recognizes that patients' preferences and clinicians' presentation of clinical information and alternatives influence each other, but found separation of the two to be analytically useful.

### EVIDENCE OF HEALTHCARE DISPARITIES

Evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services. These disparities are associated with socioeconomic differences and tend to diminish significantly, and in a few cases, disappear altogether when socioeconomic factors are controlled. The majority of studies, however, find that racial and ethnic disparities remain even after adjustment for socioeconomic differences and other healthcare access-related factors (for more extensive reviews of this literature, see Kressin and Petersen, 2001; Geiger, this volume; and Mayberry, Mili, and Ofili, 2000).

Studies of racial and ethnic differences in cardiovascular care provide some of the most convincing evidence of healthcare disparities. The most rigorous studies in this area assess both potential underuse and overuse of services and appropriateness of care by controlling for disease severity using well-established clinical and diagnostic criteria (e.g., Schneider et al., 2001; Ayanian et al., 1993; Allison et al., 1996; Weitzman et al., 1997) or matched patient controls (Giles et al., 1995). Several studies, for example, have assessed differences in treatment regimen following coronary angiography, a key diagnostic procedure. These studies have demonstrated that differences in treatment are not due to clinical factors such as racial differences in the severity of coronary disease or overuse of services by whites (e.g., Schneider et al., 2001; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997). Further, racial disparities in receipt of coronary revascularization procedures are associated with higher mortality among African Americans (Peterson et al., 1997).

Healthcare disparities are also found in other disease areas. Several studies demonstrate significant racial differences in the receipt of appropriate cancer diagnostic tests (e.g., McMahon et al., 1999), treatments (e.g., Imperato et al., 1996), and analgesics (e.g., Bernabei et al., 1998), while controlling for stage of cancer at diagnosis and other clinical factors. As is the case in studies of cardiovascular disease, evidence suggests that disparities in cancer care are associated with higher death rates among minorities (Bach et al., 1999). Similarly, African Americans with HIV infection are less likely than non-minorities to receive antiretroviral therapy (Moore et al., 1994), prophylaxis for pneumocystic pneumonia, and protease inhibitors (Shapiro et al., 1999). These disparities remain even after adjusting for age, gender, education, CD4 cell count, and insurance coverage (e.g., Shapiro et al., 1999). In addition, differences in the quality of HIV care are associated with poorer survival rates among minorities, even at equivalent levels of access to care (Bennett et al., 1995; Cunningham et al., 2000).

Racial and ethnic disparities are found in a range of other disease and

health service categories, including diabetes care (e.g., Chin, Zhang, and Merrell, 1998), end-stage renal disease and kidney transplantation (e.g., Epstein et al., 2000; Kasiske, London, and Ellison, 1998; Barker-Cummings et al., 1995; Ayanian et al., 1999), pediatric care and maternal and child health, mental health, rehabilitative and nursing home services, and many surgical procedures. In some instances, minorities are *more* likely to receive certain procedures. As in the case of bilateral orchiectomy and amputation, however (which African Americans undergo at rates 2.4 and 3.6 times greater, respectively, than their white Medicare peers; Gornick et al., 1996), these are generally less desirable procedures.

**Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.**

**Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.**

**Recommendation 2-2: Increase healthcare providers' awareness of disparities.**

### RACIAL ATTITUDES AND DISCRIMINATION IN THE UNITED STATES

By way of context, it is important to note that racial and ethnic disparities are found in many sectors of American life. African Americans, Hispanics, American Indians, and Pacific Islanders, and some Asian-American subgroups are disproportionately represented in the lower socioeconomic ranks, in lower quality schools, and in poorer-paying jobs. These disparities can be traced to many factors, including historic patterns of legalized segregation and discrimination. Unfortunately, some discrimination remains. For example, audit studies of mortgage lending, housing, and employment practices using paired "testers" demonstrate persistent discrimination against African Americans and Hispanics. These studies illustrate that much of American social and economic life remains ordered by race and ethnicity, with minorities disadvantaged relative to whites. In addition, these findings suggest that minorities' experiences in the world outside of the healthcare practitioner's office are likely to affect their perceptions and responses in care settings.

**Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic**

**inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.**

### **ASSESSING POTENTIAL SOURCES OF DISPARITIES IN CARE**

The studies cited above suggest that a range of patient-level, provider-level, and system-level factors may be involved in racial and ethnic healthcare disparities, beyond access-related factors.

#### **Patient-Level Variables: The Role of Preferences, Treatment Refusal, and the Clinical Appropriateness of Care**

Racial and ethnic disparities in care may emerge, at least in part, from a number of patient-level attributes. For example, minority patients are more likely to refuse recommended services (e.g., Sedlis et al., 1997), adhere poorly to treatment regimens, and delay seeking care (e.g., Mitchell and McCormack, 1997). These behaviors and attitudes can develop as a result of a poor cultural match between minority patients and their providers, mistrust, misunderstanding of provider instructions, poor prior interactions with healthcare systems, or simply from a lack of knowledge of how to best use healthcare services. However, racial and ethnic differences in patient preferences and care-seeking behaviors and attitudes are unlikely to be major sources of healthcare disparities. For example, while minority patients have been found to refuse recommended treatment more often than whites, differences in refusal rates are small and have not fully accounted for racial and ethnic disparities in receipt of treatments (Hannan et al., 1999; Ayanian et al., 1999). Overuse of some clinical services (i.e., use of services when not clinically indicated) may be more common among white than minority patients, and may contribute to racial and ethnic differences in discretionary procedures. Several recent studies, however, have assessed racial differences relative to established criteria (Hannan et al., 1999; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997) or objective diagnostic information, and still find racial differences in receipt of care. Other studies find that overuse of cardiovascular services among whites does not explain racial differences in service use (Schneider et al., 2001).

Finally, some researchers have speculated that biologically based racial differences in clinical presentation or response to treatment may justify racial differences in the type and intensity of care provided. For example, racial and ethnic group differences are found in response to drug therapies such as enalapril, an angiotensin-converting-enzyme inhibitor used to reduce the risk of heart failure (Exner et al., 2001). These differ-



ences in response to drug therapy, however, are not due to “race” *per se* but can be traced to differences in the distribution of polymorphic traits between population groups (Wood, 2001), and are small in relation to the common benefits of most therapeutic interventions. Further, as noted above, the majority of studies document disparities in healthcare services and disease areas when interventions are equally effective across population groups—making the “racial differences” hypothesis an unlikely explanation for observed disparities in care.

**Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.**

#### Healthcare Systems-Level Factors

Aspects of health systems—such as the ways in which systems are organized and financed, and the availability of services—may exert different effects on patient care, particularly for racial and ethnic minorities. Language barriers, for example, pose a problem for many patients where health systems lack the resources, knowledge, or institutional priority to provide interpretation and translation services. Nearly 14 million Americans are not proficient in English, and as many as one in five Spanish-speaking Latinos reports not seeking medical care due to language barriers (The Robert Wood Johnson Foundation, 2001). Similarly, time pressures on physicians may hamper their ability to accurately assess presenting symptoms of minority patients, especially where cultural or linguistic barriers are present. Further, the geographic availability of healthcare institutions—while largely influenced by economic factors that are outside the charge of this study—may have a differential impact on racial and ethnic minorities, independent of insurance status (Kahn et al., 1994). A study of the availability of opioid supplies, for example, revealed that only one in four pharmacies located in predominantly non-white neighborhoods carried adequate supplies, compared with 72% of pharmacies in predominantly white neighborhoods (Morrison et al., 2000). Perhaps more significantly, changes in the financing and delivery of healthcare services—such as the shifts brought by cost-control efforts and the movement to managed care—may pose greater barriers to care for racial and ethnic minorities than for non-minorities (Rice, this volume). Increasing efforts by states to enroll Medicaid patients in managed care systems, for example, may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic

minority communities (Leigh, Lillie-Blanton, Martinez, and Collins, 1999). In addition, research indicates that minorities enrolled in publicly funded managed care plans are less likely to access services after mandatory enrollment in an HMO, compared with whites and other minorities enrolled in non-managed care plans (Tai-Seale et al., 2001).

### **Care Process-Level Variables: The Role of Bias, Stereotyping, Uncertainty**

Three mechanisms might be operative in healthcare disparities from the provider's side of the exchange: bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) held by the provider about the behavior or health of minorities (Balsa and McGuire, 2001). Patients might also react to providers' behavior associated with these practices in a way that also contributes to disparities. Unfortunately, little research has been conducted to elucidate how patient race or ethnicity may influence physician decision-making and how these influences affect the quality of care provided. In the absence of such research, the study committee drew upon a mix of theory and relevant research to understand how clinical uncertainty, biases or stereotypes, and prejudice might operate in the clinical encounter.

#### *Clinical Uncertainty*

Any degree of uncertainty a physician may have relative to the condition of a patient can contribute to disparities in treatment. Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g., race). The doctor can therefore be viewed as operating with prior beliefs about the likelihood of patients' conditions, "priors" that will be different according to age, gender, socioeconomic status, and race or ethnicity. When these priors—which are taught as a cognitive heuristic to medical students—are considered alongside the information gained in a clinical encounter, both influence medical decisions.

Doctors must balance new information gained from the patient (sometimes with varying levels of accuracy) and their prior expectations about the patient to determine the diagnosis and course of treatment. If the physician has difficulty accurately understanding the symptoms or is less sure of the "signal"—the set of clues and indications that physicians rely upon to make diagnostic decisions—then he or she is likely to place greater weight on the "priors." The consequence is that treatment decisions and patients' needs are potentially less well matched.

### *The Implicit Nature of Stereotypes*

A large body of research in psychology has explored how stereotypes evolve, persist, shape expectations, and affect interpersonal interactions. Stereotyping can be defined as the process by which people use social categories (e.g., race, sex) in acquiring, processing, and recalling information about others. The beliefs (stereotypes) and general orientations (attitudes) that people bring to their interactions help to organize and simplify complex or uncertain situations and give perceivers greater confidence in their ability to understand a situation and respond in efficient and effective ways (Mackie, Hamilton, Susskind, and Rosselli, 1996).

Although functional, social stereotypes and attitudes also tend to be systematically biased. These biases may exist in overt, explicit forms, as represented by traditional bigotry. However, because their origins arise from virtually universal social categorization processes, they may also exist, often unconsciously, among people who strongly endorse egalitarian principles and truly believe that they are not prejudiced (Dovidio and Gaertner, 1998). In the United States, because of shared socialization influences, there is considerable empirical evidence that even well-meaning whites who are not overtly biased and who do not believe that they are prejudiced typically demonstrate unconscious implicit negative racial attitudes and stereotypes (Dovidio, Brigham, Johnson, and Gaertner, 1996). Both implicit and explicit stereotypes significantly shape interpersonal interactions, influencing how information is recalled and guiding expectations and inferences in systematic ways. They can also produce self-fulfilling prophecies in social interaction, in that the stereotypes of the perceiver influence the interaction with others in ways that conform to stereotypical expectations (Jussim, 1991).

### *Healthcare Provider Prejudice or Bias*

Prejudice is defined in psychology as an unjustified negative attitude based on a person's group membership (Dovidio et al., 1996). Survey research suggests that among white Americans, prejudicial attitudes toward minorities remain more common than not, as over half to three-quarters believe that relative to whites, minorities—particularly African Americans—are less intelligent, more prone to violence, and prefer to live off of welfare (Bobo, 2001). It is reasonable to assume, however, that the vast majority of healthcare providers find prejudice morally abhorrent and at odds with their professional values. But healthcare providers, like other members of society, may not recognize manifestations of prejudice in their own behavior.

While there is no direct evidence that provider biases affect the qual-

ity of care for minority patients, research suggests that healthcare providers' diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients' race or ethnicity. Schulman et al. (1999), for example, found that physicians referred white male, black male, and white female hypothetical "patients" (actually videotaped actors who displayed the same symptoms of cardiac disease) for cardiac catheterization at the same rates (approximately 90% for each group), but were significantly less likely to recommend catheterization procedures for black female patients exhibiting the same symptoms. Weisse et al. (2001), using a similar methodology as that of Schulman, found that male physicians prescribed twice the level of analgesic medication for white "patients" than for black "patients." Female physicians, in contrast, prescribed higher doses of analgesics for black than for white "patients," suggesting that male and female physicians may respond differently to gender and/or racial cues. In another experimental design, Abreu (1999) found that mental health professionals subliminally "primed" with African American stereotype-laden words were more likely to evaluate the same hypothetical patient (whose race was not identified) more negatively than when primed with neutral words. And in a study based on actual clinical encounters, van Ryn and Burke (2000) found that doctors rated black patients as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice, more likely to lack social support, and less likely to participate in cardiac rehabilitation than white patients, even after patients' income, education, and personality characteristics were taken into account. These findings suggest that while the relationship between race or ethnicity and treatment decisions is complex and may also be influenced by gender, providers' perceptions and attitudes toward patients are influenced by patient race or ethnicity, often in subtle ways.

#### *Medical Decisions Under Time Pressure with Limited Information*

Studies suggest that several characteristics of the clinical encounter increase the likelihood that stereotypes, prejudice, or uncertainty may influence the quality of care for minorities (van Ryn, 2002). In the process of care, health professionals must come to judgments about patients' conditions and make decisions about treatment, often without complete and accurate information. In most cases, they must do so under severe time pressure and resource constraints. The assembly and use of these data are affected by many influences, including various "gestalts" or cognitive shortcuts. In fact, physicians are commonly trained to rely on clusters of information that functionally resemble the application of "prototypic" or

stereotypic constellations. These conditions of time pressure, resource constraints, and the need to rely on gestalts map closely onto those factors identified by social psychologists as likely to produce negative outcomes due to lack of information, to stereotypes, and to biases (van Ryn, 2002).

*Patient Response: Mistrust and Refusal*

As noted above, the responses of racial and ethnic minority patients to healthcare providers are also a potential source of disparities. Little research has been conducted as to how patients may influence the clinical encounter. It is reasonable to speculate, however, that if patients convey mistrust, refuse treatment, or comply poorly with treatment, providers may become less engaged in the treatment process, and patients are less likely to be provided with more vigorous treatments and services. But these kinds of reactions from minority patients may be understandable as a response to negative racial experiences in other contexts, or to real or perceived mistreatment by providers. Survey research, for example, indicates that minority patients perceive higher levels of racial discrimination in healthcare than non-minorities (LaVeist, Nickerson, and Bowie, 2000; Lillie-Blanton et al., 2000). Patients' and providers' behavior and attitudes may therefore influence each other reciprocally, but reflect the attitudes, expectations, and perceptions that each has developed in a context where race and ethnicity are often more salient than these participants are even aware of. In addition, it is clear that the healthcare provider, rather than the patient, is the more powerful actor in clinical encounters. Providers' expectations, beliefs, attitudes, and behaviors are therefore likely to be a more important target for intervention efforts.

**Finding 3-1: Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.**

**Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.**

## INTERVENTIONS TO ELIMINATE RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE

### Legal, Regulatory, and Policy Interventions

#### *“De-Fragmentation” of Healthcare Financing and Delivery*

Racial and ethnic minorities are more likely than whites to be enrolled in “lower-end” health plans, which are characterized by higher per capita resource constraints and stricter limits on covered services (Phillips et al., 2000). The disproportionate presence of racial and ethnic minorities in lower-end health plans is a potential source of healthcare disparities, given that efforts to control for insurance status in studies of healthcare disparities have not taken detailed account of variations among health plans. Such socioeconomic fragmentation of health plans engenders different clinical cultures, with different practice norms, tied to varying per capita resource constraints (Bloche, 2001).

Equalizing access to high-quality plans can limit such fragmentation. Public healthcare payors such as Medicaid should strive to help beneficiaries access the same health products as privately-insured patients. This recommendation is also reflected in the IOM *Quality Chasm* report’s strategies for focusing health systems on quality, in its call to “eliminate or modify payment practices that fragment the care system” (IOM, 2001, p. 13).

#### **Recommendation 5-1: Avoid fragmentation of health plans along socioeconomic lines.**

#### *Strengthening Doctor-Patient Relationships*

Several lines of research suggest that the consistency and stability of the doctor-patient relationship is an important determinant of patient satisfaction and access to care. Having a usual source of care is associated, for example, with use of preventive care services (Agency for Healthcare Research and Quality, 2001). In addition, having a consistent relationship with a primary care provider may help to address minority patient mistrust of healthcare systems and providers, particularly if the relationship is with a provider who is able to bridge cultural and linguistic gaps (LaViest, Nickerson, and Bowie, 2000). Minority patients, however, are less likely to enjoy a consistent relationship with a provider, even when insured at the same levels as white patients (Lillie-Blanton, Martinez, and Salganicoff, 2001). This is due in part to the types of health systems in

which they are enrolled and the relative lack of providers located in minority communities.

Health systems should attempt to ensure that every patient, whether insured privately or publicly, has a sustained relationship with an attending physician able to help the patient effectively navigate the healthcare bureaucracy. Federal and state performance standards for Medicaid managed care plans, for example, should include guidelines to ensure the stability of patients' assignments to primary care providers (and these providers' accessibility), reasonable patient loads per primary care physician, and time allotments for patient visits.

**Recommendation 5-2: Strengthen the stability of patient-provider relationships in publicly funded health plans.**

Patient and provider relationships will also be strengthened by greater racial and ethnic diversity in the health professions. Racial concordance of patient and provider is associated with greater patient participation in care processes, higher patient satisfaction, and greater adherence to treatment (Cooper-Patrick et al., 1999). In addition, racial and ethnic minority providers are more likely than their non-minority colleagues to serve in minority and medically underserved communities (Komaromy et al., 1996). The benefits of diversity in health professions fields are significant, and illustrate that a continued commitment to affirmative action is necessary for graduate health professions education programs, residency recruitment, and other professional opportunities.

**Recommendation 5-3: Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.**

*Patient Protections*

Much of the political focus on Capitol Hill in the summer of 2001 was devoted to managed care regulation. To one extent or another, the various bills debated would all extend protections to enrollees in private managed care organizations, providing avenues for appeal of care denial decisions, improving access to specialty care, requiring health plans to disclose information about coverage, banning physician "gag" clauses, and providing other legal remedies to resolve disputes. Publicly funded health plans, however, are not addressed in these legislative proposals. Given that many minorities are disproportionately represented among the publicly insured who receive care within managed care organizations, the same patient protections that apply to the privately insured should apply to those in publicly funded plans (Hashimoto, 2001).

**Recommendation 5-4: Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.**

*Civil Rights Enforcement*

Enforcement of regulation and statute is also an important component of a comprehensive strategy to address healthcare disparities, but unfortunately has been too often relegated to low-priority status. The U.S. DHHS Office of Civil Rights (OCR) is charged with enforcing several relevant federal statutes and regulations that prohibit discrimination in healthcare (principally Title VI of the 1964 Civil Rights Act). The agency, however, has suffered from insufficient resources to investigate complaints of possible violations, and has long abandoned proactive, investigative strategies (Smith, 1999). Complaints to the agency declined in the early 1990s, but have increased in recent years, while funding has remained level in terms of appropriated dollars but lower in terms of spending power after adjusting for inflation (U.S. Commission on Civil Rights, 2001). The agency should be equipped with sufficient resources to better address these complaints and carry out its oversight responsibilities.

**Recommendation 5-5: Provide greater resources to the U.S. DHHS Office for Civil Rights to enforce civil rights laws.**

**Health Systems Interventions**

A variety of interventions applied at the level of health systems may be effective as a part of a comprehensive, multi-level strategy to address racial and ethnic disparities in healthcare.

*Evidence-Based Cost Control*

In the current era of continually escalating healthcare costs, cost containment is an important goal of all health systems. To the extent possible, however, medical limit setting by health plans should be based on evidence of effectiveness. The application of evidence to healthcare delivery, such as through the use of evidence-based guidelines, can help to address the problem of potential underuse of services resulting from capitation or per case payment methods, as noted in the IOM *Quality Chasm* report (IOM, 2001). Evidence-based guidelines offer the advantages of consistency, predictability, and objectivity that general, discretionary advisory statements do not. In addition, because evidence-based guidelines



and standards directly promote accountability, they also indirectly affect equity of care.

In actual practice, however, a pragmatic balance must be sought between the advantages and limitations of guidelines, such as the tension between the goal of standardization versus the need for clinical flexibility. Disclosing health plans' clinical protocols offers one means of achieving this balance, as it would aid both private sector and public efforts in balancing the virtues of rules and discretion. To achieve this, private accrediting entities and state regulatory bodies could require that health plans publish their clinical practice protocols, along with supporting evidence, thereby opening these protocols to professional and consumer review (Bloche, 2001).

**Recommendation 5-6: Promote the consistency and equity of care through the use of evidence-based guidelines.**

*Financial Incentives in Healthcare*

Financial factors, such as capitation and health plan incentives to providers to practice frugally, can pose greater barriers to racial and ethnic minority patients than to white patients, even among patients insured at the same level. Low payment rates limit the supply of physician (and other healthcare provider) services to low-income groups, disproportionately affecting ethnic minorities (Rice, this volume). Inadequate supply takes the form of too few providers participating in plans serving the poor, and provider unwillingness to spend adequate time with patients. This time pressure may contribute to poor information exchange between physicians and members of minority groups.

If appropriately crafted, however, financial incentives to physicians can serve a positive role in efforts to reduce disparities in care. Economic rewards for time spent engaging patients and their families can help physicians to overcome barriers of culture, communication, and empathy. In addition, incentives that encourage physicians to adhere to evidence-based protocols for frugal practice and to engage in age- and gender-appropriate disease screening can promote efficient, quality care and penalize deviations, regardless of race or ethnicity. Further, financial incentives linked to favorable clinical outcomes, where reasonably measurable (e.g. control of diabetes, asthma, and high blood pressure) can also promote equity of care (Bloche, 2001). Again, this recommendation is consistent with the IOM *Quality Chasm* report, which calls for healthcare organizations, clinicians, purchasers, and other stakeholders to "align the incentives inherent in payment and accountability processes with the goal of quality improvement" (IOM, 2001, p.10).

**Recommendation 5-7: Structure payment systems to ensure an adequate supply of services to minority patients and limit provider incentives that may promote disparities.**

**Recommendation 5-8: Enhance patient-provider communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.**

#### *Interpretation Services*

As noted above, many racial and ethnic minorities find that language barriers pose a significant problem in their efforts to access healthcare. Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision making, or ethical compromises (e.g., difficulty obtaining informed consent; Woloshin et al., 1995). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance (Manson, 1988), and decreased satisfaction with services (Carrasquillo et al., 1999; David and Rhee, 1998; Derose and Baker, 2000).

Broader use of professional interpretation services has been hampered by a number of logistical and resource constraints. For example, in some regions of the country, few trained professional interpreters are available, and reimbursement for interpretation services via publicly funded insurance such as Medicaid is often inadequate. Greater resources are needed to support professional interpretation services, and more research and innovation should identify effective means to harness new technologies (e.g., simultaneous telephone interpretation) to aid interpretation.

**Recommendation 5-9: Support the use of interpretation services where community need exists.**

#### *Community Health Workers*

Community health workers—often termed lay health advisors, neighborhood workers, indigenous health workers, health aides, *consejera*, or *promotora*—fulfill multiple functions in helping to improve access to healthcare. Community health workers can serve as liaisons between patients and providers, educate providers about community needs and the culture of the community, provide patient education, contribute to continuity and coordination of care, assist in appointment attendance and adherence to medication regimens, and help to increase the use of preventive and primary care services (Brownstein et al., 1992; Earp and Flax,

1999; Jackson and Parks, 1997). In addition, some evidence suggests that lay health workers can help improve the quality of care and reduce costs (Witmer et al., 1995), and improve general wellness by facilitating community access to and negotiation for services (Rodney et al., 1998).

**Recommendation 5-10: Support the use of community health workers.**

*Multidisciplinary Teams*

Research demonstrates that multidisciplinary team approaches—including physicians, nurses, dietitians, and social workers, among others—can effectively optimize patient care. This effect is found in randomized controlled studies of patients with coronary heart disease, hypertension, and other diseases, and has extended to strategies for reducing risk behaviors and conditions such as smoking, sedentary lifestyle and obesity (Hill and Miller, 1996). Multidisciplinary teams coordinate and streamline care, enhance patient adherence through follow-up techniques, and address the multiple behavioral and social risks faced by patients. These teams may save costs and improve the efficiency of care by reducing the need for face-to-face physician visits and improve patients' day-to-day care between visits. Further, such strategies have proven effective in improving health outcomes of minorities previously viewed as "difficult to serve" (Hill and Miller, 1996). Multidisciplinary team approaches should be more widely instituted as strategy for improving care delivery, implementing secondary prevention strategies, and enhancing risk reduction.

**Recommendation 5-11: Implement multidisciplinary treatment and preventive care teams.**

**Patient Education and Empowerment**

Increasingly, researchers are recognizing the important role of patients as active participants in clinical encounters (Korsch, 1984). Patient education efforts have taken many forms, including the use of books and pamphlets, in-person instruction, CD-ROM-based educational materials, and internet-based information. These materials guide patients through typical office visits and provide information about asking appropriate questions and having their questions answered, communicating with the provider when instructions are not understood or cannot be followed, and being an active participant in decision-making. While evaluation data are limited, particularly with respect to racial and ethnic minority patients, preliminary evidence suggests that patient education can improve pa-

tients' skills and knowledge of clinical encounters and improve their participation in care decisions.

**Recommendation 5-12: Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.**

### Cross-Cultural Education in the Health Professions

Given the increasing racial and ethnic diversity of the U.S. population, the development and implementation of training programs for healthcare providers offers promise as a key intervention strategy in reducing healthcare disparities. As a result, cross-cultural education programs have been developed to enhance health professionals' awareness of how cultural and social factors influence healthcare, while providing methods to obtain, negotiate and manage this information clinically once it is obtained. Cross-cultural education can be divided into three conceptual approaches focusing on *attitudes* (cultural sensitivity/awareness approach), *knowledge* (multicultural/categorical approach), and *skills* (cross-cultural approach), and has been taught using a variety of interactive and experiential methodologies. Research to date demonstrates that training

#### Summary of Findings

**Finding 1-1:** Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.

**Finding 2-1:** Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

**Finding 3-1:** Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.

**Finding 4-1:** Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.

**Finding 4-2:** A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

### Summary of Recommendations

#### General Recommendations

**Recommendation 2-1:** Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.

**Recommendation 2-2:** Increase healthcare providers' awareness of disparities.

#### Legal, Regulatory, and Policy Interventions

**Recommendation 5-1:** Avoid fragmentation of health plans along socioeconomic lines.

**Recommendation 5-2:** Strengthen the stability of patient-provider relationships in publicly funded health plans.

**Recommendation 5-3:** Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.

**Recommendation 5-4:** Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.

**Recommendation 5-5:** Provide greater resources to the U.S. DHHS Office for Civil Rights to enforce civil rights laws.

#### Health Systems Interventions

**Recommendation 5-6:** Promote the consistency and equity of care through the use of evidence-based guidelines.

**Recommendation 5-7:** Structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities.

**Recommendation 5-8:** Enhance patient-provided communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.

**Recommendation 5-9:** Support the use of interpretation services where community need exists.

is effective in improving provider knowledge of cultural and behavioral aspects of healthcare and building effective communication strategies. Despite progress in the field, however, several challenges exist, including the need to define educational core competencies, reach consensus on approaches and methodologies, determine methods of integration into the medical and nursing curriculum, and develop and implement appropriate evaluation strategies. These challenges should be addressed to realize the potential of cross-cultural education strategies.

**Recommendation 6-1: Integrate cross-cultural education into the training of all current and future health professionals.**

**Recommendation 5-10:** Support the use of community health workers.

**Recommendation 5-11:** Implement multidisciplinary treatment and preventive care teams.

**Patient Education and Empowerment**

**Recommendation 5-12:** Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.

**Cross-Cultural Education in the Health Professions**

**Recommendation 6-1:** Integrate cross-cultural education into the training of all current and future health professionals.

**Data Collection and Monitoring**

**Recommendation 7-1:** Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.

**Recommendation 7-2:** Include measures of racial and ethnic disparities in performance measurement.

**Recommendation 7-3:** Monitor progress toward the elimination of healthcare disparities.

**Recommendation 7-4:** Report racial and ethnic data by OMB categories, but use subpopulation groups where possible.

**Research Needs**

**Recommendation 8-1:** Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.

**Recommendation 8-2:** Conduct research on ethical issues and other barriers to eliminating disparities.

**DATA COLLECTION AND MONITORING**

Standardized data collection is critically important in the effort to understand and eliminate racial and ethnic disparities in healthcare. Data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities, help health plans to monitor performance, ensure accountability to enrolled members and payors, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. Federal and state-supported data collection

efforts are scattered and unsystematic, and many health plans, with a few notable exceptions, do not collect data on enrollees' race, ethnicity, or primary language.

A number of ethical, logistical, and fiscal concerns present challenges to data collection and monitoring, including the need to protect patient privacy, the costs of data collection, and resistance from healthcare providers, institutions, plans and patients. In addition, health plans have raised significant concerns about how such data will be analyzed and reported. The challenges to data collection should be addressed, as the costs of failing to assess racial and ethnic disparities in care may outweigh new burdens imposed by data collection and analysis efforts.

**Recommendation 7-1: Collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.**

**Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.**

**Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.**

**Recommendation 7-4: Report racial and ethnic data by federally defined categories, but use subpopulation groups where possible.**

#### NEEDED RESEARCH

While the literature that the committee reviewed provides significant evidence of racial and ethnic disparities in care, the evidence base from which to better understand and eliminate disparities in care remains less than clear. Several broad areas of research are needed to clarify how race and ethnicity are associated with disparities in the process, structure, and outcomes of care. Research must provide a better understanding of the contribution of patient, provider, and institutional characteristics on the quality of care for minorities. Research has been notably absent in other areas. More research is needed, for example, to understand the extent of disparities in care faced by Asian-American, Pacific-Islander, American Indian and Alaska Native, and Hispanic populations, and to better understand and surmount barriers to research on healthcare disparities, including those related to ethical issues in data collection.

**Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.**

**Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.**

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# 1

## Introduction and Literature Review

Despite steady improvement in the overall health of the U.S. population, racial and ethnic minorities, with few exceptions, experience higher rates of morbidity and mortality than non-minorities. African Americans, for example, experience the highest rates of mortality from heart disease, cancer, cerebrovascular disease, and HIV/AIDS than any other U.S. racial or ethnic group. American Indians disproportionately die from diabetes, liver disease and cirrhosis, and unintentional injuries. Hispanic Americans are almost twice as likely as non-Hispanic whites to die from diabetes. In addition, some Asian-American subpopulations experience rates of stomach, liver, and cervical cancers that are well above national averages. The reasons for these health status disparities are complex and poorly understood, but may largely reflect socioeconomic differences, differences in health-related risk factors, environmental degradation, and direct and indirect consequences of discrimination (Williams, 1999).

Differences in access to healthcare are also likely to play a role in these health disparities. Hispanics, Asian Americans, American Indians and Alaska Natives, and African Americans are less likely than whites to have health insurance, have more difficulty getting healthcare, and have fewer choices in where to receive care. Hispanic and African-American patients are also more likely to receive care in hospital emergency rooms, and are less likely than whites to have a regular primary care provider (Collins, Hall, and Neuhaus, 1999).

Concern is growing, however, that even at equivalent levels of access to care, racial and ethnic minorities experience a lower quality of health services and are less likely to receive even routine medical procedures

than white Americans. For example, relative to whites, African Americans and Hispanics are less likely to receive appropriate cardiac medication (e.g., thrombolytic therapy, aspirin and beta blockers) or to undergo coronary artery bypass surgery, even when variations in such factors as insurance status, income, age, co-morbid conditions, and symptom expression are taken into account (Ayanian et al., 1993; Hannan et al., 1999; Ramsey et al., 1997; Johnson et al., 1993; Canto et al., 2000). African Americans with end-stage renal disease are less likely to receive peritoneal dialysis and kidney transplantation (Kasiske, London, and Ellison, 1998; Barker-Cummings, McClellan, Soucie, and Krisher, 1995; Gaylin et al., 1993), and African-American and Hispanic patients with bone fractures seen in hospital emergency departments are less likely than whites to receive analgesia (Todd et al., 2000; Todd, Samaroo, and Hoffman, 1993). In terms of quality of care, a recent study of Medicare patients revealed that African-American patients with congestive heart failure or pneumonia received poorer quality care than whites, using explicit process criteria and implicit review by physicians (Ayanian, Weissman, Chasen-Taber, and Epstein, 1999). Further, these differences are associated with greater mortality among African-American patients (Peterson et al., 1997).

#### STUDY CHARGE AND COMMITTEE ASSUMPTIONS

These disparities prompted Congress in 1999 to request an Institute of Medicine (IOM) study to assess disparities in the kinds and quality of healthcare received by U.S. racial and ethnic minorities and non-minorities. Specifically, Congress requested that the IOM:

- Assess the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage);
- Evaluate potential sources of racial and ethnic disparities in healthcare, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels; and
- Provide recommendations regarding interventions to eliminate healthcare disparities.

In its interpretation of the charge, the study committee assumes responsibility for assessing variation in the quality of healthcare services provided to individuals of different racial and ethnic backgrounds, independently of patients' insurance status, education, income, or other factors that are known to affect access to care. This is a somewhat artificial and difficult distinction, as many access-related factors, such as the type

of health insurance coverage that healthcare consumers purchase or are provided, as well as their level of education and other unmeasured aspects of socioeconomic status (e.g., assertiveness in seeking care) significantly affect the quality and intensity of healthcare that they receive, and are highly correlated with race and ethnicity. The relationship of these variables to healthcare quality is therefore highlighted where appropriate in this report. For purposes of addressing the study charge, however, the committee's focus extends only to the direct and indirect effects of race and ethnicity in the process, structure, and outcomes of healthcare.

Further, the committee assumes that *healthcare* refers to the continuum of services provided in traditional healthcare settings—including public and private clinics, hospitals, community health centers, nursing homes, and other healthcare facilities—as well as home-based care. These include services provided by a range of healthcare professionals, including physicians, nurses, physician assistants, psychologists, and other licensed professionals. The term *healthcare services* refers to the provision of preventive, diagnostic, rehabilitative and/or therapeutic medical or health services to individuals or populations. *Quality of care* refers to the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. These definitions, and their interrelationship, are best summarized in the 1999 IOM report, *Measuring the Quality of Health Care*:

The IOM stated . . . that “quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (IOM, 1990, p. 21). This definition has been widely accepted and has proven to be a robust and useful reference in the formulation of practical approaches to quality assessment and improvement (Blumenthal, 1996). Several ideas in this definition deserve elaboration.

The term *health services* refers to a wide array of services that affect health, including those for physical and mental illnesses. Furthermore, the definition applies to many types of healthcare practitioners (physicians, nurses, and various other health professionals) and to all settings of care (from hospitals and nursing homes to physicians' offices, community sites, and even private homes). . . .

The inclusion in the definition of both *populations* and *individuals* draws attention to the different perspectives that need to be addressed. On the one hand, there is concern with the quality of care that individual organizations, health plans, and clinicians deliver. On the other hand, attention must be paid to the quality of care across the entire system. In particular, one must ask whether all parts of the population have access to needed and appropriate services, whether services meet or exceed their expectations, and whether their health status is improving. That focus embraces all groups, whether or not they have access to care and whether they are



defined by cultural heritage, sociodemographic characteristics, geography (e.g., a state or a region), or diagnosis. It recognizes that such individuals will include the most vulnerable, whether the source of vulnerability is economic, the rarity or severity of the health problem, physical frailty, or physical or emotional impairment. (Institute of Medicine, 1999a; emphasis in text).

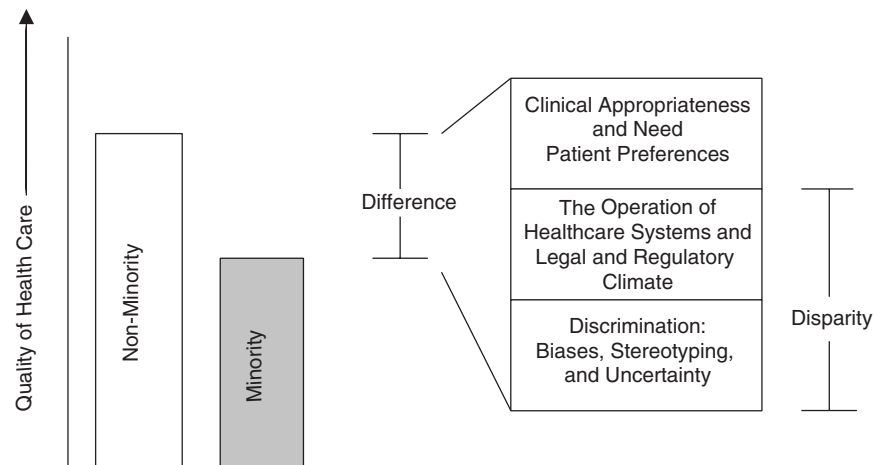
The study committee defines *disparities* in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences,<sup>1</sup> and appropriateness of intervention (Figure 1-1). The committee's analysis is focused at two levels: 1) the operation of healthcare systems and the legal and regulatory climate in which health systems function; and 2) discrimination at the individual, patient-provider level. Discrimination, as the committee uses the term, refers to differences in care that result from biases, prejudices, stereotyping, and uncertainty in clinical communication and decision-making. It should be emphasized that these definitions are not legal definitions. Different sources of federal, state and international law define discrimination in varying ways, some focusing on intent and others emphasizing disparate impact.

Finally, in defining *racial and ethnic minority groups*, the committee uses the definitions provided by the federal Office of Management and Budget in its proposed Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (Office of Management and Budget, 2001). The revised standards (see Box 1-1) establish five categories for "racial" groups (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, and White), and two categories for "ethnic" groups (Hispanic or Latino and Not Hispanic or Latino).<sup>2</sup> It should be noted that these definitions have been subject to considerable criticism, including:

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<sup>1</sup>The committee defines patient *preferences* as patients' choices regarding healthcare that are based on a full and accurate understanding of treatment options. As discussed in Chapter 3 of this report, patients' understanding of treatment options is often shaped by the quality and content of provider-patient communication, which in turn may be influenced by factors correlated with patients' and providers' race, ethnicity, and culture. Patient preferences that are not based on a full and accurate understanding of treatment options may therefore be a source of racial and ethnic disparities in care. The committee recognizes that patients' preferences and clinicians' presentation of clinical information and alternatives influence each other, but found separation of the two to be analytically useful.

<sup>2</sup>Consistent with the OMB classification scheme, the terms "African American" and "black" are used interchangeably throughout this report, as are the terms "Hispanic" and "Latino."



**FIGURE 1-1** Differences, disparities, and discrimination: Populations with equal access to healthcare. SOURCE: Gomes and McGuire, 2001.

- reinforcement of the concept of “race” as reflecting genetic or biologic differences between population groups;
- failure to reflect the fluid and dynamic nature of sociopolitical identity, and
- failure to reflect the way many Americans choose to define themselves (Institute of Medicine, 1999b).

Nonetheless, the committee adopts these racial and ethnic definitions because they are commonly accepted among researchers, and most federally funded research utilizes these terms. Further, as will be noted below, access to and the allocation of healthcare resources differ with striking consistency across these population groups, making them useful in tracking disparities in care.

To summarize, racial and ethnic minorities are less likely than whites to possess health insurance (Collins, Hall, and Neuhaus, 1999), are more likely to be beneficiaries of publicly funded health insurance (e.g., Medicaid [The Henry J. Kaiser Family Foundation, 2000b]), and even when insured, may face additional barriers to care due to other socioeconomic factors, such as high co-payments, geographic factors (e.g., the relative scarcity of healthcare providers and healthcare facilities in minority communities), and insufficient transportation. These access-related factors are likely the most significant barriers to equitable care, and must be addressed as an important first step toward eliminating healthcare disparities. The

**BOX 1-1**  
**Revised Standards for the Classification of Federal Data on Race and Ethnicity**

Categories for Race:

**American Indian or Alaska Native.** A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

**Asian.** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

**Black or African American.** A person having origins in any of the black racial groups or Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

**Native Hawaiian or Other Pacific Islander.** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

**White.** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Categories for Ethnicity:

**Hispanic or Latino.** A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino."

**Not Hispanic or Latino.**

SOURCE: Office of Management and Budget, 2001.

committee is asked, however, to assess whether other factors may contribute to health-care disparities once these "threshold" factors (i.e., racial and ethnic differences in income, health insurance status, and geography) are held constant, and to specifically address whether bias, discrimination, or stereotyping at the individual, institutional, and health systems levels may explain some part of these disparities. To a great extent, attempts to separate the relative contribution of these factors risks presenting an incomplete picture of the complex interrelationship between racial and ethnic minority status, socioeconomic differences, and discrimination in the United States. For example, as will be discussed in Chapter 2, racial and ethnic housing segregation is a by-product of both historic and contemporary racism and discrimination, as well as socioeconomic differences (itself the legacy of poorer opportunities for many minority groups). The committee therefore stresses that attempts to "parcel out" access-

related factors from the quality of healthcare for minorities remains an artificial exercise, and that policy solutions must consider the historic and contemporary forces that contribute to differences in access to and quality of healthcare.

### **THE RELATIONSHIP BETWEEN RACIAL AND ETHNIC DISPARITIES IN HEALTH STATUS AND HEALTHCARE**

The health gap between minority and non-minority Americans has persisted, and in some cases, has increased in recent years. African-American men, for example, experienced an average life expectancy of 61 years in 1960, compared with 67 years for their white male peers; in 1996, this gap increased to 8 years, as white males enjoyed an average life expectancy of 74 years, relative to 66 years for African-American males. American-Indian men in some regions of the country can expect to live only into their mid-fifties. Further, African-American and American-Indian infant mortality rates remain approximately 2.5 and 1.5 times higher, respectively, than rates for whites (Collins, Hall, and Neuhaus, 1999).

As noted above, the reasons for these health status disparities are complex. Individual risk factors for poor health are pronounced among many racial and ethnic minorities, yet these risks are confounded by the disproportionate representation of minorities in the lower socioeconomic tiers. Moreover, socioeconomic position in and of itself is correlated with health status, independently of individual risk factors, as people in each ascending step along the socioeconomic gradient tend to have better health, even when individual health risk factors are accounted for (Kaplan, Everson, and Lynch, 2000). Cultural factors also play an important role in health disparities; among some immigrant Hispanic populations, for example, birth outcomes have been found to be better than among those of their U.S.-born peers, suggesting that sociocultural risk *increases* with subsequent generations living in the United States (Korenbrot and Moss, 2000). Further, environmental health risks, such as degradation, air, water, and soil pollution, and other physical health hazards are more prevalent in low-income racial and ethnic minority communities. These and other risk factors associated with health and poor health illustrate that racial and ethnic disparities in health status largely reflect differences in social, socioeconomic, and behavioral risk factors and environmental living conditions (House and Williams, 2000). Healthcare is therefore necessary but insufficient in and of itself to redress racial and ethnic disparities in health status (Williams, 1999). A broad and intensive strategy to address socioeconomic inequality, concentrated poverty in many racial and ethnic minority communities, inequitable and segregated housing and educational facilities, individual behavioral risk factors, as well as disparate access to

and use of healthcare services is needed to seriously address racial and ethnic disparities in health status.

### **WHY ARE RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE IMPORTANT?**

The preceding discussion should not be interpreted as suggesting that racial and ethnic disparities in healthcare are unimportant, either to individuals in need of care or to a society that prides itself on equality of opportunity. To the contrary, disparities in healthcare are problems that have significant implications for health professionals, administrators and policymakers, and healthcare consumers of all backgrounds.

For the health professions, racial and ethnic disparities in healthcare pose moral and ethical dilemmas that will be among the most significant challenges of today's rapidly changing health systems. Increasingly, physicians and other health professionals are faced with a complex set of societal expectations. On one hand, they are expected to adhere to the highest ethical standards of service that mandate fairness and compassion. On the other hand, physicians are placed in the position of serving as managers of vital, yet limited healthcare resources. Their decisions may result in the allocation of more resources to some individuals than to others, resulting in the unequal distribution of healthcare across population groups. These challenges occur in the context of increasing financial and bureaucratic pressures on healthcare providers, which may exacerbate the problem of inequitable care. Yet the public's trust in the health professions may be irrevocably harmed should the healthcare industry be engaged, even inadvertently, in "social triaging." It is vitally important to preserve this trust, which is already fragile in many racial and ethnic minority communities, as it can significantly affect patients' willingness to seek care and adhere to treatment regimens.

Health professionals and policymakers must also be cognizant of the importance of healthcare as a resource that is tied to social justice, opportunity, and the quality of life for individuals and groups. The productivity of the workforce is closely linked with its health status, yet if some segments of the population, such as racial and ethnic minorities, receive a lower quality and intensity of healthcare, then these groups are further hindered in their efforts to advance economically and professionally. It is therefore important from an egalitarian perspective to expect equal performance in healthcare, especially for those disproportionately burdened with poor health.

From a public health standpoint, racial and ethnic disparities in healthcare threaten to hamper efforts to improve the nation's health. As will be discussed in Chapter 3, the United States is becoming increasingly

diverse; while white Americans currently constitute 71% of the population, by the year 2050 nearly one in two Americans will be a person of color (U.S. Bureau of the Census, 2000). These groups, as noted earlier, experience a poorer overall health status and lower levels of access to healthcare than white Americans, and experience a disproportionate burden of chronic and infectious illness. This higher burden of disease and mortality among minorities has profound implications for all Americans, as it results in a less healthy nation and higher costs for health and rehabilitative care. All members of a community are affected by the poor health status of its least healthy members—infectious diseases, for example, know no racial/ethnic or socioeconomic boundaries. For this reason, the federal *Healthy People 2010* initiative has established an overarching goal of eliminating health disparities, noting that “the health of the individual is almost inseparable from the health of the larger community, and . . . the health of every community in every State and territory determines the overall health status of the Nation” (U.S. Department of Health and Human Services, 2000a, p. 15).

From an economic standpoint, the costs of inadequate care may have significant implications for overall healthcare expenditures. Poorly managed chronic conditions or missed diagnoses can result in avoidable, higher subsequent healthcare costs. For example, inadequately treated and managed diabetes can result in far more expensive complications, such as kidney disorder requiring dialysis or transplantation. To the extent that minority beneficiaries of publicly funded health programs are less likely to receive high quality care, these beneficiaries—as well as the taxpayers that support public healthcare programs—may face higher future healthcare costs.

Further, the problem of racial and ethnic disparities in healthcare poses a significant dilemma for a society that is still wrestling with a legacy of racial discrimination (Byrd and Clayton, this volume). Public opinion polls indicate that the vast majority of Americans abhor any form of racial discrimination and believe that all Americans should—and do—enjoy equal opportunities in accessing educational and job opportunities, as well as healthcare (Morin, 2001). Yet this ideal falls far from reality in many sectors of American life, including healthcare, as will be discussed in later sections of this report. The discrepancy between Americans’ widely held values and beliefs regarding the importance of equality and the reality of persistent racial inequities tears at the social fabric of the nation and contributes to the gulf of understanding between racial, ethnic and socioeconomic groups.

Finally, for the population at large, racial and ethnic disparities in healthcare raise concerns about the overall quality of care in the United States. Given that racial and ethnic minority groups experience greater

challenges and barriers to high quality care, their experiences expose healthcare systems' greatest weaknesses and problems—problems that any American may face in attempting to access healthcare. In this context, the extent to which minorities are well or poorly served provides an important indicator of the state of healthcare in the nation. The provision of equitable care that does not vary by patient race, ethnicity, gender, and age is therefore among one of the six overarching goals identified in the Institute of Medicine's *Crossing the Quality Chasm* report (IOM, 2001a). As the *Chasm* report suggests, evidence of unequal or substandard care for some segments of the population, particularly on the basis of group membership, should raise the concern that the provision of care may be inconsistently and subjectively administered. Inequities in care, therefore, expose a threat to quality care for all Americans.

For all of these reasons, should evidence be available to suggest that racial and ethnic disparities in care are widespread, these disparities would be unacceptable.

#### EVIDENCE OF RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE

The literature review that follows summarizes articles published in peer-reviewed journals within the last 10 years, with an emphasis on the most recent publications. In selecting literature to review, the committee identified studies that assess racial and ethnic variation in healthcare while controlling for differences in access to healthcare (e.g., by studying similarly insured patients or by statistically adjusting for differences in insurance status) and/or socioeconomic status. To ensure that the committee's search was not limited to studies with "positive" findings of racial and ethnic differences in care, searches were conducted for studies that attempted to assess variations in care by patient socioeconomic status and geographic region. These studies were included if the researchers assessed racial or ethnic differences in care while controlling, as noted above, for patient access-related factors. In addition, the committee focused its review on those studies that attempt to assess the contribution of a range of other potential confounding variables, such as racial and ethnic differences in disease severity, stage of illness progression, patient preferences for non-invasive procedures or to avoid complex treatments, types of settings where care is received (e.g., public vs. private clinics, teaching vs. non-teaching hospitals), availability of procedures (e.g., whether catheterization is offered on-site), suitability of intervention (e.g., whether subtle racial differences in response to treatments may counter-indicate use), as well as other factors. Further, the committee paid particular attention to studies that assessed the appropriateness of services relative to established

clinical guidelines. To the extent that these studies shed light on potential sources of disparities in care, they are summarized in this review. The committee's criteria for selecting literature to review are listed in Box 1-2.

Almost all of the studies reviewed by the committee contained one or more weaknesses of study design, methodology, or data analysis that limited the committee's ability to draw findings and conclusions. These weaknesses are noted below, where appropriate. The majority of studies of racial and ethnic disparities in care, for example, use odds ratios, which is a consequence of using logistic regression models, rather than risk ratios to assess the extent of disparities in care. Relative to risk ratios, odds ratios exaggerate the apparent effect of a co-variable when the prevalence of the dependent variable is above 5%-10%. The committee therefore cautions that in some instances, the magnitude of racial and ethnic disparities as reported in the literature may be exaggerated. In addition, as will be discussed below, no single study adequately controlled for all potential confounding factors (e.g., patient preferences, racial differences in disease severity or presentation, geographic availability of specific services or procedures) simultaneously. The committee therefore considered findings in light of the preponderance of evidence and the merits of each individual study. Noting the importance of assessing study strengths and limitations in context, Mayberry and colleagues (2000) write, "[t]he methodological inadequacy of an individual study may be a relatively moot point in the context of the body of literature that gives consistent findings and in which one study, often the more recent study, may overcome the specific failing of a previous investigation" (Mayberry, Mili, and Ofili, 2000, p. 116).

This review yielded over 100 studies (summarized in Appendix B) that assessed racial and ethnic variation in a range of clinical procedures, including the use of diagnostic and therapeutic technologies. This body of literature, however, represents only a fraction of the published studies that investigate racial and ethnic differences in access to and use of healthcare services. Geiger (this volume), for example, has identified over 600 such articles published over the last three decades. For a more comprehensive review of this literature, the reader is referred to Geiger (this volume) or the reviews of Mayberry and colleagues (Mayberry, Mili, and Ofili, 2000); Kressin and Petersen (2001); Sheifer, Escarce, and Schulman (2000); Ford and Cooper (1995); and the AMA Council on Ethical and Judicial Affairs (1990).

### Cardiovascular Care

Some of the strongest and most consistent evidence for the existence of racial and ethnic disparities in care is found in studies of cardiovascu-



### **BOX 1-2 Criteria for Literature Review**

To assess the evidence regarding racial and ethnic differences in health-care, the committee conducted literature searches via PUBMED and MEDLINE databases to identify studies examining racial and ethnic differences in medical care for a variety of disease categories and clinical services. Searches were performed using combinations of following keywords:

- *Race, racial, ethnicity, ethnic, minority/ies, groups, African American, Black, American Indian, Alaska Native, Native American, Asian, Pacific Islander, Hispanic, Latino.*
- *Differences, disparities, care*
- *Cardiac, coronary, cancer, asthma, HIV, AIDS, pediatric, children, mental health, psychiatric, eye, ophthalmic, glaucoma, emergency, diabetes, renal, gall bladder, ICU, peripheral vascular, transplant, organ, cesarean, prenatal, hip, hypertension, injury, surgery/surgical, knee, pain, procedure, treatment, diagnostic.*

This search yielded over 600 citations. To further examine this evidence base and address the study charge that called for an analysis of “the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care,” only studies that provided some measure of control or adjustment for racial and ethnic differences in insurance status (e.g., ability to pay/insurance coverage or comorbidities) were included in the literature review. Other “threshold” criteria included:

- Publication in past 10 years (1992-2002; this criterion was established because more recent studies tend to employ more rigorous research methods and present a more accurate assessment of contemporary patterns of variation in care);
- Publication in peer-reviewed journals;
- Elimination of studies focused on racial and ethnic differences in health status (except as it is affected by the quality of healthcare) and healthcare access, as well as publications that were editorials, letters, published in a foreign language, were non-empirical, or studies that controlled for race or ethnicity; and
- Inclusion only of studies whose primary purpose was to examine variation in medical care by race and ethnicity, contained original findings, and met generally established principles of scientific research (e.g., studies that stated a clear research question, provided a detailed description of data sources, collection, and analysis methods, included samples large enough to permit statistical analysis, and employed appropriate statistical measures).

In addition, to ensure the comprehensiveness of the review, the committee examined the reference lists of major review papers that summarize this literature (e.g., Geiger, this volume; Kressin and Petersen, 2001; Bonham, 2001; Sheifer, Escarce, and Schulman, 2000; Mayberry, Mili, and Ofili, 2000; Ford and Cooper, 1995). Articles not originally identified in the initial search were retrieved and analyzed for appropriateness of inclusion in the committee's review. Finally, to ensure that the committee's search was not limited to studies with "positive" findings of racial and ethnic differences in care, searches were conducted for studies that attempted to assess variations in care by patient socioeconomic status and geographic region. These studies were included if the researchers assessed racial or ethnic differences in care while controlling, as noted above, for patient access-related factors.

To assess the quality of this evidence base, the committee ranked studies on several criteria:

- Adequacy of control for insurance status (studies of patients covered under the same health system or insurance plan were considered to be more rigorous than studies that merely assessed the availability of health insurance among the study population);
- Use of appropriate indicators for patient socioeconomic status (e.g., studies that measured patients' level of income, education, or other indicators of socioeconomic status);
- Analysis of clinical data, as opposed to administrative claims data (see limitations of administrative claims data noted below);
- Prospective or retrospective data collection (prospective studies were considered to be more rigorous than retrospective analyses);
- Appropriate control for patient co-morbid conditions;
- Appropriate control for racial differences in disease severity or stage of illness at presentation;
- Assessment of patients' appropriateness for procedures (e.g., studies that provide primary diagnosis and include well-defined measures of disease status, as in studies of cardiovascular care that assess racial differences in care following angiography) or that compare rates of service use relative to standardized, widely accepted clinical guidelines; and
- Assessment of racial differences in rates of refusal or patient preferences for non-invasive treatment.

Studies that met the committee's "threshold" criteria are summarized in Appendix B. Many of these studies are summarized in this chapter, with an emphasis on more rigorous studies, as defined by the committee's quality criteria, above.

lar care. The most rigorous studies in this area assess both potential underuse and overuse of services and appropriateness of care using well-established clinical and diagnostic criteria. Several studies, for example, have assessed racial and ethnic differences in cardiovascular care relative to RAND criteria for the necessity of revascularization procedures. These studies have therefore been able to demonstrate that differences in treatment are not due to factors such as racial differences in the severity of coronary disease.

No one study reviewed by the committee simultaneously controlled for all of the variables likely to confound the relationship between race/ethnicity and receipt of care. In addition, in almost all cases, studies that employ rigorous measures of potential confounding variables find that racial and ethnic disparities diminish once these variables are included in multivariate analysis. The preponderance of studies, however, find that even after adjustment for many potentially confounding factors—including racial differences in access to care, disease severity, site of care (e.g., geographic variation or type of hospital or clinic), disease prevalence, comorbidities or clinical characteristics, refusal rates, and overuse of services by whites—racial and ethnic disparities in cardiovascular care remain. This conclusion was also reached by authors of all major review articles that the committee identified in its search, including Kressin and Petersen (2001); Mayberry, Mili, and Ofili (2000); Sheifer, Escarce, and Schulman, (2000); Ford and Cooper (1995); Gonzalez-Klayman and Barnhart (1998); the AMA Council on Ethical and Judicial Affairs (1990); and Geiger (this volume).

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#### *Studies Using Administrative Databases*

Data from several large, national datasets have been analyzed and demonstrate both national and regional patterns of disparities in care. These datasets typically rely on administrative claims data to assess differences in receipt of services. A variety of limitations should be noted regarding administrative claims data. One, these data provide little or no information regarding co-morbid illnesses, the severity of disease, or the stage at which illness was detected. Findings of racial differences in these studies therefore cannot rule out the possibility that minority patients

might be less appropriate for specific clinical services. Second, administrative data provide little indication as to whether patients were presented with all clinical options, whether patients accepted or refused recommendations, or whether the physician did not recommend clinical procedures. Third, these data typically provide no information regarding patients' education level or other socioeconomic background information. Given that whites generally enjoy higher socioeconomic and educational status, and given the correlation between these attributes and care-seeking behavior (e.g., greater assertiveness in seeking care), socioeconomic status is potentially a significant confounding factor. Fourth, administrative data typically provide no information regarding the appropriateness of services relative to patients' needs, and therefore overuse of services among whites and/or underuse among minorities cannot be ruled out.

Nonetheless, the consistency of findings from these studies, many using large sample sizes, is striking. Ford et al. (1989), for example, assessed rates of coronary arteriography and coronary artery bypass graft surgery (CABG) among nearly 4 million patients with acute myocardial infarction sampled in the National Hospital Discharge Survey (NHDS). The authors found that African-American men and women were significantly less likely to undergo CABG or angiography than whites. Escarce et al. (1993), McBean et al. (1994), and Gornick et al. (1996) found significant racial differences in rates of cardiovascular procedures among Medicare patients, with African-American patients approximately one-half to one-third less likely to receive services. Similarly, Goldberg et al. (1992), in an analysis of over 86,000 Medicare patients, found that whites were nearly four times more likely than African Americans to receive CABG, after adjusting for age- and gender-related differences in rates of myocardial infarction (MI). When data were analyzed by state, the authors found greater racial differences in CABG rates in the Southeast, particularly in non-metropolitan areas. For whites, CABG rates were significantly associated with the availability of thoracic surgeons and location in the Southeast, but physician availability and location were not correlated with CABG rates for African Americans.

To address some of the deficiencies of studies using administrative data, several studies have adjusted for the influence of variables such as site of care (e.g., geographic location or type of hospital or clinic) to assess racial differences in the receipt of coronary revascularization procedures. Ayanian et al. (1993) assessed racial differences in rates of revascularization following angiography and the relationship of these differences to hospital characteristics among more than 27,000 Medicare patients. Controlling for age, sex, region, Medicaid eligibility, and principal and secondary diagnoses, the authors found that whites were 78% more likely than African Americans to receive a revascularization procedure. These

differences were apparent in public, private, teaching, non-teaching, and urban/suburban hospitals, as well as in hospitals where patients were referred to other facilities for revascularization procedures and those that offer such procedures in-house. Similarly, Weitzman et al. (1997) assessed rates of performance of cardiac procedures in relation to gender, race, and geographic location among 5,462 patients in four states (North Carolina, Mississippi, Maryland, and Minnesota) hospitalized for MI. After controlling for the severity of MI and co-morbid conditions, blacks admitted to teaching hospitals in this study were significantly less likely to receive percutaneous transluminal coronary angiography (PTCA), CABG, or thrombolytic therapy. Similarly, blacks admitted to non-teaching hospitals were significantly less likely to receive these procedures.

Giles et al. (1995) used data from NHDS to assess race and sex differences in the rate of receipt of catheterization, PTCA, or coronary artery bypass surgery (CABS), while adjusting for differences in the type of hospital admission, insurance status, and disease severity among 10,348 patients hospitalized with acute myocardial infarction (AMI). Significant differences by race and gender were found after statistical adjustment and a patient matching procedure, which matched individuals admitted to the same hospital and who underwent a cardiac procedure with individuals who did not undergo a procedure. With white males as the referent, black men were less likely to receive catheterization or CABS, while black women were less likely to receive catheterization, PTCA, or CABS. Among only those patients who underwent catheterization (and therefore had access to a cardiologist), black women were less likely to receive subsequent PTCA or CABS.

Similarly, Allison et al. (1996) assessed the rate of receipt of thrombolysis, beta-adrenergic blockade and aspirin in a retrospective medical record review of 4,052 patients hospitalized in all acute care hospitals in Alabama with principle discharge diagnosis of AMI. After controlling for patient age, gender, clinical factors, severity of illness, algorithm-determined candidacy for therapy, and hospital characteristics (e.g., rural vs. urban, teaching vs. non-teaching), the authors found that white patients were 50% more likely to receive thrombolytics than black patients. No differences were found in receipt of beta-blockers or aspirin by patient race.

In one of the few studies to assess rates of revascularization procedures among a multiethnic sample of patients, Carlisle et al. (1995) found that African Americans, Hispanics, and Asian Americans were significantly less likely than whites to receive coronary angiography, CABG, and/or angioplasty, controlling for primary diagnosis, age, gender, insurance type, income, and co-morbid factors. When differences in the volume of revascularization procedures among hospitals were controlled,

however, Asian Americans did not differ from whites in the rates of cardiac procedures. African-American and Hispanic patients remained less likely than whites to receive angioplasty, and African Americans were less likely to receive CABG when hospital characteristics were controlled. Similarly, Herholz et al. (1996) analyzed discharge data for 982 Mexican-American and white patients hospitalized for definite or possible myocardial infarction. Mexican Americans received 38% fewer medications than whites, even after adjusting for clinical and demographic characteristics. Mexican Americans were less likely to receive almost all major medications, especially antiarrhythmics, anticoagulants, and lipid-lowering therapy. Using data from the same study as Herholz et al. (1996), Ramsey et al. (1997) found that after adjusting for age, sex, previous diagnosis of coronary heart disease, MI, diabetes mellitus, hypertension, occurrence of congestive heart failure during MI, and location and type of MI, Mexican Americans were less likely to receive PTCA, but not aortocoronary bypass surgery, than whites.

Other studies indicate that the likelihood of receiving revascularization procedures varies by the stage or typical sequence of events leading to care. Blustein, Arons, and Shea (1995), for example, found that among patients hospitalized for acute myocardial infarction, race and insurance status significantly predicted the likelihood of 1) gaining initial admittance to a hospital that offers revascularization services; 2) actually receiving revascularization following initial admission; or 3) receiving revascularization services following transfer or subsequent readmission. Whites, those with private insurance, and those with more severe heart disease were more likely to gain initial admittance to hospitals providing revascularization services. Once hospitalized, whites, males, those with private insurance, and those with more severe disease were more likely to actually receive revascularization. Racial disparities grew larger as patients “progressed” through the phases leading to revascularization.

#### *Studies of the Role of Financial and Institutional Characteristics*

Several studies suggest that financial and institutional characteristics may mediate the relationship between the use of cardiac procedures and patient race, in some cases significantly attenuating or eliminating racial and ethnic disparities. Leape et al. (1999) explored racial differences in revascularization procedures as a function of demographic characteristics and type of hospital among 631 patients at 13 New York City hospitals for whom revascularization procedures were deemed clinically necessary according to RAND criteria. The authors found no racial differences in rates of revascularization procedures among African-American patients (72%), Hispanic patients (67%) and white patients (75%). Rates of revascu-

larization were significantly lower, however, among patients initially seen in hospitals that did not provide revascularization services (and therefore had to refer patients to other hospitals) than those treated in settings that did provide revascularization (59% to 76%, respectively). Subsequent criticism of the study noted that the limited sample and geographic setting, coupled with the fact that most of the facilities studied offered both angiography and revascularization on-site, may have limited the study's ability to detect group differences in procedure use (Kressin and Peterson, 2001).

Similarly, Gregory et al. (1999) studied the relationship between the availability of hospital-based invasive cardiac procedures and racial differences in the use of these services. The authors studied records of 13,690 black and white New Jersey residents hospitalized with a primary diagnosis of AMI. For all patients, the likelihood of receiving catheterization within 90 days of AMI was significantly greater among those hospitalized in facilities that provided cardiac services. Black patients in this sample were more likely to be admitted first to hospitals equipped to perform cardiac catheterization and/or PTCA or CABG. Despite this, blacks were less likely to receive catheterization than whites within 90 days of admission, even after controlling for age, sex, health insurance status (for those younger than age 65), anatomic location of primary infarct, co-morbidities, and the availability of cardiac services. Similarly, blacks were less likely than whites to receive revascularization procedures within 90 days of admission, again after controlling for patient demographic and clinical factors and availability of cardiac services.

Other researchers have assessed whether racial and ethnic disparities in healthcare are mediated by the type of health system in which care is delivered. Taylor et al. (1997), for example, abstracted chart reviews from 1,441 patients with principal or secondary diagnosis of AMI receiving care in one of 125 military hospitals. The authors found no differences in rates of catheterization procedures between white and "non-white" patients (all patients who described their race or ethnicity as other than white or Caucasian, including African Americans) during AMI admission or between white and black patients. Similarly, no differences were found in rates of revascularization (PTCA or CABG) between white and "non-white" patients or between white and black patients. No differences were found in mortality or rates of readmission within 180 days following initial discharge. However, white patients were significantly more likely than non-white patients to be considered for future catheterization. Among studies of disparities in Veterans Administration hospitals, which significantly reduce financial barriers to care, findings are mixed. Mickelson et al. (1997) found no differences between white and Hispanic VA patients in receipt of cardiovascular procedures following AMI. In

contrast, Peterson et al. (1994), Mirvis et al. (1994), Whittle et al. (1993), and Mirvis and Graney (1998) all found that African-American VA patients were less likely to receive cardiovascular procedures. Sedlis et al. (1997) found that therapeutic cardiac procedures (surgery or PTCA) were offered more frequently for white VA patients (72.9%) than African-American VA patients (64.3%). This difference could not be explained by simple clinical differences between the two groups. Even though they were offered care at lower rates, however, African-American patients were more than twice as likely as whites to refuse invasive procedures. In contrast, Petersen et al. (2002) found significant differences in rates of thrombolytic therapy and bypass surgery among a sample of African-American and white VA patients with a confirmed diagnosis of acute myocardial infarction, with black patients receiving lower rates of these invasive procedures. Like Sedlis et al. (1997), Petersen et al. assess racial differences in rates of refusal for these procedures, but found no differences in rates of refusal when angiography, PTCA, or bypass surgery were offered.

Daumit et al. (1999), in one of the few studies to longitudinally assess receipt of cardiovascular procedures among a cohort of patients, followed nearly 5,000 African-American and white patients with end-stage renal disease (ESRD) to determine whether the acquisition of health insurance (ESRD patients are eligible for Medicare and generally enter a comprehensive system of care, if not already enrolled in one, upon diagnosis) could reduce racial and ethnic disparities in receipt of cardiovascular procedures (ESRD patients are at high risk for cardiovascular disease). Prior to development of ESRD, white patients were nearly three times more likely than African-American patients to receive catheterization, angioplasty, or CABG, even after controlling for clinical and socioeconomic variables. At follow-up, this disparity diminished to the point where whites were only 40% more likely to receive a cardiovascular procedure. Significantly, among patients who were already enrolled in Medicare at baseline, racial disparities in cardiovascular procedures disappeared at follow-up. Daumit et al. caution, however, that "a substantial baseline disparity between black and white patients . . . exists in the privately insured and Medicare subgroups, providing evidence against acquisition of health insurance as the only factor in narrowing the ethnic gap" (Daumit et al., 1999, p. 179). As with many of the studies reviewed above, however, this study did not obtain detailed clinical data or information on patient preferences, which could explain some of the observed differences (Kravitz, 1999).

These studies strongly suggest that addressing racial and ethnic gaps in insurance coverage is one of the most important factors in narrowing the racial and ethnic gap in cardiovascular services. Health insurance alone does not completely eliminate disparities, however, as the studies



above illustrate. This finding is confirmed in a study of cardiovascular care in the United Kingdom, which offers universal access and free care at the point of use. In a prospective study of 2,552 patients seen in London hospitals who were deemed “appropriate” for cardiovascular procedures according to standardized criteria, Hemingway et al. (2001) found that “non-white” patients were more likely to receive only medical treatment (received by 20% of these patients), rather than CABG (received by 14% of these patients), after controlling for demographic and clinical variables. These differences were not found among white patients similarly deemed appropriate for invasive treatment.

#### *Studies to Assess Appropriateness of Services*

Critics of many of the studies reviewed above charge that comparisons of minority patients’ receipt of revascularization procedures with that of whites’ may identify differences caused by overuse of procedures by whites, rather than clinical necessity. To address this concern, several studies have examined use of coronary procedures relative to established criteria for necessity. Hannan et al. (1999) assessed rates of CABG among 1,261 post-angiography patients who would benefit from CABG according to RAND appropriateness and necessity criteria. Controlling for age, gender, severity of disease, patient risk status, type of insurance, and other clinical characteristics, the authors found that African-American and Hispanic patients were significantly less likely than whites to undergo CABG. Similarly, Laouri et al. (1997), using RAND/UCLA criteria for necessity of revascularization procedures, found that African Americans were half as likely as whites to undergo necessary CABG and one-fifth as likely to undergo PTCA. In this study, patients at public hospitals were less likely to undergo PTCA than those at private hospitals. Conigliaro et al. (2000) also assessed racial variation in coronary revascularization relative to RAND appropriateness criteria at six hospital sites that offered CABG on site or at an adjacent university hospital. This was a VA patient population with few financial barriers to care. Further, all patients had unstable angina or acute myocardial infarction and had undergone coronary angiography. Overall, African-American patients were found to be less likely than whites to undergo CABG and PTCA, but when RAND appropriateness criteria were considered, African Americans were still less likely to receive CABG when deemed “necessary.”

In a larger study, Canto et al. (2000) studied the use of reperfusion therapy among more than 26,000 patients meeting eligibility criteria as a result of acute myocardial infarction. After controlling for clinical and demographic characteristics, the authors found that African Americans

were slightly less likely than whites to undergo reperfusion therapy. Further, Schneider et al. (2001) used RAND criteria to assess whether overuse of PTCA or CABG by whites explained racial differences in revascularization rates among 3,960 African-American and white Medicare patients. As with other studies cited above, Schneider et al. found that whites were more likely than African Americans to receive PTCA and CABG. When assessed relative to RAND appropriateness criteria, white males were found to be nearly 2.5 times more likely to receive PTCA than African Americans when the procedure was judged to be “inappropriate;” no other racial or gender differences were found in rates of inappropriate CABG. The authors conclude, however, that the racial difference in rates of inappropriate PTCA “was not sufficiently large to account for more than a small fraction of the substantial disparities in rates of revascularization between white patients and African-American patients” (Schneider et al., 2001b, p. 334).

These studies of disparities in cardiovascular care relative to appropriateness criteria offer an important means of assessing whether observed racial and ethnic differences in care may be “explained” by differences in clinical necessity. It should be noted, however, that even among studies employing objective criteria to assess racial and ethnic differences in care relative to clinical necessity, “there may not always be a perfect fit between the clinical indications considered by the [panel evaluating appropriateness] and the characteristics of real patients” (Kravitz, 1999).

In a more comprehensive study of whether racial disparities in receipt of revascularization procedures reflect clinical necessity or merely overuse among whites, Peterson et al. (1997) assessed racial differences in receipt of coronary angioplasty and CABG among patients with documented coronary disease, and assessed whether differences were associated with survival. Peterson et al. followed 12,402 patients seen annually at Duke University Medical Center for an average of five and a half years, and found that African Americans were 13% less likely than whites to undergo angioplasty and 32% less likely to undergo CABG during the study period. Racial differences in procedure rates were more marked among patients with severe disease. Analysis of survival benefit of surgery also revealed racial differences; among patients expected to survive more than one year, 42% of African Americans underwent surgery, compared with 61% of whites. Finally, analysis of the adjusted five-year mortality rate among patients revealed that African-American patients were 18% more likely than whites to die. The Peterson et al. study can be criticized on the grounds that the findings may not generalize beyond the single study setting. Nevertheless, the study provides strong evidence that lower rates of intervention among this sample of African-American patients were associated with lower rates of survival.

*Summary of Literature on Racial and Ethnic Disparities in Cardiovascular Care*

The literature reviewed above illustrates that racial and ethnic disparities in cardiovascular care are robust and consistent across a range of studies conducted in different geographic regions with diverse patient populations seen in a range of clinical settings. This literature does not, however, provide a clear account of the sources of these disparities; rather, these studies provide clues regarding the types of factors that are *not* likely to fully explain disparities in cardiovascular care. Racial differences in clinical presentation or disease severity do not fully explain differences in receipt of services (Hannan et al., 1999; Lauori et al., 1997; Conigliaro et al., 2000; Canto et al., 2000), although minority and non-minority patients may not respond equally well to some therapeutic interventions, as will be discussed in Chapter 3. White patients have been found to use some clinical services at higher rates than minorities, even when not necessarily indicated. Therefore, when minority patients' use of services is compared with that of whites, differences may be observed. But this "overuse" of cardiovascular procedures by whites does not fully explain disparities in care (Schneider et al., 2001), and studies that assess racial differences in care relative to established clinical criteria still find significant differences (Conigliaro et al., 2000b; Hannan et al., 1999; Laouri et al., 1997). Racial and ethnic disparities in cardiovascular services are found among patients insured by Medicare (Gornick et al., 1996; McBean et al., 1994; Escarce et al., 1993), and among patients in VA settings (Peterson et al., 1994; Mirvis et al., 1994; Whittle et al., 1993; Mirvis and Graney, 1998; Sedlis et al., 1997; Petersen et al., 2002), although these findings are not consistent (Mickelson et al., 1997). Significantly, however, even among patients whose care is covered by nationalized health plans (e.g., Great Britain), minority racial and ethnic groups are found to receive fewer clinical services (Hemingway et al., 2001).

Several studies find that African-American patients are more likely than whites to refuse invasive procedures (e.g., Hannan et al., 1999; Oddone et al., 1998; Sedlis et al., 1997), but when the relative contribution of patient refusal to racial differences in care is assessed, this factor is not found to account completely for these disparities. Further, physician recommendation appears to be the major factor in determining whether patients receive invasive cardiac procedures (Hannan et al., 1999). These factors as potential sources of disparities will be assessed in greater detail in Chapter 3.

Almost all of the studies reviewed here find that as more potentially confounding variables are controlled, the magnitude of racial and ethnic disparities in care decreases. In a few studies, disparities disappeared

entirely when appropriate confounding variables were included in multivariate analysis. In general, these findings are limited to studies of patients seen in universally accessible care settings, such as the U.S. Department of Defense healthcare systems (e.g., Taylor et al., 1997), or studies employing small samples in one or a handful of clinical settings (e.g., Leape et al., 1999). These findings strongly suggest that access-related factors, such as insurance status, ability to pay, and characteristics of institutional and clinical settings are the largest contributors to observed racial and ethnic disparities in cardiovascular care. The vast majority of studies assessing disparities in cardiac care, however, find that racial and ethnic disparities persist even after variations in insurance status are controlled.

As a “second level” analysis of the quality of evidence regarding racial and ethnic disparities in cardiovascular care, the committee identified a subset of studies that permit a more detailed analysis of the relationship between patient race or ethnicity and quality of care, while considering potential confounding variables such as clinical differences in presentation and disease severity. Several criteria were established to identify these studies, using generally accepted criteria of research rigor and quality. To begin, the committee identified only studies using clinical, as opposed to administrative data, for the reasons cited above. Secondly, the committee identified studies that provided appropriate controls for likely confounding variables, and/or employed other rigorous research methods. These criteria included the use of adequate control or adjustment for racial and ethnic differences in insurance status; prospective, rather than retrospective data collection; adjustment for racial and ethnic differences in co-morbid conditions; adjustment for racial and ethnic differences in disease severity; comparison of rates of cardiovascular services relative to measures of appropriateness; and assessment of patient outcomes.

Several caveats should be noted in undertaking this approach. One, studies using clinical data allow researchers to better assess whether disparities in care exist and are significant after potential confounding factors such as clinical variation and the appropriateness of intervention are taken into account. However, these studies often are limited to small patient samples in one or only a few clinical settings, therefore sacrificing statistical power and potentially underestimating the role of institutional variables as contributing to healthcare disparities. Second, assessments of racial and ethnic differences in patients’ clinical outcomes following intervention must be made with caution. Patients’ outcomes following medical intervention reflect a wide range of factors, some of which are unrelated to the intervention itself (e.g., the degree of social support available to patients following treatment) and may vary systematically by race or ethnicity. In addition, a finding of no racial or ethnic differences in

patient outcomes (e.g., survival) despite disparate rates of treatment should not be interpreted as demonstrating that disparities in the use of medical intervention are inconsequential. In such instances, researchers should ask whether equivalent rates of intervention might be associated with *better* patient outcomes among minorities. Finally, this second level of analysis should not be interpreted as suggesting that the larger literature presented above is insufficient to draw conclusions regarding disparities in healthcare. Almost all of the individual studies reviewed earlier possess limitations, but the collective body of this evidence is robust. Despite these caveats, this second review afforded an opportunity to assess whether racial and ethnic disparities in care remain when racial differences in clinical presentation and other potentially confounding variables are controlled. Studies were considered in this second review only if they met four of six criteria noted above, in addition to the “threshold” criteria that studies employ clinical databases. Thirteen studies were identified through this process (see Table B-2 in Appendix B). Of these, only two (Leape et al., 1999; Carlisle et al., 1999) found no evidence of racial and ethnic disparities in care after adjustment for racial and ethnic differences in insurance status, co-morbid factors, disease severity, and other potential confounders as noted above. The remaining studies found racial and ethnic disparities in one or more cardiac procedures, following multivariate analysis. Almost all studies found that adjustment for one or more confounding factors reduced the magnitude of unadjusted racial and ethnic differences in care. Among the five studies that collected data prospectively, however, all found racial and ethnic disparities remained after adjustment for confounding factors.

### Cancer

Studies of racial disparities in cancer diagnosis and treatment are less clear and consistent than studies of cardiac care, in part because many studies rely on data that use crude or incomplete indicators of the type of treatment provided and/or do not control for co-morbid factors. Variations in the extent of disease among patients are rarely well controlled, and the comprehensiveness of treatment cannot be evaluated. In addition, many studies indicate that ethnic minorities are diagnosed at later stages of cancer progression, further confounding efforts to assess the quality of treatment. Nonetheless, several studies demonstrate significant racial differences in the receipt of appropriate cancer treatments and analgesics.

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In one of the largest early studies of racial disparities in cancer care, Diehr et al. (1989) assessed the quality of care for 7,781 women treated for breast cancer in 107 hospitals relative to 10 dimensions of breast cancer care established by a panel of experts convened by the National Cancer Institute (NCI). While African Americans were less likely than whites to have health insurance, were less likely to be treated by an experienced, board-certified physician, and were more likely to be treated in large, public hospitals, racial differences in care persisted when these and other clinical and demographic factors were controlled. African-American women were less likely than white women to receive progesterone receptor assays (a prognostic test), were less likely to receive radiation therapy in combination with radical/modified mastectomy, and were less likely to receive rehabilitation support services following mastectomy.

Similarly, Harlan et al. (1995) assessed variations in the use of radical prostatectomy and radiation to treat prostate cancer by geographic area, age, and race. Data for 67,693 men with localized and regional cancer, obtained from Surveillance, Epidemiology, and End Results (SEER) program database, revealed that black men aged 50 to 69 years were less likely than similarly aged white men to undergo prostatectomy. For black and white men aged 70 to 79 years, rates of prostatectomy were similar in 1984, but became significantly divergent by 1991, as a larger proportion of white men underwent the procedure. In 1991, a significantly higher proportion of black men aged 50 to 59 years received radiation. For all age groups in 1991, twice as many blacks as whites (12.5% vs. 6.6%) received no treatment. In a similar analysis of 4,154 Medicare claims for radical prostatectomy to treat prostate cancer, Imperato et al. (1996), found that rates of prostatectomy were lower among African Americans than among whites, with the black/white ratio ranging from 0.59 in 1991 to 0.86 in 1993.

McMahon et al. (1999) assessed the contribution of patient age, sex, race, urbanicity, per capita income, and education level of patients' com-

munity, and availability of physicians, internists, and gastroenterologists per 100,000 population to predict use of diagnostic procedures for colon cancer among all Medicare Part B transactions in the state of Michigan from 1986 to 1989. African Americans were more likely than whites to receive a barium enema only, were less likely to receive a combination of barium enema and sigmoidoscopy, and were less likely to undergo colonoscopy. While this study could not control for stage of disease and the reason for performing diagnostic procedures, it suggests that African Americans received less effective diagnostic evaluations. Relative to whites, African Americans in this study received 28% fewer sigmoidoscopic examinations—which are generally considered to be more technically advanced diagnostic procedures than barium enema—despite a 20% higher incidence of colon cancer.

African-American cancer patients are also less likely to receive post-treatment surveillance care. Elston Lafata et al. (2001) assessed colorectal cancer surveillance care among 251 patients enrolled in a managed care organization at diagnosis, and found that within 18 months of treatment, over half of the total cohort received a colon examination (55%), nearly three-fourths had received carcinoembryonic antigen (CEA) testing, and nearly six in ten (59%) received metastatic disease testing. Whites were more likely than African Americans, however, to receive CEA testing and displayed a slight but non-significant trend toward higher rates of colon examination. The small sample size and single setting of this study, however, may limit these findings.

In one of the few studies to analyze the effect of both stage of illness at the time of diagnosis and reasons for no receipt of treatment, Merrill, Merrill, and Mayer (2000) assessed the receipt of surgery or radiation therapy among 8,119 white and African-American women with invasive cervical cancer. Overall, 8.03% of whites and 11.64% of blacks did not receive either radiation therapy or surgery. For both blacks and whites, the odds of not receiving treatment increased with older age, distant and unstaged disease (vs. localized disease), unknown grade (vs. well-differentiated disease), and unknown lymph node (vs. no lymph node) status. Blacks were more likely to be diagnosed unstaged and were less likely to have localized disease; once stage was accounted for, racial differences in treatment status became insignificant. However, among those not treated, blacks were more likely than whites to have treatment not recommended (53.68% vs. 40.32%). Of those cases not receiving therapy, few were due to patient refusal (3.76% among whites, 5.88% among blacks).

Similarly, Howard, Penchansky, and Brown (1998) assessed racial differences in breast cancer survival among 246 black and white women who sought care for breast cancer in one of three health maintenance organizations (HMOs). No significant racial differences were

found in stage of disease, utilization of health services before diagnosis of breast cancer, or receipt of breast examination. However, African-American patients were more likely to die than whites (30% vs. 18%, respectively) and experienced shorter average survival (1.63 years vs. 2.77 years, respectively). Two percent of whites and eight percent of African Americans missed two or more appointments following diagnosis; after adjusting for the number of appointments made, African Americans were more likely than whites to miss appointments. Missed appointments and stage of diagnosis were strongly associated with survival, and reduced the impact of race on survival. As with the study by Elston Lafata et al. (2001), however, findings of this study are limited by the small sample size and study setting.

In a larger study, Ball and Elixhauser (1996) assessed racial differences in treatment for colorectal cancer among over 20,000 patients in a national sample. Among patients with primary tumor and no metastasis, African Americans were 41% less likely than whites to receive a major procedure for treatment of colorectal cancer (i.e., colon resection, total cholecystectomy, colonoscopy, or bronchoscopy), after controlling for patient demographic characteristics, comorbidities, therapeutic complications, and hospital characteristics. Among patients with metastasis, African-American patients were 27% less likely to receive a major treatment. Bach et al. (1999) found similar results in a study of nearly 11,000 Medicare patients with a diagnosis of resectable non-small-cell lung cancer. The authors found that African-American and white patients who underwent surgery had similar rates of survival at five years (39.1% and 42.9%, respectively). No racial differences were found in survival rates at five years for those patients who did not undergo surgery (4% among African Americans and 5% among whites). African Americans, however, were 12.7% less likely to undergo resection, a difference that was not due to comorbid factors, age, gender, income, geographic region, or type of Medicare insurance. Further, using survival analysis, the authors estimate that 308 African-American patients would have been alive at five years if black patients had undergone surgery at a rate similar to that of white patients.

Racial and ethnic differences are also found in the use of analgesics to manage pain due to cancer. Bernabei et al. (1998) assessed the adequacy of pain management among 13,625 elderly and minority cancer patients admitted to nursing homes following treatment. More than a quarter of patients who experienced daily pain (26%), as assessed by self-report and independent raters, received no pain medication. After adjusting for gender, cognitive status, communication skills, and indicators of disease severity (e.g., explicit terminal prognosis), being bedridden, number of diagnoses, and use of other medications, the authors found that African Americans had a 63% greater probability of being untreated for pain rela-



tive to whites. Older age, low cognitive performance, and increased number of other medications were also associated with failure to receive any analgesic agent. Similarly, Cleeland et al. (1997) assessed the adequacy of pain management among minority patients receiving care in settings that primarily serve minorities vs. patients who receive care in settings where few minority patients are treated. In addition, the authors compared the adequacy of analgesia received by minority patients vs. that received by non-minority patients, as determined by independent, widely accepted pain assessment criteria. Sixty-five percent of patients in this study who reported pain received inadequate pain medication. Patients treated in settings where the patient population was primarily black or Hispanic and those who were treated at university medical centers were more likely to receive inadequate analgesia (77%) than those who received treatment in settings where the patient population was primarily white (52%). In addition, minority patients were more likely to be undermedicated for pain than white patients (65% vs. 50%, respectively), and were more likely to have the severity of their pain underestimated by physicians.

As is the case with some studies of cardiovascular care, the type of health system in which minority patients access care may influence the quality of cancer care received. Optenberg and colleagues, for example (Optenberg et al., 1995), assessed the long-term survival of 1,606 black and white prostate cancer patients who were active duty personnel, dependents, or retirees eligible for care in the military medical system. Black patients in this study presented at a significantly higher stage of cancer development than whites (26.4% of blacks presenting with distant metastases compared to 12.3% of whites), and demonstrated a greater percentage of recurrence (30.6% vs. 21.4%, respectively). There were no significant racial differences in wait time to receive treatment, and no significant differences were found in the type of treatment when stratified by stage of presentation. Overall, stage, grade, and age were found to affect survival, but not race. When analyzed by stage, blacks demonstrated longer survival for distant metastatic disease. Similarly, Dominitz et al. (1998) assessed racial differences in receipt of treatment and survival among 3,176 patients with colorectal cancer treated in the "equal access" Veterans Administration (VA) health system. After adjusting for patient demographic characteristics, co-morbidities, distant metastases, and tumor location, no significant racial differences were found in rates of receipt of surgical resection (70% among blacks, 73% among whites), chemotherapy (23% for both black and whites), or radiation therapy (17% among blacks, 16% among whites). Five-year relative survival rates were similar for black and white patients (42% vs. 39% respectively). These findings are not consistent, however; Dominitz et al. (2002), for example, assessed rates of surgical intervention versus chemotherapy and radia-

tion therapy among a sample of African-American and white male veterans diagnosed with esophageal cancer and treated at VA hospitals. The authors found that after controlling for a variety of patient demographic and clinical characteristics, African-American patients with esophageal adenocarcinoma were less likely to undergo surgery than whites, but had similar rates of chemotherapy and radiation therapy. Similarly, black patients with squamous cell carcinoma were less likely than whites to undergo surgical resection, but were more likely to receive radiation therapy and chemotherapy. Further, in contrast to Optenberg et al. (1995) and his earlier study (Dominitz et al., 1998), in this study Dominitz and colleagues (2002) found that post-treatment mortality was higher for African-American than white patients with squamous cell carcinoma.

### Cerebrovascular Disease

Racial and ethnic variation in the rates of diagnostic tests and clinical procedures for cerebrovascular disease have not been studied as extensively as variation in cardiac procedures, despite the relatively higher risk among African Americans for stroke (Mitchell et al., 2000). Moreover, few studies have compared rates of procedures conditional upon angiography or other diagnostic testing. The preponderance of studies, however, finds generally lower rates of diagnostic and therapeutic procedures among African Americans with cerebrovascular disease.

Oddone et al. (1999) studied racial differences in rates of carotid artery imaging among patients diagnosed with transient ischemic attack, ischemic stroke, or amaurosis fugax seen at one of four VA Medical Centers. After controlling for patients' age, co-morbid factors, clinical presentation, anticipated operative risk, and hospital, African-American patients were found to be half as likely as whites to receive carotid imaging. White patients in this study, however, were more likely to be assessed as appropriate candidates for surgery using RAND criteria because of a higher prevalence of significant carotid artery stenosis among blacks.

Mitchell and colleagues (Mitchell et al., 2000) assessed rates of tests and treatment (including noninvasive cerebrovascular tests, cerebral angiography, carotid endarterectomy, and anticoagulant therapy) for cerebrovascular disease among a sample of Medicare patients admitted to hospitals with a principal diagnosis of transient ischemic attack (TIA). Further, they assessed the relative probability of receiving care from a neurologist. After adjusting for comorbid illness (including hypertension and prior history of stroke), ability to pay (using a proxy based on dual Medicaid-Medicare eligibility and area of residence), and other clinical and demographic variables, the authors found that African Americans were 83% less likely than whites to receive noninvasive cerebrovascular

testing. Among those receiving noninvasive testing, African Americans were 54% as likely to receive cerebral angiography, and among those receiving angiography, the odds of African Americans receiving carotid endarterectomy was 0.27. African Americans were 62% less likely than whites to receive anticoagulant therapy, but this difference was not statistically significant given the small number of African-American subjects. African-American patients were 21% less likely than whites to receive care from a neurologist. Overall, patients who received care from a neurologist were more likely to receive both noninvasive and invasive cerebrovascular testing, but were significantly less likely to undergo surgery. The authors note that while the findings could have been affected by unmeasured differences in the severity of carotid artery stenosis that could explain the lower rates of carotid endarterectomy among African Americans (African Americans are less likely to have extracranial disease that is most amenable to carotid endarterectomy), this difference would not explain the disparity in rates of testing (Mitchell et al., 2000).

### **Renal Transplantation**

African Americans are at greater risk for end-stage renal disease (ESRD) than white Americans. Although African Americans constitute 12% of the U.S. population, they represent almost one-third of those with ESRD. Kidney dialysis was once considered the optimal treatment for ESRD, but recent advancements in kidney transplantation techniques have made transplantation more cost-effective than dialysis. African-American patients with ESRD, however, are less likely than similar white patients to receive a kidney transplant (Epstein et al., 2000). African-American patients are also less likely than white patients to be referred for transplantation and to appear on waiting lists within the first year of Medicare eligibility (Kasiske, London, and Ellison, 1998). In addition, average waiting time for African-American patients awaiting kidney transplantation is almost twice as long as that for white patients, a difference that is not apparent for transplantation of other solid organs (Young and Gaston, 2000). These findings, however, must be interpreted with caution, as many clinical considerations complicate interpretation of these data. For example, in general, fewer African Americans than whites desire or are appropriate for transplantation, and immunologic matching criteria result in fewer donor matches for African Americans than whites.

Several studies are consistent in finding that African-American patients (and in some instances, other ethnic minority patients) are less likely to be judged as appropriate for transplantation, are less likely to appear on transplantation waiting lists, and are less likely to undergo transplantation procedures, even after patients' insurance status and other factors

are considered. Garg, Diener-West, and Powe (2001) longitudinally followed adult ESRD patients to assess racial differences in rates of placement on transplantation waiting lists over time. The authors found that lower rates of placement on the waiting list for blacks than whites persisted after adjustment for differences in both sociodemographic characteristics and health status, and that the gap between blacks and whites did not narrow over time. Epstein and colleagues (2000), in a study of patients with end-stage renal disease from four regional networks in geographically diverse areas, found that African-American patients were less likely than white patients to be rated as appropriate candidates for transplantation, according to expert-identified criteria (9.0% vs. 20.9%, respectively). Among patients considered appropriate for transplantation, however, African-American patients were less likely than whites to be referred for evaluation (90.1% vs. 98.0% respectively), were less likely to be placed on a waiting list (71.0% vs. 86.7% respectively), and were less likely to ultimately undergo transplantation (16.9% vs. 52.0%, respectively). Similarly, in a study of over 41,000 patients awaiting transplantation, Kasiske, London, and Ellison (1998) found that white patients were more likely to be placed on waiting lists before initiating maintenance dialysis than African-American, Hispanic, or "Asian/other" patients. Other factors predicting being placed on waiting lists before dialysis included patients' age, receipt of a prior transplant, level of education, employment status, insurance status, receiving insulin, listing for kidney and pancreas transplant vs. kidney only, and listing through a center that performs a high volume of procedures.

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African-American patients are also found to be less likely to receive dialysis as an initial treatment for ESRD. Barker-Cummings, McClellan, Soucie, and Krisher (1995) found that after controlling for patients' sociodemographic and clinical characteristics (including age, education, social support, home ownership, functional status, albumin level, presence of hypertension, history of MI, peripheral neuropathy, and comorbid diabetes), African Americans were half as likely as white patients to be initially treated with peritoneal dialysis.

Some evidence suggests that African-American patients are less likely than whites to desire kidney transplantation. Ayanian, Cleary, Weissman, and Epstein (1999) found that African-American male patients were sig-

nificantly less likely than white males to report wanting a transplant. This difference was not significant among female patients. However, even when differences in preference were taken into account, African-American patients were much less likely than white patients to have been referred to a transplant center for evaluation (50.5% of African-American women vs. 70.7% of white women, and 53.9% of African-American men vs. 76.2% of white men), and to have been placed on a waiting list or to have received a transplant within 18 months after initiating dialysis (31.9% of African-American women vs. 56.5% of white women, and 35.3% for African-American men vs. 60.6% of white men). Similarly, Alexander and Sehgal (1998) found that African-American patients were less likely than white patients to be “definitely interested” in receiving a transplant, to complete pre-transplant workup, and finally, to progress on waiting lists to receive a transplant. These analyses controlled for patient age, gender, cause of renal failure, years receiving dialysis, and median income of patients’ zip code area. Ozminkowski et al. (1997) surveyed 456 ESRD patients to assess the effects of patient sociodemographic characteristics, health and functional status, and attitudes about dialysis or transplantation on waiting list entry and receipt of a cadaver kidney transplant. The authors found that approximately 60% of the differences between African-American and white waiting list entry rates and 52% of the black-white differences in transplantation rates were due to race-related differences in socioeconomic status, health and functional status, severity of illness, biological factors, the existence of contraindications to transplantation, transplant center characteristics, and patients’ attitudes about dialysis and transplantation.

At least one study has assessed the influence of patients’ clinical and non-clinical factors, including race, on physicians’ recommendations for renal transplantation. Thamer et al. (2001) surveyed 271 nephrologists who were presented with scenarios that varied the age, race, gender, living situation (alone or with family), history of compliance with treatment, diabetic status, residual renal function status, HIV status, weight, and cardiac ejection fraction of hypothetical patients. Asian-American males were less likely than white males to be recommended for transplantation, as were women, those with a history of non-compliance, low cardiac ejection fraction, overweight, or positive HIV status. The fact that African-American and white “patients” were recommended for transplantation at similar rates suggests that the observed black-white differences may emerge at other steps in the transplantation process, according to the authors. The low rate of recommendation for Asian-American males, however, is inconsistent with the fact that Asians have the highest cadaveric allograft survival rates of all racial and ethnic groups, the authors note.

## HIV/AIDS

HIV infection continues to spread more rapidly among African-American and Hispanic populations than any other racial/ethnic group in the United States. While federal programs have been expanded in recent years to increase the availability of antiretroviral therapies, especially among low-income and ethnic minority populations, minorities face greater barriers than whites to appropriate care. African Americans with HIV infection are less likely to receive antiretroviral therapy, less likely to receive prophylaxis for pneumocystic pneumonia, and less likely to receive protease inhibitors than non-minorities with HIV. These disparities remain even after adjusting for age, gender, education, and insurance coverage (Shapiro et al., 1999). Differences in the quality of HIV care may be related to survival rates, even at equivalent levels of access to care. Cunningham et al. (2000), for example, in a study of relative risk of six-year mortality for Hispanic, African-American, and white patients hospitalized as a result of HIV-related illness, found that Hispanics experience twice the risk of dying as whites, after controlling for sociodemographic characteristics, (e.g., access to care and insurance) and clinical characteristics (e.g., severity of illness and disease stage). Use of antiretroviral drugs prior to hospitalization did not diminish the impact of ethnicity on survival.

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African Americans with HIV infection are less likely to receive antiretroviral therapy, less likely to receive prophylaxis for pneumocystic pneumonia, and less likely to receive protease inhibitors than non-minorities with HIV. These disparities remain even after adjusting for age, gender, education, and insurance coverage.

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Shapiro et al. (1999) assessed racial/ethnic, gender, and other socio-demographic variations in care (number of care-seeking visits and use of protease inhibitors [PI] or nonnucleoside reverse transcriptase inhibitors [NNRTI]) for persons infected with HIV. Adjusting for insurance status, CD4 cell count, sex, age, method of exposure to HIV, and region of country, African-American and Hispanic patients were 24% less likely than whites to receive PI or NNRTI at initial assessment. This disparity declined to 8% at the final assessment stage, a difference that remained statistically significant. On average, blacks waited 13.5 months to receive these medications, compared with 10.6 months for whites.

Moore et al. (1994) assessed use of anti-retroviral drugs and prophylactic therapy to treat *Pneumocystis carinii* pneumonia (PCP) in an urban population infected with HIV. No racial differences were found in the stage of HIV disease at the time of presentation. However, 63% of eligible

whites, but only 48% of eligible blacks received antiretroviral therapy, and PCP prophylaxis was received by 82% of eligible whites and only 58% of eligible blacks. African-American patients were significantly less likely than whites to receive antiretroviral therapy or PCP prophylaxis. Noting that whites were more likely to report a usual source of care (59%) than African Americans (34%), the authors suggested that increased access to regular healthcare providers among minorities might reduce disparities in HIV treatment.

Bennett et al. (1995) assessed quality of care for *Pneumocystis carinii* pneumonia (PCP) among white, Hispanic and African-American patients with HIV receiving care in either Veterans Administration (VA) hospitals or non-VA systems. For all patients, regardless of the type of hospital in which they were treated, anti-PCP medications were initiated within two days of admission for 70% to 77% of patients. Approximately 60% of patients underwent a bronchoscopy at some point during hospitalization. Black and Hispanic patients at non-VA hospitals, however, were more likely to die during hospitalization, and were less likely to undergo bronchoscopy in the first two days of admission. No racial differences were found in use of bronchoscopy, receipt of anti-PCP medications within two days of admission, or mortality in VA hospitals.

### Asthma

African Americans, particularly those living in urban areas characterized by concentrated poverty, are at greater risk of morbidity and mortality due to asthma. It is unclear if the greater prevalence of asthma among African Americans is due to biologic or genetic predisposition, socioeconomic factors, or environmental living conditions, although high rates of air pollutants in urban communities is likely a key factor (Institute of Medicine, 1999c). Management and control of the disease is affected by socioeconomic as well as cultural considerations; African Americans are more likely to receive treatment for asthma in emergency rooms, and are more likely to use inhaled bronchodilator medications than inhaled corticosteroids, suggesting that management of the disease in this population has been focused more on acute symptom control as opposed to suppression of chronic airway inflammation. These patterns are not fully explained by socioeconomic differences between blacks and whites (Zoratti et al., 1998).

Zoratti and colleagues (Zoratti et al., 1998), in a study of African-American and white patients enrolled in a managed care system, found that after controlling for income, marital status, gender, and age, African-American patients were more likely than whites to access care in emergency rooms, were hospitalized more often, and were less likely to be

seen by an asthma specialist. African Americans were also more likely to use oral corticosteroids and were less likely to be prescribed inhaled anticholinergic medications. The authors note that the population at highest risk for the most severe asthma and the poorest management of the disease had the least access to specialists and the appropriate medications to manage chronic symptoms. While this study was unable to assess the severity of disease in the patient population and could not assess long-term follow-up, African Americans seen in emergency rooms appeared not to receive appropriate rates of referral to specialty care. The authors speculate that several barriers to referral may exist, particularly for low-income African Americans, including geographic distance from specialists (who are primarily located in suburban and higher-income communities), the presence of other life demands and challenges, and assumptions on the part of primary care physicians that low-income patients would be unable to maintain compliance with treatment regimens.

A combination of poor patient understanding of asthma management and inadequate physician monitoring may contribute to disparities in asthma care. Blixen et al. (1997) surveyed 24 African-American patients with asthma who were treated in an emergency department for acute asthma symptoms, and found that despite having relatively high levels of access to care (half reported belonging to an HMO, 54% lived within 10 minutes away from a regular source of healthcare, and 70.8% reported having a regular physician to treat their asthma), the disease was typically poorly managed. Overall disease-related quality of life scores suggested that these respondents experienced poorer quality of life related to asthma than white patients assessed with the same instrument in prior studies. Fewer than half (45.8%) used NIH-recommended prophylactic anti-inflammatory medication, and a majority (70.8%) managed symptoms with an inhaled beta agonist inhaler. Over half (58.3%) knew what a home peak flow meter was, but fewer than half reported that their doctor had recommended its use and only 29.2% had one in the home. A majority (62.5%) made one to three visits to the emergency departments within the past three months, and fewer than half reported speaking with their physician or nurse about asthma-related problems.

In contrast, in a study of over 5,000 patients to assess the consistency of asthma care in relation to national guidelines, Krishnan et al. (2001) found that after controlling for patient age, education, employment, and symptom frequency, no significant differences existed between African-American and white patients in use of medication regimens and asthma specialty care. Findings of racial or ethnic differences in asthma care are therefore somewhat mixed, and may vary as a function of the educational level of patient populations studied.



### Diabetes

African Americans, Hispanics, and Native Americans experience a 50%-100% higher burden of illness and mortality due to diabetes than white Americans, yet the disease appears to be more poorly managed among minority patients. In a study of nearly 1,400 Medicare beneficiaries with a diagnosis of diabetes, Chin, Zhang, and Merrell (1998) found that even after controlling for patients' gender, education, and age, African-American patients were less likely to undergo a measurement of glycosylated hemoglobin, lipid testing, ophthalmologic visits, and influenza vaccinations than white patients. African-American patients with diabetes were also more likely to use hospital emergency departments and had fewer physician visits. Similarly, Cowie and Harris (1997) found that African-American non-insulin dependent diabetes patients were more likely to be treated with insulin than whites and Mexican Americans. No significant differences were found among the racial and ethnic groups, however, in rates of visits to specialists for diabetes complications, physician testing of blood glucose, and screening for hypertension, retinopathy, and foot problems. In addition, a higher proportion of African-American patients than non-Hispanic whites and Mexican Americans were found to receive patient education, but the median number of hours of instruction was lower for African Americans. Harris et al. (1999) found that while the majority of subjects in a nationwide study of adults with type 2 diabetes used pharmacologic treatment to manage the disease, a higher proportion of African-American patients were treated with insulin and a higher proportion of Mexican-American patients were treated with oral agents when compared with non-Hispanic whites. Multiple daily insulin injections were also more common among whites. Further, a larger percentage of African-American women and Mexican-American men were found to have poor glycemic control (HbA1c > 8%) when compared with other groups. There was no relationship between glycemic control and patient socioeconomic status or access to care for any racial or ethnic group.

### Analgesia

Given the role of cultural and linguistic factors in both patients' perceptions of pain and in physicians' ability to accurately assess patients' pain (to be discussed in greater detail in Chapter 3), it is reasonable to suspect that healthcare disparities might be greater in pain treatment and other aspects of symptom management than in treatment of objectively verifiable disease. Several studies have documented underuse of analgesics among minority patients, both in in-patient and outpatient settings.

Todd, Samaroo, and Hoffman (1993), for example, found that among Hispanic and non-Hispanic white patients with long-bone fracture treated at the UCLA Medical Center emergency department, Hispanic patients were twice as likely as white patients to receive no pain medication, even after controlling for patient, injury, and physician characteristics. A follow-up study (Todd, Lee, and Hoffman, 1994) revealed that physicians' assessments of pain severity did not differ among Hispanic and non-Hispanic white patients presenting to the emergency department with extremity trauma, ruling out physicians' ability to assess pain as a possible explanation for disparities in analgesic use. Todd and colleagues (Todd et al., 2000) also found that after controlling for time since injury, time in the emergency department, need for fracture reduction, and payer status, African-American patients with long-bone fractures seen in emergency rooms were less likely than whites to receive analgesia. Similarly, as noted above, Bernabei et al. (1998), in a study of elderly nursing home residents with cancer, found that African Americans were 63% more likely than whites to receive no pain medication, after accounting for patients' gender, marital status, severity of illness, and cognitive status. Cleeland et al. (1997) found that minority cancer patients were more likely than whites to receive inadequate pain medication.

Study findings regarding use of analgesia, however, are not entirely consistent. Ng et al. (1996), for example, found that white and African-American post-operative patients were prescribed more narcotics than Asian-American and Hispanic patients. This difference persisted after adjustment for age, gender, preoperative use of narcotics, health insurance, and pain site. These findings suggest that cultural and linguistic barriers, which may have been more pronounced among Hispanic and Asian-American patients, may indeed play a significant role in physicians' ability to detect pain symptoms. These findings are in contrast to that of Todd and colleagues (Todd, Lee, and Hoffman, 1994; Todd, Samaroo, and Hoffman, 1993), who controlled for patient characteristics such as language in finding that Hispanic patients seen in emergency care settings were less likely to receive analgesia. In addition, Weisse et al. (2001) used an experimental design to assess primary care physicians' recommendations regarding treatment of hypothetical patients presenting with pain (kidney stone pain or lower back pain) or a control condition (sinusitis). Symptom presentation and severity were held constant, but the investigators varied the "patients'" race (African American or white) and gender. No overall racial or gender differences were found in treatment recommendations. However, when the physicians' recommendations were analyzed by gender, a significant interaction was observed. Male physicians prescribed higher doses of pain treatment to white than African-American patients and to male than female patients. Female physicians, on the

other hand, prescribed higher doses to African Americans than whites and females than males. Among “patients” presenting with sinusitis, no overall differences were observed in physicians’ decisions to treat patients with antibiotics, but white patients were prescribed a longer course of antibiotics and were prescribed refills more often than African-American patients. These findings lead the authors to conclude that male and female physicians respond differently to patients’ gender and race.

### **Rehabilitative Services**

Studies of racial differences in the use of rehabilitative services, such as occupational or physical therapy, yield mixed results. Hoenig, Rubenstein, and Kahn (1996) assessed racial and other sociodemographic and geographic differences in the use of physical and occupational therapy among elderly Medicare patients with acute hip fracture. Assessing records of 2,762 Medicare patients treated in 297 randomly selected hospitals from five states, the authors found that after controlling for patient clinical characteristics, African-American patients (63%) were more likely to receive a lower intensity of physical or occupational therapy than non-African Americans (43%). Similarly, Harada et al. (2000) assessed use of physical therapy among patients hospitalized in acute and/or postacute settings following hip fracture, and found that African-American patients were less likely than whites to receive acute physical therapy only, were less likely to receive therapy in both acute care and skilled nursing facilities, and were more likely to receive no physical therapy at all.

In contrast, Horner et al. (1997), in a study of inpatient utilization of physical and occupational therapy following stroke, found that a larger proportion of African American patients received physical or occupational therapy during hospitalization. After adjusting for clinical and socioeconomic factors associated with the use of physical and occupational therapy, however, no racial differences were found in the likelihood of use of therapy or time to initiate therapy (African Americans = 6.6 days, whites = 7.4). Similarly, no racial differences were found in length of physical or occupational therapy in days or as a proportion of hospital stay.

### **Maternal and Child Health**

In recent years, several federal and state initiatives have been implemented to promote access to appropriate prenatal, perinatal and postnatal care for pregnant women and their children. Despite these efforts,

many of which have been directed at low-income and uninsured women, racial and ethnic disparities have been found with modest consistency in a range of maternal and child health services.

Aron et al. (2000) assessed differences in rates of cesarean delivery by patient race and insurance status among over 25,000 women seen in 21 hospitals in northeastern Ohio. While the unadjusted overall rate of cesarean delivery was similar in white and non-white (over 90% African-American and other racial and ethnic groups) patients, adjusted analyses that controlled for clinical risk factors revealed that non-white patients were more likely to receive cesarean delivery. In contrast, Braveman et al. (1995) found that after adjusting for insurance status and personal, community, medical, and hospital characteristics, black women were 24% more likely to undergo cesarean than whites. Latino women were also at a slightly elevated risk for cesarean delivery compared with whites. Among women who delivered high-birth-weight babies, gave birth at for-profit hospitals, or resided in communities where 25% or more of the population were non-English speaking, cesarean delivery was more likely among non-whites and was more than 40% more likely among black women than white women.

Brett, Schoendorf, and Kiely (1994) assessed use of prenatal care technologies (i.e., ultrasonography, tocolysis, amniocentesis) among African-American, Hispanic, and white women, and found inconsistent racial differences in these services, after controlling for maternal age, education, marital status, location of residence, birth order, timing of first prenatal care visit, and plural births. Amniocentesis was used substantially less frequently by black women, while black women underwent ultrasonography slightly less frequently than white women. Black women with singleton births were slightly more likely to receive tocolysis than white women, although the risk of idiopathic pre-term delivery is estimated to be three times higher in black women. Black women with plural births received tocolysis two-thirds as often as white women.

In a study of civilian vs. military outcomes in prenatal care utilization, birth weight distribution, and fetal and neonatal mortality rates, Barfield et al. (1996) found that prenatal care utilization was lower for black patients than white patients in both military and civilian populations. The magnitude of the disparity was lower, however, in the military population. Similarly, Kogan et al. (1994) assessed self-reported receipt of prenatal care advice from providers among over 8,300 white and African-American women. After adjusting for age, marital status, education, income, site of prenatal care, type of payment, maternal health behaviors, when trimester care began, and prior adverse pregnancy outcomes, the authors found that white women were more likely to report receiving advice for alcohol and smoking cessation than African-American women.

Breast-feeding promotion narrowly missed significance with a trend toward more advice for white women. A significant interaction between race and marital status emerged, such that black single women were 1.4 times more likely than single white women to not receive advice on drug cessation, while there were no racial differences among married women.

### Childrens' Health Services

As is the case with maternal and infant health services, several federal and state initiatives have been initiated to improve access to healthcare among low-income children and adolescents (most notably, the federal State Child Health Insurance Program [SCHIP]). Several studies note racial and ethnic disparities in hospital-based and outpatient child health services. However, no studies to date have assessed the effectiveness of SCHIP in reducing racial and ethnic disparities in care.

Furth et al. (2000) assessed access to kidney transplantation among over 3,000 African-American and white youth under age 20 with ESRD. Controlling for factors such as age, gender, cause of ESRD, family socioeconomic status (SES), incident year of ESRD, ESRD network, and facility characteristics, the authors found that African-American youth were 12% less likely than white patients to be activated on the kidney transplant wait list. Family socioeconomic characteristics, however, reduced this disparity; the relative hazard for black patients in the lowest SES quartile being activated on the wait list was .84, compared with relative hazard of 1.0 for black patients in the highest SES quartile.

Hahn (1995) assessed use of prescription medications between two samples of children (ages 1 to 5 and ages 6 to 17) who had at least one ambulatory care visit in 1987. Among children aged one to five, African-American children were half as likely to receive prescription medication compared with white children. Adding health factors to the model did not change this relationship. However, the addition of numbers of physician visits reduced these differences, such that they were no longer significant. There was no difference in the probability of receiving medication for Hispanic children compared with white children. After controlling for age, maternal education, insurance, poverty status, source of care, geographic location, health status, number of bed days, number of reduced activity days, and physician visits, black children received the fewest number of medications. The average number of medications for black children was 86.5% compared to that of white children, while Hispanic children averaged 94.1% of medications compared to that of white children. Among children aged 6 to 17 years, African-American and Hispanic children were 46% and 38% less likely, respectively, to receive any prescription medication compared with white children. The addition of

health factors and numbers of physician visits did not change these relationships, and they remained after controlling for age, maternal education, insurance, poverty status, source of care, geographic location, health status, number of bed days, number of reduced activity days, and physician visits. Similarly, Zito et al. (1998) found that white children were twice as likely to receive psychotropic prescriptions compared with African-American children.

A study examining parents' perceptions of pediatric care found striking racial and ethnic differences. Weech-Maldonado et al. (2001) used data from the National Consumer Assessment of Health Plans (CAHPS) Benchmarking database and found that minority parents, particularly non-English speakers, were less satisfied than white parents with pediatric services, after controlling for parents' gender, age, education, and their children's health status. African-American and American-Indian parents were found to be less satisfied than whites in getting needed care, the timeliness of care, provider communication, and health plan services. Among Asian-American and Hispanic parents, parental satisfaction was lower than for whites only among those who were non-English speakers. Asian-American and Hispanic non-English speakers rated staff helpfulness, timeliness of care, provider communication, health plan services, and getting needed care lower than did white parents, while Asian-American and Hispanic parents who were proficient in English did not differ significantly from whites on any reports of care.

### **Mental Health Services**

Several studies document racial and ethnic variation in receipt of mental health services. Significantly, the U.S. Surgeon General recently completed a major report assessing racial and ethnic disparities in mental health and mental healthcare that reviews much of the available literature. That report finds that more so than in other areas of health and medicine, mental health services are "plagued by disparities in the availability of and access to its services," and that "these disparities are viewed readily through the lenses of racial and cultural diversity, age, and gender" (U.S. DHHS, 2001a, p. vi). Major findings of the report include that: mental illnesses are real and disabling conditions that affect all populations (regardless of race/ethnicity); striking disparities are found for racial and ethnic minorities; and these disparities impose a greater disability burden on racial and ethnic minorities. In addition to universal barriers to quality care (e.g., cost, fragmentation of services), the report notes that other barriers, such as mistrust, fear, discrimination, and language differences carry special significance for minorities in mental health treatment, as these barriers affect patients' thoughts, moods, and behav-

ior. Communication and trust are particularly critical in treatment, the report notes, and differences in the cultural perspectives of the patient and clinician/healthcare system must be acknowledged and addressed (U.S. DHHS, 2001a).

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Several studies have examined disparate use of psychotropic medications and mental health services and find disparities, with minorities in some cases receiving *higher* quantities of medications. For example, in a study examining prescriptions of antipsychotic medications by physicians in psychiatric emergency services, Segal, Bola, and Watson (1996) found that African-American patients received more oral doses and injections of antipsychotic medications. The 24-hour dosage of antipsychotic medication given to African Americans was also significantly higher than for other patients. Analyses controlled for several clinical factors including presence of psychotic disorder, severity of disturbance, dangerousness, psychiatric history, if physical restraints were used, hours spent in the emergency service, clinician’s efforts to engage patient in treatment, and whether optimum time was spent on the evaluation. The study also found that the tendency to overmedicate African-American patients was lower when a clinician’s efforts to engage the patients in treatment were rated as being higher. Models predicting number of medications, number of oral and injected antipsychotic and 24-hour dosage became non-significant.

In contrast, a study examining medication prescribed for depression yielded different results. Melfi and colleagues (2000) assessed antidepressant treatment in a population of Medicaid beneficiaries diagnosed with depression. Analyses controlled for age, gender, Medicaid eligibility status, and several clinical factors. Forty-four percent of whites and 27.8% of blacks received antidepressant treatment within 30 days of the first indicator of depression. White patients were more likely to receive antidepressants than black patients and patients in the other/unknown racial category.

An examination of privately insured federal employees, conducted by Padgett and colleagues (1994), assessed racial and ethnic differences in use of inpatient psychiatric services. Analyses controlled for a variety of predisposing factors (e.g., education, family size, racial/ethnic composition of residing county), enabling factors (region of country, salary, high

or low option selected for insurance coverage), and need factors (annual medical expenses, family's annual medical expenses, other family member receipt of inpatient psychiatric care, sum of outpatient mental health visits by other family members). No significant differences were found among blacks, whites and Hispanics as to the probability of a psychiatric hospitalization or in number of inpatient psychiatric days.

### **Racial and Ethnic Differences in Other Clinical and Hospital-Based Services**

Several studies document racial and ethnic disparities in other clinical and hospital-based services. Ebell et al. (1995) assessed the rate of survival by patient race following in-hospital cardiopulmonary resuscitation (CPR) of 656 patients at one of three teaching hospitals. Black patients in this study were less likely than non-black patients to have an admitting diagnosis of myocardial infarction (MI), were less likely to have a history of coronary artery disease, but had a higher severity of illness according to a standard screening instrument. Controlling for these variables, black patients were found to have poorer survival to discharge than non-black patients. Because resuscitation was provided in-hospital, differences in ambulance response time, access to telephones, or other community factors could not account for this difference. Further, because there were no significant racial differences in the success of the resuscitation effort, the difference in survival appears to be related to the quality of care after resuscitation, or to other unmeasured factors.

Devgan et al. (2000) assessed surgical treatment for glaucoma among large samples of African-American and white Medicare patients, and found that African-American patients received argon laser trabeculoplasty or trabeculectomy surgery at nearly half of expected rates, once the age-race prevalence of glaucoma was considered. Arozullah et al. (1999) assessed rates of laparoscopic cholecystectomy among more than 16,000 Veterans Administration (VA) patients diagnosed with gall bladder or biliary disease. After controlling for patient age, marital status, co-morbid illness, year of surgery, and hospital geographic location, the investigators found that African-American patients who underwent cholecystectomy were less likely than white patients to undergo the laparoscopic procedure. In contrast, another study of VA patients (Selim et al., 2001) found that among patients presenting with low-back pain, "non-white" patients in higher levels of pain were more likely to receive lumbar spine radiographs than white patients experiencing similar pain levels, although this racial difference disappeared after controlling for clinical characteristics.

Fewer studies have assessed the quality of basic healthcare services.



In one such study, Ayanian et al. (1999) utilized explicit process criteria and implicit review by physicians to assess the quality of care for patients hospitalized with congestive heart failure and pneumonia. Using records from a stratified random sample of over 2,000 Medicare beneficiaries, the authors found that among patients with congestive heart failure, African Americans received a lower overall quality of care than other patients by implicit review, but not explicit review. Among patients with pneumonia, African-American patients received a lower quality of care by explicit criteria, but not explicit review. These differences persisted in analyses adjusting for patient and hospital characteristics. Adjusted analyses also revealed no significant differences in quality of care for patients from poor communities, as compared with other patients. Similarly, in a review of discharge data from over 1.7 million patients assessed via the Hospital Cost and Utilization Project (HCUP-2), Harris, Andrews, and Elixhauser (1997) found that African Americans were less likely than whites to receive major therapeutic procedures for 37 of 77 conditions, and more likely than whites to receive a major therapeutic procedure in 9.1% of conditions studied. These differences persisted even after controlling for patients' age, expected pay source, indicators of clinical condition, and hospital-level characteristics (e.g., bed size, public ownership, teaching status, and urban location).

In a study of racial differences in mortality and resource use among patients admitted to intensive care units, Williams et al. (1995) found no significant differences in risk-adjusted in-hospital mortality. The authors did find, however, that African-American patients had a shorter length of stay and lower resource use in the first seven days compared with white patients. For example, whites received more technological monitoring (arterial and pulmonary artery catheters, pulse oximetry), more laboratory testing, and a greater proportion of life-saving treatments. These differences persisted after adjusting for patient characteristics and insurance status, leading the researchers to conclude that these differences could reflect undertreatment for African Americans or overutilization of services by whites.

In another study of Medicare patients, Wilson, May, and Kelly (1994) assessed racial differences in receipt of total knee arthroplasty among older adults with osteoarthritis. The authors found that while osteoarthritis was slightly, but not significantly, more common among African Americans, whites were more likely to receive total knee arthroplasty. This relationship held true at all income levels and could not be explained by prior procedures or the use of alternative procedures.

White-Means (2000) assessed the use of long-term care services (paid caregiver, therapist, mental health, dentist, foot doctor, optometrist, chiropractor, ER visit, doctor visits, prescription medications) by disabled

elderly Medicare patients, as a function of medical conditions and disabilities, income, insurance status, regional and rural residence, whether unpaid caregivers provide in-home services, and sociodemographic characteristics (e.g., gender, education). Given similar medical conditions, African-American patients were found to be less likely to use long-term care services, particularly prescription medications and physician services. African-American patients who lived in rural areas, small cities, and western states or who had more joint and breathing problems were more likely to use services. Differences in personal attributes (e.g., income, health) did not fully explain racial differences in use of prescriptions and physician services. Similarly, Khandker and Simoni-Wastila (1998) assessed racial differences in use and level of use of prescription drugs among a sample of Medicaid patients, controlling for age, sex, and Medicaid eligibility characteristics. African-American children were found to use 2.7 fewer prescriptions compared with white children. African-American adults used 4.9 fewer prescriptions, and African-American elders used 6.3 fewer prescriptions than white elders. White Medicaid enrollees had higher use and spending than black enrollees across most high-volume therapeutic drug categories.

In a study of primary care, Shi (1999) assessed patients' perceptions of intake, service delivery, referral, and follow-up among nearly 15,000 white, African-American, Hispanic, and Asian respondents to the Medical Expenditure Panel Survey (MEPS). Controlling for patients' perceived need for care, ability to obtain services, and frequency of use of care, Shi found that African-American, Hispanic, and Asian-American patients tended to experience greater barriers to receiving primary care. Hispanic patients were over 40% less likely to have a usual source of care, while those African-American and Hispanic patients who did report a regular primary care provider tended to reference a facility (hospital or clinic) rather than an individual provider. African Americans were less likely to have a primary care specialist as a regular provider. All three minority groups were 39% to 48% more likely than whites to report long waiting periods before seeing their care provider, but Asian-American patients were more likely than any racial/ethnic groups to report that getting an appointment was "very difficult." On an encouraging note, this study also found that overwhelming numbers of whites and minority patients reported confidence in their provider and that their usual care provider "listened to them"—over 90% agreement for all groups.

A small number of studies have assessed racial and ethnic differences in preventable hospitalizations. Preventable hospitalizations are those that might not have occurred had patients received timely and appropriate preventive care in the case of acute conditions, as well as effective and continuous care for chronic conditions. Gaskin and Hoffman (2000) as-

sessed rates of preventable hospitalizations among children, working-age adults, and the elderly, while adjusting for a range of sociodemographic (e.g., age, income, insurance status), community-level (e.g., neighborhood characteristics, physicians, and hospital beds per capita), and health status (e.g., co-morbidities) variables. Results indicated that African Americans and Hispanics were significantly more likely to be hospitalized for preventable conditions than whites, even after adjusting for patient differences in healthcare needs, socioeconomic status, insurance coverage, and the availability of primary care providers. Subsequent analyses of individuals within similar health insurance plans confirmed that these differences exist independently of insurance status. The findings were limited by the lack of information on the competency of providers seen by minority patients, the adequacy of insurance plans, and personal health-seeking behavior.

Minority patients are more likely to undergo amputation than white patients. Such is the case with limb amputation, where more than 50,000 procedures are performed each year among patients with diabetes. Guadagnoli et al. (1995) assessed racial differences in the use of amputation and leg-sparing surgery among a random sample of Medicare patients. The authors found that African-American patients were nearly twice as likely as whites to undergo above-knee amputation, and were slightly more likely than whites to undergo toe and/or foot amputation, controlling for co-morbid disease, prior hospitalizations, geographic region, hospital teaching status, and other factors. Whites, on the other hand, were more likely to undergo lower-extremity arterial revascularization and percutaneous transluminal angioplasty than African-American patients. The study did not, however, control for disease severity, although the authors note that controls for co-morbid disease and prior hospitalizations may attenuate this potential confounding factor. Similarly, Gornick et al. (1996), in a study of 26.3 million Medicare beneficiaries, found that African Americans were more likely than whites to undergo bilateral orchiectomy or amputation of the lower limbs, even after controlling for income differences. Finally, Collins et al. (2002) assessed racial and ethnic differences in rates of lower extremity amputation versus lower extremity bypass revascularization among a sample of VA patients with peripheral arterial disease. In this prospective study, the authors statistically adjusted for a range of factors that may be associated with the use of amputation versus revascularization (e.g., presence of diabetes, hypertension, heart disease, or other co-morbid conditions, behavioral risk factors such as smoking or alcohol use, geographic location of the VA hospital), and found that African-American and Hispanic patients were 1.5 and 1.4 times, respectively, more likely than white patients to undergo amputation than revascularization (Collins et al., 2002).

### Gaps in Existing Research

While the research reviewed here points to significant variation in access to and use of services by race and ethnicity, several gaps exist that must be addressed to develop a more comprehensive understanding of racial and ethnic disparities in healthcare. The most significant gap in this research is the failure to identify mechanisms by which these disparities occur. A robust research agenda is needed to better understand how the process and structure of care may vary by patient race (see chapter on “Needed Research”). Such research must consider the range of influences on patients’ and providers’ attitudes and expectations in the clinical encounter, clinical decision-making processes employed by healthcare providers and the influence of patient race in these processes, the nature and quality of communication between patients and providers (particularly as it occurs across cultural and/or linguistic lines), the environments and settings in which care is delivered, and other factors that will be discussed later in this report. In addition, as noted below, no research has yet illuminated the relative contribution of these factors to the healthcare disparities observed in the literature.

Assessing sources of disparities in care in the current literature is also complicated by many methodological considerations. Attempts to control for SES differences are inconsistent, with some researchers employing patient income or education as sole indicators of SES, and others using proxy variables such as estimates of income on the basis of patients’ zip code information. Most studies control for insurance status, but some combine data from patients insured via different types of health systems (e.g., HMO or fee-for-service) or different sources of insurance coverage (e.g., public vs. private).

Some studies have explicitly examined differences in where racial and ethnic groups receive care (e.g., public vs. private healthcare settings), and clinical factors such as stage of illness progression at presentation (e.g., on average, ethnic minority cancer patients present at later stages of disease progression, thereby limiting treatment options) or other co-morbid factors that may limit treatment options. Other studies have attempted to control for the quality of diagnostic evaluation and disease severity. Adequate assessment of these factors, however, is often limited by a lack of sufficient information in administrative claims data upon which many studies are based. These datasets often rely on crude or incomplete measures of disease severity and the types of treatment provided, and contain limited information on prior diagnoses or treatments. Further, most studies (with the exception of several studies of cardiovascular care) lack comparison to standards for the appropriateness of care,

leaving open the question of whether care received was sufficient given the type and severity of disease.

Finally, one of the most significant limitations of existing research is the failure to analyze differences in care beyond comparisons of African-American and white patients. With the exception of a few large studies conducted in ethnically diverse regions of the United States such as California and New York, few studies have assessed whether disparities in care exist for Hispanic and Asian-American populations. Further, few studies have examined subgroup differences within these populations. These issues are particularly salient for Hispanic and Asian-American subgroups, whose healthcare may be complicated by linguistic and cultural differences, immigration status, and other access-related issues.

### **The Extent of Racial and Ethnic Disparities in Healthcare**

As the discussion above suggests, many factors influence the provision and receipt of diagnostic and therapeutic healthcare services. Further, healthcare outcomes are influenced by a wide variety of factors, many of which are beyond the scope of clinical factors such as the efficacy of treatment protocols. Assessing the relative contribution of the many patient, provider, and system-level influences on care is therefore an imprecise exercise. Similarly, assessing the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care is not likely to yield reliable estimates.

Some studies have attempted to assess the extent of racial and ethnic disparities in a small number of key indicators of healthcare use. Weinick, Zuvekas, and Cohen (2000) assessed racial and ethnic differences in access to and use of healthcare services (i.e., having a usual source of care and the use of ambulatory care services), and evaluated the magnitude of these differences above and beyond access-related factors such as insurance status, income, and other socioeconomic characteristics. The authors found that after adjusting for health insurance, income, age, sex, marital status, education, health status, region of the country, and residence in a metropolitan area, Hispanics and African Americans were significantly more likely to lack a usual source of care and were less likely to use any ambulatory care services than white Americans. Hispanics were nearly 10% more likely to lack a usual source of care, and African Americans and Hispanics were nearly 9% and over 10% less likely, respectively, to have made any ambulatory care visits. The authors performed additional analyses to assess the extent of these disparities, simulating conditions in which all racial and ethnic groups earned equivalent income and were insured at the same level. For all groups, 55% to 77% of the observed differences remained, demonstrating that "health insurance coverage and

income typically each account for only about one fifth, and never even as much as one half, of the disparities . . . observed" (Weinick, Zuvekas, and Cohen, 2000, p.43). The authors acknowledge, however, that these racial and ethnic disparities in the use of services could be related to unmeasured factors, such as job-related and non-financial barriers, poor cultural and linguistic access, an inadequate geographic distribution of healthcare providers in racial and ethnic minority communities, and other factors.

More such studies are needed to assess the relative contribution of access-related factors (e.g., insurance status), other socioeconomic and geographic variables (e.g., patients' education, income, and the availability of healthcare providers in a community), and racial and ethnic differences in healthcare preferences and attitudes to determine the extent of disparities in care. This research is needed across a range of health conditions. Currently, however, this research does not present a sufficient empirical foundation to assess the extent of racial and ethnic healthcare disparities. The committee therefore concludes that while evidence of racial and ethnic disparities in care appears consistently across a range of health conditions and medical procedures, attempts to assess or quantify the extent of these disparities, based on evidence currently available, are not likely to prove to be reliable or valid.

#### SUMMARY

Racial and ethnic minority patients are found to receive a lower quality and intensity of healthcare and diagnostic services across a wide range of procedures and disease areas. This finding is remarkably consistent and robust, as only a handful of the several hundred studies reviewed here and by others (e.g., Geiger, this volume; Kressin and Peterson, 2001; Mayberry et al., 2000) find no racial and ethnic differences in care. In studies where patients' sociodemographic characteristics (e.g., education level, income), insurance status (e.g., public or privately funded insurance) and clinical factors (e.g., co-morbid illness, severity of disease) are controlled, these racial and ethnic differences are generally attenuated, but rarely disappear completely. Further, in a few well-designed, prospective studies, these disparities in care have been linked to poorer clinical outcomes and higher mortality among minorities (Peterson et al., 1997; Bach et al., 1999).

Insurance status, in particular, emerges in several studies as a key predictor of the quality of care that patients receive. The privately insured generally receive a higher quality of care than those who are insured through publicly funded sources (e.g., Medicaid), or those who have no health insurance. Racial and ethnic minorities are disproportionately represented between the latter two categories, yet when sources of insur-

ance are controlled statistically or by study design, race and ethnicity remain as significant predictors of the quality of care. This disparity is best illustrated in studies of care among Medicare populations (Gornick et al., 1996), which reveal lower rates of use of effective, higher technology diagnostic and therapeutic procedures among minorities for illnesses such as heart disease, cancer, and other chronic illnesses, and higher rates of less desirable procedures, such as amputation and bilateral orchiectomy.

The quality of care that minority and non-minority patients receive is also partly a function of where these populations tend to receive care. Several studies note that patient care is of lower quality in non-teaching hospitals, public hospitals and clinics than in teaching hospitals or private settings. While some minorities are more likely to receive care in the former settings, they are more likely to access care in emergency departments, and are less likely to have a regular source of care (Collins, Hall, and Neuhaus, 1999). Further, minorities tend to have lower access than whites to specialty care, and are less likely to be treated in settings that offer higher-technology procedures—all factors related to the quality of care in the studies reviewed here. Again, however, when these variables are controlled statistically or by study design, racial and ethnic minorities tend to receive a lower quality of care.

Most studies have compared the quality of care received by minority patients relative to that of whites as the standard of comparison. This type of analysis, however, fails to provide a complete picture of the appropriateness of care, as whites may over-utilize some services, and racial differences in the severity of disease at presentation or treatment response may contraindicate the use of similar therapeutic interventions. Some of the best-designed studies reviewed here, however, assessed the quality of care provided relative to well-established clinical criteria, and use objective diagnostic measures to assess the extent and severity of disease. In these studies, race and ethnicity again typically emerge as significant predictors of the quality of care received, indicating that disparities in care are not simply a function of disproportionate use by whites or greater disease severity among minorities.

These findings appear consistently in studies of differences in care received by African-American and white populations, and increasingly, in studies involving Hispanic patients. A few studies suggest that Asian Americans also are less likely to receive the same quality of care as whites (e.g., Carlisle et al., 1995). This review produced no studies where the quality of care for American Indian, Alaska Native, or Pacific Islander populations were explicitly studied, or where the sample size of these populations permitted analysis. Further, in few instances were subgroups of these populations explicitly studied. As will be discussed in a later

chapter, research is urgently needed to assess the quality of care for these populations relative to the burden of illness.

A few of the studies that find no racial and ethnic differences in care indicate that characteristics of health systems may serve an important role in mediating these disparities. Studies of patients in military healthcare systems reviewed here indicate a lower prevalence of racial or ethnic differences in the quality of healthcare that active-duty personnel or their families receive. Similarly, some studies of patients in VA systems demonstrate reductions in racial and ethnic differences in care, although these studies are less consistent. Future research must assess the range of factors that distinguish these health systems from other private or publicly funded systems to better understand how patient race and ethnicity are related to care and care outcomes. For example, the impact of differences in provider profiles should be investigated, as VA hospitals commonly are staffed by a larger percentage of trainees than other systems. Nonetheless, these studies suggest that characteristics of these health systems, perhaps related to universal or equal access to care, may attenuate disparities that are typically found in other systems.

Collectively, these findings support the hypothesis that patients' race and ethnicity significantly predict the quality and intensity of care that they receive. Succeeding chapters of this report will review the historical context in which these disparities occur, and examine the types of settings in which minorities typically receive care, as well as the characteristics of healthcare providers that serve them. Potential sources of healthcare disparities will be closely examined, including patient preferences; provider biases, stereotyping, and clinical decision-making; and the impact of financial and institutional characteristics of health systems on the quality of care for minority patients. Finally, several strategies to eliminate these disparities are proposed, and future research directions are outlined.

**Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.**

**Racial and ethnic disparities in healthcare exist. These disparities are consistent and extensive across a range of medical conditions and healthcare services, are associated with worse health outcomes, and occur independently of insurance status, income, and education, among other factors that influence access to healthcare. These disparities are unacceptable.**



## 2

# The Healthcare Environment and Its Relation to Disparities

Many aspects of the healthcare environment influence the quality of care received by U.S. racial and ethnic minority groups. The historical evolution of healthcare for persons of color, the current financial and organizational structures of health systems, the settings in which care is delivered, and the nature of the workforce providing care may, both independently and jointly, influence the quality of care that minorities receive. This chapter describes some of these environmental factors and the influences they may have on healthcare for racial and ethnic minorities.

The first two sections of this chapter describe aspects of the social and economic contexts in which racial and ethnic minority groups live in the United States. These sections review: a) the health, health insurance, and linguistic status of these groups, and b) racial attitudes and patterns of segregation and discrimination in various sectors of American life. The third section reviews the history of segregated healthcare and contemporary settings in which racial and ethnic minorities receive healthcare, including the influence and importance of community health centers. The last section focuses on the healthcare workforce in minority communities—how this workforce originated, where individuals practice, who they serve, and the influence of international medical graduates on healthcare in minority communities. The chapter concludes with a discussion of medical education, how affirmative action has served to increase the presence of underrepresented minorities in the health professions workforce, and how recent legal challenges to affirmative action have affected and may have a future impact on the healthcare workforce.

Much of the data presented in this chapter are drawn from available literature and large national data sources, such as the U.S. Census and the National Center for Vital and Health Statistics. Where possible, data on subpopulations of racial and ethnic groups (e.g., Cuban American, Puerto Rican, Mexican American, and other subgroups of the Hispanic population) are presented. This information is supplemented, where appropriate, by qualitative data regarding the experiences of racial and ethnic minority patients and healthcare professionals. These data, presented in individuals' own words, are offered as a means of understanding some of patients' and providers' experiences and perceptions of how race or ethnicity may affect both care processes and the systems and settings in which care takes place. As such, these data are not intended to substitute for empirical findings. Rather, they serve to "give voice" to the experiences of key actors in healthcare disparities, and illuminate how healthcare disparities are perceived by patients and their providers. Qualitative data were gathered via three mechanisms:

- Roundtable discussions with minority healthcare consumers, professionals and advocates at one of two large national conferences (the Asian American and Pacific Islander Health Forum conference and the Indian Health Service Research Conference, both held in April, 2001);
- Liaison panel discussions with consumer and professional groups, federal agency representatives, and minority health advocates held in the spring and summer, 2001;
- Focus group sessions conducted during this same time period; and interviews with American Indian and Alaska Native tribal leaders and a cadre of healthcare providers serving American Indian and Alaska Native communities (Joe, this volume).

For more information on these data collection activities and a summary of focus group and liaison panel findings, please see Appendixes A and D.

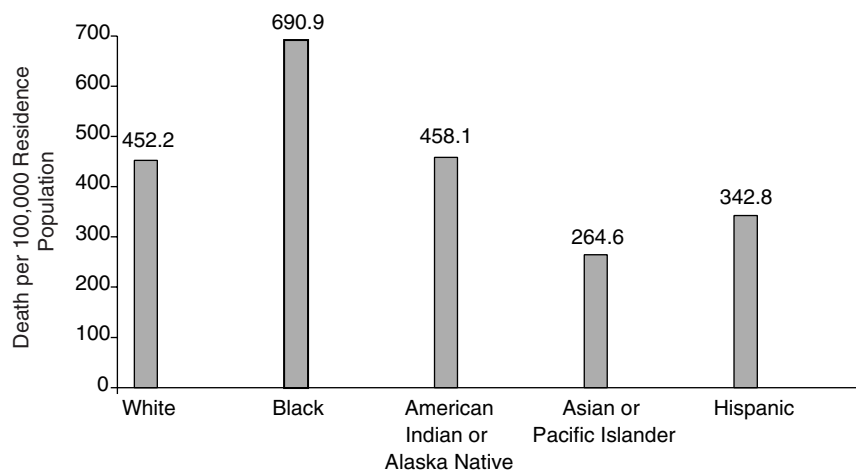
## **THE HEALTH, HEALTH INSURANCE, AND LANGUAGE STATUS OF RACIAL AND ETHNIC MINORITY POPULATIONS**

This section provides an overview of factors that influence healthcare and healthcare needs of minority populations—including their health and insurance status, and linguistic barriers to care.

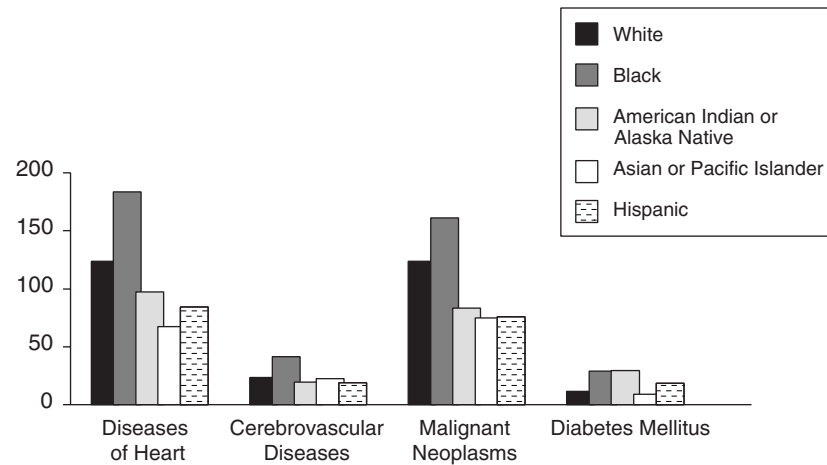
### **Health Status**

Some racial and ethnic minorities experience higher rates of chronic and disabling illnesses, infectious diseases, and mortality than white

Americans. As depicted in Figure 2-1, African Americans have the highest rates of morbidity and mortality of any U.S. racial and ethnic group. The mortality rate for African Americans is approximately 1.6 times higher than that for whites—a ratio that is identical to the black/white mortality ratio in 1950 (Williams and Rucker, 2000). American Indians and Alaska Natives also experience higher mortality rates than whites, accompanied by low life expectancy. And while other racial and ethnic minorities experience lower overall mortality rates than whites, these data mask both inter-group variation (e.g., among Hispanics, Puerto Ricans experience higher infant mortality rates than whites [National Center for Health Statistics, 2000]), and an elevated burden of disease among some groups for specific causes of mortality. As depicted in Figure 2-2, some causes of mortality, such as diabetes, disproportionately affect African-American, Hispanic, and American Indian/Alaska Native populations. In addition, some subpopulations of racial and ethnic groups experience an elevated incidence and mortality due to specific diseases. Alaska Natives experience the highest rates of colon and rectal cancers of any racial or ethnic group in the United States (Institute of Medicine, 1999b). Korean Americans have the highest rates of stomach cancer (48.9 per 100,000 population) among U.S. males, followed by Japanese Americans (30.5 per 100,000 population; Institute of Medicine, 1999b). Similarly, Vietnamese-American women experience the highest incidence of cervical cancer in the United States, at rates nearly six times higher than that of white women (Institute of Medicine, 1999b).



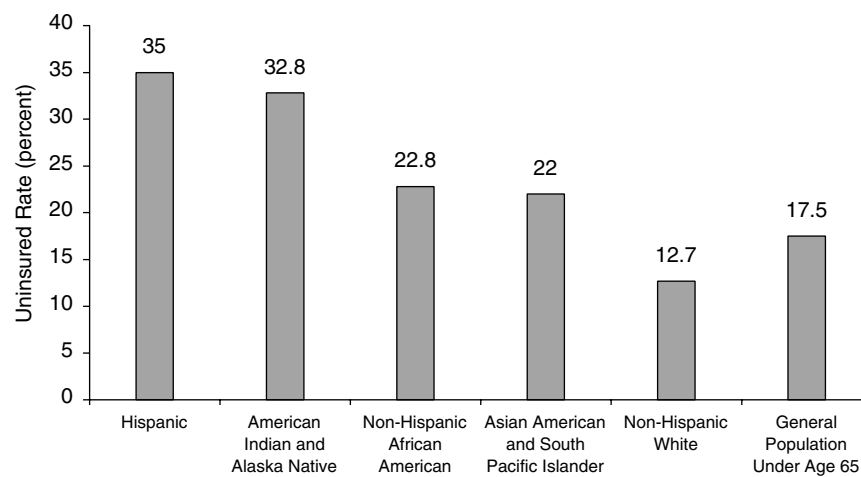
**FIGURE 2-1** Age-adjusted death rates for all causes of death by race and Hispanic origin: United States, 1950-1998. SOURCE: Health, United States, 2000 (2001).



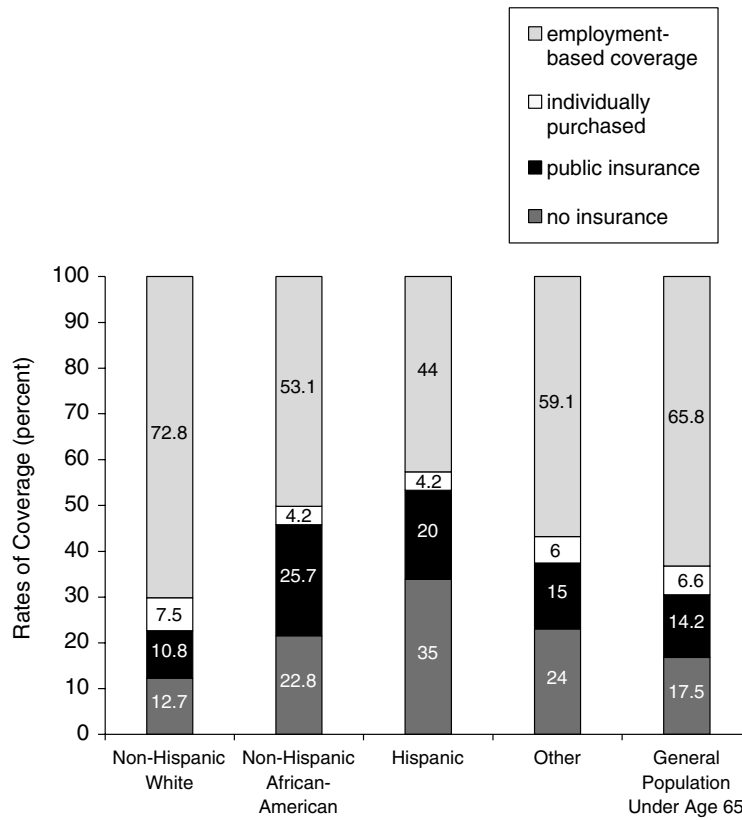
**FIGURE 2-2** Age-adjusted death rates for selected causes of death by race and Hispanic origin: United States, 1950-1998. SOURCE: Health, United States 2000 (2001).

### Insurance Status

Racial and ethnic minority Americans are significantly less likely than white Americans to possess health insurance (see Figures 2-3 and 2-4). The problem is particularly acute among the working poor and individuals who have no employment-based insurance, and among whom minori-



**FIGURE 2-3** Probability of being uninsured for population under age 65, by race and ethnicity. SOURCE: Hoffman and Pohl, 2000.



**FIGURE 2-4** Sources of health insurance for population under age 65, by race and ethnicity, 1999. NOTE: Numbers may not add to 100 percent due to respondents reporting more than one source of coverage and due to rounding. SOURCE: Fronstin, 2000.

ties, particularly Hispanic Americans, are over-represented. Lack of insurance poses the most significant barrier to care. Insurance status, perhaps more than any other demographic or economic factor, determines the timeliness and quality of healthcare, if it is received at all (Institute of Medicine, 2001b).

#### *African Americans*

African Americans are less likely to possess private or employment-based health insurance relative to white Americans, and are more likely to be covered via Medicaid or other publicly funded insurance (see Figure

2-4). In addition, African Americans are almost twice as likely as non-Hispanic whites to be uninsured. High rates of uninsurance among this population occur despite the fact that over 8 in 10 African Americans are in working families, as a disproportionate percentage of African Americans work in jobs that provide no health insurance (The Henry J. Kaiser Family Foundation, 2000a). As illustrated in Figure 2-3, the probability of being without health insurance coverage for African Americans is 22.8 percent, compared with 17.5 percent in the general population.

#### *American Indians and Alaska Natives*

The U.S. government is obligated through treaty and federal statutes to provide healthcare to members of federally recognized American Indian tribes. This trust, however, has not been fully met, for several reasons. The federal Indian Health Service (IHS) provides healthcare services primarily on Indian reservations, which are home to only a minority of American Indians (as few as 30%), as the majority of the population currently lives in urban or other non-reservation areas (Brown et al., 2000). To obtain IHS care, Indians must travel to their home reservation. Not surprisingly, a large majority (80%) of American Indians and Alaska Natives report no access to IHS facilities (The Henry J. Kaiser Family Foundation, 2000a). Although the federal government contracts with a number of urban Indian health organizations to provide services, such federal support is often limited. In general, the agency's resources (slightly over \$2 billion was appropriated to the agency in fiscal year 1998) are far below needs. In fiscal year 1997, for example, the agency reported \$1,430 in per capita expenditures, a figure that is 1.4 to 2.8 times below the per capita spending of other federal health programs and agencies such as Medicaid (\$3,369) and the Veterans Administration (\$5,458) (National Indian Health Board, 2001).

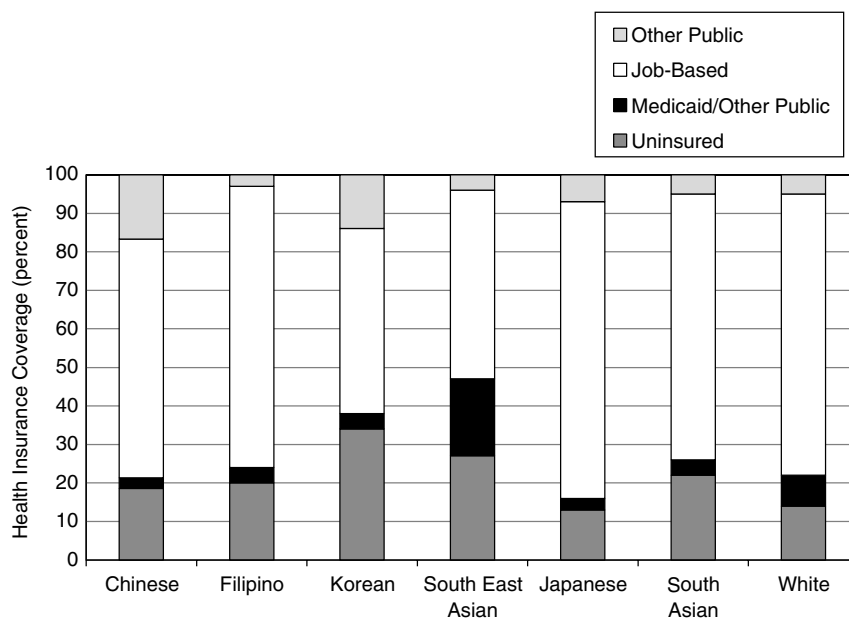
Figure 2-3 indicates that nearly one-third of American Indians and Alaska Natives (32.8%) lack health insurance, compared with 17.5% in the general population. Slightly less than half of American Indians and Alaska Natives have job-based health insurance, while one quarter receive Medicaid insurance and a similar proportion are uninsured or report only IHS coverage (The Henry J. Kaiser Family Foundation, 2000).

#### *Asian Americans and Pacific Islanders*

Some of the ethnic subgroups among Asian Americans and Pacific Islanders (API) have disproportionately high rates of uninsurance (Brown et al., 2000; Hoffman and Pohl, 2000). Rates vary considerably, although

generally, only 64% of API populations have job-based health insurance, compared with nearly three-fourths of whites (73%). Nearly one-fourth of API populations are uninsured (see Figure 2-3). Generally, rates of public insurance are lower for Asian Americans and Pacific Islanders, except for some Southeast-Asian subpopulations (Brown et al., 2000).

Within API subgroups, Korean Americans are least likely to have health insurance. Less than half have job-based insurance (49%), while over one-third (34%) are uninsured and 14% receive Medicaid or other publicly funded insurance. Similarly, South East-Asian (e.g., Vietnamese, Cambodian, Laotian) and South-Asian (e.g. Indian, Pakistani, Bangladeshi) populations are disproportionately uninsured (27% and 22%, respectively). Less than half (49%) of South East-Asians have job-based insurance, while nearly seven in ten South-Asians (69%) have job-based insurance. Two in ten Chinese-American and Filipino-American families are uninsured (The Henry J. Kaiser Family Foundation, 2000b). These data are depicted in Figure 2-5.



**FIGURE 2-5** Health insurance coverage by Asian-American and Pacific-Islander subgroups vs. whites (Ages 0-64), 1997. SOURCE: The Henry J. Kaiser Family Foundation, 2000b.

### *Hispanic Americans*

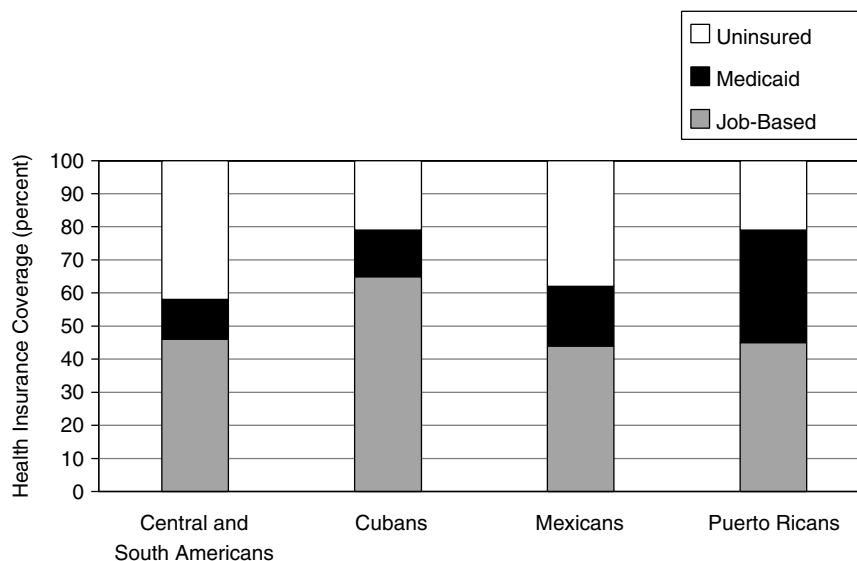
Hispanic Americans face greater barriers to health insurance than all other U.S. racial and ethnic groups. The probability of being uninsured among Hispanic Americans is 35 percent, compared with 17.5 percent for the general population (Hoffman and Pohl, 2000). This disparity, depicted in Figures 2-3 and 2-4, largely results from the lack of job-based insurance provided to Hispanic Americans, who disproportionately work in blue-collar and service-oriented jobs. The vast majority (87%) of uninsured Hispanics are in working families, yet only 43% of Hispanics receive health insurance through work. Further, nearly one-third of Hispanics (30%) work for an employer who does not offer health insurance to workers (The Henry J. Kaiser Family Foundation, 2000b). The high rate of uninsurance among Hispanics is also a reflection of a lower-than-average rate of participation in publicly funded health plans. In families with incomes less than the federal poverty level, 45 percent of all Hispanics are uninsured, compared with 32 percent of non-Hispanic whites (Fronstin, 2000). Differing eligibility standards may play a significant role in the lower rates of coverage for Hispanics under some publicly funded insurance plans, as many state and federal guidelines do not permit coverage for extended family members or families where married spouses live in the same household.

Hispanic subgroups vary in rates and sources of insurance coverage. Cuban Americans experience the highest rates of job-based or other private insurance (65%), and along with Puerto Ricans, are least likely to be uninsured (21%). Less than half of Puerto Rican, Central and South American-descendent, and Mexican Americans have job-based or other private insurance (45%, 46% and 44%, respectively), and over one-third of Puerto Rican Americans (34%) are insured by Medicaid or other publicly funded programs. More than 4 in 10 Central and South American descendent-Americans are uninsured (42%), as are 38% of Mexican Americans. These data are displayed in Figure 2-6.

### **Linguistic Barriers**

Many racial and ethnic minority Americans experience language barriers. These barriers range from low or no English proficiency to limited proficiency in speaking, reading or comprehending English. In healthcare settings, these linguistic barriers can present significant challenges to both patients and providers, despite federal regulations that encourage and support the use of interpreters (Office of Civil Rights, U.S. Department of Health and Human Services, 2000). According to the 1990 U.S. Census, 14 million people living in the United States have no or limited English-language skills



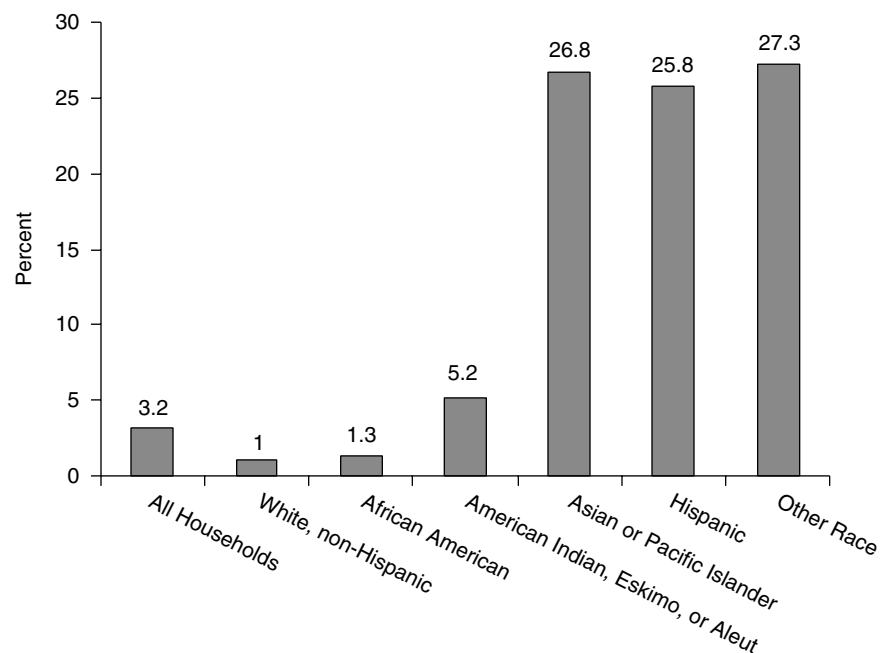


**FIGURE 2-6** Health insurance coverage among Latino subgroups (Ages 0-64), 1997. SOURCE: The Henry J. Kaiser Family Foundation, 2000b.

(data from the 2000 Census are not available as of this writing). These populations can be found throughout the United States, although they are disproportionately represented in large urban centers and in five states (more than 10% of the population in California, New York, Texas, New Mexico, and Hawaii have limited English-language skills [Woloshin et al., 1995]). Nearly 8 million individuals (7,741,259) live in linguistically isolated households, e.g., households in which no person over age 14 speaks English “very well” (U.S. Bureau of the Census, 1993). The percentage of individuals living in linguistically isolated households for each racial and ethnic group is depicted in Figure 2-7.

#### *Hispanic or Latino*

More than 1 in 4 (25.3%) Hispanic individuals in the United States live in a linguistically isolated household. These include 4,560,000 individuals in over 1.5 million households. In addition, nearly 8 million Hispanic Americans (7,716,000) do not speak English “very well” (U.S. Bureau of the Census, 1993). Given recent population shifts (e.g., an increase in foreign-born Hispanic immigrants), it is likely that these figures grossly underestimate the number of Hispanic Americans with limited or low English proficiency.



**FIGURE 2-7** Percentage linguistically isolated households, by race and ethnicity, United States, 1990. SOURCE: U.S. Bureau of the Census, 1993.

#### *American Indian and Alaska Native*

More than one in 20 American Indians or Alaska Natives lives in a household in which no adolescent or adult speaks English “very well.” According to the 1990 U.S. Census, 281,990 persons aged five years or older speak one of the American Indian languages at home; half of these (142,886) speak Navajo. Nearly 170,000 American Indians or Alaska Natives do not speak English “very well,” and over 32,000 American Indian or Alaska Native households are linguistically isolated (U.S. Bureau of the Census, 1993).

#### *Asian Americans and Pacific Islanders*

Large segments of Asian-American and Pacific Islander communities face linguistic isolation. According to 1990 U.S. Census estimates, more than 1.5 million Asian or Pacific Islander Americans live in linguistically isolated households. Over half of Laotian, Cambodian, and Hmong families are linguistically isolated, while between 26%-42% of Thai, Chinese,

Korean, and Vietnamese families live in similar conditions. Figure 2-8 displays the percentage of Asian American households that are linguistically isolated.

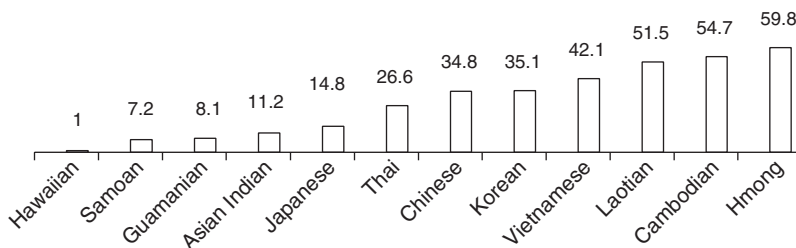
### Healthcare Providers

Many healthcare providers are acutely aware of the impact of language barriers and other cultural differences and how these factors affect their healthcare practice. In a recent survey of physicians who participate in the “Healthy Families” programs, L.A. Care (the local health authority of Los Angeles County) found that 71% of providers believe that language and culture are important in the delivery of care to patients. Slightly over half (51%) believe that their patients did not adhere to medical treatments as a result of cultural or linguistic barriers. Yet, over half of these providers (56%) report not having had any form of cultural competency training (Cho and Solis, 2001).

## RACIAL ATTITUDES AND DISCRIMINATION IN THE UNITED STATES

*“There are those that don’t get promoted because of their race or whatever. The reason [may be because] they’re not well liked by administration or it may be just that they [administrators] don’t want that person in that setting because of their race—that is out there. Racism is alive and well, and those of us who think that it’s not are living in some kind of dream world.” (African-American nurse)*

*“I’ve had both positive and negative experiences. I know the negative one was based on race. It was [with] a previous primary care physician when I discovered I had diabetes. He said, ‘I need to write this prescription for these pills, but*



**FIGURE 2-8** Percentage of Asian Americans that are linguistically isolated, by subgroup. SOURCE: U.S. Bureau of the Census, 1990 General Population Characteristics.

*you'll never take them and you'll come back and tell me you're still eating pig's feet and everything...then why do I still need to write this prescription.' And I'm like 'I don't eat pig's feet.'"* (African-American patient)

*"My name is . . . [a common Hispanic surname] and when they see that name, I think there is some kind of prejudice [against] the name . . . we're talking about on the phone, there's a lack of respect. There's a lack of acknowledging the person and making one feel welcome. All of the courtesies that go with the profession that they are paid to do are kind of put aside. They think they can get away with a lot because 'Here's another dumb Mexican.'"* (Hispanic patient)

*"If you speak English well, then an American doctor, they will treat you better. If you speak Chinese and your English is not that good, they would also kind of look down on you. They would [be] kind of prejudiced."* (Chinese patient)

The first chapter reviewed evidence of disparities in the process, structure, and outcomes of healthcare. This information alone presents an incomplete picture of the social, political, and economic contexts in which racial and ethnic disparities occur. In particular, to understand the question of whether discrimination occurs in healthcare, it is necessary to review what is known about racial attitudes and racial discrimination in other aspects of American life. This section reviews this evidence, with the goals of:

- illuminating trends in racial attitudes that may be assumed to carry over into healthcare settings; and
- understanding the persistence and pervasive quality of discrimination that has characterized the American racial and ethnic minority experience.

Indeed, towards this latter goal, it is useful to consider that the concept of "race" depends fundamentally on the existence of social hegemony. As Michael Omi (2001) notes, "[t]he idea of race and its persistence as a social category is only given meaning in a social order structured by forms of inequality—economic, political, and cultural—that are organized, to a significant degree, by race" (Omi, 2001, p. 254).

### **Racial Attitudes and Relations**

*"Often times, the system gets the concept of black people off the 6 o'clock news, and they treat us all the same way. Here's a guy coming in here with no insurance. He's low breed."* (African-American patient)

Racial attitudes and relations in recent decades have been characterized by both progress and strife. Sociologist Lawrence Bobo (2001) notes five trends regarding racial attitudes and race relations in this period that offer, at times, a conflicting picture of race in America. The first, more positive trend is that Americans' attitudes toward the goals of integration and equality have improved steadily over the past three decades. Second, this trend has not resulted in increasing public support for policies or other significant efforts to improve educational, employment, housing, and other opportunities for U.S. racial and ethnic minorities. Third, white Americans continue to express support for negative stereotypes of minority groups in surprisingly large numbers, even though few of these individuals would identify themselves as bigoted or racist. Fourth, white and non-white Americans differ significantly in their perception of the prevalence of racial discrimination in the United States. Finally, minorities' attitudes regarding race relations suggest a deepening level of alienation from U.S. society.

Regarding the first trend, Bobo notes that racial attitudes in America have improved significantly over the past 50 years. In the 1940s, for example, opinion surveys indicated that over two-thirds of white Americans endorsed the view that African-American and white children should attend separate schools, a view that was reflected in both formal policy and practice. Over half of respondents felt that public transportation should be segregated by race, and that whites should receive preference over minorities in access to jobs. By 1995, 96% of white Americans expressed the view that black and white children should be allowed to attend the same schools. Similarly, by the 1970s, few whites endorsed the view that public transportation should be segregated, or that whites should receive preferential treatment in hiring. In 1965, slightly more than 60% of whites stated that they would not move if a black family moved next door; by 1995, well over 90% shared this belief. Bobo concludes that over time, "support for principles of racial equality and integration has been sweeping and robust. So much so, that it is reasonable to describe it as a change in fundamental norms with regard to race" (Bobo, 2001, p. 273).

Despite these positive overall trends, Americans' attitudes cannot be characterized as wholly egalitarian with regard to racial minorities, particularly when asked about policies and practices that might increase their direct contact with minority groups. For example, while the vast majority of Americans support school integration in principle, when asked whether they would send their own children to integrated schools, support declines as the degree of contact with minorities increases. When asked if they would object to sending their children to a school with a "few" black children, over 90% of whites report no objection. If black children consti-

tuted half of the school enrollment, support dips to approximately three-quarters of respondents. If the school is presented as “mostly black,” support falls to below 50%. While these trends have remained fairly stable since the mid-1970s, white support for sending their children to “mostly black” schools has fallen to below 40% at various points, particularly in the early and mid-1980s. Similarly, the percentage of white respondents who report that they would move should their neighborhood become integrated increases linearly with the proportion of blacks as residents (Bobo, 2001).

In addition, a substantial proportion of white Americans continue to endorse negative stereotypes about minorities. The 1990 General Social Survey (GSS) revealed that whites viewed blacks more negatively relative to whites on a number of dimensions, including intelligence (54% rated blacks as less intelligent in relation to whites), industriousness (62% rated blacks as lazier than whites), propensity towards violence (56% rated blacks as more prone to violence), and preference for living on public assistance (78% rated blacks as preferring to live off of welfare as compared with whites). Whites also rated Hispanics more negatively in relation to whites along the same dimensions, as 31% of whites gave Hispanics a low rating relative to whites in intelligence, 47% rated Hispanics as “lazier” than whites, 54% rated Hispanics as more prone to violence, and 59% believed that Hispanics are more likely than whites to prefer to live off of welfare (Bobo, 2001). It should be noted, however, that these percentages may be conservative due to tendencies among the general public to respond in a socially desirable, non-racist manner.

Negative stereotyping of minorities is not limited to African Americans and Hispanics. A recent survey commissioned by the Committee of 100 to study Americans’ attitudes toward Asian Americans found that at least 1 in 4 Americans holds decidedly negative attitudes toward Chinese Americans, and an additional 43% hold “somewhat negative” attitudes. Many responses suggested that a significant segment of Americans fear Chinese Americans’ influence and power; over one-third (34%) of respondents believe that Chinese Americans have “too much influence in the U.S. high technology sector,” while 23% believe that Chinese Americans have “too much power in the business world.” Nearly one in three (32%) respondents believe that Chinese Americans “always like to be at the head of things,” and nearly 1 in 4 believes that Americans are losing jobs at the hands of Chinese Americans. Nearly 1 in 3 believe that Chinese Americans are more loyal to China than to the United States, and 46% of those surveyed believe that “Chinese Americans passing on information to the Chinese government is a big problem.” Respondents who endorsed 5 or more of the 12 negative stereotypes posed about Chinese Americans—25% of the sample—were found to hold overwhelmingly negative atti-

tudes toward Chinese Americans. These respondents, who tended to have lower levels of education, lower incomes, and were more likely from the South, believe in large majorities—ranging from 68% to 73%—that Chinese Americans “don’t care what happens to anyone but their own kind,” and are “taking away too many jobs from Americans” (Edsall, 2001).

Not surprisingly, white and non-white Americans hold widely diverging views of the prevalence of racial discrimination. A 1995 poll, for example, found that nearly nine in ten African Americans (88%) felt that police treat blacks unfairly, compared with 47% of whites (Schuman et al., 1997). In another poll, slightly over one in five whites (22%) but 57% of African Americans endorsed the view that blacks are discriminated against “a lot” (ABC News/Lifetime Television, 1999). Bobo (2001) cites a survey that finds African Americans to be three times as likely as whites to feel that there is “a lot” of discrimination against blacks in attaining “good-paying” jobs. Nearly 70% of African Americans endorsed this view, compared with slightly more than 20% of whites. Interestingly, 40% of Hispanics and slightly over 10% of Asian Americans supported this view. When asked whether Hispanics face “a lot” of discrimination in getting good-paying jobs, Hispanics (60%) were three times as likely as whites (20%) and one and a half times as likely as African Americans to endorse this view. Bobo (2001) summarizes these data, stating, “[minorities] not only perceive more discrimination, they also see it as more ‘institutional’ in character . . . [whereas] many whites tend to think of discrimination as either mainly a historical legacy of the past or as the idiosyncratic behavior of the isolated bigot” (Bobo, 2001, p. 281).

Strikingly, white Americans’ perceptions of minorities appear to be based on inaccurate notions of racial progress. A national survey conducted by the Washington Post, The Henry J. Kaiser Family Foundation, and Harvard University revealed that “whether out of hostility, indifference or simple lack of knowledge, large numbers of white Americans incorrectly believe that blacks are as well off as whites in terms of their jobs, incomes, schooling, and healthcare” (Morin, 2001, p. 1). Over seven in ten (71%) white Americans surveyed expressed the view that African Americans enjoy the same or greater opportunities than whites; 65% of whites endorse this view with respect to Hispanics. In terms of income, 42% of whites surveyed believe that African Americans are better off or about the same as the “average white person,” and nearly half (49%) believe that African Americans have similar or higher levels of education. Half of surveyed whites endorsed the view that African Americans hold similar or better jobs than whites. More than six in ten (61%) whites believe that African Americans have equal or better access to healthcare as whites, and nearly half (48%) of these respondents believe that Hispanics have equal or better access to healthcare (Morin, 2001). All of these responses are inaccurate

with respect to major demographic data collected by the U.S. Bureau of the Census and other data sources, as outlined in this chapter.

The following sections illustrate that despite the more optimistic view of some that unfair treatment on the basis of race is rare, racial discrimination persists in a wide range of important aspects of American life.

### Racial Discrimination

*"I felt that because of my race that I wasn't serviced as well as a Caucasian person was. The attitude that you would get. Information wasn't given to me as it would have [been given to] a Caucasian. The attitude made me feel like I was less important. I could come to the desk and they would be real nonchalant and someone of Caucasian color would come behind me and they'd be like 'Hi, how was your day?'" (African-American participant)*

#### *What Is Discrimination?*

Discrimination, the differential and negative treatment of individuals on the basis of their race, ethnicity, gender, or other group membership, has been the source of significant policy debate over the past several decades. Federal and state laws adapted since the landmark 1964 Civil Rights Act outlaw most forms of discrimination in public accommodations, access to resources and services, and other areas. While this legislation appears to have spurred significant change in some segments of American society, such as in the overt behavior of lenders and real estate agents, debate continues regarding whether and how discrimination persists today. Conservative legal scholars and social scientists argue that discrimination has largely been eliminated from the American landscape (Thernstrom and Thernstrom, 1997; D'Souza, 1996), while others argue that discrimination has simply taken on subtler forms that make it difficult to define and identify. Complicating this assessment is the fact that while individual discrimination is often easier to identify, *institutional discrimination*—the uneven access by group membership to resources, status, and power that stems from facially neutral policies and practices of organizations and institutions—is harder to identify. Further, it is difficult to distinguish the extent to which many racial and ethnic disparities are the result of discrimination or other social and economic forces.

There is little doubt among researchers who study discrimination, however, that the United States' history of racial discrimination has left a lasting residue, even in a society that overtly abhors discrimination. "Deliberate discrimination by many institutions in American society in the past had left a legacy of [social and] economic inequality between whites and minorities that exists today . . . [but] legal evidence of discrimination



in specific cases is not the same as statistical measures of the overall level at which discrimination exists" (Turner and Skidmore, 1999, p. 5-6).

### **Mortgage Lending**

African-American and Hispanic applicants for conventional home mortgages are rejected at rates greater than twice that of white applicants (U.S. Department of Housing and Urban Development, 1999). But are these disparities due to minorities' generally lower credit ratings and lower income—important predictors of loan outcomes that are themselves by-products of past discrimination?

After controlling for measures of creditworthiness, such as loan type, property and credit, data compiled by the Federal Reserve Bank of Boston revealed large differences in loan denial rates between minority and white applicants. Hispanic and African-American applicants faced an 80% greater likelihood of loan denial. The Urban Institute reanalyzed these data and replicated the finding that creditworthiness or technical factors could not explain the disparity. These researchers concluded that "the Boston Fed Study results provide such strong evidence of differential denial rates (other things being equal) that they establish a presumption that discrimination exists, effectively shifting the 'burden of proof' to lenders" (Turner and Skidmore, 1999, p. 12).

A 1999 Urban Institute study of mortgage lending practices found that minorities face discrimination in several stages of the mortgage lending process. Paired testers sought loans using similar credit histories, incomes and financial histories, and presented the same mortgage needs. Overall, minorities received less information about loan products and were accorded less time with lending officers. Further, they were quoted higher lending rates than whites in most of the cities where tests were conducted. Potentially discriminatory practices began at early stages of the loan process, such as pre-application inquiries, and persisted through to the loan approval stage (Turner and Skidmore, 1999).

### **Housing Discrimination**

Despite the presence of fair housing and anti-discrimination laws, American cities remain starkly segregated by race. Massey (2001), in an analysis of the largest 30 U.S. cities, finds that residential segregation is most profound and consistent over time among African Americans, and is less prominent, but still significant among Hispanic and Asian-American families. Using the indices of dissimilarity (the relative number of minorities who would have to change geographic locations so that an even racial distribution could be achieved) and isolation (the percentage of mi-

norities residing in the geographic unit of the average minority individual), Massey found that, on average, African Americans live in communities that are overwhelmingly African American, with dissimilarity indices averaging 77.8 in northern cities and 66.5 in southern cities (indices above 60 are considered high). In six metropolitan areas (Chicago, Cleveland, Detroit, Gary, New York, and Newark), isolation indices for African Americans are 80 or more, indicating that in these cities, the average African American lives in a neighborhood that is more than 80% black. Further, other measures indicate that many African-American communities are characterized by "hypersegregation;" that is, African Americans tend to be concentrated in compact, densely packed, contiguous tracks in central cities. Black residents in these areas are unlikely to ever come into contact with non-blacks in their neighborhoods or in adjoining neighborhoods, and would have "little direct experience with the culture, norms, and behaviors of the rest of American society, and have few social contacts with members of other racial groups" (Massey, 2001, p. 410).

Patterns of segregation among Hispanic and Asian-American populations, in contrast, are less stark than that of African Americans. The dramatic increase of both Asian and Hispanic immigrants to the United States has led to large concentrations of these populations in some urban areas, but other segments of these populations have achieved remarkable levels of integration with whites. In several cities with large Hispanic populations, such as Brownsville and McAllen (Texas) and Miami (Florida), Hispanic segregation is high, with isolation indices averaging 77.2. This suggests that more than 3 of 4 Hispanics lacks regular neighborhood contact with individuals from other racial and ethnic backgrounds. In cities that are not majority Hispanic, concentration of Hispanics is less likely, with dissimilarity indices averaging 49.6 (suggesting that about half of communities in these cities are segregated by race and ethnicity) and isolation indices averaging 45.1 (both are in the moderate range). Asian-American segregation indices are quite moderate, with dissimilarity indices averaging 40.6 and isolation indices averaging 20.6 (Massey, 2001).

These patterns of segregation are not merely the product of socioeconomic differences, Massey notes. Segregation of African Americans, for example, occurs independently of social class. African-American families earning at least \$50,000 annually are as likely to live in neighborhoods as segregated as those in which African-American families earning less than \$2,500 per year reside. Further, the most affluent African Americans are even more segregated than lower-income Asian-American and Hispanic families; blacks earning more than \$50,000 annually live in more segregated conditions than Asian-American or Hispanic families earning less than \$2,500 annually (Massey, 2001).

Importantly, segregation does not appear to result merely from the choices of African-American and other minority groups to live apart from white Americans. Polling data indicate that African Americans strongly endorse the idea of residential integration, and would prefer to live in racially mixed neighborhoods. Virtually all African Americans endorse the statement that "black people should have a right to live wherever they can afford to," and over 70% would vote for a community law to enforce this right (Bobo, Schuman, and Steeh, 1986). Nearly 90% of African Americans state that they would be willing to live in any racially mixed area (Farley et al., 1994).

Similarly, most white Americans endorse the view that housing opportunities should be open to all and that housing discrimination should be abolished. In practice, however, white Americans' attitudes shift significantly with increasing residential segregation, as measured by polling data and patterns of movement after previously all-white neighborhoods become integrated. Farley et al. (1994) asked white residents in the Detroit metro area if they would feel uncomfortable in a neighborhood where 7% of the residents were black; 13% of respondents reported that they would be unwilling to enter such a neighborhood. When the percentage of black residents is presented as one-fifth of the total, one-third of whites reported that they would be unwilling to enter. If 30% of residents are African American, 59% of whites reported that they would be unwilling to move in, 44% reported that they would feel uncomfortable, and 29% reported that they would try to leave if they lived in such a neighborhood. If 50% of residents are African American, 73% of whites report that they would not want to live in the neighborhood, 65% reported that they would feel uncomfortable, and 53% would try to leave. In actual practice, the presence of smaller percentages of African Americans in previously all-white neighborhoods initiates a pattern of destabilization whereby whites tend to leave in large numbers. Summarizing studies of neighborhood racial transformation, Massey (2001) notes that the presence of one African-American family among every five white families tends to fuel a process of neighborhood turnover; in some cases, this turnover has accelerated when African Americans have numbered as few as three percent of a neighborhood (Massey, 2001).

Despite the existence of federal laws barring discrimination in housing, racial discrimination appears to be a key mechanism preventing neighborhood integration. Prior to passage of the 1968 Fair Housing Act, racial discrimination was institutionalized in the real estate industry and was widely practiced. Today, Massey (2001) states, minority home seekers, particularly African Americans, are more likely than not to face discrimination when attempting to purchase or rent a home. This discrimination occurs largely in the form of subtle, covert barriers. Housing audit studies, for example, provide a powerful means of assessing the likeli-

hood of discriminatory practices. Auditors are trained to present comparable needs and desires in home purchases or rental properties, and are provided with similar socioeconomic traits. These studies, according to Massey, consistently indicate that housing discrimination has persisted in the years following passage of the Fair Housing Act. The U.S. Department of Housing and Urban Development's (HUD) Housing Discrimination Study, for example, was conducted in 20 audit sites around the United States and revealed that white auditors were, on average, provided with 45% more housing options in the rental market and 34% more options in the sales market than black auditors. In addition, whites were shown additional units 65% more often than blacks. Subtle "steering" of minority auditors away from predominantly white neighborhoods increased the likelihood of discrimination to 60%; in total, between 60% and 90% of the housing shown to white auditors were not shown to comparable black auditors (Yinger, 1995). For Hispanics, the likelihood of discriminatory treatment was equally high, as Hispanic auditors faced unfavorable treatment 43% of the time when seeking rental units, and 45% of the time when seeking to purchase a home (Fix, Galster, and Struyk, 1993).

White auditors also received greater assistance in obtaining credit; in 46% of encounters, whites received more favorable credit assistance in sales transactions and were offered more favorable terms in 17% of rental transactions. In addition, greater credit assistance was provided to whites; of all instances in which agents discussed a fixed-rate mortgage, 89% were with white auditors, as were 91% of instances in which adjustable-rate loans were discussed (Yinger, 1995).

These findings have been replicated in several other housing audit studies conducted in different locations in the United States. Galster (1990) found that racial steering occurred in approximately 50% of transactions, and that "selective commentary" from agents was common (including positive comments provided to white auditors regarding predominantly white neighborhoods that are not provided to African-American auditors). While housing audits have largely focused on the possibility of discrimination against African Americans, a few studies suggest that Hispanics face similar discrimination, particularly among darker-skinned Hispanics or those who identify themselves as mixed European and Indian ancestry (Massey, 2001). The consistency of these findings, coupled with data noting persistent racial segregation in the vast majority of American communities, prompts Massey to conclude, "rather than declining in significance, race remains the dominant organizing principle of U.S. urban housing markets" (2001, p. 420).

The consequences of such segregation for individual health status are significant (Williams, 2001; Massey, 2001). Many community resources that affect health, including access to employment and educational opportunities, are inequitably distributed; a close association exists between

a group's spatial position in society and its socioeconomic opportunities. For example, some communities are characterized by better schools, safer streets, better public services, fewer environmentally based health hazards, and better access to quality healthcare. African Americans, regardless of income, tend to be segregated in neighborhoods characterized by fewer of these resources and higher levels of health risks. "Compared with whites of similar socioeconomic status," Massey (2001) notes, "blacks tend to live in systematically disadvantaged neighborhoods, even within suburbs" (2001, p. 392).

### **Employment**

Audit studies using matched pairs of minority and non-minority auditors have also revealed consistent patterns of discrimination in hiring. As in housing audit studies, these studies carefully match testers on such attributes as educational level and personality characteristics, and carefully coach testers to ensure consistent responses to typical job interview questions. Fix, Galster, and Struyk (1993), for example, report findings from two studies of housing discrimination that assessed unfavorable treatment encountered by qualified job applicants responding to advertisements in major newspapers for entry-level positions. The first, conducted in San Diego and Chicago, assessed unfavorable treatment of Hispanics compared with white applicants. Because this study was part of a larger project assessing the potential adverse impact of new immigration legislation that banned the hiring of undocumented aliens, Hispanic testers were selected who "looked Hispanic and had definite accents" (Fix, Galster, and Struyk, 1993, p. 19). The second study, conducted in Chicago and Washington, D.C., assessed potential discriminatory treatment of African-American applicants relative to whites. Findings revealed that opportunity denial (defined as the denial of opportunity to obtain an application, obtain an interview, or receive an offer of employment) occurred 20% of the time in black-white audits and 31% of the time in Hispanic-Anglo audits, across all study sites. In other words, in nearly one-third of instances Hispanic applicants were denied an application, denied an interview, or did not receive an offer of employment while the matched white auditor received the opposite outcome.

### **Criminal Justice**

#### *Minority Youth in the Juvenile Justice System*

Minority youth are overrepresented in the juvenile justice system in the United States. While minorities (African Americans, Hispanics, Asian

Americans, and American Indians) constituted only about one-third of juveniles in the United States in 1997, they represent two-thirds of detained and committed youth in juvenile facilities. These disparities are most pronounced among African-American youth; while they comprise 15% of the juvenile population, they account for more than one in every four juvenile arrests and 45% of delinquent cases involving detention. Further, nearly half (46%) of juvenile cases waived to criminal courts in 1996/7 involved African American youth (Office of Juvenile Justice and Delinquency Prevention, 1999).

Overrepresentation of minority youth in juvenile justice systems occurs in all 50 states and the District of Columbia. According to data collected by the U.S. Office of Juvenile Justice and Delinquency Prevention (OJJDP), minority youth face a higher probability than white youth of being arrested, referred to court intake, held in short-term detention, petitioned for formal processing, adjudicated delinquent, and confined in a secure juvenile facility. While these disparities may reflect a greater level of involvement in crimes (e.g., African-American youth are involved in 39% of violent crimes, as reported by victims), African-American youth disproportionately account for juvenile arrests for violent crime (44%) and confinement (45%), suggesting differential treatment by race (U.S. Office of Juvenile Justice and Delinquency Prevention, 1999).

A growing number of well-controlled studies demonstrate that minority youth are treated differently in the juvenile justice system than white youth, even considering the severity of crime and differences in rates of offenses. Minority youth, for example, are more likely than whites to be placed in public secure facilities, while white youth are more likely to be housed in private facilities or diverted from the juvenile justice system (U.S. Office of Juvenile Justice and Delinquency Prevention, 1999). These disparities are most pronounced at the beginning stages of processing within the juvenile justice system, but tend to accumulate as juveniles move through stages of the juvenile justice system. OJJDP researchers note that approximately two-thirds of studies of racial differences in processing demonstrate that race influences decision-making in the juvenile justice system, leading researchers to conclude that "there is substantial evidence that minority youth are treated differently from majority youth within the juvenile justice system" (U.S. Office of Juvenile Justice and Delinquency Prevention, 1999, p. 3).

### **What Is the Relationship Between Racial and Ethnic Disparities in Healthcare and Broader Racial Attitudes and Discrimination?**

The study committee considered studies of racial and ethnic discrimination in sectors outside of healthcare as an important aspect of the evi-

dence base to better understand the contexts in which care is delivered to racial and ethnic minority patients. These data are not meant to imply that inferences can be drawn from this literature regarding possible discrimination in healthcare settings. To the contrary, most social scientists agree that individuals with higher levels of education (such as healthcare professionals) generally hold more egalitarian attitudes than less educated individuals and abhor racial or ethnic prejudice and discrimination. In addition, as will be noted in later sections of this report, healthcare professionals are sworn to beneficence, and the vast majority are drawn to their disciplines out of feelings of compassion and a strong desire to heal. Data on the persistence of racial and ethnic discrimination in other sectors of American life are important, however, because they are likely to affect the clinical encounter and process of healthcare delivery in at least three ways:

- experiences of discrimination, whether real or perceived, are experiences that minority patients are likely to bring to the clinical encounter, and are thereby likely to shape their expectations, attitudes and behaviors toward providers and health systems;
- minority patients encountering health systems are likely to interact with many individuals in addition to healthcare providers, such as administrative and clerical staff, who may be expected to mirror social attitudes and trends regarding race and ethnicity; and
- healthcare providers, like all other individuals, are likely influenced in their racial and ethnic attitudes by broader social trends.

#### **THE CONTEXT OF HEALTHCARE DELIVERY FOR RACIAL AND ETHNIC MINORITY PATIENTS—AN HISTORICAL OVERVIEW**

*“What would you recommend (to the IOM) to better understand what minorities experience in getting healthcare?” (Focus Group Moderator)*

*“Understand what the past healthcare history has been to Native Americans. Maybe just having an understanding of how Native American healthcare has been across the U.S., not just here in the Southwest, but everywhere. I think that would make [healthcare providers] effective because they would know what’s happened in the past and not repeat the same mistakes.” (American Indian healthcare consumer)*

This section presents a discussion of the history of healthcare service delivery for racial and ethnic minority populations in the United States. The discussion is focused on the experience of African Americans only because historical documentation of healthcare for this group is more extensive than for other racial and ethnic minorities. It is not meant to exemplify other groups’ healthcare experiences and histories (for a discus-

sion of aspects of the history of U.S. healthcare for American Indians and Alaska Natives, see Joe, this volume). An historical account of the healthcare experience of African Americans is illustrative, however, of how the historic context shapes the contemporary structure of and access to care for racial and ethnic minorities. This section will discuss how the legacy of segregated and inferior healthcare for African Americans continues to reverberate in today's healthcare settings. Important factors such as the makeup of the healthcare workforce, primary settings in which racial and ethnic minorities receive care, opportunities for training of minority healthcare providers, and other aspects of the structure and delivery for healthcare for many African Americans are shaped by these historical trends.

#### **A BRIEF HISTORY OF LEGALLY SEGREGATED HEALTHCARE FACILITIES AND CONTEMPORARY *DE FACTO* SEGREGATION**

From the earliest periods in America's history, sharp divisions across racial and ethnic lines were customary in virtually all sectors of society, including healthcare. The origins of racially segregated healthcare systems can be traced back to slavery. While these systems were loosely organized, plantation health services were the earliest and one of the only systems comparable to today's managed-care plans (Smith, 1999). Plantation owners, as employers, had a significant financial interest in preserving the health of their employees (Byrd and Clayton, this volume). Slaves received care in hospitals-of-sorts on plantations. In some states, white physicians organized hospitals for slaves, or contracted with plantation owners to provide care to their slaves (Smith, 1999).

The early and mid 1800s also saw the emergence in America of scientific theories about race. Polygenism, and movements such as anthropometry, phrenology, and craniometry (theories that human races were distinct and hierarchical biological species) were at the forefront of scientific inquiry. Black soldiers during the Civil War were often used as subjects in studies comparing races to demonstrate black inferiority (Byrd and Clayton, this volume).

After emancipation, the plantation system of medical care ended and the Freedmen's Bureau was established by the federal government to provide assistance to former slaves. The medical department of the Bureau established nearly 100 hospitals for freed slaves. However, by 1868 only one (Howard University Medical Center) remained (Smith, 1999). After this point, African Americans received healthcare in segregated facilities in northern hospitals created by local governments. In the south, where most African Americans resided, local municipalities and states began to provide payments to hospitals to subsidize care for the underserved,



which included segregated care for the poor (Smith, 1999). American Indians, who experienced displacement and high mortality, had little contact with health systems until the second half of the 19th century. This healthcare, administered by the government, was also poor, inadequately funded, and not sensitive to culture (Byrd and Clayton, this volume).

As the country approached the 20th century, two major social transformations converged to sharpen the racial divisions in healthcare services (Smith, 1999). First, with the development of surgical and other medical advances, both public and voluntary hospitals became important practice sites. Middle- and upper middle-class citizens began paying for services at these facilities, shifting power away from hospital boards to medical staff, who decided who received what kind of care. Second, the passage of Jim Crow laws solidified racial divides by legally separating facilities that provided care to black and white communities. In the scientific community, theories such as Darwinism, eugenics, and later, psychometric testing were developed to explain and predict the inferiority of certain groups, such as immigrants, African Americans, the poor, and the mentally retarded (Byrd and Clayton, this volume).

As hospital facilities became more important to the practice of medicine, organizations such as the American College of Surgeons sought to standardize hospital practices, which enabled medical staffs at hospitals to become more organized and exercise control over practices in their facilities (Smith, 1999). This essentially resulted in the exclusion of minority physicians from practicing in these institutions. Marginalized groups, including African Americans, American Indians, Hispanic Americans, and others from racial or religious minority groups were isolated, excluded from training, and professionally segregated (Byrd and Clayton, this volume). The response by minority physicians was to create their own facilities. American Indians and Alaska Natives, by treaty agreements, in large part received their healthcare through the Federal government. However, the diversity and dispersion within the Native American community made it difficult to provide consistent and reliable care (Byrd and Clayton, this volume). In a parallel movement, issues of payment for medical care became prominent as these services became increasingly important in peoples' lives. Questions about whether care should be based on need or ability to pay became influenced, in part, by race (Byrd and Clayton, this volume).

The passage of civil rights legislation in 1964 and Medicare and Medicaid legislation in 1965 stimulated profound changes in the structure of healthcare. With mandated integration, one of the most significant changes was the closing of black hospitals (Smith, 1999). Between 1961 and 1988, 70 black hospitals either closed or merged with white facilities. This transformation was taking place while white hospitals were experi-

encing growth and financial prosperity. While on the surface these closings may have seemed like a mere shifting of service sites, they had quite profound and devastating effects in minority communities. These closings meant a loss of geographic convenience and accessibility to care, a sense of safety with known institutions, and a loss of a major source of employment in the community (Smith, 1999). In addition to the loss of these facilities, a similar fate was befalling many public facilities that had provided access to many minority patients.

Another major, and more recent, shift in healthcare structure began in the late 1980s with the rise of managed care. This movement was initiated as both private and public payers were overwhelmed by rising costs and were searching for alternative ways to control their expenditures. By 1996, two-thirds of African Americans and Latinos with private insurance were enrolled in managed care plans. The transformation of Medicare programs to managed care formats led to further downsizing of large urban hospitals (Smith, 1999).

#### **Historical Determinants of the Contemporary Minority Health Professions Workforce**

During the post-Reconstruction period, several “Negro” medical schools and hospitals emerged. Eight medical schools for African Americans were established between 1865 and 1910 [Howard University Medical School, Washington, D.C. (1868); Meharry Medical College, Nashville, Tennessee (1876); Leonard (Shaw) Medical School, Raleigh, North Carolina (1882-1915); Louisville National Medical College, Louisville, Kentucky (1887-1911); Flint Medical College, New Orleans, Louisiana (1889-1911); Knoxville Medical College, Knoxville, Tennessee (1895-1910); the Medical Department of the University of West Tennessee (1900-1923); and Chattanooga National Medical College, Chattanooga, Tennessee (ca. 1902)] (Cobb, 1981). At least nine northern medical schools had admitted blacks by 1860. As a result, by 1895 there were approximately 385 black doctors, 7% of whom had been trained in white medical schools. Numbers of African Americans graduating from white institutions gradually increased, and in 1905, 14.5% of the country’s 1,465 black physicians were from white medical schools (Duke University Medical Center, 1999).

Training black health professionals was essential to African-American communities during the prolonged post-Reconstruction period of crushing poverty, poor health status and inadequate or absent healthcare (Byrd and Clayton, this volume). Abraham Flexner’s 1910 report on the status of minority health and minority health professionals reinforced this need. Flexner severely criticized medical education in the United States, noting that many U.S. medical schools had poor facilities, inadequate fac-

ulty with little scientific basis for instruction, and functioned principally as “diploma mills.” These proprietary schools offered after-hours education and training, and contributed to the tension regarding the social and professional place for inexpensive medical education and primary care (Martensen, 1995). These tensions have not been completely resolved today. In this climate, the medical establishment was agitating for control and educational reform. More than 200 medical schools were founded in the United States between 1800 and 1900 (Stevens, Goodman, and Mick, 1978). At the end of the 20th century, the United States had the highest physician-to-population ratio in the world (Smith, 1999). Flexner believed strongly in the German scientific tradition he had experienced at the new Johns Hopkins University and suggested in the report that only university-based medical schools were appropriate for the responsibility and challenge of training physicians. Regarding the education of Negro physicians, he reports:

“The medical care of the Negro race will never be wholly left to Negro physicians. Nevertheless, if the Negro can be brought to feel a sharp responsibility for the physical integrity of his people the outlook for their mental and moral improvement will be distinctly brightened. The practice of the Negro doctor will be limited to his own race, which in turn will be cared for better by good Negro physicians than poor white ones. But the physical well-being of the Negro is not only of moment to the Negro himself. Ten million of them live in close contact with sixty million whites. Not only does the Negro himself suffer from hookworm and tuberculosis; he communicates them to his white neighbors, precisely as the ignorant and unfortunate white contaminates him. Self-protection not less than humanity offers weighty counsel in this matter; self-interest seconds philanthropy. The Negro must be educated not only for his sake, but for ours. He is, as far as human eye can see, a permanent fact in the nation. He has his rights and due and value as an individual; but he has, besides, the tremendous importance that belongs to a potential source of infection and contagion.

The pioneer work in educating the race to know and practice fundamental hygiene principles must be done largely by the Negro doctor and Negro nurse. It is important they both be sensibly and effectively trained at the level at which their services are now important. The Negro is perhaps more easily ‘taken in’ than the white; and as his means of extricating himself from a blunder are limited, it is all the more cruel to abuse his ignorance through any sort of pretense. A well-taught Negro sanitarian will be immensely useful; an essentially untrained Negro wearing an M.D. degree is dangerous.” (Flexner, 1910, as quoted in Smith, 1999, p. 15).

The Flexner report had an enormous impact on medical education and the entire healthcare delivery system. The American Medical Association and major philanthropic organizations closed ranks behind the report. The AMA's Council on Medical Education pushed states to restrict eligibility for state licensure to physicians graduating from approved medical schools (Smith, 1999). Within a few years the number of medical schools was reduced from approximately 155 to 70 (Smith, 1999). The curriculum was lengthened, entrance requirements were raised, and the scientific content of the curricula was increased (Byrd and Clayton 2001). These reforms were costly and many institutions were unable to survive the changes demanded by reformers. These changes, however, forever altered the class background of those trained to become physicians. Many poorer, part-time, and night students found economic barriers to medical education insurmountable, and the proportion of students from working-class and poor families remained steady at approximately 15% for most of the 20th century (Ziem, 1977). Medical education therefore was largely limited to a predominantly upper-class, white, and male population (Ziem, 1977).

This increase in training costs had profound effects on the availability of doctors, particularly in the African-American community. In fact, the physician-to-population ratio among black Americans in 1974, twenty years after the *Brown v. Board of Education* Supreme Court decision that outlawed segregation in schools was worse than in the 1940s (Blackwell, 1977). Further hampering black progress, integration of the nation's medical schools was not seriously addressed until a decade after the 1954 *Brown v. Board of Education* decision. In 1948, for example, one-third of all medical schools were officially closed to blacks and many more failed to accept a single black student until two decades later (Raup and Williams, 1964).

By 1920, only two black medical schools remained, Howard University Medical School and Meharry Medical College (Smith, 1999). The closure of the other black medical schools dramatically reduced the community resource that produced many of their primary care physicians. These closures ensured that the segregation of healthcare in hospitals, in the health professions, and the professional societies would become entrenched in U.S. society. While the black population made up about 10% of the total population in the mid-1950s, for example, black physicians made up only about 2.2% of all physicians (Reitzes, 1958). The nation's overall physician-to-population ratio was 1 to 770. For the nonwhite population, however, the physician-to-population ratio was 1 to 4,567, and the black physician-to-population ratio was 1 to 3,736 (Reitzes, 1958). This disparity was not surprising, given that the burden of training black healthcare professions increasingly fell to only a few institutions. In 1956,

74% of all black medical students attended Howard or Meharry (Ziem, 1977). It was not until 1969 that all of the nation's medical schools enrolled more black students than did Howard or Meharry alone (Ziem, 1977).

During the late 19th and early 20th century, black physicians and community leaders had built their own hospitals in several cities around the country. Many of these hospitals served as major training centers for black health professionals. Medical specialists were in very short supply in the black communities, and access to white hospitals—even for those doctors who graduated from white medical schools—was limited. For African-American physicians, acquiring specialty training or hospital expertise was rare, because these doctors were denied opportunities to access specialty training (Byrd and Clayton, 2001). Failure to acquire the requisite credentials automatically excluded blacks from academic medicine and prestigious hospital staff appointments.

To compound these problems, organized medicine and local specialty societies failed to open doors for minorities to gain equal footing in the profession. The American Medical Association's (AMA) refusal to require its affiliates to desegregate until the mid-1960s made it virtually impossible for most black physicians to gain privileges at white hospitals because local society membership was a prerequisite (Byrd and Clayton, 2001). Smith (1999) described a fear among black medical leaders that the American College of Surgeons standardization efforts could eventually eliminate black hospitals and black medical professionals. In response, the black medical leadership formed its own organization, the National Medical Association (NMA), which was founded in 1895. Blacks were, in effect, excluded from AMA affiliates and the existing medical establishment, unable to fully open the doors to training opportunities until the Civil Rights Era.

#### THE SETTINGS IN WHICH RACIAL AND ETHNIC MINORITIES RECEIVE HEALTHCARE

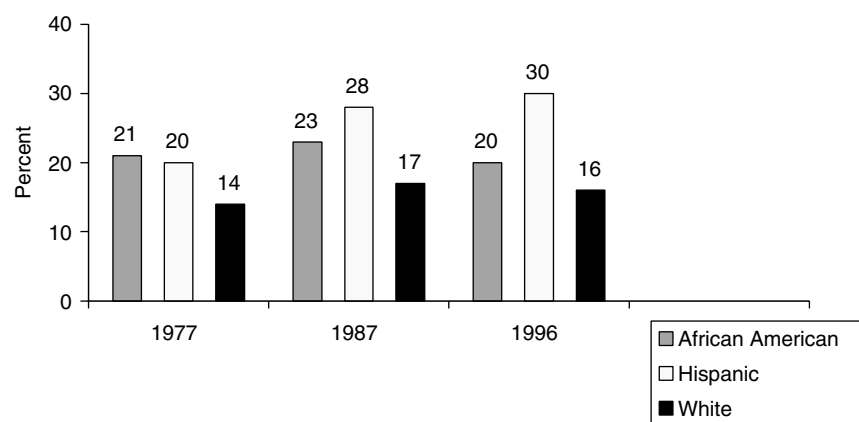
*"So you're talking about [the] hospital. I think [large] hospitals, their equipment, [they have] more equipment, I'm talking about [a] large hospital, a hospital versus clinics. I like to go to a place where they have more, a lot of equipment, and complete their services so I don't have to go to different places. I can go to . . . a central place where they'll be able to take care of everything. And then language again, that's important. A Chinese interpreter [is necessary]." (Asian-American patient)*

The legacy of racial segregation of healthcare is, in many respects, mirrored in stark racial and ethnic differences in the contexts in which

care is received. Rates of health insurance vary greatly among racial and ethnic groups, as do primary sites where care is received, and who delivers this care. Most of these racial and ethnic differences are due to socioeconomic factors. For example, as will be discussed in Chapter 3, patients with Medicaid have difficulty accessing private sector office-based care (Lillie-Blanton et al., 2001) and are more often relegated to public hospitals and clinics. New studies indicate, however, that even when income and education are controlled, minorities are more likely to receive care in the lowest quality facilities with the least likelihood of appropriate follow-up.

Minorities have more difficulty than the majority population in locating a “usual source” of medical care (see Figure 2-9). African-American and Latino patients report greater difficulty than whites obtaining medical care at a consistent location. In 1996, for example, almost a third of Latino patients reported having a regular healthcare provider. Similarly, more minority patients report having little or no choice in where to go for medical care. Twenty-eight percent of African Americans and 30% of Hispanics report this difficulty, compared with 16% of whites and 21% of Asian-American adults (Lillie-Blanton et al., 2001).

In the 1980s, African Americans and Latinos were more likely than their white counterparts to receive care in hospital outpatient departments (particularly teaching and public hospitals), community-based clinics, and emergency rooms as usual sources of care (Lillie-Blanton et al., 2001; Smith, 1999; Gaskin, 1999). Persons with public or no insurance were also more likely to receive care in these settings (Cornelius et al., 1991, as cited

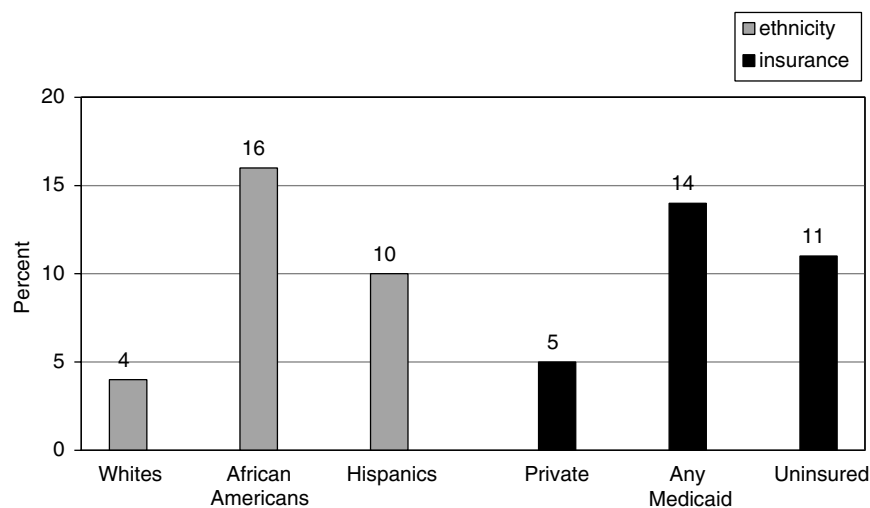


**FIGURE 2-9** No usual source of medical care. SOURCE: 1996 Medical Expenditure Panel Survey, as cited in Lillie-Blanton et al., 2001.

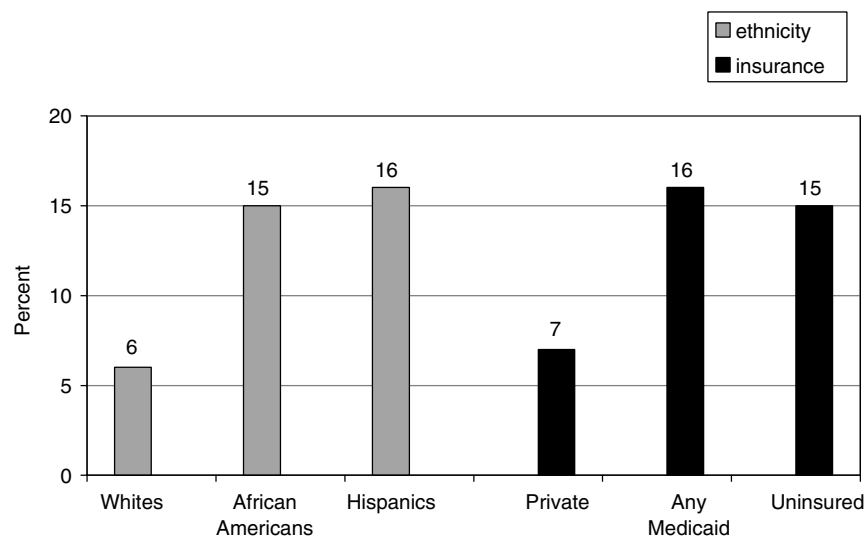
in Lillie-Blanton et al., 2001). In a study to assess whether ethnicity is associated with site of care beyond insurance coverage, Lillie-Blanton, Martinez, and Salganicoff (2001) analyzed data from the 1996 Medical Expenditure Panel Survey (MEPS), and found that African Americans and Latinos, regardless of insurance coverage, were almost twice as likely as whites to receive care from a hospital-based provider (Figures 2-10 and 2-11). Those who were uninsured were also more likely to rely on hospitals for care.

Many people from racial and ethnic backgrounds are disproportionately served by safety net urban hospitals, defined as those facilities whose Medicaid utilization rate exceeds one standard deviation above the mean Medicaid utilization rate for urban hospitals in the state. Ethnic minorities comprise 43% of patients seen at these hospitals, but make up only 19% of patients seen at other urban hospitals (Collins et al., 1999). Approximately half of African-American (47%) and Hispanic (53%) adults under age 65 report relying on safety net emergency rooms, outpatient departments, or clinics for their healthcare, compared with 30% of whites.

Children's healthcare service use reveals similar patterns. White children see physicians at twice the rate of minority children (Collins et al., 1999). However, African-American and Latino children are over-represented in emergency rooms and hospital outpatient departments (Table 2-1; Lillie-Blanton et al., 2001). Even across type of insurance, African-



**FIGURE 2-10** Site of care: Hospital outpatient departments and emergency rooms. SOURCE: Medical Expenditure Survey, 1997, as cited in Lillie-Blanton et al., 2001.



**FIGURE 2-11** Site of care: Other non-hospital facilities. SOURCE: Medical Expenditure Survey, 1997, as cited in Lillie-Blanton et al., 2001.

**TABLE 2-1** Site of Usual Source of Care by Insurance and Race/Ethnicity, Children 0–17, 1996

	Office-based % (SE)	Hospital Clinic or Outpatient Dept. % (SE)	ER % (SE)
<i>Private Health Insurance</i>			
White	93.6 (0.8)	6.3 (0.8)	0.1 (0.1)
African American	89.5 (2.3)	10.1 (2.2)	0.4 (0.4)
Latino	85.9 (2.4)	13.7 (2.4)	0.4 (0.3)
<i>Medicaid</i>			
White	90.1 (2.3)	9.9 (2.3)	0.0 (0.0)
African American	74.6 (3.8)	22.8 (3.7)	2.7 (1.8)
Latino	80.3 (3.2)	18.8 (3.1)	0.9 (0.6)
<i>Uninsured</i>			
White	90.8 (2.3)	8.3 (2.1)	0.9 (0.6)
African American	73.7 (6.1)	24.1 (6.2)	2.2 (1.9)
Latino	81.6 (3.2)	17.2 (3.1)	1.2 (0.8)

SOURCE: Medical Expenditure Panel Survey, 1996, as cited in Lillie-Blanton et al., 2001.



American and Latino children are more likely to receive care in these settings than their white counterparts.

Racial and ethnic minority patients are also more likely to report experiencing difficulty in accessing specialists. Eight percent of whites, 16% of blacks, 22% of Hispanics, and 26% of Asian Americans report this difficulty (Collins et al., 1999). Within the Asian-American community, Chinese Americans indicated the most difficulty (21%). Among Medicare beneficiaries age 65 and older diagnosed with diabetes, black patients were less likely to have had an office visit with a cardiologist or eye specialist (Collins et al., 1999).

### **Impact of Community Health Centers on Healthcare in Minority and Medically Underserved Areas**

During the 1960s, several new federal efforts were developed to increase healthcare services in poor communities. To this end, services such as the National Health Service Corps and the Community and Migrant Health Centers Program were initiated to help strengthen the workforce in medically underserved communities (Heinrich, 2000). By 1996, 625 community health centers (CHCs) provided services at over 3,900 sites (COGME, 1998). Today, these facilities serve underserved rural areas, migrant and seasonal farm worker communities, and urban communities. These federally funded CHCs include four programs: community health centers, migrant health centers, healthcare for the homeless, and healthcare for residents of public housing (COGME, 1998). CHC services are provided by primary care and other physician specialists, nurse practitioners, physician assistants, certified nurse midwives, dentists, and psychiatrists.

The vast majority (approximately two-thirds) of patients served by CHCs are non-white (COGME, 1998). In some communities, CHCs are the predominant source of care. In others, local governments have created and funded primary care clinics using the federal CHC model, helping to fill the void left by a lack of office-based providers. By the mid-1990s, rates of Hispanic visits to community health centers were 700% higher than for whites. For black, non-Hispanic individuals, visits to CHCs were 550% higher than white, non-Hispanic visits (Table 2-2).

The CHC model has proven effective not only in increasing access to care, but also in improving health outcomes for the often higher-risk populations they serve. The continuity of care has been found to be better in CHCs than in hospital outpatient departments or physician offices, and a study examining preventable hospitalizations among medically underserved communities found that in communities served by federally qualified health centers, rates of preventable hospitalizations

**TABLE 2-2** Number of Primary Care Visits Made to Primary Care Delivery Sites in the United States in 1994

	Overall				Community Health Centers				Physician's Offices				Hospital Outpatient Departments				
	In Thousands		Per 100 Persons Per Year		In Thousands		Per 100 Persons Per Year		In Thousands		Per 100 Persons Per Year		In Thousands		Per 100 Persons Per Year		
<i>Race/Ethnicity</i>																	
Hispanic	28,087	(8.6)	109.1	(15.1)	3608	(31.7)	14.0	(10.6)	21,205	(7.3)	82.4	(15.3)	3275	(15.3)	12.7		
Black, non-Hispanic	27,425	(804)	91.0	(29.5)	3356	(29.5)	11.1	(6.8)	19,930	(6.8)	66.1	(19.4)	4140	(19.4)	13.7		
Asian/Pacific Islander	11,910	(3.7)	141.0	(4.7)	539	(4.7)	6.4	(3.7)	10,903	(3.7)	129.1	(202)	468	(202)	5.5		
White, non-Hispanic	257,622	(79.2)	134.9	(34.1)	3891	(34.1)	2.0	(82.2)	240,265	(82.2)	125.8	(63.1)	13,466	(63.1)	7.0		
<i>Health Insurance Payer</i>																	
Medicare	49,117	(15.1)	N/A	(10.6)	1375	(10.6)	N/A	(15.4)	44,899	(15.4)	N/A	(13.3)	2843	(13.3)	N/A		
Medicaid	38,120	(11.7)	N/A	(9.7)	5151	(9.7)	N/A	(9.1)	26,367	(9.1)	N/A	(30.9)	6602	(30.9)	N/A		
Private	190,681	(58.7)	N/A	(21.2)	2754	(21.2)	N/A	(62.0)	180,226	(62.0)	N/A	(36.1)	7701	(36.1)	N/A		
Uninsured	33,376	(10.3)	N/A	(25.7)	3339	(25.7)	N/A	(9.4)	27,458	(9.4)	N/A	(12.1)	2579	(12.1)	N/A		
Other payment	13,758	(4.2)	N/A	(2.7)	350	(2.7)	N/A	(4.1)	11,758	(4.1)	N/A	(7.6)	1623	(7.6)	N/A		

SOURCE: Forrest & Whelan, 2000.

Visit counts were multiplied by sampling weights, which account for the multistage sample design and nonresponse of in-scope practitioners, to obtain national estimates. Rates were based on the U.S. Bureau of the Census estimates of the U.S. civilian noninstitutionalized population as of July 1, 1994. N/A indicates that visit rates were not calculated by health insurance payer because denominators were not available.

were lower than in communities not serviced by these centers (Epstein, 2001). Patients in underserved areas served by these centers had 5.8 fewer preventable hospitalizations per 1,000 population over three years than those in underserved areas not served by a federally qualified health center.

While CHCs were developed on the premise that they would service all patients regardless of their ability to pay, limited federal subsidies have forced many clinics to reduce the amount of uncompensated care they provide. Between 1981 and 1991, federal funding increased at half the rate of increase in the urban consumer price index for medical care (Rosenbaum and Dievler, 1992, as cited in COGME, 1998). Changes in the cost of medical technology, shift of services from inpatient to outpatient settings, and Medicare's Prospective Payment System have placed a strain on many hospitals. While most have remained operational, approximately 5% of non-federal community hospitals closed between 1985 and 1988, a rate two to three times higher than in the preceding four years (GAO, 1990). Concerned about loss of their Medicaid patient base, many CHCs have begun participating in managed care arrangements. By 1996, almost half (45%) of CHCs participated in such arrangements (Shi et al., 2000). This shift has generated fears among some that these centers will be less able to serve patients who need care the most, with declines in Medicaid reimbursement and increased difficulty providing non-reimbursable services under managed care (GAO, 1995; Shi et al., 2000). In fact, recent studies suggest that CHCs provide care to a smaller proportion of uninsured patients, while they are serving increasing proportions of Medicaid patients under managed care (Shi et al., 2001).

## THE HEALTHCARE PROFESSIONS WORKFORCE IN MINORITY AND MEDICALLY UNDERSERVED COMMUNITIES

### Demographics of Healthcare Providers

The historical antecedents of physician and other healthcare provider training, as discussed above, significantly shape the current landscape of health professions education and the healthcare workforce. In this section, data on the demographic profile of healthcare providers that work primarily in racial and ethnic minority communities is reviewed.

#### *Physicians*

Minority medical graduates, including African Americans, Asian Americans, Hispanics, and American Indians, represent 9% of the country's physicians. Of these 9%, one-third (33.3%) is African American, 40.1% are

Asian American, one-fourth (24.9%) is Hispanic, and 1.8% is American Indian (AAMC, 2000). These minority graduates are more likely to work in states with large minority populations, such as California, New York, and Texas (AAMC, 2000). Underrepresented racial and ethnic minorities (African Americans, Mexican Americans/Chicanos, mainland Puerto Ricans, and American Indians/Native Americans) represent a smaller subset of this population, as less than 6% of the U.S. physician workforce is composed of individuals from these backgrounds. Significantly, well over 1 in 4 Americans is African American, Hispanic, or American Indian/Alaska Native (U.S. Bureau of the Census, 2000).

Minority physicians are more likely than their non-minority peers to work in hospital-based practices. Whereas only 1 in 5 (21.4%) of all physicians nationally work in hospital-based practices, nearly one-third (32.1%) of African American physicians, over half (50.3%) of Asian American physicians, over 1 in 3 (35%) of Hispanic physicians, and nearly 2 in 5 (39.3%) of American Indian/Alaska Native physicians work in such settings. Non-minority physicians are more likely to work in office-based practices, as 3 in 5 (60.5%) work in such settings, compared with 55.7% of African Americans, 40.8% of Asian Americans, 54.8% of Hispanics, and 53.1% of American Indian/Alaska Natives. Minority physicians are far more likely than non-minorities to be residents or fellows, owing to the generally younger age of minority physicians (AAMC, 2000). In terms of specialty practice, minorities are more likely to be found in family practice (11.5% of African American, 12.7% of Hispanic, and 24.7% of American Indian/Alaska Native physicians are family practitioners, compared with 9.9% of all physicians), obstetrics-gynecology (12.1% of African American, 8.3% of Hispanic, and 7.3% of American Indian/Alaska Native physicians are found in OB/GYN, compared with 6% of all physicians), and pediatrics (10.1% of African American and 11.1% of Hispanic physicians are pediatricians, compared with 8.7% of all physicians), but are poorly represented in other specialties, such as cardiology, surgery, and psychiatry (AAMC, 2000).

Among physicians participating in managed care arrangements, Asian-American physicians are more likely to be in solo practice (56%), while African-American physicians are more likely to practice in staff-model HMOs (19%), white physicians are more likely to be in group practice (45%), and Latino physicians were more likely to be in a hospital- or clinic-based practice (25%). Latino physicians are least likely to have managed care patients compared with physicians of other racial or ethnic groups, even after controlling for their lower rate of board certification. Twenty-six percent of Latino physicians had no managed care patients compared with 10% for African-American physicians, 13% for white physicians, and 14% for Asian physicians (Mackenzie et al., 1999).

### *Nurses*

In 2000, 12.3 percent of registered nurses were racial and ethnic minorities. Nearly 5% of all nurses self-reported as African American, 3.5% as Asian, 2% as Hispanic, 0.5% as American Indian/Alaska Native, 0.2% as Native Hawaiian/Pacific Islander, and 1.2% reported being of two or more racial backgrounds. A larger percentage (86.4%) of minority nurses were employed in nursing, as compared with 81% of white, non-Hispanic nurses. Minority nurses were also more likely to work full-time (U.S. Health Resources and Services Administration, 2001).

Geographically, there are distinct patterns of practice between the minority and non-minority nursing workforce (Table 2-3). Recent estimates revealed that black nurses were more likely to practice in the south and middle Atlantic regions of the country. Hispanic nurses were represented in higher proportions in the west and east south-central areas. Asian/Pacific Islander nurses were more likely to be found practicing in the Pacific and mid-Atlantic states. The west south-central and Mountain areas of the United States were the sites with the highest percentages of American Indian and Alaskan Native nurses. The most common employment setting for minority as well as non-minority nurses was in hospitals (U.S. Health Resources and Services Administration, 2001).

### **Impact of International Medical Graduates (IMGs) on the Workforce in Minority Communities**

An important phenomenon began to emerge during the 1930s and 1940s that would have a profound effect on the healthcare provided to racial and ethnic minorities, as the numbers of international medical graduates (IMGs) securing residency training positions in U.S. hospitals, especially those serving underserved urban and rural communities, began to increase sharply. Between 1933 and 1940, the composition of the 5,056 immigrant physicians admitted to the United States was predominantly European (Stevens, Goodman, and Mick, 1978). By the 1960s, however, immigration policies had changed such that visas were easily attainable and institutions were beckoning Third World IMGs to the United States for training because of a perceived short supply of physicians (Stevens, Goodman, and Mick, 1978). This movement was occurring as courts ended federally sponsored hospital segregation and as Medicare and Medicaid legislation was passed by Congress. Concurrently, the Civil Rights era laid the groundwork for significant changes in access to healthcare facilities and services for racial and ethnic minorities as well as for the poor and elderly.

**TABLE 2-3 Percent Distribution of Registered Nurse Population in Each Geographic Area by Racial/Ethnic Background: March 1996**

Race/Ethnicity Estimated RN population in area	U.S.	New England	Middle Atlantic		South Atlantic		East South Central		West South Central		East North Central		West North Central		Mountain	Pacific
			Atlantic	Atlantic	Central	Central	Central	Central	Central	Central	Central	Central	Central	Central		
	2,558,874	176,951	443,846	460,460	141,705	215,200	452,080	198,952	137,739	331,941						
White (non-Hispanic)	89.7	96.5	86.8	87.4	92.1	85.6	93.9	96.6	92.4	83.5						
Black (non-Hispanic)	4.4	1.3	5.6	7.3	6.3	5.0	2.8	1.4	1.1	3.1						
Asian/Pacific Islander	3.4	0.8	5.4	2.7	0.5	3.8	2.0	0.5	1.7	8.3						
American Indian/Alaska Native	0.5	0.1	0.2	0.2	0.3	1.3	0.3	0.6	1.4	0.7						
Hispanic	1.6	0.4	1.2	1.4	0.5	3.7	0.7	0.5	2.5	3.5						
Other	0.7	0.8	1.0	1.0	0.2	0.5	0.4	0.4	0.8	1.0						

SOURCE: National Sample Survey of Registered Nurses, March 2000.

The 1967 report of the National Advisory Commission on Health Manpower (NACHM) sparked renewed efforts to recruit IMGs when it declared a national shortage of physicians (COGME, 1998). The geographic maldistribution of physicians that had been systematically discussed for over 30 years as a problem became a public agenda item. By and large, health professionals had chosen to locate and practice in affluent urban and suburban communities, while large numbers of minorities and the poor had limited access to care. The NACHM report was one of several that led to the rapid expansion of existing undergraduate medical education programs as well as the creation of new medical schools.

Three decades later, the number of students graduating from United States medical schools doubled and the number of IMGs who entered residency training programs each year almost doubled between 1988 and 1994, from 3,600 to 6,700 (COGME, 1996). The number of first-year residency positions filled increased to 140% of the yearly U.S. medical school graduates. The physician-to-population ratio (excluding resident physicians) increased by 65%, from 115 to 190 physicians per 100,000 (COGME, 1996). Most of this increase was in the medical specialties, increasing the specialist physician-to-population ratio 121% from 56 to 123 specialists per 100,000 population (COGME, 1996).

Healthcare expenditures also rose dramatically during this period. Federal spending for all health services just before Medicare and Medicaid was enacted in 1965 was \$4 billion, rising to \$15.7 billion in 1970, \$33.8 billion in 1975, and \$65.7 billion in 1980. During the same period of time, state and local spending increased from the pre-Medicare/Medicaid level of \$4.8 billion to \$31.3 billion. The poor greatly increased their use of healthcare services. By 1976, poor children averaged 65% more physician office visits, poor adults averaged 27% to 33% more visits, and the elderly poor averaged 18% more visits than in 1964. In fact, the poor in each age group increased their use of health facilities more than the non-poor (U.S. Department of Health and Human Services, 1980), contributing to the increased demand for healthcare professionals.

Today, IMGs are a significant part of the U.S. health workforce. The number of residency positions filled by IMGs in 1998-99 was 25,415, or more than one-fourth (26%) of all residents on duty in U.S. hospitals in 1998-99 (COGME, 1999). Many work in minority and medically underserved communities, where few other physicians choose to practice. Verghese (1994) and White (1993) concluded that individual IMGs have established themselves as critical providers of healthcare services in selected rural underserved areas. Most, however, locate in large cities, and practice in urban underserved areas. They are disproportionately distributed in teaching hospitals with high percentages of Medicaid low-pay or no-pay patients. Sixteen percent of all teaching hospitals had an entire

resident staff consisting of greater than 40% IMGs (MedPAC, 1999). A detailed survey of the healthcare providers working in nine of the poorest neighborhoods in New York City revealed that greater than 70% of the physicians were graduates of foreign medical schools (Bellochs and Carter, 1990). The data also revealed that only 24% of the practicing physicians were board certified, while the citywide average was 64%. Many other investigators (Fosset et al., 1990; Mitchell, 1991; Mitchell and Cromwell, 1980; Perloff et al., 1986a) have documented that physicians in urban areas who accept Medicaid patients are more likely to be foreign medical graduates and are less likely to be board certified than those who do not accept Medicaid. Ginzberg (1994) summarized his study of healthcare for the poor in four of the nations largest cities:

A long-term trend of abandonment and avoidance by physicians had drained the low-income neighborhoods in all four metropolitan areas of private practitioners; physician-population ratios were as low as 1: 10,000 to 1: 15,000, in contrast to affluent neighborhoods with ratios of 1: 300 or even higher. Moreover, the majority of practitioners serving the poor consisted of foreign medical graduates, many with indifferent professional competence and language problems that impeded effective communication. Deterred by the low reimbursement rates paid by state Medicaid programs...the majority of U.S. trained physicians refused to accept Medicaid patients or limited the numbers they were willing to treat, leaving the field to group practices with questionable standards (Medicaid mills) that thrived on volume throughput (Ginzberg, 1994, p. 1465).

While from varied geographic locations around the globe, the largest share of IMGs working in the United States today are from South Asian nations. Table 2-4 illustrates the country of origin for the top 10 countries with the highest number of medical graduates in the United States.

**TABLE 2-4** Top 10 Countries with Highest Proportion of Medical Graduates in the United States

Country	Percentage of the U.S. IMG Population
India	19.5%
Pakistan	11.9%
Philippines	8.8%
Ex-USSR	3.1%
Egypt	2.6%
Dominican Republic	2.5%
Syria	2.5%
United Kingdom	2.4%
Germany	2.3%
Australia	2.1%

SOURCE: The Educational Commission for Foreign Medical Graduates, 1992.



The cultural, racial, and ethnic diversity of IMG healthcare providers, who constitute more than 25% of the resident physicians in the United States, is broad. Most are new to this country and are learning to live within its vast sociocultural complexities, while also trying to learn to deal with an ambiguous welcome into the U.S healthcare delivery system with its own rigid, complex and demanding subculture (Stevens, Goodman, and Mick, 1978). As these authors note, two-thirds of IMGs are unprepared for the experience, having relied upon friends or family for advice. Many do not have the luxury of selecting a hospital in which to practice; rather, they accept the job that is offered. Often IMGs enter the United States thinking of themselves as “internationally mobile scientists” with knowledge and skills that are transferable anywhere in the world, only to be jolted by the reality of being treated as an alien or outsider inside the hospital (Stevens, Goodman, and Mick, 1978). In one survey (Stevens, Goodman, and Mick, 1978), 13% of IMGs felt that they were inadequately informed about the location of the American hospitals, including the fact that many large hospitals are in high-poverty areas of major cities. For others, complex malpractice claims and standards may pose problems, as well as large caseloads, documentation requirements, long hours, a fast pace, and language difficulties.

The 12th CoGME Report (1999) observed that “when physician and patient differ with respect to race, ethnicity, language, religion and values, ensuring fair, equitable, and culturally sensitive care is more challenging.” The opportunity for miscommunication and cultural gaffes between IMGs and minority patients abound and could be manifest in the way healthcare services are provided or received by the communities served. This cultural configuration has existed for nearly 50 years in many of the largest metropolitan teaching hospitals serving millions of racial and ethnic minorities. However, this racial/ethnic interface has been inadequately studied to determine the impact it has on minority patients’ perceptions of their healthcare experience, utilization of services, trust, compliance, health status, and quality of care.

#### THE PARTICIPATION OF RACIAL AND ETHNIC MINORITIES IN HEALTH PROFESSIONS EDUCATION

*“I heard an Anglo doctor complaining that his daughter is having trouble getting into medical school. Then another doctor jumps in, another Anglo, “Oh don’t worry about it. I know the admissions coordinator. I’ll get her in. I’ll give him a call and she’ll be in.” When does a Hispanic or black student have those advantages, the connections? I certainly didn’t have any connections, and I still don’t have any connections. I couldn’t get my son into medical school if I tried.”*  
(Hispanic physician)

*“When I was in medical school I had a racist comment by one of the white students. He said the only reason why you’re here, it wasn’t said to me but I overheard it, the only reason why black students are here is because they’re black and this that and the other. What was really interesting was that OK, sure I’m black, but I don’t take the black test, I don’t take the black boards, we take the same exams.” (African American physician)*

In the late 1960s, many U.S. medical colleges and other health professions organizations began a concerted effort to expand opportunities for careers in the health professions to ethnic minorities who, for a variety of historic, social, political, and economic reasons, had not previously enjoyed such opportunities. The Association of American Medical Colleges (AAMC) and other groups actively encouraged member institutions to improve outreach programs and matriculation efforts targeted to minority students, in the hope that their rates of participation in health professions would achieve parity with the proportion of racial and ethnic minorities in the U.S. population (Nickens and Ready, 1999). This goal was established not only because its attainment would help to rectify inequities in educational opportunities, but also because of a growing appreciation that minority healthcare professionals are more likely to work in minority and medically underserved communities, thereby addressing a growing public health need.

By 1974, 10% of all medical school matriculants were underrepresented minorities (AAMC, 2000). This proportion decreased significantly in the wake of the U.S. Supreme Court’s *Bakke* decision in 1976, but other efforts, such as AAMC’s “Project 3000 by 2000,” initiated in 1990, resulted in significant increases that exceeded 1974 levels. Between 1990 and 1994, the number of underrepresented minority (URM) students increased 36.3% to 101,414 students, or 12.4% of the total number of medical school matriculants. Since that time, however, the number and proportion of new URM medical school enrollees has declined significantly. Enrollment of African-American students in medical schools, for example, declined 8.7% between 1994 and 1996 (Carlisle and Gardner, 1998). The greatest declines have occurred in public medical schools, which prior to 1996 enrolled a greater proportion of URM students than private institutions. Over 60% of public institutions experienced declines in URM student enrollment since 1994—a collective decrease of 9.1% in minority student matriculation at these institutions—while only 44% of private medical schools experienced such declines (Carlisle and Gardner, 1998).

While the reasons for these declines are complex, some evidence indicates that the declines have immediately followed significant policy shifts regarding affirmative action and higher education admissions procedures. Several legislative and judicial challenges to affirmative action

policies in 1995, 1996, and 1997 (notably, the Fifth District Court of Appeals finding in *Hopwood v. Texas*, the California Regents decision to ban race or gender-based preferences in admissions, and passage of the California Civil Rights Initiative [Proposition 209] and Initiative 200 in Washington state) have forced many higher education institutions to abandon the use of race and gender as factors in admissions decisions. Subsequently, public medical schools in California, Louisiana, Mississippi, and Texas (the latter three states are subject to the *Hopwood* ruling) accounted for 44% of the decrease in URM matriculation in medical schools nationwide (Carlisle and Gardner, 1998a). In 1997, African-American student enrollment in Texas' public medical schools dropped 54% (Carlisle and Gardner, 1998b). And among California's public and private medical schools, URM enrollment declined 32% in 1998 from its peak in the mid-1990s (Grumbach et al., 2001). Because of the large minority populations in these states, much of the nationwide decline in URM enrollment reflects the trends noted above, while more modest minority enrollment declines in states unaffected by legislative or judicial rulings may reflect administrators' greater caution or perceived pressure to scale back affirmative admissions policies.

This decline in the numbers of underrepresented minority students in health professions education programs raises significant concerns regarding the ability of the healthcare workforce to address the nation's future health service needs. Racial and ethnic minorities are four times more likely to receive care from non-white physicians than white physicians (Moy and Bartman, 1995). Further, racial and ethnic minority physicians are more likely to practice in minority and medically underserved communities. A study of physicians' practices in California found that on average, over half (52%) of patients in the practices of African-American physicians were African American, compared with nine percent among non African-American physicians. Among Hispanic physicians, average caseloads approached 55% Hispanic patients, compared with 20% among non-Hispanic physicians (Komaromy, Grumbach, Drake, et al., 1996). Yet African-American and Hispanic physicians constitute less than 6% of the physician workforce.

The racial/ethnic diversity of health professionals also has broader implications for health service costs and improvements in the quality of care. For example:

- Healthcare professionals from racial and ethnic minority groups have generally been more successful in recruiting minority patients to participate in clinical research. Such efforts are critical to link scientific advancements with quality service delivery in underserved communities.

- The quality of healthcare depends as much on physicians' scientific competence as on an understanding of cultural, social, and economic factors that influence the health of patients, the ways in which they seek care, and their response to medical treatment. Racial and ethnic diversity of health professions faculty and students helps to ensure that all students will develop the cultural competencies necessary for treating patients in an increasingly diverse nation (Association of American Medical Colleges, 1998).
- Racial and ethnic minorities disproportionately receive medical care in hospital emergency settings. Such care is more costly than routine medical care and preventive health services. Healthcare professionals from minority and underserved communities may be better poised to tailor preventive health and primary care programs and services to minority populations, thereby reducing associated costs.

#### SUMMARY

Racial and ethnic disparities in healthcare emerge from an historic context in which healthcare has been differentially allocated on the basis of social class, race, and ethnicity. Unfortunately, despite public laws and sentiment to the contrary, vestiges of this history remain and negatively affect the current context of healthcare delivery. And despite the considerable economic, social, and political progress of racial and ethnic minorities, evidence of racism and discrimination remain in many sectors of American life. This persistent pattern of inequality suggests that interventions to eliminate disparities must be comprehensive and sustained, and that raising public and healthcare provider awareness of the problem is an important first step. Toward this end, a number of public and private organizations have developed educational campaigns targeted toward healthcare consumers, their providers, policymakers, and other "stakeholders." These efforts include, but are not limited to: the public education efforts of U.S. DHHS, which recently launched its "Closing the Health Gap" campaign to heighten awareness of health disparities; Diversity Rx, which provides a clearinghouse of information on language, culture, and improving healthcare services for minorities; and The Henry J. Kaiser Family Foundation, which has developed a number of publications targeted to the general public regarding healthcare disparities.

**Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.**

**Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.**  
Public education to increase awareness of racial and ethnic disparities in healthcare is an important first step toward eliminating these disparities. Media campaigns and other educational efforts to increase awareness of disparities should be targeted to broad audiences, including healthcare consumers, payors, providers, and health systems administrators.

**Recommendation 2-2: Increase healthcare providers' awareness of disparities.**  
Organizations responsible for the education, training, and licensure of health and medical professionals should develop special initiatives to increase levels of awareness of healthcare disparities among current and future healthcare providers.

### 3

## Assessing Potential Sources of Racial and Ethnic Disparities in Care: Patient- and System-Level Factors

The literature reviewed earlier in this report demonstrates that evidence of racial and ethnic disparities in healthcare is persuasive and remarkably consistent across a range of health conditions and procedures, and cannot be fully explained by differences in access to care, such as insurance status. Moreover, the literature suggests several sources for these disparities. This evidence, however, does not suffice for an authoritative, comprehensive, unambiguous account of how disparities arise. A number of uncertainties confound efforts to synthesize what is known empirically about stereotypes and prejudice, doctor-patient relations, clinical judgment and patient preferences, as well as the social, institutional, financial, and legal forces that shape the practice of medicine. Yet an effort at such a synthesis is essential to construct an evidence-based account of how disparities in care emerge, and of what might be done to eliminate these disparities.

To begin, this chapter presents a model of how disparities might occur. This model builds upon the wide foundation of empirical evidence but makes reasoned inferences when they are necessary to explain observed disparities. The committee makes such inferences when, in our judgment, they are more probable than not and when practical consequences, in the form of recommended actions to ameliorate known disparities, follow from these inferences. In doing so, the committee acknowledges that gaps in our understanding about causation remain and that further research has the potential to enhance understanding.

The chapter then presents a review of empirical literature that raises hypotheses regarding potential sources of racial and ethnic disparities in

healthcare. This literature is suggestive of a range of sources of disparities, some of which lie just beyond the conscious perception of individual actors (e.g., patients, providers, health systems administrators) in clinical encounters. They include systemic (e.g., those related to health system administration, financing, accessibility and geographic location), patient-level (e.g., the clinical appropriateness of care, patients' attitudes, preferences, and expectations regarding healthcare), and care process-level (e.g., physician biases, stereotyping, and uncertainty) factors. This chapter, however, will focus on the two former sets of variables. As depicted in Figure 1-1, these include "patient-level" variables, and variables related to the operation of healthcare systems and the legal and regulatory contexts in which health systems function. Chapter 4 will focus the analysis on care process variables, including the roles of clinician bias, prejudice, stereotyping, clinical uncertainty, and patient mistrust. According to the study committee's conceptualization, racial and ethnic *differences* in care may arise from all three sets of variables. *Disparities* in care, however, emerge from the characteristics of and the operation of healthcare systems, as well as the legal and regulatory climate in which care is delivered, and from the process of care (i.e., factors emerging from the provider-patient interaction).

The following section presents a guiding framework that depicts the likely interplay of health systems characteristics, patient-level factors, and care process variables in fostering racial and ethnic disparities in healthcare.

## A MODEL: SOURCES OF HEALTHCARE DISPARITIES

### The Role of Clinical Discretion

An integrated model of how racial and ethnic disparities in care emerge is presented in Figure 3-1. According to this model, patients present to healthcare providers with varied healthcare needs, expectations, and preferences, some of which are socio-culturally determined. Providers, in turn, possess expectations and beliefs that are shaped both by their professional training and experience, as well as by their social experiences and broader societal norms and structures. These encounters take place within healthcare systems and settings that are broadly influenced by institutional design factors (such as the ease of care access), and financial forces (such as incentives to providers and patients to limit service use and healthcare costs). These systems operate within legal and cultural contexts that influence how healthcare is delivered and the behavior of both patients and providers.

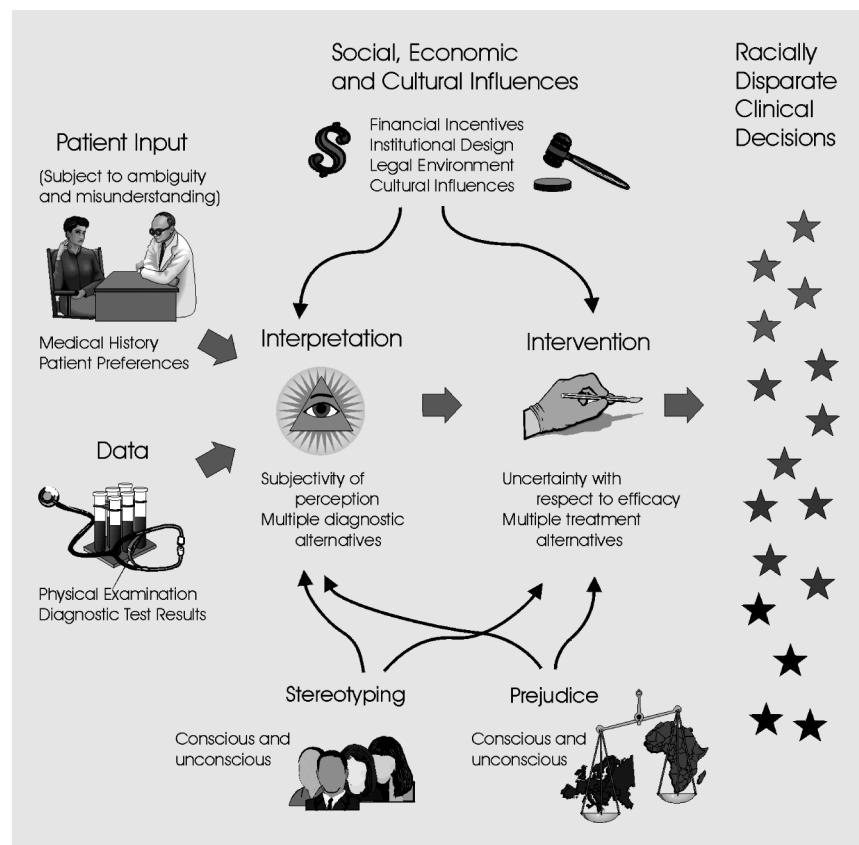


FIGURE 3-1 An integrated model of healthcare disparities.

Central to this model is the role of personal discretion in determining the care that patients receive. Three sets of actors possess and exercise discretion: clinical caretakers, utilization managers remote from the bedside, and patients themselves. Patients' medical histories, physical exam findings, and diagnostic test results often present a level of uncertainty to physicians, and patients vary enormously in their help-seeking behavior, ways of presenting their symptoms and histories, and responses to medical recommendations (Bursztajn, 1990). Clinicians typically have multiple diagnostic and therapeutic options, and choices from among them sometimes do not rest firmly on empirical evidence. In addition, physician perception of clinical signs and symptoms is sometimes incomplete (Eddy, 1996), while decisions concerning diagnostic and therapeutic in-



tervention are no less ambiguous. Significant variations in the incidence of many common medical and surgical procedures have been documented within small geographic areas and between individual practitioners (Wennberg, 1999). These variations reflect, in many instances, both the subjectivity of clinical judgment and the lack of professional consensus about best practice. Further, the lack of firm scientific support for some medical decisions both engenders variations in clinical practice and makes it difficult in many cases to reach evidence-based conclusions concerning the appropriateness of particular practices.

In and of itself, the discretion exercised by patients, providers, and utilization managers does not produce racial and ethnic disparities in healthcare. In most cases, patients and providers are able to work together in an iterative process to match patients' needs with appropriate treatment, regardless of race or ethnicity. Discretion and ambiguity, however, create conditions in which race or ethnicity may become salient in the process of diagnosis and treatment in ways that make disparities more likely to occur, as explained below.

#### *The Patient as Discretionary Actor: Subjectivity and Variability*

A substantial research literature in psychiatry and psychology, sociology, and anthropology documents large differences in how people experience, understand, and discuss illness (Goff et al., 1998). Patients' experience and reporting of pain and other symptoms have been found to vary greatly (Bonham, 2001), as has patients' help-seeking behavior relative to health professionals (Milewa et al., 2000). The relationships between such variation and differences in how clinical caretakers go about the diagnosis and treatment of disease have been less well studied. But the subjectivity and incompleteness of clinical perception leave room for differences in patients' experience, understanding, and reporting of symptoms to affect professional judgment and action. These differences, moreover, interact with differences in patients' values and attitudes toward clinical caretakers to shape patients' healthcare choices. To the extent that such variation correlates with patients' race and ethnicity, it is therefore a potential contributor to differences in healthcare use.

#### *Clinical Caretakers as Discretionary Actors: Subjectivity and Uncertainty*

Medical care at the dawn of the 21st century has achieved heights thought improbable even a few decades ago. Advances in diagnostic techniques, scientific understanding of the human genome and underlying disease processes, and new, high-tech interventions have led to break-

throughs in treating and preventing disease. Despite these gains, however, many medical decisions must be made in the absence of solid evidence as to the efficacy of diagnostic and therapeutic measures or rigorous scientific understanding of the pathophysiology of disease (Mushlin, 1991). Efforts to better understand pathophysiology are further complicated by variations in clinical expression in individuals with different genetic, environmental, and cultural backgrounds. In addition, even the most technologically sophisticated diagnostic interventions (e.g., magnetic resonance imaging and X-ray and positron tomography) reveal little about the biochemistry and physiology of the diseases they detect. To add to this uncertainty, medicine's diagnostic constructs are themselves limited in their predictive (and thus therapeutic) value by the incompleteness of the pathophysiologic understandings that undergird them (Bloche, 2001).

Moreover, healthcare providers' ability to assess patients' clinical signs and symptoms and gather a relevant medical history is constrained by a number of factors. As noted above, patients' ability to understand and describe their presenting concerns varies not only by cultural, linguistic, and other sociodemographic background factors, but may also vary from day to day. The variability and subjectivity of patients' clinical presentations is compounded by physicians' differences in perception, cultural and psychological sensitivity, and conceptual frameworks for evaluating illness. Similarly, many laboratory tests are open to varying interpretations. Radiologists sometimes give conflicting readings of the same X-ray, tomogram, or other scan, and pathologists sometimes report conflicting interpretations of slides sent for assessment of possible malignancy. Many clinical and laboratory data are likewise open to differing clinical interpretations by physicians with varying conceptual frameworks, perceptions, and biases. As will be discussed in the next chapter, it is reasonable to speculate that the resulting diagnostic subjectivity could permit clinical uncertainty, racial and ethnic biases, and stereotypes to influence the process and outcomes of clinical evaluation, resulting in racial and ethnic disparities in medical diagnosis.

Physicians' decisions regarding appropriate therapeutic interventions introduce still another level of uncertainty, subjectivity, and variability. Despite clinical medicine's gains noted above, accurate, evidence-based prediction of the efficacy of many therapeutic alternatives for most patients is lacking (Bloche, 1999), and geographic variations in clinical practice patterns are common (Wennberg, 1999). In the absence of guidance from prospective and retrospective clinical studies, physicians base their therapeutic judgments on such factors as their training, prior clinical success and failure, and practice norms among professional peers (Bauchner, Simpson, and Chessare, 2001). Inevitably, physicians' subjective under-

standings of their patients' needs play a role; thus psychological sensitivity, cultural and language competency, and conscious and unconscious stereotypes and biases may also influence therapeutic decision-making. Further, uncertainty about treatment options in itself, even absent biases or stereotypes, can lead to disparate treatment of racial and ethnic minority groups, as will be discussed in Chapter 4. In addition, organizational, financial, and legal influences shape therapeutic judgment. Such institutional and policy forces are often geared toward promoting cost-effective and efficient care, but may disproportionately and negatively affect minority patients (Bloche, 2001).

*Utilization Managers as Discretionary Actors: Uncertainty at a Distance*

Variation and subjectivity in healthcare practice may also emerge at the level of health systems, particularly in managed care arrangements where utilization managers are charged with authorizing physicians' and patients' requests for reimbursement for services. Except where contractually bound by clinical practice protocols, utilization managers evaluate the necessity of claims from among a range of diagnostic and therapeutic alternatives acceptable within one or another subset of the medical community. This evaluation often occurs on a case-by-case basis, without the guidance of recorded precedent or other administrative means for pursuing consistency between utilization management decisions in similar cases. In some cases, doctors and patients who seek pre-approval for planned treatments or who pursue internal appeals when pre-approval is denied know little or nothing about their health plans' past pre-approval practices in similar cases. Health plans that employ clinical practice protocols as cost management tools sometimes treat these protocols as trade secrets, not to be disclosed to patients or medical practitioners. The consequence of these administrative arrangements is that there is ample room (and little visibility) for discretion and inconsistency in the treatment of clinically similar cases (Bloche, 2001).

The following sections review available empirical evidence and present an analysis of how discretion, subjectivity, and preferences of patients, providers and utilization managers may contribute to healthcare disparities. Consistent with the committee's model of sources of racial and ethnic differences in care, these sources are divided into patient-level variables (such as preferences, needs, and the clinical appropriateness of care), and factors related to health systems and the legal and regulatory context of healthcare. Factors arising from the clinical encounter that may contribute to disparities are addressed in Chapter 4.

**PATIENT-LEVEL VARIABLES—PREFERENCES, MISTRUST,  
TREATMENT REFUSAL, BIOLOGICAL DIFFERENCES, AND  
OVERUSE OF SERVICES**

**Patients' Preferences**

To a great extent, patients' values, fears and hopes, and other psychological characteristics influence the level and type of care they receive. Patients' trust and doubts about medical advice, as well as their level of comfort with the effectiveness and potential unintended effects of interventions, directly influence their willingness to accept physicians' recommendations. In addition, patients' preferences are influenced by their tolerance for pain and discomfort, attitudes about long-term/short-term tradeoffs, and levels of social and emotional support. These factors also influence physicians' recommendations, in that the physician may directly assess or infer patients' attitudes toward particular interventions and may tailor recommendations accordingly. To the extent that minority patients express greater reluctance to accept physician recommendations, patients' preferences have the potential to contribute to healthcare disparities. Evidence that minority patients are more likely than whites to decline invasive and/or high-tech procedures is reviewed below.

For many racial and ethnic minorities, however, preferences for treatment are often difficult to separate from mistrust of health professions that stems from racial discrimination and the history of segregated and inferior care for minorities (Byrd and Clayton, this volume). Some researchers have not distinguished between these aspects of minority patients' historic experiences and preferences for treatment, and have contrasted "preferences" and racial discrimination as competing explanations for healthcare disparities. This account overlooks the interaction between patients' "preferences" and their experiences of discrimination. As Bloche (2001) notes, "For many African Americans, doubts about the trustworthiness of physicians and healthcare institutions spring from collective memory of the Tuskegee experiments (Brandt, 2000) and other abuses of black patients by largely white health professionals (Randall, 1996; King, 1998). This legacy of distrust, which, some argue, contributes to disparities in healthcare provision by discouraging African Americans from seeking or consenting to state-of-the-art medical services, is thus itself a byproduct of past racism" (Bloche, 2001, p. 105).

Minority patients' negative experiences with care providers in the clinical encounter can also diminish their preferences for robust treatment, and may thereby contribute to racial disparities. It is reasonable to assume that experiences of real or perceived discrimination in healthcare settings, as evidenced by providers' overt behavior (e.g., as in the ex-

amples from focus group data presented in Chapter 2) or more subtle, subjective mistreatment (e.g., healthcare providers' low expectations for compliance or expressions of low empathy for minority patients) can affect patients' feelings about their clinical relationships and thereby dampen their interest in vigorous diagnostic and therapeutic measures. It is therefore necessary to distinguish patient "preferences" from experiences or perceptions of discrimination and not neglect the ways in which patients' preferences can be shaped by provider behavior. In addition, patients' preferences for treatment may be limited by the quality and completeness of information presented by the healthcare provider. Thus, should providers fail to present minority patients with a full range of treatment options, whether out of prejudice, stereotyping, biases, or uncertainty about the diagnosis or appropriate clinical course of action, patients' preferences will be limited by the information they are presented. These dynamics will be addressed in greater detail in Chapter 4.

#### *Minority Patient Preferences Regarding Providers and Racial Concordance*

Minority patients' experiences, values, and expectations regarding healthcare may significantly influence their preferences for the race or ethnicity of their providers. A growing body of evidence suggests that racial and ethnic minority patients are generally more satisfied with the care that they receive from minority physicians. Saha, Komaromy, Koepsell, and Bindman (1999), for example, found that African-American patients with African-American healthcare providers were more likely than those with non-minority providers to rate their physicians as excellent in providing healthcare, in treating them with respect, in explaining their medical problems, in listening to their concerns, and in being accessible. Hispanic patients who received care from Hispanic physicians did not rate their physicians as significantly better than Hispanic patients with non-Hispanic healthcare providers, but were more likely to be satisfied with their overall healthcare.

Similarly, Cooper-Patrick and her colleagues (Cooper-Patrick et al., 1999) assessed patients' ratings of the quality of interpersonal care in racially concordant and racially discordant settings. Using a measure of physicians' participatory decision-making (PDM) style, the authors surveyed over 1800 adults (including 43% white, 45% African American, and 12% other race or ethnicity) who were seen in 1 of 32 primary care settings by physicians who were either African American (25% of the physician sample), white (56%), Asian American (15%), or Latino (3%). Overall, African-American patients were found to rate their visits as significantly less participatory than whites, after adjusting for patient age, gender, education, marital status, health status, and length of the patient-physician

relationship. Further, patients in race-concordant relationships rated their visits as significantly more participatory than patients in race-discordant relationships.

LaVeist and Nuru-Jeter (in press) examined predictors of racial concordance between patient and provider and the effect of race concordance on satisfaction among a sample of white, African-American, and Hispanic patients. Among all racial and ethnic groups, patients who reported having at least some choice in selecting a physician were more likely to have a race-concordant physician. Having a race-concordant physician was also associated with higher income for African Americans and not speaking English as a primary language among Hispanics. After adjusting for patients' age, sex, marital status, income, health insurance status, and whether the respondent reported having a choice in physician, African-American patients in race-concordant relationships were found to report higher satisfaction than African Americans in race-discordant relationships. Further, Hispanic patients in race-concordant relationships reported greater satisfaction than patients from other racial and ethnic groups in similarly concordant relationships.

While these studies lend important information regarding patients' perceptions of the interpersonal quality of care, few studies have corroborated this data with more objective assessments of the patient-provider interaction in racially concordant and discordant settings. Cooper and Roter (this volume) describe a study that assessed this relationship using post-visit surveys and audiotape analysis among a sample of 143 white and 110 African-American patients seen by 1 of 13 white or 18 African-American primary care doctors. Cooper and colleagues found that the average length of visits was shortest among white physicians with African-American patients (13.2 minutes), and was longest among African-American physicians seeing white patients (18.4 minutes). Visits by African-American patients were characterized by greater physician verbal dominance overall, but physician verbal dominance was highest in visits between white physicians and African-American patients, and lowest among white patients seen by African-American physicians. In addition, visits between white physicians and African-American patients were the least patient-centered, while the African-American physician-white patient interaction was characterized by the highest levels of patient centeredness. However, patients in race-concordant relationships rated their physicians' decision-making styles as more participatory. The finding that African-American physicians were more patient centered and spent more time with white patients, according to Cooper and Roter, suggests two possibilities. One is that African-American physicians, by virtue of their educational success and professional standing, presumably have had greater opportunities to develop skills in communicating with

individuals from the dominant culture than white physicians have had to develop communication skills with individuals from minority cultures. This suggests that African-American physicians are likely to be bicultural (i.e., able to function effectively in the dominant culture as well as in minority cultures) or are acculturated (i.e., have assumed traits of the dominant culture). Secondly, African-American physicians may “overcompensate” for perceived deficiencies of their own group by adopting behaviors that indicate less respect for themselves or members of their own group (Cooper and Roter, this volume).

A significant limitation of these studies is the lack of random assignment of patients with physicians, introducing selection factors as a potential confound. In fact, Saha et al. (1999) found that African-American and Hispanic patients who had the ability to choose their provider were more likely to choose a racially or ethnically concordant physician. A significant proportion (42%) of Hispanic patients in this study reported selecting Hispanic physicians because of linguistic barriers with other providers. Nonetheless, these studies demonstrate that racial concordance is associated with greater participatory decision-making, greater patient-centered care, lower levels of physician verbal dominance, and greater patient satisfaction. In turn, evidence from other studies indicates that patient satisfaction is associated with greater patient compliance with treatment regimens, participation in treatment decisions, and use of preventive care services (Cooper and Roter, this volume). For racial and ethnic minorities, according to Cooper-Patrick and colleagues (1999), racial concordance may increase the likelihood that they will “share cultural beliefs, values, and experiences in the society [with their provider], allowing them to communicate more effectively and to feel more comfortable with one another” (p. 588).

Little evidence exists, however, to directly demonstrate that the quality of care provided is better when minority patients and their providers are of the same racial or ethnic group. Evidence of the efficacy of race-concordant patient and provider relationships is only indirect, as patient satisfaction, participation, and patient-centeredness of care are also associated with greater adherence to clinical regimens, greater participation in health screening and preventive medicine, and in some cases, health outcomes (Cooper-Patrick et al., 1999). Chen et al. (2001) suggest the opposite—that racial disparities persist in care even when minority patients are treated by minority physicians. The authors performed a retrospective analysis of data obtained from a sample of Medicare patients hospitalized with acute myocardial infarction (MI) to determine whether racial differences in rates of cardiac catheterization were related to the race of attending physician. Consistent with other studies, the authors found that African-American patients were less likely than white patients to re-

ceive catheterization within 60 days after MI. No significant differences were found, however, between African-American and white attending physicians in rates of catheterization among these patients. Among patients treated by African-American physicians, 38 percent of black patients and 50 percent of white patients received catheterization. Among patients treated by white physicians, 38 percent of black patients and 46 percent of whites received the procedure. Chen et al. conclude that “racial discordance between the patient and the physician does not explain differences between black patients and white patients in the use of cardiac catheterization” (2001, p. 1447).

While some newspaper accounts of this study suggested that racial bias is not a likely source of disparities in care (Associated Press, May 9, 2001), this interpretation appears premature. Several methodological problems complicate interpretation of the results obtained by Chen et al. Data on the race of the attending physician were missing for nearly one-third of the initial patient sample. In addition, African-American patients were more likely to be cared for in public or teaching hospitals, where greater barriers exist to receipt of catheterization, such as the availability of the procedure on-site. The most serious methodological problem, however, was the determination of the race of the attending physician (“the clinician who is largely responsible for the care of the patient from the beginning of the hospital episode”). Upon closer examination, it becomes apparent that the African-American physicians of these patients tended to be internists, not cardiologists, when compared with the white attending physicians. While these physicians may all refer patients for the procedure, the determination of who receives the procedure is typically made by the cardiologist. Thus, the authors compare two different physician pools who cared for these African-American patients post-myocardial infarction—African-American internists versus white cardiologists—to assess differences in utilization of a procedure that is specifically performed by and managed by cardiologists. Notably, of the nearly 20,000 cardiologists in the United States during the study period in 1994 and 1995, only 316 (approximately 1.5%) were African American.

### **Minority Patient Mistrust and Experiences of Discrimination**

Some racial and ethnic minorities express greater levels of mistrust of healthcare providers and the medical establishment than white Americans, citing breaches of trust that have previously occurred between minorities and the scientific and medical communities (Swanson and Ward, 1995). In addition, survey research generally indicates that ethnic minority patients perceive higher levels of racial discrimination in healthcare settings than non-minorities. For example, in a survey of 781 African-



American and 1,003 white cardiac patients, LaVeist, Nickerson, and Bowie (2000) found that while the majority of these patients did not tend to endorse the existence of widespread racism in medical settings, African-American patients were four times more likely than whites to believe that racial discrimination is common in doctors' offices, and were significantly more likely to mistrust healthcare systems. Similarly, Lillie-Blanton et al. (2000) found that of a nationwide, random sample of whites and minorities, 30% of Hispanics and 35% of African Americans believe that racism is a "major problem" in healthcare, compared with 16% of whites. Well over half of the minorities in this sample (58% of Hispanics and 65% of African Americans) are "very or somewhat" concerned that they or a family member could be treated unfairly when seeking medical care because of their race or ethnic background, while less than 1 in 4 whites (22%) endorse this view. Finally, nearly three times as many African Americans (64%) as whites (23%) believe that African Americans receive a lower quality of healthcare compared with whites; over twice as many Hispanics (56%) as whites (27%) endorse this view when comparing whites and Hispanics.

In a study of healthcare consumers conducted by the Seattle and King County (WA) Department of Public Health (Hobson, 2001), researchers found that nearly one-third of African Americans report having experienced discrimination at some point in their lifetimes when seeking healthcare, and 16% reported such experiences in the past year. More than one-fifth of Hispanic patients reported similar experiences of discrimination in healthcare settings at any point in their lives, and between 7% and 19% of Asian-American subgroups reported such experiences. Significantly, for almost all ethnic groups, respondents who reported experiences of discrimination were more likely to report a delay in seeking needed healthcare than those who did not report experiences of discrimination; this effect was almost uniform (95%) among African Americans who reported experiences of discrimination.

### **Patient Refusal of Recommended Treatment**

Some researchers have speculated that patient refusal may contribute to disparities in care, noting that African-American and other ethnic minority patients may be more likely to refuse invasive procedures. Schecter et al. (1996), for example, found that African-American patients were more likely than whites to refuse physicians' recommendations that they undergo cardiac catheterization. Similarly, Sedlis et al. (1997) found that 15.4% of African-American patients treated at Veterans' Administration hospitals refused invasive cardiac procedures (surgery or percutaneous

transluminal coronary angioplasty) when offered, compared with 8.3% among white patients, a difference that the authors conclude may help to explain observed differences in rates of receipt of procedures. The same study, however, revealed that invasive cardiac procedures were recommended more frequently by physicians for white patients (72.9%) than for African-American patients (64.3%), even following diagnostic cardiac catheterization and initial assessment confirming that all the patients were potential candidates for surgery or angioplasty. Thus, physicians' judgments of suitability for procedures in this study contributed to racial variations in care even before patients were presented with surgical options.

Several other studies find no racial differences in rates of refusal of recommended procedures, or find that patient refusal does not fully account for disparities in receipt of care. Petersen et al. (2002) assessed use of cardiac procedures among a sample of African-American and white VA patients with diagnosed acute MI, and found that black patients were less likely to receive thrombolytic therapy or bypass surgery than whites, even when only patients with high-risk coronary anatomy were examined. Black and white patients did not differ, however, in rates of refusal of angiography, angioplasty, and coronary bypass surgery. Lauori et al. (1997) found that patient refusal of recommended cardiovascular procedures could not explain racial differences in "necessary" revascularization procedure rates. Similarly, Hannan et al. (1999) found that among patients deemed appropriate for a revascularization procedure but who did not receive it, a primary gatekeeper physician did not recommend the procedure in 90% of cases. In a study of African-American and white patients suffering from end-stage renal disease, Ayanian et al. (1999) found that African Americans were less likely than whites to desire a transplant. However, racial differences in rates of renal transplantation remained after adjustment for patients' preferences and expectations about transplantation, sociodemographic characteristics, the type of dialysis facility where they received treatment, perceptions of their care, health status, the cause of renal failure, and the presence or absence of co-morbid illness. Other studies, such as Canto et al. (2000), excluded patients who refused the recommended intervention (in this case, reperfusion therapy), but still found racial differences in receipt of therapy.

In summary, few studies have specifically examined racial differences in rates of refusal of treatment recommendations, or why such differences may occur. Of these studies, the majority find that minority patients are more likely than whites to refuse treatment (particularly invasive treatments). Patient preferences are therefore a likely contributor to racial and ethnic disparities in healthcare. The studies reviewed by the committee, however, find that patient preferences do not fully account for observed disparities, suggesting that other sources of disparities may also be opera-

tive, perhaps in interaction with patients' attitudes and preferences. In addition, other studies find that minority patients are more likely than whites to perceive that discrimination is a problem in healthcare settings, and are more likely to believe that minority patients receive poorer care than non-minority patients. Minority patients' greater likelihood of refusal of treatment may therefore be linked to a wide range of factors, including real or perceived negative experiences in healthcare settings, negative experiences in other settings (e.g., housing, employment—see Chapter 2), or the history of inferior treatment that minorities have received by the medical and scientific community (Byrd and Clayton, this volume). Further, as noted in Chapter 1, patients' preferences must be understood in the context of information provided to the patient by his or her healthcare provider. Should providers fail to provide clear, accurate, understandable information about the range of treatment options, then patients' consent for treatment cannot be considered fully informed. It is important to distinguish these sources of patient preferences, because as will be noted in Chapter 4, higher minority patient refusal linked to negative experiences in clinical encounters or incomplete disclosure may constitute discrimination.

#### **Biological Differences That May Justify Differences in Receipt of Care**

Chen et al. (2001) and other researchers speculate that racial differences in clinical characteristics may contraindicate the use of the same therapeutic procedures at similar rates in both African-American and white patients. For example, some African-American patients who have had an MI may be more likely than whites to have negative or unclear electrocardiograms at the time of presentation, complicating diagnosis. In addition, African-American and white patients may respond differently to some therapeutic regimens. Exner et al. (2001), for example, found that African-American patients with left ventricular dysfunction were less likely than whites with the same disorder to benefit from enalapril, an angiotensin-converting-enzyme inhibitor. In this study, similar doses of enalapril therapy or a placebo were provided to matched African-American and white patients. Enalapril was associated with a 44% reduction in the risk for hospitalization for heart failure among white patients, but with no significant reduction in risk for hospitalization among African-American patients.

These racial differences in response to pharmacologic and other therapeutic regimens may reflect genetic differences, differences in the pathogenesis of diseases, and environmental factors, such as differences in diet and health-related behaviors. Genetic differences may reflect dif-

ferences in the distribution of polymorphic traits—including drug receptors or drug-metabolizing enzymes—across all racial and ethnic groups, rather than traits unique to any one group (Wood, 2001). Further research is needed to determine racial differences in response to pharmacologic intervention to assist physicians in weighing individual patients' likely treatment response. It is important to note, however, that many therapeutic regimens have proven efficacious for minority as well as non-minority populations. As noted in Chapter 1, several studies document that these procedures are provided at lower rates to African-American and minority patients where racial differences in response to treatment cannot justify differences in application (Canto et al., 2000; Todd et al., 2000; Bach et al., 1999; Gregory et al., 1999; Hannan et al., 1999; Peterson et al., 1997; Allison et al., 1996; Ball and Elixhauser, 1996; Gornick et al., 1996; Herholz et al., 1996; Imperato et al., 1996; Harlan et al., 1995; Ayanian et al., 1993).

### **Overuse of Clinical Services by White Patients**

Several researchers have suggested that racial and ethnic disparities in care may arise in part from the overuse of services among white patients, rather than differences in service utilization arising from clinical necessity. White patients enjoy generally higher levels of education and may have greater access to and means of gathering information about their presenting concerns and possible diagnostic and treatment options. They may also feel more comfortable advocating for themselves and urging their physician to provide desired services. Racial differences would therefore be expected to be pronounced for optional or non-essential services and procedures. As noted in Chapter 1, however, several studies have tested the "overuse" hypothesis by examining use of clinical procedures relative to established criteria for necessity. These studies demonstrate that in the case of essential services, African-American and minority patients tend to receive a lower quality of care than whites when assessed relative to established quality criteria. Hannan et al. (1999), for example, assessed rates of coronary artery bypass grafting (CABG) among 1,261 post-angiography patients who would benefit from CABG according to RAND appropriateness and necessity criteria. Controlling for age, gender, severity of disease, patient risk status, type of insurance, and other clinical characteristics, the authors found that African-American and Hispanic patients were 36% less likely than whites to undergo CABG. Similarly, Laouri et al. (1997) used RAND/UCLA criteria for necessity of revascularization procedures and found that African Americans were half as likely as whites to undergo necessary CABG and one-fifth as likely to undergo percutaneous transluminal coronary angioplasty (PTCA). In a larger study, Canto et al. (2000) studied the use of reperfusion therapy

among more than 26,000 patients meeting eligibility criteria as a result of acute MI. After controlling for clinical and demographic characteristics, the authors found that African Americans were slightly less likely than whites to undergo reperfusion therapy. Further, Schneider et al. (2001b) found that while overuse of PTCA was greater among white men than among minorities, this difference did not fully account for racial differences in revascularization.

To further address the question of whether racial disparities in receipt of revascularization procedures reflect clinical necessity or merely overuse among whites, Peterson et al. (1997) assessed racial differences in receipt of coronary angioplasty and CABG among patients with documented coronary disease, and assessed whether differences were associated with survival. The investigators followed 12,402 patients seen at Duke University Medical Center, and found that African Americans were 13% less likely than whites to undergo angioplasty and 32% less likely to undergo CABG. Racial differences in procedure rates were more marked among patients with severe disease. Analysis of survival benefit of surgery also revealed racial differences; among patients expected to survive more than one year, 42% of African Americans underwent surgery, compared with 61% of whites. Finally, analysis of the adjusted five-year mortality rate among patients revealed that African-American patients were 18% more likely than whites to die.

### HEALTH SYSTEMS-LEVEL VARIABLES

Aspects of health systems—such as the ways in which systems are organized and financed, and the “ease” of accessing services—may exert different effects on patient care, particularly for racial and ethnic minorities. Complicated reimbursement procedures and structures, for example, may deter patients with low literacy or limited English proficiency from seeking care. Similarly, time pressures on physicians may hamper the ability of providers to accurately assess presenting symptoms of minority patients, especially where cultural or linguistic barriers are present. Further, the geographic availability of healthcare institutions—while largely influenced by economic factors that are outside the charge of this study—may have a differential impact on racial and ethnic minorities, independently of insurance status. This means that even among minorities and non-minorities insured at the same level, the ease of accessing services and racial differences in where care is typically received may contribute to disparities. Perhaps most significantly, rapid changes in the financing and delivery of healthcare services—such as the dramatic shifts brought by cost-control efforts and the movement to managed care—may pose greater barriers to care for racial and ethnic minorities than for non-mi-

norities (Rice, this volume). Increasing efforts by states to enroll Medicaid patients in managed care systems, for example, may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic minority communities (Leigh, Lillie-Blanton, Martinez, and Collins, 1999). Finally, legal and regulatory policy with regard to healthcare can create a context in which healthcare disparities are not tolerated or implicitly accepted. These potential influences on the quality of care for racial and ethnic minority patients are discussed below, along with supporting evidence.

### **Language Barriers**

As noted in Chapter 2, nearly 14 million Americans are not proficient in English. Linguistic concordance between patient and provider is important, however, as language allows the provider to construct an accurate medical and social history, and assess the patient's belief about health and illness. Language is also an important tool for clinicians to establish an empathic connection with patients (Woloshin et al., 1995), and to reach agreement with patients on treatment decisions and prescribe a course of action. The failure of patients and providers to communicate effectively with each other may result in misunderstandings of patients' concerns, misdiagnosis, or unnecessary testing. In addition, miscommunication can result in poor patient compliance, inappropriate follow-up, and poor patient satisfaction. To the extent that healthcare systems and institutions fail to address language barriers and assist communication between patients and providers, language mismatches are a fertile source of racial and ethnic disparities in care.

Several studies suggest that care processes and outcomes are affected by linguistic barriers. Perez-Stable, Napoles-Springer, and Miramontes (1997), for example, assessed the effects of ethnicity and language concordance between patients and their physicians on health outcomes, use of health services, and clinical outcomes among a sample of Spanish-speaking and non-Spanish-speaking Hispanic and non-Hispanic patients at a university-affiliated general medicine practice. Of the 74 Spanish-speaking Latinos, 60% were treated by clinicians who spoke Spanish, while 40% were treated by non-Spanish-speaking clinicians. After controlling for patient age, gender, education, number of medical problems, and number of prescribed medications, the authors found that having a language-concordant physician was associated with better patient self-reported physical functioning, psychological well-being, health perceptions, and lower pain.

Baker et al. (1996) surveyed 467 native Spanish-speaking and 63 English-speaking patients presenting with non-urgent medical problems

in a hospital emergency department to assess patients' reports of the use and need for interpretation. Interpretation, which is usually provided at the discretion of healthcare workers, was provided for only 26% of the Spanish-speaking patients. Just over half (52%) of the Spanish-speaking patients who were seen without a translator felt that interpretation was not necessary, but an additional 22% of the patients who did not receive interpretation felt that it was necessary. Of the patients who received interpretation services, almost half (49%) received interpretation services by a physician or a nurse. But when both the providers' Spanish and the patients' English were poor, interpretation was not called in over one-third (34%) of encounters. In these instances, 87% of patients felt an interpreter should have been called.

Baker et al. (1996) went further to assess patients' understanding of their medical condition and treatments. They found that only 38% of patients who did not have an interpreter when they thought one was necessary reported that their understanding of their condition was good or excellent. Nearly 3 in 5 (58%) reported that their understanding of their treatment was good or excellent, and 90% wished that their examiner had explained their diagnosis or treatment better. However, when patients' knowledge of their diagnosis and treatment were assessed objectively using a standardized measure, no significant differences were found between those who received interpretation and those did not have an interpreter and thought one was necessary (Baker et al., 1996).

David and Rhee (1998) examined the impact of language barriers on patient compliance with medication, satisfaction with care, and preventive testing. Spanish-speaking patients who possessed good English skills and did not need an interpreter were more likely than Spanish-speaking patients who had low English skills and used an interpreter to report that the side effects of medications were explained, and reported greater satisfaction with medical care. Surprisingly, while large majorities of both "cases" (Spanish-speaking patients with low English proficiency who used interpretation) and "controls" (Spanish-speaking patients who reported not needing interpretation) reported that their doctors discussed mammography and clinical cancer screening tests, significantly more cases than controls received these screening tests, leading the authors to speculate that testing served as a substitute for verbal communication.

Interpretation in healthcare settings has commonly been provided in one of several ways. Professional interpretation, using formally trained interpreters who demonstrate proficiency in mediating communication between languages and an understanding of medical terminology, remains rare. Without such services, one of three "sub-optimal" (Woloshin et al., 1995) strategies may be used: 1) the language skills of patients and providers; 2) the skills of family or friends; or 3) ad hoc interpretation

from non-clinical employees (e.g., a clerk, aide, or custodian) or bilingual bystanders (e.g., other patients). These strategies are less desirable than professional interpretation because they can interfere with the patient-provider relationship and introduce error into interpretation. Ebden et al. (1988), for example, recorded and analyzed ad hoc interpretation encounters and found that 23% to 52% of words and phrases were incorrectly interpreted. Perhaps more importantly, ad hoc interpretation raises significant concerns regarding patient privacy. The use of bystanders, friends, or family, particularly children, as interpreters undermines patient privacy and may suppress the patient's willingness to discuss sensitive concerns (U.S. DHHS Office for Civil Rights, 2000).

### **Availability and Access to Services**

Literature reviewed in Chapter 1 suggests that the quality of care for minority and non-minority patients may differ in part as a function of where these patients receive care. Even among equally insured patient populations, studies note differences in the quality of care provided, with private, teaching, and high-volume settings generally providing better quality care than public, non-teaching institutions. Significantly, minorities' access to better quality facilities is often limited by the geographic distribution of care facilities and patterns of residential segregation (see Chapter 2), which results in higher-quality facilities being less accessible to minorities.

Leape et al. (1999) tested this hypothesis by assessing racial differences in revascularization procedures as a function of hospital characteristics among 631 patients admitted to 13 New York City hospitals. Revascularization procedures were deemed clinically necessary for all 631 patients, according to RAND criteria. The authors found no significant racial differences in rates of revascularization procedures among African-American patients (72%), Hispanic patients (67%) and white patients (75%). Rates of revascularization were significantly lower, however, among patients initially seen in hospitals that did not provide revascularization services (and therefore had to refer patients to other hospitals) than those treated in settings that did provide revascularization.

Similarly, Kahn et al. (1994) assessed the quality of care received by nearly 10,000 poor and/or African-American Medicare patients aged 65 years or older admitted to one of 297 acute care facilities for treatment of congestive heart failure, acute myocardial infarction, pneumonia, or stroke. For all patients, processes of care (as assessed by measures of physician and nurse clinical decision-making, technical diagnostic and therapeutic processes, and monitoring processes) were of lower quality in rural hospitals and best in urban teaching hospitals. No overall differ-



ences in the quality of care or mortality rates were found by race and poverty status. The authors note, however, that African-American patients and those who were from poor neighborhoods were 1.8 times as likely as whites and those not from poor neighborhoods to receive care in urban teaching hospitals, which generally provide better quality care. After adjusting for sickness at admission, patient and hospital characteristics (i.e., removing the effect of blacks and people from poor neighborhoods receiving better care in urban teaching hospitals), and other clinical factors, African-American patients and those who were from poor neighborhoods received a lower overall process-of-care and were 1.4 times more likely to be discharged in an unstable condition. The authors conclude that “the greater frequency of use of urban teaching hospitals by patients who are black or poor almost completely offsets the worse process of care they receive within each hospital. This phenomenon . . . should be considered in studying the care received for groups of patients whose care may be influenced by the setting in which it is provided” (Kahn et al., 1994, p. 1172).

Geographic factors have also been found to contribute to minorities’ lower rates of access to pharmaceutical products. Morrison et al. (2000) examined the relationship between the racial and ethnic composition of New York City neighborhoods and the availability of opioid supplies of pharmacies to assess patients’ ease of filling palliative care prescriptions. After controlling for the proportion of elderly persons at the census-block level and for crime rates at the precinct level, the authors found that only 25% of pharmacies in predominantly non-white neighborhoods (those in which less than 40% of residents are white) had sufficient opioid supplies to treat patients in severe pain. In contrast, 72% of pharmacies in predominantly white neighborhoods (those characterized by over 80% white residents) carried sufficient opioid supplies to treat patients in severe pain.

### **Maneuvering Through Clinical Bureaucracies**

Racial and ethnic differences in rates of referral for specialty medical care can emerge in any of several steps in the process of care. Maneuvering through the bureaucratic and administrative “maze” commonly found in modern hospitals and clinics is essential in accessing clinical resources, yet some racial and ethnic groups, for a variety of reasons, may experience less success in navigating through such bureaucracies. Clinical caretakers, for example, are critical actors in helping patients access clinical resources. If these caretakers’ advocacy efforts are adversely influenced by clinical uncertainty, stereotypic thinking, and/or lesser personal engagement with patients (to be discussed in the next chapter), it is reasonable to surmise that racial and ethnic minorities will be at a disadvantage

in negotiating the medical bureaucracy. Thus, despite formal “equality” in access, minorities may experience differences in the rates with which they receive clinical services. To compound these difficulties, to the extent that minority patients are more likely to experience a subjective sense of disempowerment—whether because of a lack of cultural or linguistic familiarity with the “culture” of medicine (Good et al., this volume), or because of perceived discrimination—these patients may be expected to less vigorously assert their needs or “to feel bitter, even resentful, and to act in a manner that conveys this bitterness, rendering clinical administrators less empathic” (Bloche, 2001, p.106). As yet, however, little empirical data are available to support these hypotheses. An important aspect of navigation through healthcare systems—the clinical referral—is discussed next.

### **Referral Patterns and Access to Specialty Care**

As noted in Chapter 2, racial and ethnic minorities report greater difficulty in obtaining referral and accessing specialty care. Einbinder and Schulman (2000), drawing on empirical literature and theory, illustrate how patient race or ethnicity may influence the referral process for invasive cardiac procedures. The initial step in the process involves the patient’s recognition of symptoms that may suggest coronary artery disease. Some evidence, the authors note, indicates that racial and ethnic minorities are less likely than whites to recognize the symptoms of coronary artery disease, and therefore may delay seeking medical treatment. Such delays may limit treatment options. A second step involves obtaining access to healthcare providers, and varies by patient race or ethnicity because of differences in insurance status, as well as the local availability of providers (minority patients are more likely than whites to live in physician shortage areas). In addition, minority patients are less likely than whites to have a regular care provider. The lack of an on-going relationship with a healthcare provider may affect referral because the evaluation and referral process requires regular medical follow-up. In the third step, patient race or ethnicity may influence the presentation of symptoms, and the ability of care providers to recognize them (this topic will be discussed in greater detail in Chapter 4). Physicians’ subsequent assessments and recommendations may therefore be based on incomplete information, or can be influenced by assumptions or unconscious stereotypes and biases, according to the authors. Patients’ acceptance of physician recommendations also plays a minor role in racial differences in referral rates, as minority patients may refuse referral for invasive testing at higher rates than whites, and physicians may not have the time or interest in discussing patients’ concerns or questions about unfamiliar procedures (see earlier

discussion of patient refusal). A sixth step identified by Einbinder and Schulman—referral for noninvasive diagnostic evaluation—may be influenced by whether the patient is being followed by a primary care provider or a cardiac specialist, and the relationship that this provider has with other specialists in order to obtain referral. Referral for cardiac catheterization is affected by many factors, according to the authors, including the availability of catheterization services and access to high-technology hospitals, the presence of co-morbid conditions, patient preferences, advanced age, or social factors that may limit patients' ability to comply with therapeutic interventions. All of these factors may disproportionately limit minority patients' ability to undergo catheterization (Einbinder and Schulman, 2000).

Few studies have empirically assessed racial disparities in medical referral. A recent study by Hargraves and colleagues (Hargraves, Stoddard, and Trude, 2001), however, assessed minority physicians' experiences in both obtaining referrals for their patients to specialists and gaining hospital admissions. As noted earlier, racial and ethnic minority physicians are disproportionately more likely to serve minority patients, and therefore play a key role in enhancing access to care for minority populations. Hargraves et al. (2001) surveyed a nationally representative sample of African-American, Hispanic, and white physicians, and asked them how often they were able to arrange referrals to specialists and obtain admissions for their patients. Controlling for physician characteristics (e.g., years in practice, gender, specialty, group or private practice, revenue from managed care, Medicaid, and Medicare) and market characteristics (e.g., local physician participation in managed care, supply of hospital beds, and specialists per capita), minority physicians were found to have greater difficulty in gaining access to care for their patients. Hispanic physicians were more likely to report problems with obtaining referrals for specialty care than their white colleagues, and African-American physicians reported experiencing greater difficulty than white physicians in arranging hospital admissions for their patients. Hargraves et al. (2001) conclude that because physicians' training, type of practice, and other local characteristics were taken into account, only a few variables, such as physicians' prestige or clout, the proximity of hospitals and specialists to their patients, or discrimination directed at the physicians or their patients could account for these differences. The study's findings are limited, however, by a lack of direct measures of characteristics of the physicians' panel of patients. Given the fact that minority physicians are more likely to work in lower-income and minority communities, their patients might differ in disease status, preferences for treatment, and health insurance status.

### Fragmentation of Healthcare Systems

“Fragmentation” of healthcare can occur when patients, even those privately insured, encounter different levels of plan coverage that influence the kinds and quality of services they receive. Multiple coverage options offered by health plans are often characterized by different types of benefits packages and different degrees of provider choice. In addition, coverage options vary in levels of pre-authorization review and financial incentives to physicians to practice frugally. At the lowest level of coverage, beneficiaries may face greater constraints in their choice of providers, settings in which care is received, and types of covered services. These differences imply that even within health plans, the medical marketplace is segmented by personal wealth and health status as well as consumer and employer preference (Bloche, 2001). This effect is seen most profoundly in the case of managed care plans comprised largely or entirely of Medicaid recipients and other poor Americans. Such plans have expanded coverage for the neediest (Rosenbaum, this volume), but further segmented the market.

There is little empirical data bearing on the question as to whether less costly, more restrictive health plans provide a poorer (or better) quality of care than more costly, less restrictive plans. However, lower per capita plan budgets mean fewer resources per capita for clinical services, given that care must be provided within a budget. On average, population groups disproportionately represented in less costly, more restrictive plans receive a lower intensity of care. Significantly, much of the research on racial and ethnic disparities in healthcare cited in Chapter 1 controls for insurance status at only a crude level (e.g., insured versus uninsured, privately insured versus publicly insured, etc.), and has not adequately controlled for variations in levels of insurance coverage. They therefore leave open the possibility that racial disparities in care result to some degree from the disproportionate presence of socioeconomically disadvantaged groups in less costly plans.

Furthermore, fragmentation of healthcare financing and provision may foster the development of disparate clinical practice norms, arising from distinct institutional cultures and provider and patient characteristics as well as from different levels of fiscal constraint. The fragmentation ensuing from the Medicaid program’s statutory design merits mention as a special case. Because of Medicaid’s low reimbursement rates for doctors and hospitals, its poor, disproportionately minority beneficiaries are subject to largely separate, often segregated systems of hospital and neighborhood clinics (Rosenbaum, this volume; Watson, 1995). These systems often adopt their own norms of medical practice, shaped by tight resource constraints. In addition, Medicaid’s low reimbursement rates drastically

restrict Medicaid beneficiaries' ability to access private physicians, and prevents many Medicaid patients from being admitted to hospitals in the absence of a private doctor with hospital admitting privileges (Rosenbaum, this volume), unless admitted as "community service" inpatients. Even in these instances, such patients are more likely to be cared for primarily by house staff as opposed to private attending physicians. Congress further reinforced Medicaid's low payment scales and largely separate systems of care with repeal of the Boren Amendment, which required Medicaid payments to doctors and hospitals to be "reasonable and adequate" and gave healthcare providers a federal cause of action against state Medicaid programs<sup>1</sup> (Bloche, 2001).

### **U.S. Department of Defense and Veterans Administration Healthcare Systems**

Additional evidence of the impact of health systems on the ability of racial and ethnic minority patients to receive quality healthcare emerges from studies of large healthcare systems run by the U.S. Department of Defense (DoD) and Department of Veterans Affairs (VA). While findings are mixed, some studies suggest that racial and ethnic healthcare disparities are reduced or eliminated in these systems. These findings appear more consistently in studies of DoD systems, which ensure universal access to care, than in VA systems, which significantly reduce financial barriers to care among veterans. Taylor et al. (1997), for example, found no racial differences in rates of catheterization or revascularization among more than 1,400 military patients seeking care for acute myocardial infarction. And as noted above, Optenberg et al. (1995) studied more than 1,600 African-American and white active duty military personnel, their dependents, or military retirees with prostate cancer served in DoD healthcare facilities. They found no significant racial differences in waiting time to receive treatment after initial diagnoses, type of treatment, and survival rates once stage of presentation and other clinical and demographic

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<sup>1</sup>42 U.S.C.A. §1396a(a)(13)(C) (1982 & Supp. V 1987), repealed by Balanced Budget Act of 1997, Pub. L. No. 105-33, §4712(c), 111 Stat. 509 (1997). A state plan for medical assistance must "provide . . . for payment . . . of hospital services, nursing facility services, and services in an intermediate care facility for the mentally retarded provided under the plan through the use of rates (determined in accordance with methods and standards developed by the State . . .) which the State funds, and makes assurances satisfactory to the [Health and Human Services] Secretary, are reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards and to assure that individuals eligible for medical assistance have reasonable access . . . to inpatient hospital services of adequate quality."

factors were considered. In a study of prenatal birth outcomes among civilian and military women, Barfield et al. (1996) found that rates of prenatal care utilization were lower, and rates of low birth weight and fetal and neonatal mortality higher among African-American women than white women, but that these racial disparities were lower (but still significant) among the military population. In addition, a recent study of VA systems found modest racial differences in mortality rates among African-American and white patients admitted for pneumonia, angina, congestive heart failure, chronic obstructive pulmonary disease, diabetes, or chronic renal failure, but these differences suggested *better* survival rates for minority patients (Jha et al., 2001).

Other studies, however, note significant racial differences in VA systems in rates of procedures such as cardiac catheterization. Peterson et al. (1994), Mirvis et al. (1994), Whittle et al. (1993), and Mirvis and Graney (1998) all found African-American VA patients less likely to receive cardiovascular procedures than white VA patients. Sedlis et al. (1997) found that therapeutic cardiac procedures (surgery or PTCA) were offered more frequently for white VA patients (72.9%) than African-American VA patients (64.3%). This difference could not be explained by simple clinical differences between the two groups. Conigliaro et al. (2000) found that although African-American VA patients were less likely than white VA patients to undergo CABG and PTCA, when RAND appropriateness criteria were considered, African Americans were still less likely to receive CABG when deemed "necessary." Oddone et al. (1999) studied racial differences in rates of carotid artery imaging among patients diagnosed with transient ischemic attack, ischemic stroke, or amaurosis fugax seen at one of four VA Medical Centers. After controlling for patients' age, comorbid factors, clinical presentation, anticipated operative risk, and hospital, African-American patients were found to be half as likely as whites to receive carotid imaging.

Evidence for racial and ethnic disparities in care in VA systems is therefore mixed, but suggests that financial, structural and institutional factors of these systems, as well as the universally available care for military personnel in DoD systems may serve to attenuate some disparities in care. For example, physicians in both DoD and VA systems are salaried, eliminating the role of financial incentives to physicians to recommend or withhold specialized procedures (Okelo et al., 2001). In addition, other practices of these health systems related to larger quality improvement goals may also serve to attenuate disparities. The VA, for example, has instituted clinical decision support programs for physicians, which provide automated, time-sensitive and context-sensitive clinical reminders at the point of care, such as prescription checks and preventive care information. These clinical supports rely on a computerized patient record

system that provides patients' medical and social histories, discharge summaries and progress notes, allergies, prior laboratory results, and other information. Clinical reminder notifications provided through these computerized data systems are largely based on the VA's national clinical practice guidelines. In addition, clinical care is evaluated relative to performance measures in six domains (quality, functional status, patient satisfaction, access, cost, and healthy communities). Most of the measures used to assess progress in these domains are based on "best practices" formally supported by evidence-based medicine (Swift, 2001). Such practice guidelines, as will be discussed in Chapter 5, may help to reduce variations in care due to clinical discretion and/or uncertainty.

Significantly, some evidence also suggests that when patients' race or ethnicity is unknown (e.g., when treatment decisions are made by a group of conferring physicians based solely on clinical data), racial and ethnic disparities in care may be attenuated. Okelo et al. (2001) assessed whether racial differences in recommendations for cardiac revascularization persisted when patients' race or ethnicity is unknown. The authors described the treatment decision-making procedures of cardiologists at the Cleveland VA Medical Center, who review clinical data of each patient considered for revascularization absent information about patients' race or ethnicity. Following this procedure, Okelo et al. found no overall racial differences in recommendation for revascularization. After adjusting for patients' age, co-morbidities, location and number of coronary stenoses, left ventricular function, and previous CABG, the authors found that white patients were more likely to undergo CABG and African-American patients were slightly (but not significantly) more likely to undergo PTCA. These findings lead Okelo et al. to conclude that "when only clinical factors are considered, the rates of recommendations for revascularization will be similar for white and African-American patients; but the type of revascularization procedure may differ by ethnicity and may depend, in part, on clinical factors" (Okelo et al., 2001, p. 698).

### **The Managed Care Revolution**

Managed healthcare remains the predominant model of cost containment in an era of continuing escalation of healthcare costs and overall health expenditures. Most managed care organizations employ various forms of either supply-side (i.e., incentives to healthcare providers to practice frugally) or demand-side (i.e., incentives to patients to constrain the use of services) cost containment strategies, or combinations of both as part of managed competition strategies (Rice, this volume). As part of broader efforts to contain costs, improve the quality of care, and increase market share, some managed care organizations employ standardized

practice protocols and collect data on patient satisfaction and outcomes of care. As such, managed care offers the potential to help eliminate disparities in healthcare. In many other areas, however, managed care has introduced new institutional dynamics that may enhance the conditions in which racial and ethnic disparities in healthcare can occur.

Utilization review and practice guidelines, for example, may be used by some managed care organizations (MCOs) to ensure that physicians provide services deemed medically appropriate. In this vein, it may be assumed that prospective utilization management, when applied in a standardized fashion, offers the prospect of ensuring that clinical care is consistent across patient groups. As noted earlier in this chapter, however, the subjectivity and ambiguity of clinical situations make standardized practice difficult, and guidelines cannot be developed for all clinical contingencies (Bloche, 2001). As a result, utilization managers must, in many instances, authorize reimbursement under conditions where considerable ambiguity and uncertainty exist. Under these conditions, advocacy by committed clinical caretakers may influence utilization managers' decisions. Typically, such advocacy is more likely to occur where patients and their providers have an established relationship and where providers have the time and resources to pursue claims. Minority patients, as noted below, are less likely than whites to receive care from private physicians and are less likely to have a regular primary care provider—even when compared to whites at the same insurance level (Lillie-Blanton et al., 2001). It is therefore possible that minorities may be less likely to benefit from the advocacy of their provider. The outcomes of competition for resources within a plan also hinge on utilization managers' discretion. With the exception of the studies cited below (see, for example, Lowe et al., 2001), there has been little research into subjective influences on utilization reviewers' decisions in ambiguous cases. Possible influences may include different degrees of sponsorship and advocacy on behalf of patients from their provider, which may be associated with patients' socioeconomic status, and utilization managers' assumptions about which patients are most likely to appeal utilization decisions (Bloche, 2001).

Another supply-side constraint employed by many MCOs is the practice of cost control via devolution of financial risk, thereby shifting responsibility for cost control to practicing physicians. Economic rewards for frugality and penalties for costly tests, treatments, and referrals have become common in contemporary clinical practice (Rice, 1997; Rice, this volume). The result has been increased reliance on the discretion of gatekeeping clinical caretakers to set limits and manage scarce resources. As noted in the model depicted in Figure 3-1, such discretion may allow cognitive, affective, social and cultural factors to influence clinical discretion in racially disparate ways. It may also affect medical resource alloca-



tion decisions, in that physicians' suspicions and fears about which patients will protest or sue if denied a test or treatment may influence (even at a subconscious level) the distribution of resources (Bloche, 2001).

While more research must be conducted to fully test these hypotheses, evidence indicates that low-income and ethnic minority patients are less likely to have a regular provider, are more likely to be denied claims, and are less satisfied with many aspects of the care they receive in managed care settings. In a study of low-income African-American, Hispanic, and white patients enrolled in managed care and fee-for-service plans in four states, Leigh and colleagues found that for all three groups, those enrolled in managed care plans were less likely to have a regular provider than those enrolled in fee-for-service plans (Leigh, Lillie-Blanton, Martinez, and Collins, 1999). African-American and Hispanic patients enrolled in managed care plans, however, were more likely than whites enrolled in MCOs to lack a regular provider, as approximately two of every five (38% among African Americans and 42% among Hispanics) lacked a regular provider, compared with 27% of whites enrolled in such plans. In addition, African-American patients enrolled in managed care plans were more than twice as likely as African Americans enrolled in fee-for-service plans to report that they did not obtain needed care. Further, when asked about "the extent to which your physician cares about you," Hispanic patients enrolled in managed care plans were nearly twice as likely as Hispanics enrolled in fee-for-service plans to rate their physicians' level of concern as "fair" or "poor" (Leigh, Lillie-Blanton, Martinez, and Collins, 1999).

Similarly, Phillips et al. (2000) used 1996 Medical Expenditure Panel Survey (MEPS) data to compare the experiences of 22,087 African-American, Hispanic, Asian-American, and non-Hispanic white patients enrolled in either managed care plans or other types of health systems (e.g., fee-for-service plans). Overall, survey respondents reported generally high levels of satisfaction with care, but minorities reported experiencing greater barriers to care than white patients. In particular, Hispanics experienced the greatest difficulty of the surveyed groups in obtaining care (24%), followed by Asian Americans (16%). Three in ten Hispanics reported lacking a usual source of care, as did two in ten African Americans and 21% of Asian Americans. Whites were least likely to report these barriers to care. In addition, and in contrast to Leigh et al. (1999) above, Phillips et al. found that among all racial and ethnic groups, those enrolled in managed care plans were more likely to report having a usual source of care than those enrolled in non-managed care plans. Minorities enrolled in managed care plans, however, tended to experience greater dissatisfaction with their usual source of care than those not enrolled in managed care plans. Asian Americans enrolled in managed care plans

were 10 times more likely than Asian Americans enrolled in other types of plans to express dissatisfaction with their usual source of care; Hispanics enrolled in managed care plans were 4 times more likely to express this belief; while whites enrolled in managed care plans were only 1.5 times more likely than whites enrolled in non-managed care plans to endorse this view.

Research also suggests that managed care organizations' gatekeeper policies may pose greater barriers to care for minority patients. Lowe et al. (2001), for example, assessed racial differences in rates of gatekeeper approval for emergency department (ED) services sought by more than 15,000 African-American and white patients at an urban hospital. Nearly three-fourths (73%) of the ED visits analyzed were by African-American patients, and over two-thirds (67%) of visits were by Medicaid beneficiaries. Following a triage assessment by ED staff, 4.4% of visits were denied authorization for services, most commonly because they were deemed "minor" or non-urgent. African-American patients were more likely to receive low triage scores upon presentation; however, after adjusting for patients' age, gender, day and time of ED visit, type of MCO and triage score, African Americans were nearly 1.5 times more likely to be denied authorization for care. Patients who were covered by a Medicaid MCO or those covered by MCOs with mixed Medicaid and commercial patient populations were also more likely than those covered by purely commercial MCOs to be denied authorization for care. The authors note it unlikely that the gatekeepers who approved or denied authorization knew the race or ethnicity of patients presenting in the ED, as they generally did not know the patients and were not informed by ED staff of the patients' race. Therefore, these disparities could have emerged from other sources, such as ED staff's initial triage assessments, advocacy efforts by primary gatekeepers on behalf of patients (as discussed above), or other unmeasured factors (Lowe et al., 2001).

Finally, some of the most significant support for the hypothesis that managed care may pose greater barriers to care for racial and ethnic minorities than whites is provided by Tai-Seale and colleagues (Tai-Seale, Freund, and LoSasso, 2001). Using a "natural experiment," the authors assessed the differential effects of mandatory enrollment in managed care plans on use of clinical services by African-American and white Medicaid beneficiaries. A "difference-in-differences" econometric approach controlled for both time trends in demand for services and for fixed characteristics of beneficiaries that may have affected their use of services. African-American beneficiaries, including both children and adults, experienced significant declines in the use of physician services relative to whites. This relationship was found even when trends in service use unrelated to managed care were controlled by comparing service use to ben-

eficiaries not subject to mandatory enrollment in managed care plans (Tai-Seale et al., 2001).

### **Supply-Side Cost Containment and Demand for Clinical Services**

When patients are well insured, demand for clinical services is not constrained by demand-side prices. Because of low co-payment and/or generous insurance coverage of healthcare expenses, these patients will tend to display a higher demand for clinical services. Such is the case when previously uninsured or underinsured patients are provided with better health insurance, as their use of services (and subsequently, their healthcare costs) increases. In these circumstances, health plans will often use supply-side constraints to encourage doctors to engage in more frugal practice. These cost-containment efforts may involve capitation (providing a set fee for all patients seen in a health system or practice), devolution of financial risk to providers, or other practices (Rice, this volume). Similarly, limitations on the availability of physicians or resources within hospitals or clinics may also induce supply-side constraints. These supply-side constraints can engender demand-supply mismatches within hospitals (Joskow, 1981) and other clinical institutions, as patients will be less able to access all desired providers or services.

These demand-supply mismatches have the potential to contribute to racial and ethnic disparities in care. Excess demand for a hospital's services creates multiple internal queues for these services (Harris, 1979). Competition for these services within institutions may turn on the ability of providers to use their influence in advocating for their patients. As Bloche (2001) observed, "Absent bright-line, easy-to-apply criteria for prioritizing among patients in a queue, the politics of personal influence and professional hierarchy shape resource allocation. Attending physicians with the professional stature and/or political skills to push to the head of the queue in clinically ambiguous situations will do so on behalf of the patients to whom they feel most committed. Conversely, house staff and less influential attending physicians will have more difficulty making their way up the queue" (Bloche, 2001, p. 107).

As noted above, racial and ethnic minority patients are less likely to be seen by a private physician, or to have a regular primary care provider, even when insured at the same level as whites (Lillie-Blanton et al., 2001). Moreover, they are more likely to receive care in hospital clinics and other settings characterized by rapid staff turnover and lack of continuity of care providers. Under these circumstances, it is reasonable to assume that physician advocacy on behalf of patients will be less likely, either because the physician is less familiar with patients that he or she does not regu-

larly treat, or because resource constraints such as capitation prevent physicians from meeting all patients' demands for services (Rice, this volume). Therefore, patients cared for by physicians in settings that support continuity of clinical relationships may have preferred access to services when demand-supply mismatch conditions exist.

### **Legal and Regulatory Policy and Healthcare Disparities**

A number of legal and regulatory mechanisms exist that, in theory, may serve to remedy discriminatory healthcare practice. In some cases, however, these mechanisms are insufficient by themselves to address discriminatory practices, or cannot be implemented without addressing significant obstacles. A few of these mechanisms are briefly described below, as a means of providing examples of how legal and regulatory tools, while well-intended, often fail to address the complexity of racial and ethnic discrimination in healthcare.

#### *Medical Tort Law and Clinical Discretion*

Medical malpractice law, in some cases, has served as an effective response to departures from standards of competent practice. Its application to the problem of healthcare discrimination, however, has been limited.

In theory, medical malpractice law prescribes a unitary level of care, regardless of health insurance status or ability to pay. Tort doctrine assumes that a "correct" standard of care can be discerned from physician-experts through the adversary process. Yet, as noted above, clinical practice patterns and styles vary widely. Without high-quality data about the efficacy of alternative approaches, physician-experts cannot provide testimony that distinguishes scientifically between "correct" and "incorrect" clinical practice variations. So long as the care at issue in a medical malpractice case adhered to one or another widely accepted practice variation, it can be defended by resorting to like-minded physician-experts. Without empirical evidence that the practice variation at issue is "wrong," the requirement that plaintiffs shoulder the burden of proof on the issue of negligence in tort cases poses a high barrier to legal success. The lack of such evidence poses another obstacle to malpractice plaintiffs. Plaintiffs must shoulder the burden of proof as to whether the negligence they allege was in fact the cause of the harm that occurred. In the absence of high-quality evidence concerning the comparative efficacy of alternative courses of treatment, proof that a defendant physician's choice of one treatment over another resulted in harm (or a diminished probability of a favorable outcome) is more difficult. Racial disparities in care that fall

within the range of widely accepted clinical practice variations are thus not easily amenable to correction through the operation of medical malpractice law (Bloche, 2001).

Moreover, only a small proportion of arguable errors of clinical judgment—arguable based on empirical grounds for preferring one approach over another—result in medical malpractice suits (Weiler, 1993). Even smaller proportions yield monetary settlements or judgments, and poor people and members of disadvantaged minority groups are less likely than other Americans to sue their doctors (Burstin et al., 1993). Medical malpractice law is therefore of weak utility as a mechanism to address racial and ethnic discrimination in healthcare.

#### *Emergency Medical Treatment and Active Labor Act*

The federal Emergency Medical Treatment and Active Labor Act (EMTALA)<sup>2</sup> requires federally funded hospitals (e.g., those that participate in Medicare or Medicaid) that operate emergency rooms to screen all emergency room patrons for “emergency medical conditions” regardless of patients’ ability to pay, and to provide stabilizing treatment for emergency conditions. Further, these hospitals are required to refrain from discharging patients or transferring them to other facilities (also known as “patient dumping”) on economic grounds. Judicial interpretation of EMTALA, however, has been criticized as having weakened the law’s force as a deterrent to disparate treatment in the emergency room (Bloche, 2001). Federal appellate court panels in several circuits have ruled that the mandatory emergency screening examination required by EMTALA need not meet national standards of care, but rather, should conform only to the screening hospital’s regular practice. Plaintiffs, as a result, commonly experience difficulty pursuing suits alleging violations of EMTALA, as they must challenge local hospital policy, often without the assistance of physicians familiar with emergency room screening practice at the hospital they intend to sue or other evidence of violations of hospital emergency room procedures. As Bloche (2001) notes, “the resulting ‘code of silence’ problem is obvious: avoidance of the ‘code of silence’ barrier was a principal reason for the shift from community to national standards of care in medical malpractice law” (Bloche, 2001, p. 110). The difficulties encountered by plaintiffs in suing to enforce EMTALA may lead to cursory evaluation and transfer or discharge of members of disproportionate numbers of minority patients, whether because of no or insufficient insurance, racial discrimination, or unconscious bias. To add to this difficulty, state laws mandating

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<sup>2</sup>EMTALA, 42 U.S.C. §1395dd (1995).

emergency room screening have generally been construed and applied with similar permissiveness (Rosenblatt et al., 1997).

### *The Unfulfilled Potential of Title VI*

Title VI of the Civil Rights Act of 1964 bars discrimination in health-care and other services by all entities that receive federal funds. Title VI therefore applies to the vast majority of U.S. hospitals and clinics, given the large percentage of these care settings that rely significantly or in part on Medicaid or Medicare reimbursement. Significantly, the law extends beyond intentional discrimination to prohibit many facially neutral practices that may result in disparate negative effects on racial and ethnic minorities and other disadvantaged groups. The impact of Title VI in desegregating healthcare and ensuring the equitable treatment of all patients has been enormous. Despite resistance to desegregation in the early years following the law's passage, for example, the enforcement of Title VI by federal investigators, aided by activists and health professionals, resulted in many previously segregated hospitals opening their doors and wards to all patients who could pay (Smith, 1999). Evidence of discrimination in some sectors of the healthcare industry, however, remained. Discriminatory practices such as denial of admitting privileges to African-American physicians,<sup>3</sup> refusal of admission to patients lacking attending physicians with staff privileges, high prepayment requirements for black patients, and discriminatory routing of ambulances continued in some instances (Smith, 1999). In these cases, the DHHS Office for Civil Rights (OCR) has enacted such measures as revising requirements for staff privileges, eliminating prepayment requirements, and requiring changes in ambulance routes (Rosenbaum et al., 2000).

Despite these gains, some argue that Title VI has yet to fulfill its potential as a tool to eliminate discrimination in healthcare (Perez, this volume; Bloche, 2001). For example, the federal regulations promulgated pursuant to Title VI did not offer detailed compliance instruction to healthcare institutions (Rosenbaum, 2000; U.S. Commission on Civil Rights, 1999), making it difficult for even the well-intended institutions to assess what practices may run afoul of the law. More significantly, federal Title VI regulations held that Medicare's payments to physicians do not constitute "federal financial assistance" under Title VI. This rule

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<sup>3</sup>Some hospitals pursued the facially neutral strategy of refusing to grant privileges to physicians who were not members of their local medical societies. The difficulty for African-American doctors (and their patients) in some localities, was that these medical societies (which received no "federal financial assistance" and were thus beyond Title VI's reach) refused admission to blacks (Smith, 1999).

meant that private physicians were not subject to Title VI, despite the fact that virtually all other federal payments to private actors are treated by the regulations as “federal financial assistance,” triggering Title VI protections (Rosenbaum, 2000). If physicians who accept Medicare were subject to Title VI, the law would have given DHHS (and private plaintiffs) a powerful civil rights enforcement tool, applicable not only to racial disparities in the care provided to Medicare patients but also to disparate treatment of non-Medicare patients by physicians who accept Medicare. Given that most physicians accept Medicare, and given their important role as key decisionmakers with respect to use of hospital resources and services, extending the reach of Title VI to Medicare coverage of physician services would subject most of the private healthcare sector to Title VI enforcement.

The reach and effectiveness of Title VI can be improved by addressing these gaps. More specific regulatory guidance, based on empirical research regarding potential disparate impact and means to improve access to and quality of care for minority patients, will enable healthcare institutions to develop more finely crafted policies and will help enforcement efforts by drawing distinctions between allowable and potentially illegal practices (Bloche, 2001). More robust DHHS monitoring and enforcement, similar in scope to the early efforts of the Department following passage of Title VI, can help to re-establish federal leadership work toward the elimination of care disparities (Smith, 1999). In addition, application of Title VI to private physicians who accept Medicare would extend the law’s reach to a significant segment of the healthcare industry.

Furthermore, the application of Title VI beyond intentional discrimination to include policies that may create disparate racial impacts could be an important tool for civil rights enforcement. Disparate impact could be assessed using institution-specific statistical evidence of disparities in healthcare provision. Such evidence may suffice to state a *prima facie* case of discrimination, requiring a healthcare provider to justify policies and practices that result in racially disparate clinical decisions (Barnes and Weiner, 1999). Establishing proof of institution-specific disparities—and of causal links between such disparities and particular policies and practices—will pose significant challenges. The possibility of institution-specific databases sufficiently powerful to serve this probative purpose is speculative, but the ongoing effort to establish electronic clinical record-keeping (see Chapter 7) may make such evidence increasingly accessible to civil rights enforcement authorities.

Despite the promise of this type of data, however, new challenges have emerged within the last year that will limit private parties’ ability to seek legal relief under Title VI from policies with disparate racial impact (Perez, this volume). In *Alexander v. Sandoval*, the U.S. Supreme Court

held that Title VI did not create a private right of action concerning policies with disparate impact, absent discriminatory intent. This action therefore places the greatest burden of civil rights enforcement with U.S. DHHS, which will shape Title VI's future as a health policy tool through its civil rights enforcement policies.

### SUMMARY

This chapter presents a review of evidence regarding potential sources of racial and ethnic differences in healthcare, once access-related factors such as patient education, income, and insurance status are held constant. Consistent with the committee's definitions of *differences*, *disparities*, and *discrimination* in care, several sources are identified. Those related to patients' preferences, needs, and racial or ethnic differences in the clinical appropriateness of care may contribute to differences in the quality or intensity of care provided, but these are not sources of healthcare disparities, as they do not imply undue differential treatment on the basis of race or ethnicity. Disparities in care, on the other hand, likely emerge from a range of sources, such as characteristics of healthcare systems and the legal and regulatory context of healthcare delivery. In the next chapter, sources of disparities arising from the clinical encounter will be examined in greater detail.

**Finding 3-1: Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.**

**Evidence suggests that several sources may contribute to healthcare disparities, including healthcare providers, patients, utilization managers and healthcare systems. In the current era of healthcare delivery, clinical decision-making increasingly involves this large number of individuals, who are subject to an array of systems influences that may contribute to healthcare disparities.**



## 4

# Assessing Potential Sources of Racial and Ethnic Disparities in Care: The Clinical Encounter

Previous chapters have assessed the extent of racial and ethnic disparities in healthcare, and have identified potential sources of these disparities. Disparities are found to arise from an historic and social context in which racial and ethnic minorities received inferior healthcare, reflecting broader socioeconomic disadvantage among minorities and societal discrimination. When seen by a healthcare provider, minorities typically have been treated in segregated healthcare systems that today remain largely segmented by socioeconomic class. When differences in treatment attributable to insurance, access to care, health status, and other factors are eliminated, however, racial and ethnic healthcare disparities still remain.

As discussed in Chapter 3, factors related to patients' needs and preferences, as well as the characteristics of health systems and the legal and regulatory contexts in which care is delivered, may explain some of the racial and ethnic differences in care that remain once access-related factors are controlled. In this chapter, aspects of the clinical encounter that may contribute to disparities—including patients' and providers' attitudes, expectations, and behavior—are assessed. When these encounters systematically produce racial and ethnic disparities, they may constitute discrimination. As noted in Chapter 1, the study committee defines *discrimination* as differences in care that emerge from biases and prejudice, stereotyping, and uncertainty in communication and clinical decision-making. It should be emphasized that this definition is not intended in a legal sense. Different sources of federal, state and international law de-

fine discrimination in varying ways, with some focusing on intent and others emphasizing disparate impact.

Three mechanisms might be operative in producing discriminatory patterns of healthcare from the provider's side of the exchange: 1) bias (or prejudice) against minorities; 2) greater clinical uncertainty when interacting with minority patients; and 3) beliefs (or stereotypes) held by the provider about the behavior or health of minorities (Balsa and McGuire, 2001a). Patients might also react to providers' behavior associated with these practices in a way that contributes to disparities. If minority patients mistrust doctors' advice, they may be less likely to follow it, potentially accounting for some part of healthcare disparities.

To many observers, the mechanism behind disparities that comes most immediately to mind is provider prejudice: doctors and other providers might have a lower regard for minority patients and treat them less well. Prejudice is the least subtle of the mechanisms likely involved in clinical disparities, and does not require a sophisticated understanding of doctor-patient interaction to see how it might work. The same is not true, however, for other mechanisms. Clinical uncertainty and stereotypes lead to disparities through processes requiring some understanding of medical decision-making. To appreciate how these second and third mechanisms might work, and how patient response affects clinical interactions, it is necessary to keep in mind some salient features of the medical encounter.

#### **MEDICAL DECISIONS UNDER TIME PRESSURE WITH LIMITED INFORMATION**

In the process of healthcare, doctors and other healthcare providers often must reach judgments about patients' conditions and make decisions about treatment without complete and accurate information. Moreover, they frequently must do so under severe time pressure and resource constraints. These conditions contribute to clinical uncertainty, as providers must weigh a vast array of information, presented both by the patient and from diagnostic test data. This uncertainty opens the possibility that medical decisions and the course of treatment will reflect subjective variability and preferences of the physician (Eisenberg, 1986; Wennberg, 1999). Under conditions of time pressure, problem complexity, and high cognitive demand, physicians' attitudes may therefore shape their interpretation of this information and their expectations for treatment, such as the likelihood of patient compliance.

To add to this uncertainty, as clinicians and their patients work together, both parties are involved in highly complex processes of decision-making, requiring the acquisition of a wide array of diverse information

and the weighting of these data on various dimensions of salience. The assembly and use of these data are affected by many influences, including various heuristics that introduce significant problems for recall and weighting. In conditions such as these, it may be assumed that cognitive shortcuts have significant value to any decision-maker. Physicians, in fact, are commonly trained to rely on gestalts that functionally resemble the application of “prototypic” or stereotypic constellations. That is, physicians use clusters of information in making diagnostic and other complex judgments that must be arrived at without the luxury of the time and other resources to collect all the information that might be relevant. These conditions of time pressure and resource constraints are common to many clinical encounters, and map closely onto those identified as producing negative outcomes due to lack of information, to stereotypes, and to prejudice (van Ryn and Burke, 2000; van Ryn, 2002).

Patients may also hold stereotypes of clinicians that would come into play under these conditions of stress and demand for rapid and complex cognition. These stereotypes may paint the physician as an arrogant clinician, or as “the white man who experiments on minority patients,” or as a person who cannot be trusted to provide the whole truth. Even if the parties would, upon direct inquiry, deny the reality of such stereotypes in the particular circumstance, they may still unconsciously act from these perspectives in a pressured situation. The following sections present a more detailed discussion of the mechanisms by which disparities can arise in the clinical encounter. We explain how the mechanisms work, and consider the evidence in support of the empirical importance of each mechanism.

### HEALTHCARE PROVIDER PREJUDICE OR BIAS

Prejudice is defined in psychology as an unjustified negative attitude based on a person’s group membership (Dovidio et al., 1996). Prejudice, when held explicitly, may become part of a “reasoned” and normative pattern of behavior that becomes discriminatory. While it is reasonable to assume that the vast majority of healthcare providers find prejudice morally abhorrent and at odds with their professional values, healthcare providers, like other members of society, may not recognize manifestations of prejudice in their own behavior. Socially conditioned implicit prejudice may be manifested in healthcare providers’ nonverbal behaviors reflecting anxiety (e.g., increased rate of blinking), aversion (e.g., reduced eye contact) or avoidance (e.g., more closed postures) when interacting with minority rather than white patients.

Empirical support for the presence of biased or prejudicial attitudes among healthcare providers is limited but growing. Some research sug-

gests that differences in care may result from conscious or unconscious biases on the part of physicians and other healthcare providers. Schulman et al. (1999), for example, assessed physicians' recommendations for management of chest pain after they viewed vignettes of "patients" (actually actors) who complained of symptoms of coronary artery disease. "Patients" varied only in race (black or white), sex, age (55 or 70 years), level of coronary risk, and the results of an exercise stress test. As originally reported in the published findings, Schulman et al. found that physicians were less likely to recommend cardiac catheterization procedures for women (odds ratio = 0.6, suggesting that they were 40% less likely to be recommended for catheterization) and African Americans (odds ratio = 0.6, again suggesting that this group was 40% less likely to be referred for catheterization) than for whites and men.

These results as reported, however, overstated the likelihood of referral for African Americans and women relative to whites and men. In a rebuttal to Schulman et al., Schwartz, Woloshin, and Welch (1999) demonstrated that had the study authors calculated the relative chance of referral using risk ratios, rather than odds ratios, the probability of African Americans being referred for cardiac catheterization was only 7% lower than for whites. In addition, Schwartz et al. demonstrated that significantly lower rates of referral were found only in the case of African-American women, whose rate of referral was approximately 12% less than that for white men, white women, and African-American men. There were no significant differences in rates of referral among the latter three groups, suggesting that a more accurate interpretation of the data would be that the effect of race on physician's referral patterns is modified by gender. Furthermore, Schwartz et al. contend that referral rates for catheterization alone do not constitute a "gold standard" of care; to the contrary, these authors assert, the assumption that "more testing"—i.e., catheterization for all patients who present with cardiac symptoms—represents better care is unfounded. Less testing, in some instances, may result in more appropriate care (Schwartz et al., 1999).

In a reply to Schwartz et al. (1999), Schulman, Berlin, and Escarce (1999) agree that calculation of risk ratios would have been more appropriate as a means of assessing differences in referral rates. They note, nonetheless, that the findings of the study are consistent with the hypothesis that clinical decision-making may be influenced by physicians' conscious or subconscious perceptions on the basis of patients' race and gender, rather than on objective data. And while catheterization may not be appropriate for all patients even given similar objective preliminary test results, Schulman and colleagues, referring to the robust findings of studies that indicate lower rates of referral among blacks for catheterization, write, "we doubt that the lower utilization rates observed

consistently among black patients reflect an effort to provide more appropriate care to these patients" (Schulman, Berlin, and Escarce, 1999, p. 286).

In another experimental design, Abreu (1999) assessed whether conscious or non-conscious stereotypes would influence the clinical impressions of mental health professionals. Abreu "primed" these clinicians with either African-American stereotypes (e.g., "Negroes," "blacks," "blues," "rhythm") or neutral words (e.g., "water," "then," "about," "things") flashed on a computer screen for 80 milliseconds. Clinicians were then asked to evaluate the same hypothetical patient on a number of dimensions, including general impressions as well as clinical features. Abreu found that therapists primed with stereotype-laden words rated the patient significantly less favorably on hostility-related attributes than therapists exposed to neutral words, demonstrating that "therapists can be affected by African-American stereotypes in ways that produce negative or positive first impressions, depending on the nature of the attribute that is rated" (Abreu, 1999, p. 387).

Another experimental study using patient vignettes also found variations in physician recommendations when patient demographic variables were manipulated, although results were mediated by physician gender. In a study of primary care physicians' recommendations for pain management, Weisse et al. (2001) presented vignettes of patients suffering from identical symptoms of kidney stone pain, lower back pain, and as a control condition, sinusitis. Nearly 80% of the physician sample was white, while 15% were Asian American or Pacific Islander. In each case, only the race (African American or white) and gender of the "patient" was manipulated. The authors found that male physicians prescribed higher doses of hydrocodone for white "patients" than black "patients" suffering from back pain and renal colic, while female physicians prescribed higher doses of analgesic for black "patients" than white "patients." In both cases, findings were robust: male physicians prescribed twice as much hydrocodone to white patients than black patients, while female physicians prescribed the reverse. No other patient-physician race and gender interactions were observed. These findings, the authors suggest, imply that male and female physicians may react differently to gender and/or racial cues. While few other studies have replicated this finding, the study also implies that healthcare providers' perceptions of and attitudes towards patients are potentially influenced by a range of factors, and illustrates the complexity of disentangling the effects of race, ethnicity, and gender as they influence patient-provider interaction. More research is needed to better understand these processes, and to specifically assess

how physicians' race, ethnicity, or gender may influence their attitudes toward and perceptions of patients.

Another experimental study, using first- and second-year medical students as subjects, assessed whether the race and gender of hypothetical patients influenced students' perceptions of presenting symptoms. Rathore et al. (2000) randomly assigned 164 medical students to view a video of either a black female or white male actor who presented with the same symptoms of angina. Students were then asked to rate the patients' health status, based on their assessment of how the patients' presenting symptoms would affect their quality of life. They were also asked to provide a diagnosis of "definite" or "probable" angina. The authors found that students were more likely to provide a diagnosis of "definite" angina for the white male patient than the black female patient, but rated the health status of the black female patient as lower than that of the white male. Thus, these subjects assessed the white male patient's cardiac symptoms to be more severe, yet perceived the black female patient's quality of life to be lower, despite objectively similar presentations from the two "patients." Minority students, however, did not rate the health status of the black female patient as significantly different than that of the white patient. When examined by students' gender, Rathore et al. found that the male students tended to rate the black female's health status as lower than the white male, while female students did not rate the two patients' health status differently (Rathore et al., 2000).

In a study conducted in a clinical setting, Finucane and Carrese (1990) assessed when and how patients' race was referenced during house staff case presentations. In this study, the chief medical resident surreptitiously recorded oral case presentations during a 2-month period, and assessed, using *a priori* criteria, whether and how often the patient's race was mentioned, and whether potentially "unflattering characteristics" (e.g., low intelligence, uncooperativeness, unkemptness) were also noted. Race was noted in the vast majority (16 of 18) of cases involving black patients, but only in about half (19 of 36) of cases involving white patients. Among patients to whom house staff ascribed unfavorable characteristics, race was mentioned in 10 of 10 cases involving black patients, but in only 4 of 9 cases involving white patients. Findings of this study must be interpreted with caution, however, as the study suffers from a very small sample size and is limited by the single study setting. In addition, the authors employed no objective means of assessing whether the unfavorable characteristics ascribed to patients resulted from a true difference in the prevalence of these characteristics, rather than from racial bias.

In another study based on actual clinical encounters, van Ryn and Burke (2000) surveyed 193 physicians to assess their perceptions of 842

patients (57% white and 43% African American) following post-angiogram hospital visits. The authors asked physicians to rate their patients on a variety of personal characteristics such as intelligence, self-control, education level, pleasantness, rationality, independence, and responsibility. In addition, the authors asked physicians to rate their feelings of affiliation toward the patient and their perceptions of their patients' degree of social support, tendencies to exaggerate discomfort, likelihood of complying with medical advice, likelihood of drug or alcohol abuse, as well as other characteristics. van Ryn and Burke also surveyed patients and assessed their frailty/sickness, depressive symptoms, social assertiveness, feelings of self-efficacy, and perceived social support. These variables, along with information about physicians' age, sex, race, and medical specialty were entered into logistic regression analyses to control for the impact of these variables on physicians' assessments of patients. The results supported the authors' hypotheses that patient race and socioeconomic background do influence physicians' perceptions, even when controlling for differences in patients' socioeconomic status, personality attributes and degree of illness. African-American patients were rated as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice, more likely to lack social support, and less likely to participate in cardiac rehabilitation than white patients. Furthermore, African-American patients were two-thirds as likely as whites to be perceived as the kind of person with whom the physician could see him/herself being friends. Finally, a significant interaction of race and socioeconomic status was found, in that at low socioeconomic (SES) levels, black patients were rated as less pleasant and less rational than whites.

These studies lend support to the hypothesis that physicians' diagnostic and treatment decisions are influenced by patient race. In addition, they suggest that these influences are complex, and that both patient and provider gender may significantly influence physicians' perceptions. They do not, however, elucidate the mechanisms by which these attitudes, biases, and stereotypes may result in differences in clinical treatment, or the degree to which these attitudes might affect the outcome of patient care. It therefore remains unclear what degree of racial and ethnic disparities may be explained by this mechanism.

As noted above, there is no evidence that any significant proportion of healthcare professionals in the United States harbors overtly prejudicial attitudes. Health professionals in general are well educated and subscribe to a professional ethic that should mitigate against discrimination on the basis of race or ethnicity. How then, could a well-meaning group of healthcare professionals, working in their usual circumstances with diverse populations of patients, create a pattern of care that appears (on the

now substantial weight of available scientific evidence) to be discriminatory? In other words, is it possible for physicians and other healthcare professionals to act in a racially biased manner without knowing it?

To begin to address this question, the following section offers a hypothesis about clinical uncertainty, and how it may affect healthcare providers' decision-making, and ultimately influence the care provided to minority patients.

### *Clinical Uncertainty*

Theory and research on clinical decision-making suggest that ambiguities in physicians' understanding and interpretation of information from patients may contribute to disparities in care (Balsa and McGuire, 2001a). Any degree of uncertainty a physician has about the condition of a patient may, by itself, result in disparities in treatment. A doctor's decision-making process is nested in uncertainty. Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g., race). The exact same symptom information can lead the physician to make different clinical decisions depending on the other characteristics of the patient. Physicians can therefore be viewed as operating with prior beliefs about the likelihood of their patient's conditions, "priors" that will be different according to age, gender, SES, and possibly race/ethnicity. These priors—which are taught as a cognitive heuristic to medical students—as well as the information gained in a clinical encounter both influence medical decisions.

A doctor starting with a prior and supplementing this with new clinical information must weigh both in coming to an initial hypothesis about the source of the patient's problem. Formal models of medical decision-making view this as an application of the rules of probability (Weinstein et al., 1980).<sup>1</sup> In particular, "Bayes' rule" describes how a decision-maker combines prior beliefs with new information to make the best guess about the likelihood of some phenomenon. Among other things, Bayes' rule says that the relative weights placed on the prior and the new information depend on the strength of the evidence behind the prior and on the quality of the new information.

As an example, consider the case of a Latino male patient and a white male patient, both 50 years old and otherwise healthy. Suppose their doc-

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<sup>1</sup> A number of other explicit decision-theoretic approaches explore clinical decision-making. For other examples, see Mushlin et al. (1997) or Fendrick et al. (1995).



tor believes that the prior probability of either patient having heart problems is low and regards it to be the same for both patients. Now, suppose the Latino and the white patient both experience exactly the same symptom(s) and describe their pain to the doctor. Will the doctor come to the same clinical decision for the Latino and the white? Expression of pain symptoms differs among cultural and racial groups (Bonham, 2001). White doctors may simply understand pain reports better from members of their own racial group. When the white male talks to the doctor, the doctor relates easily to the patient's report; when the Latino tells his story, the doctor follows less well, and picks up fewer implicit clues. If we apply the terms of the Bayesian model of medical decision-making to the Latino patient, the reliability is lower because the potential error in the symptom report is higher than in the case of the white patient. With more uncertainty in the symptom report from the Latino, the Bayesian doctor puts more weight on his or her prior. The consequence could be that the white patient is referred for testing, and the Latino patient is not. Differences in medical decisions from the uncertainty mechanism can arise when the doctor has the same regard for each patient (no prejudice) and when there is no difference in the prior beliefs (stereotypes or clinical heuristics) the doctor holds for patients from the two groups. Differential treatment can therefore result from greater uncertainty associated with clinical information alone.

The effect of elevated uncertainty intervening between the patient's symptoms and the doctor's understanding of those symptoms depends on several factors (Balsa and McGuire, 2001a) and can lead to minorities getting either more or less care than whites. Suppose a psychiatrist in an emergency situation must decide whether to commit a patient after a failed suicide attempt. Unless the psychiatrist can get sufficient information to be assured that the patient is no longer a threat to harm himself, hospitalization is indicated. A black or Latino patient who is less well understood by the doctor is, in this case, more likely to be hospitalized because without sufficient information, the doctor must go with the prior that the patient might be a danger to himself.

Although the uncertainty hypothesis does not always imply that minorities receive less care, it can explain why they might sometimes receive less (and sometimes not). It also leads to the prediction that although the quantity of care for minorities may be more or less, the *match of care to need* will in general be worse for minorities because doctors have less good information with which to modify their priors about the patient's problem. Thus, the uncertainty hypothesis implies that outcomes will be worse for minorities (because of the poor match), and it also implies that minorities will rationally demand less healthcare, seek care at lower rates, and

comply less frequently, since they anticipate that the care will be less well-matched to their needs.

#### *Provider Beliefs and Stereotypes*

The mechanism of stereotypes is the most complicated of the three discussed in this chapter. We begin by briefly examining the functions of stereotypes and attitudes in general, exploring their origins, and then considering the interpersonal consequences of stereotypes in a health context. The mechanisms are illustrated by examples from the extensive body of psychological research on these processes.

#### *Functions of Stereotypes and Attitudes*

Stereotyping can be defined as the process by which people use social categories (e.g., race, sex) in acquiring, processing, and recalling information about others. The beliefs (stereotypes) and general orientations (attitudes) that people bring to their interactions serve important functions. Primarily, they help organize and simplify complex or uncertain situations and give perceivers greater confidence in their ability to understand a situation and respond in efficient and effective ways. People tend to categorize others into social groups because of the complexity of the social environment and our limited cognitive resources to organize and manage this complexity. These categories are often based on readily apparent, salient similarities, such as physical characteristics associated with sex or race (Dovidio, 1999).

The development of social stereotypes results from an individual's need to understand, to predict, and potentially to control one's environment (Mackie, Hamilton, Susskind, and Rosselli, 1996). Studies indicate that once categorization occurs, members of a group tend to be viewed as more similar to one another (the out-group homogeneity effect) and as having common characteristics. Personal traits (dispositional attributions), rather than situational or environmental attributions, are often overemphasized in stereotypes because they offer more stable explanations for the group's behavior and enhance feelings of predictability (Dovidio, 1999).

#### *Biases in Social Stereotypes and Attitudes*

Although functional, social stereotypes and attitudes also tend to be systematically biased. Humans are social animals, and people tend automatically to classify others into important, essential social categories, typically relating to dimensions such as age, gender, and skin color. These

biases may exist in overt forms, as represented by traditional forms of bigotry. However, because of their origins in virtually universal social categorization processes, they may also exist, often unconsciously, among people who strongly endorse egalitarian principles and truly believe that they are not prejudiced (Dovidio and Gaertner, 1998). For example, Devine (1989) assessed the reactions of both high- and low-prejudiced (as assessed by a pre-test) white college students to ambiguous behavior described in a vignette (e.g., an individual demanding money back from a sales clerk) after subliminally priming the students with words reflecting both African American stereotypes (e.g., “Negroes,” “lazy,” “blues,” “ghetto”) and neutral words. Both the high- and low-prejudiced participants interpreted the described behavior as more hostile after being primed with stereotype-laden words than when primed with neutral words. Other studies reveal that among people who endorse egalitarian principles, racial bias may be expressed in subtle and indirect ways that can be rationalized on the basis of factors apparently other than race, or in the form of discomfort and uncertainty in interactions involving racial and ethnic minorities (Dovidio, 1999).

Other studies of social categorization reveal that when people or objects are categorized into groups, actual differences between members of the same category tend to be perceptually minimized and often ignored in making decisions or forming impressions (Fiske, 1998). Members of the same category seem to be more similar than they actually are, and more similar than they were before they were categorized together. This forms the basis for the development of stereotypes. In addition, although members of a social category may be different in some ways from members of other categories, studies show that these differences tend to become exaggerated and overgeneralized (Fiske, 1998). Thus, categorization enhances perceptions of similarities within groups and differences between groups (particularly with respect to one’s own group), which emphasizes social difference and group distinctiveness. This process is not benign because these within- and between-group distortions have a tendency to generalize to additional dimensions (e.g., character traits) beyond those that differentiated the categories originally. Furthermore, as the salience of the categorization increases, the magnitude of these distortions also increases (Turner et al., 1987).

Moreover, in the process of categorizing people into two different groups, people typically classify themselves *into* one of the social categories and *out of* the other (Operario and Fiske, 2001; Fiske, 1998). Upon social categorization of individuals into in-groups and out-groups, people spontaneously experience more positive feelings toward the in-group. They also favor in-group members directly in terms of evaluations and resource allocations. In addition, in-group membership increases the psy-

chological bond and feelings of “oneness” that facilitate the arousal of empathy in response to others’ needs or problems. As a consequence, assistance is offered more readily to in-group than to out-group members. Furthermore, studies indicate that people are more likely to be cooperative and exercise more personal restraint when using endangered common resources when these are shared with in-group members than with others, and they work harder for groups they identify as their in-group (Tajfel and Turner, 1979). Self-categorization in terms of collective identity, in turn, increases the likelihood of the development of intergroup biases and conflict.

A number of studies demonstrate just how powerfully mere social categorization can influence differential thinking, feeling and behaving toward in-group versus out-group members. Mackie, Devos, and Smith (2000), for example, assessed whether college students who were assigned membership to a social group would develop feelings of anger, fear, and contempt toward students in other, similarly assigned groups. The investigators manipulated interactions between the groups, and found that collective support for the in-group was associated with increased feelings of anger toward the out-group and a willingness to argue, confront, oppose, and attack the out-group (Mackie, Devos, and Smith, 2000).

#### *Consequences of Stereotypes*

Stereotypes and attitudes toward members of social groups, such as those based on race and ethnicity, significantly shape the outcomes of interpersonal interactions with members of these groups. In general, individual differences in both racial stereotypes and prejudice systematically predict whites’ discriminatory actions toward blacks (Dovidio, Brigham, Johnson, and Gaertner, 1996). They do so in a variety of convergent ways and different mechanisms. For instance, studies show that people not only tend to interpret the behaviors of others in ways that are consistent with their stereotypes and attitudes about the group, but these biases also influence the way that information is subsequently recalled. When people do not have a strong memory for particular information about a group member, they “recall” information in stereotype-consistent ways (Dovidio, 1999).

People also develop expectations about others substantially on the basis of their group membership and the associated stereotypes and attitudes. Stereotypes are particularly likely to influence expectations, inferences, and impressions when people are not motivated to attend to individuating information or are limited in their capacity to process information due to other demands on their attention and thoughts (for review of this research, see Biernat and Dovidio, 2000). Because stereotypes

shape interpretations, influence how information is recalled, and guide expectations and inferences in systematic ways, they tend to be self-perpetuating. They also can produce self-fulfilling prophecies in social interaction, in which the stereotypes of the perceiver influence the interaction in ways that conform to stereotypical expectations (Jussim, 1991).

Recent evidence indicates that people do not have to be aware of their attitudes or consciously endorse stereotypes for these factors to influence their thoughts, feelings, and behaviors. Whereas “explicit” stereotypes and attitudes operate in a conscious mode, “implicit” stereotypes commonly function in an unconscious fashion (Fiske, 1998). Implicit stereotypes and attitudes develop with repeated pairings, either through direct experience or social learning of the association, between the category or object and evaluative and descriptive characteristics. In the United States, because of shared socialization influences, there is considerable research evidence that even well-meaning whites who are not overtly biased and who may not believe that they are prejudiced typically demonstrate, on average, unconscious implicit negative racial attitudes and stereotypes (Dovidio, 1999). For example, an experiment by Dovidio, Kawakami, and Gaertner (2002) found that white college students’ egalitarian explicit racial attitudes were reflected in a bias of their verbal behavior toward black compared with white confederates and their perception of their own friendliness toward white as compared with black partners. In contrast, white subjects’ implicit attitudes (as measured following subliminal presentation of black or white faces) reflected a systematic bias against blacks, particularly when spontaneous, non-verbal behaviors were assessed.

#### *Stereotypes and Healthcare Disparities*

Negative stereotypes about minorities, held explicitly or implicitly by physicians, can contribute to healthcare disparities in a number of ways. In some cases, healthcare providers may be consciously aware of their negative stereotypes of minorities, but may nonetheless view these stereotypes as accurate, functional, and appropriate for their clinical work. In these cases, the research cited above suggests that these providers will selectively attend to and recall information that confirms their stereotypes, and will tend to allow such stereotypes to enter into clinical decisions regarding the diagnosis and appropriate course of treatment.

Such cases, however, likely represent only a small minority of healthcare professionals. While the study committee could find no survey data to elucidate racial attitudes of providers, it is likely that the vast majority endorse egalitarian and non-racist attitudes. But even among these individuals, research suggests that stereotyping and social categorization are prevalent, universal processes. Subtle and unintentional types of biases

exist even among highly educated whites who support egalitarian ideals and are not consciously racially prejudiced (Biernat and Dovidio, 2000). These biases have their origins in normal and pervasive processes associated with social categorization and thus can operate without conscious awareness or control. Stereotypes, whether consciously endorsed or not, are heuristics that typically efficiently guide the perception, interpretation, storage, and retrieval of information, particularly under conditions of high cognitive demand (Mackie et al., 1996). Similarly, when individuals do not have the time, capacity, opportunity, or motivation to assess situations fully and deliberately, implicit attitudes automatically shape people's responses to objects, individuals, and groups. These conditions of time pressure, high cognitive demand, and stress are common to many healthcare settings, making these settings "ripe" for the activation of stereotypes.

van Ryn and Burke's (2000) work shows that physicians believe blacks are less likely to comply with treatment and more likely to engage in destructive health behaviors (e.g., drug abuse) that may interfere with the value of treatment. When doctors hold these beliefs, they may be less likely to recommend treatment to blacks (e.g., "it is wasteful if the patient fails to follow the treatment regimen"), or less likely to put as much effort into discerning the nature of the black patient's problem if the patient will not take care of himself (e.g., "why should I work hard for a self-destructive patient?"). These stereotypes do not have to be consciously endorsed to influence such decisions (Devine, 1989), and they typically may influence decisions without physicians being aware of their presence. These stereotypical expectations, in turn, can shape the nature of interactions in ways that lead patients to respond in stereotype-confirming ways (Sibicky and Dovidio, 1986).

Questions remain, however, about the nature of these stereotypes and how they affect clinical decisions. For example, do healthcare professionals sometimes make more benevolent, but nonetheless stereotyped assessments of minority patients, such as assuming that co-morbid factors such as alcohol or drug use are present and may complicate treatment, or that minority patients will not comply with treatment regimens? Stereotypes may also reflect well-meaning, but nonetheless harmful judgments on the part of healthcare providers. For example, physicians may be less aggressive in seeking minority patients' consent for certain medical procedures, out of a heightened (but nonetheless stereotyped) concern that minority patients' wishes to avoid aggressive or new healthcare technologies should be respected, or because of a desire to foster a sense of empowerment among minority patients relative to treatment decisions.

A general issue in the stereotyping literature is the question of whether the stereotypes are "accurate." What if the doctors studied by

van Ryn and Burke (2000) are correct in their belief that African Americans are less likely to comply with treatment? If this is true, how can a “stereotype” held by providers be regarded as a “cause” of the disparities? Is it not more correct to say that the provider’s belief is the result of racial differences in underlying patterns of health behavior? This important question can be answered at two levels. First, based on the general literature on stereotyping, we would expect that any “true” differences among racial/ethnic groups would tend to be exaggerated, particularly if the belief is negative. This “exaggeration of negative attributes” would tend to be reinforced through selective attention and recall of stereotype-confirming evidence.

Second, stereotypes can lead to unfavorable treatment of minorities, even when there are no underlying differences in healthcare attitudes of minorities and whites (Balsa and McGuire, 2001a). Providers’ expressions of implicit or explicit stereotypes can evoke responses in minority patients that can “cause” the stereotypes to be confirmed. Thus, doctors might believe that “blacks comply less frequently,” and this belief might be confirmed in their own experience. Nonetheless, the *cause* of the problem could be the belief itself, in the sense that acting with this belief, doctors may treat African-American patients differently, and this differential (less favorable) treatment may lead African Americans to comply with treatment less frequently. Thus, even without the “exaggeration/bias” feature of stereotyping behavior by the perceiver, stereotyping can persist and be harmful. This can be demonstrated with the tools of game theory (Balsa and McGuire, 2001b) to illustrate that even when two groups (blacks and whites) are objectively identical, a differential belief held by doctors may lead to differential patterns of treatment recommendations and compliance that is rational for all parties, but leads to disparities in treatment. Stereotypes—beliefs held by the doctor—can therefore turn a situation of *a priori* equality into one of *ex post* disparity.

#### PATIENT RESPONSE: MISTRUST AND REFUSAL

As noted above, racial and ethnic minority patients’ responses to healthcare providers are also a potential source of disparities. Little research has been conducted on how patients may influence the clinical encounter. It is reasonable to speculate, however, that if patients convey mistrust, refuse treatment, don’t adhere or comply poorly with treatment, providers may become less engaged in the treatment process, and patients are less likely to be provided alternative treatments and services. As noted in Chapter 3, some evidence suggests that patient refusal may contribute to disparities in care. For example, African American and other minority patients may be more likely to refuse invasive procedures. This

higher rate of refusal of recommended treatments may reflect patients' experiences of discrimination in other sectors or mistrust of authority. Some mistrust and refusal, however, might be a "rational" reaction to explicit discrimination, aversion, or disregard displayed by the provider. If minority patients perceive that their provider has a lower regard for them, they will be less likely to comply with treatment recommendations.

It should be noted, however, that despite ethnic minority patients' generally higher levels of mistrust of the medical and research establishment, most minority patients appear to be satisfied with and have confidence in their healthcare providers (Shi, 1999). Further, as Geiger (this volume) and others have noted, mistrust or perceived discrimination alone is unlikely to cause ethnic minority patients to reject potentially life-saving or highly recommended procedures that promise to improve health and decrease symptoms of illness. Therefore, future analyses of patient attributes that may be related to healthcare disparities must carefully consider the roots of these attitudes in historic and contemporary social and cultural forces, in and outside medical practice, that play a role in minority patients' perceptions of healthcare institutions.

In the absence of careful study as to how patients may influence the clinical encounter and contribute to disparities in healthcare, the committee is reluctant to speculate on how and to what extent such processes occur. It may be reasonable to assume, however, that patients' and providers' behavior and attitudes influence each other reciprocally and reflect the attitudes, expectations, and perceptions that each has developed in a context where race and ethnicity are often more salient than these participants recognize. In addition, it is clear that the healthcare provider, rather than the patient, is the more powerful actor in clinical encounters. Providers' expectations, beliefs, attitudes, and behaviors are therefore likely to be a more important target for intervention efforts.

## CONCLUSION

In the previous sections, we have considered factors arising out of doctor-patient interactions that may account, at least in part, for racial and ethnic disparities in healthcare. The committee's focus has been on understanding the *processes* that may underlie these biases. We propose that these processes have their origins in pervasive and normal distinctions based in social categorization (stereotypes, prejudice, and uncertainties in intergroup communication) and do not necessarily involve either awareness or conscious motivations to discriminate. Thus, even highly educated and socially conscious individuals, such as doctors, are susceptible to these biases. Moreover, the types of situations that promote these biases—time pressure, incomplete information, high demand on atten-



tion and cognitive resources—are those that frequently occur in the context of doctor-patient interactions. We supported these propositions with research and illustrated their likely effects.

Beyond identifying the pervasiveness and importance of these factors in healthcare outcomes, this perspective emphasizes two other fundamental issues. First, this approach highlights the fact that disparities in healthcare services may not necessarily be a matter of “less.” Within the models of bias, with the exception of the simple prejudice mechanism, the implications of the other mechanisms may be more or less in terms of quality of services. The importance of disparities in services is that minorities may have healthcare services poorly matched to their needs. A focus on the issue of matching needs to services is a more general and pertinent framework than simply focusing on equal amounts of services.

A second implication of this perspective is that it suggests different types of policies and interventions to address disparities based on different processes. The research on healthcare disparities to date does not consistently differentiate among the various mechanisms that may operate in doctor-patient interactions and underlie the disparities. At a general level, making good choices about alleviating disparities should be based on a good idea as to what causes disparities.

In summary, the committee found no direct evidence that racism, bias, or prejudice among healthcare professionals affects the quality of care for minority patients, such as that which might be available from audit studies where “testers” from different racial or ethnic groups present in clinical settings with similar clinical complaints, histories, and symptoms to assess possible differences in the quality of their treatment. In addition, no survey data suggest that even a small minority of physicians, nurses, or other healthcare professionals harbors biases or prejudices against minorities. Both of these forms of evidence present methodologic (and in the case of paired testers, ethical and legal) challenges to investigators, making it unlikely that such evidence will be available in the near future.

In the meantime, the committee is confronted with several “streams” of evidence that, while not definitive, collectively provide a sufficient base from which to draw inferences. To summarize the evidence presented in this chapter and the previous two chapters that provider prejudice, stereotyping, and biases may influence clinical care:

1. With increasing sophistication, several recent studies of racial and ethnic disparities in receipt of health services have controlled for possible confounding variables or other possible explanations for racial and ethnic differences in care, including patient preferences, overuse of services by whites, health insurance status, type of health system, patient income and education, severity or stage of disease, co-morbidity, hospital type, and

resources. These studies generally find that disparities remain and cannot be fully explained by these variables. While this literature does not provide any measure of evidence that provider biases and stereotyping explain disparities, they do illustrate that disparities cannot be “reduced” to patients’ preferences or other explanations.

2. Racial and ethnic disparities in healthcare emerge from an historic context in which healthcare has been differentially allocated on the basis of social class, race, and ethnicity. Unfortunately, despite public laws and sentiment to the contrary, vestiges of this history remain and negatively affect the current context of healthcare delivery. And despite the considerable economic, social, and political progress of racial and ethnic minorities, evidence of racism and discrimination remain in many sectors of American life.

3. Evidence from patient surveys indicates that racial and ethnic minority patients are far more likely than white patients to believe that discrimination is a problem in healthcare, and that they have personally experienced discriminatory treatment. Data from the focus groups conducted by the study committee suggest that minority patients may perceive both overt, as well as subtle forms of discrimination when seeking care.

4. There is considerable evidence that even well-meaning whites who are not overtly biased and who do not believe that they are prejudiced typically demonstrate, on average, unconscious implicit negative racial attitudes and stereotypes (e.g., Dovidio, Brigham, Johnson, and Gaertner, 1996). Both implicit and explicit stereotypes significantly shape interpersonal interactions, influencing how information is recalled and guiding expectations and inferences in systematic ways. They also can produce self-fulfilling prophecies in social interactions, in which the stereotypes of the perceiver influence the interaction with others in ways that conform to stereotypical expectations (e.g., Jussim, 1991).

5. Experimental evidence indicates that healthcare providers are influenced by patients’ race or ethnicity, and possibly gender (Schulman et al., 1999; Weisse et al., 2001), or when providers are “primed” with racial stereotypes (Abreu, 1999). Preliminary evidence also suggests that female physicians may respond to racial cues differently than male physicians (Weisse et al., 2001; Rathore et al., 2000). Minority race or ethnicity is found to be associated with generally more negative evaluations or lower rates of referral for clinical services, even when “patients” present with the same clinical condition. In addition, a survey of physicians following actual clinical encounters demonstrates that physicians endorse stereotypes about their African-American patients (who were characterized as “less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice,” and less likely “to be . . . the kind of person the physician could see him/herself being

friends with”), even after controlling for patients’ socioeconomic status, personality variables, and perceived social support (van Ryn and Burke, 2000).

6. The conditions in which many medical encounters take place—characterized by time pressure, resource constraints, and high cognitive demand—have been identified in the social psychological literature as conditions that may promote stereotyping due to the need for cognitive “shortcuts” and lack of full information to adequately assess patients.

These streams of evidence lead the committee to conclude that bias, stereotyping, prejudice, and uncertainty on the part of healthcare professionals cannot be ruled out—and indeed, appear among the many patient-level, system-level, and clinical encounter-level factors to contribute to racial and ethnic disparities in healthcare.

**Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.**

Indirect evidence indicates that bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may be contributory factors to racial and ethnic disparities in healthcare. Prejudice may stem from conscious bias, while stereotyping and biases may be conscious or unconscious, even among the well intentioned. Ambiguities in the interpretation of clinical data, barriers to patient-provider communication, and gaps in evidence of the efficacy of clinical interventions contribute to uncertainty, and therefore may promote the activation of prejudice and stereotypes. However, few studies have attempted to assess these mechanisms, and therefore direct evidence bearing on the possible role of these factors, especially prejudice, is not yet available. The committee finds strong, but circumstantial evidence for the role of bias, stereotyping, prejudice, and clinical uncertainty from a range of sources, including studies of social cognition and “implicit” stereotyping, but urges more research to identify how and when these processes occur.

Patients’ refusal or acceptance of recommendations for treatment, like other patient decisions, is the result of many influences, including information about their condition, information about treatment effectiveness and risks, trust of the clinician, preferences for treatment type and outcome, and advice of significant others. Overall, such preferences for care

should be developed by patients and their families on the basis of full and accurate information presented by a healthcare provider, but the acquisition and use of such information may be influenced by the quality of patient-provider communication and interaction, patients' expectations, values and beliefs, as well as the values and beliefs of patients' communities. To the extent that minority patients are more likely than whites to refuse treatment, such behaviorally expressed preferences may be considered a source of healthcare disparities. A small number of studies suggest that racial and ethnic minorities are slightly more likely than whites to refuse treatment, but this research has yet to distinguish the sources of minority patients' higher rates of refusal (i.e., general mistrust of healthcare providers, real or perceived experiences of discrimination in healthcare settings, or patient treatment decisions based on incomplete information from providers). These sources must be better understood to fully understand the role of patient preferences in healthcare disparities.

**Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.**

A small number of studies suggest that racial and ethnic minorities are more likely to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities. However, research has yet to distinguish the sources of minority patients' higher rates of refusal (i.e., general mistrust of healthcare providers, real or perceived experiences of discrimination in healthcare settings, or patient treatment decisions based on incomplete information from providers). These sources must be better understood to fully comprehend the role of patient preferences in healthcare disparities.

## 5

### Interventions: Systemic Strategies

The preceding analysis of sources of racial and ethnic disparities in healthcare reveals that many participants—including patients, their providers, utilization managers, and health system administrators—make decisions on a daily basis that contribute to gaps in care. These individuals operate within many contexts, including clinical care settings and health system settings that set policies for access to and utilization of services, and at a larger level, are affected by laws and policies regulating the healthcare industry. Given the role of patient, provider, and contextual factors in shaping the quality of patient care, systemic interventions directed at multiple levels offer promise to modify conditions in which healthcare disparities occur.

Systemic interventions to improve healthcare delivery for diverse populations include organizational accommodations that may promote equity in healthcare, policies that reduce administrative and linguistic barriers to care, and practices that enhance patients' knowledge of and roles as active participants in the care process. These efforts are likely to be most effective when applied in a systematic, simultaneous, multi-level, coordinated fashion, and follow a well-developed strategic plan that has support and "buy-in" from all actors involved in healthcare, including patients, their families, and the communities in which they live; clinicians; administrative staff; and health systems leadership. Systemic interventions also include changes to healthcare law and policy that promote equality of healthcare delivery.

There are many reasons why health systems may choose to adopt comprehensive strategies to eliminate racial and ethnic disparities in

healthcare. First, they may react to comply with growing state and federal guidelines that encourage, and in some cases, mandate greater responsiveness on the part of health systems to the growing diversity of the U.S. population (Brach and Fraser, 2000). Second, they may view such strategies as integral to help achieve the U.S. Department of Health and Human Services' goal of eliminating racial and ethnic disparities in health (U.S. DHHS, 2000). Third, health systems may find that developing and implementing culturally competent systems of care are consistent with the "business case" of increasing market share among racial and ethnic minority populations (Brach and Fraser, 2000). Increasingly, health plan purchasers are also finding that health system responsiveness to the needs of racial and ethnic minority patients makes good business sense. Given that over 2 of every 5 new workers is a racial or ethnic minority, many employers find that health plan efforts to improve services for these populations and narrow the healthcare gap can attract better workers and increase employee productivity (Washington Business Group on Health, 2001).

Many of these system-wide intervention objectives are reflected in the culturally and linguistically appropriate services standards (CLAS) for healthcare issued by the U.S. DHHS Office of Minority Health (OMH) in December 2000 (U.S. DHHS, 2000). These standards, which are listed in Box 5-1, are primarily directed at healthcare organizations, but OMH encourages individual providers to familiarize themselves with the standards and incorporate them into their practices.

Further, while the standards are intended to help improve care for racial and ethnic minority populations, by implication they suggest that greater attention to the importance of culture and language in healthcare settings will improve the quality of care for all populations. Noting that culture and language define how healthcare information is given and received and shape the expression and understanding of health and illness, the agency states that "healthcare is a cultural construct, arising from beliefs about the nature of disease and the human body," and that "cultural issues are . . . central in the delivery of health services treatment and preventive interventions" (U.S. DHHS, 2000, p. 80863).

A significant evidence base has accumulated for many aspects of health systems-level interventions that may improve the quality of care for minority patients. The remainder of this chapter explores several such strategies.

### LEGAL, REGULATORY, AND POLICY INTERVENTIONS

As noted in Chapter 3, institutional design and legal and regulatory governance will not eliminate racial and ethnic disparities in healthcare,

**BOX 5-1**

**U.S. Department of Health and Human Services Standards for Culturally and Linguistically Appropriate Services**

1. Healthcare Organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.
2. Healthcare Organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.
3. Healthcare Organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.
4. Healthcare Organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
5. Healthcare Organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.
6. Healthcare Organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
7. Healthcare Organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

but institutions and law make a large difference, in that they exert a broad influence over the kinds of conditions that may foster healthcare disparities. In this section, the committee suggests how healthcare institutions, legislators, and regulators might respond pragmatically to the problem of racial and ethnic disparity even as they pursue other important policy goals.

*“De-Fragmentation” of Healthcare Financing and Delivery*

Many of the studies cited earlier in this report have not taken detailed account of variations among health plans, and therefore the disproport-

8. Healthcare Organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.
9. Healthcare Organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.
10. Healthcare Organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.
11. Healthcare Organizations should maintain a current demographic, cultural, and epidemiologic profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.
12. Healthcare Organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.
13. Healthcare Organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.
14. Healthcare Organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

tionate presence of members of disadvantaged minority groups in lower-end health plans may be a major source of disparities in healthcare provision. As noted in Chapter 2, some racial and ethnic minorities are disproportionately represented in publicly financed health insurance programs (Phillips et al., 2000). And even within a broad federal program such as Medicare, for example, tiers of health systems exist (e.g., more than 60% of Medicare beneficiaries possess supplemental coverage), with minorities typically congregated at lower levels. Further, as noted in Chapter 3, low per capita resources associated with lower-end plans may result in differences in the intensity of care between lower and higher end health plans. Studies consistently demonstrate an association between insur-



ance status and use of healthcare resources. For example, patients seen in emergency departments following head injury are more likely to be admitted to the hospital and have a longer length of stay if they are privately insured, rather than publicly insured or uninsured (Svenson and Spurlock, 2001), and Medicare patients without supplemental coverage are approximately 10% less likely to have influenza vaccination, cholesterol testing, mammography, or Pap smears than those with supplemental coverage (Carrasquillo, Lantigua, and Shea, 2001). Fragmentation also engenders different clinical cultures, with different practice norms, tied to varying per capita resource constraints. The relationship between racial and ethnic maldistribution in tiered health plans, differences in the intensity and the quality of care provided by these plans, and clinical outcomes should be a national research priority (see Chapter 8). Until such research is conducted, it is reasonable to surmise that efforts to reduce the socioeconomic segmentation of the medical marketplace would help to diminish racial and ethnic disparities in healthcare provision (Bloche, 2001).

Equalizing access to high-quality plans can limit fragmentation. Public healthcare payors such as Medicaid should strive to help beneficiaries access the same health products as privately insured patients. This recommendation is reflected in the IOM *Crossing the Quality Chasm* report's strategies for focusing health systems on quality, in its call to "eliminate or modify payment practices that fragment the care system" (IOM, 2001a, p. 13). Expanding access for publicly funded beneficiaries to high-quality health plans will be expensive. Rising healthcare costs, however, threaten to increase the likelihood of fragmentation, and subsequently threaten to increase the racial and ethnic gap in healthcare.

**Recommendation 5-1: Avoid fragmentation of health plans along socioeconomic lines.**

**Medical care financing arrangements should discourage fragmentation of healthcare provision into separate tiers of providers who adhere to different standards of care and disproportionately serve separate racial and ethnic minority segments of American society. Medicaid and other government programs that mandate enrollment of beneficiaries in managed care should be prepared to pay plans at rates that give Medicaid enrollees access to the same health plan products serving substantial proportions of privately insured patients.**

*Strengthening Doctor-Patient Relationships*

Several lines of research suggest that the consistency and stability of the doctor-patient relationship is an important determinant of patient sat-

isfaction and access to care. Having a usual source of care is associated, for example, with use of preventive care services. In addition, having a consistent relationship with a primary care provider may help to address minority patient mistrust of healthcare systems and providers, particularly if the relationship is with a provider who is able to bridge cultural and linguistic gaps (LaViest, Nickerson, and Bowie, 2000). Further, as noted in Chapter 3, several lines of evidence suggest that a patient's access to clinical resources within a hospital or health plan may partly reflect his or her doctor's stature, skill, and commitment as an advocate. This suggests that minority patients may benefit from stronger bonds with physicians who understand the cultural and linguistic barriers to care faced by many minority patients navigating through health systems, and who are positioned and willing to play the advocate's role vigorously. Health systems should attempt to ensure that every patient, whether insured privately or publicly, through Medicare or Medicaid, has a sustained relationship with an attending physician able to help patients navigate the healthcare bureaucracy effectively (e.g., to help patients obtain referral and secure appropriate specialty care). This is not meant to imply that physicians should navigate health systems for their patients; rather, it is an acknowledgement that primary care providers sometimes wield great influence and leverage in helping their patients to access specialty care, clinical trials, and other healthcare resources.

Several strategies can help to promote the stability of patient and provider relationships in publicly funded health plans. Federal and state performance standards for Medicaid-managed care plans, for example, should include guidelines for the stability of patients' assignments to primary care providers and these providers' accessibility. These guidelines should also encourage reasonable patient loads per primary physician and time allotments for patient visits. Regulations governing health plans' participation in Medicare should include similar guidelines, as should private accrediting bodies' prerequisites for all health plans (Bloche, 2001).

**Recommendation 5-2: Strengthen the stability of patient-provider relationships in publicly funded health plans.**

**Policies that strengthen provider-patient relationships in publicly funded health plans and that promote the consistency of these relationships should be adopted. These include guidelines for:**

- **the stability of patients' assignments to primary care providers and these providers' accessibility;**
- **reasonable patient loads per primary physician; and**
- **reasonable time allowances for initial and follow-up patient visits (and health providers' flexibility to take additional time when needed to communicate adequately).**

Strengthening patient and provider relationships will also benefit from greater racial and ethnic diversity in the health professions. Racial concordance of patient and provider is associated with greater patient participation in care processes, higher patient satisfaction, and greater adherence to treatment (Cooper-Patrick et al., 1999). In addition, racial and ethnic minority providers are more likely than their non-minority colleagues to serve in minority and medically underserved communities (Komaromy et al., 1998b). Evidence of these benefits of diversity in health professions fields weighs in favor of robust commitment to affirmative action in medical school admissions, residency recruitment, and professional specialty training. This is not intended to suggest, however, that racial concordance of patients and providers should be encouraged as a matter of policy. Rather, it is expected that the benefits of diversity in the health professions will accrue broadly, as this diversity helps to expand the disciplines' ability to conceptualize and respond to the health needs of increasingly culturally and linguistically diverse populations.

**Recommendation 5-3: Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.**  
**To the extent legally permissible, affirmative action and other efforts are needed to increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.**

#### *Patient Protections*

Much of the political focus on Capitol Hill in the summer of 2001 was devoted to managed care regulation. To one extent or another, the various bills debated all would extend protections to enrollees in private managed care organizations, providing avenues for appeal of care denial decisions, improving access to specialty and emergency department care, and providing other legal remedies to resolve disputes. These bills were crafted on the assumption that due process protections of patient choices were necessary, despite a lack of empirical evidence that overall quality of care is inferior in managed care plans relative to fee-for-service systems. Extensive reviews of the literature do not establish whether the quality of care provided within managed care plans is worse (or better) than other health systems. However, there is some evidence that managed care may provide better care for some patient populations. For example, results of a review by Miller and Luft (1997) suggest a significantly better quality of care for some subsets of managed care enrollees, such as patients in the intensive care unit, elderly Medicare patients, and patients with acute appendicitis or cancer.

As discussed in Chapter 3, however, there are reasons and empirical evidence to be concerned about how financial incentives and decision-making within managed health plans may differentially affect racial and ethnic minority groups. Some evidence indicates that low-income and ethnic minority patients enrolled in managed care plans are less likely to have a regular provider than similar patients in fee-for-service plans (Leigh, Lillie-Blanton, Martinez, and Collins, 1999), are more likely than whites to be denied claims for emergency department visits (Lowe et al., 2001), and are less satisfied with many aspects of the care they receive in managed care settings (Phillips et al., 2000). Other studies find that the intensity of care is lower for some populations within managed care settings relative to other care systems. Tai-Seale, LoSasso, Freund, and Gerber (2001), for example, found that prenatal care use was lower among women enrolled in Medicaid managed care systems relative to women in fee-for-service systems.

Given that many minorities are disproportionately represented among the publicly insured who receive care within managed care organizations, extending the same due process protections proposed in current legislation may help to address these disparities. Other factors, however, may also justify extending the same protections, regardless of payor source. Extending legal protections only to those enrolled in private managed care plans raises concerns about the unequal application of law. As Hashimoto (2001) writes, "The [current proposals'] emphasis on individual choice, due process protections, and limiting its jurisdiction to private health plans will result in an important regulation that largely benefits the employed middle class . . . it is unfair to guarantee special legal protections to members of private managed care plans while failing to provide these same guarantees to members of publicly financed managed care programs" (Hashimoto, 2001, pp. 83-84).

**Recommendation 5-4: Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.**

*Civil Rights Enforcement*

The committee believes that education and training of healthcare providers, administrators, and consumers is an important first step as part of a comprehensive, multi-level intervention strategy to address racial and ethnic disparities in healthcare. Enforcement of regulation and statute is also an important component of such a strategy, but unfortunately has been too often relegated to low-priority status. The U.S. DHHS Office for Civil Rights (OCR) is charged with enforcing several relevant federal statutes and regulations that prohibit discrimination in healthcare (principally

Title VI of the 1964 Civil Rights Act). The agency, however, has suffered from insufficient resources to investigate complaints of possible violations, and has long abandoned proactive, investigative strategies (Smith, 1999). Complaints to the agency have increased in recent years, while funding has remained constant in actual dollars but has decreased in fiscal year 2000 to less than 60% of fiscal year 1981 funding, after adjusting for inflation (U.S. Commission on Civil Rights, 2001). This decrease in spending power has severely and negatively affected OCR's ability to conduct civil rights enforcement strategies, such as on-site complaint investigations, compliance reviews, and local community outreach and education. The agency should be equipped with sufficient resources to better address these complaints. In addition, OCR should resume the practice of periodic, proactive investigation, both to collect data on the extent of civil rights violations and to provide a deterrent to would-be lawbreakers. As will be discussed in Chapter 7, LaVeist and Gibbons (2001) suggest a two-tiered strategy in which routine data collection and monitoring can be used to identify health systems that display persistent disparities, followed by field investigations—possibly by trained, paired testers.<sup>1</sup> While audits of healthcare facilities are largely untested and methodologies must be developed for fair and appropriate assessment of discrimination in healthcare settings, such a strategy offers a promising “last line” of defense against civil rights violations.

**Recommendation 5-5: Provide greater resources to the U.S. DHHS Office for Civil Rights to enforce civil rights laws. Congress and the U.S. Department of Health and Human Services should provide adequate funding to the U.S. DHHS Office for Civil Rights to expand the agency's capabilities to address civil rights complaints and carry out its oversight responsibilities.**

### HEALTH SYSTEMS INTERVENTIONS

Research suggests that a variety of interventions applied at the level of health systems may be effective as a part of a comprehensive, multi-level strategy to address racial and ethnic disparities in healthcare.

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<sup>1</sup>Paired testing strategies, in which auditors of differing race, ethnicity, or gender are matched for a variety of socioeconomic and personality characteristics, have been used successfully to identify discrimination in housing, employment, and mortgage lending practices. This strategy is discussed in Chapter 2.

*Evidence-Based Cost Control*

As discussed in Chapter 3, medical science has made tremendous advances that have transformed clinical practice. Many innovations are available to healthcare providers, and the use of evidence-based practice guidelines to improve and standardize care has increased. Despite these developments, variations in practice patterns are still observed across geographic areas and types of healthcare institutions, and utilization managers still exert considerable discretion in making decisions regarding healthcare resource allocation. To the extent possible, given the gaps in knowledge about medical care's efficacy and the difficulty of anticipating all clinical contingencies, clinical practice and utilization decisions should be based on evidence-based guidelines. Such application of evidence to healthcare delivery can help to address the problem of potential underuse of services resulting from capitation or per case payment methods, as noted in the IOM *Quality Chasm* report (IOM, 2001a). Practice guidelines may be a useful tool in the effort to eliminate racial and ethnic disparities in healthcare, given the advantages of guidelines over general, discretionary standards—including consistency, predictability, and at least the appearance of objectivity.

A pragmatic balance must be sought, however, between the advantages and limitations of guidelines. The goal of standardized care must be weighed against the need for clinical flexibility. One means to address this balance—disclosing health plans' clinical protocols—would aid both private sector and public efforts in balancing the virtues of rules and discretion. Private accrediting entities and state regulatory bodies could require that health plans' clinical practice protocols be published—with supporting evidence—and thus open them to professional and consumer review.

Clinical guidelines that are not backed by evidence and argument should not be entitled to deference in administrative or legal proceedings that involve challenges to health plans' application of such guidelines. But where guidelines do have empirical support, even if the evidence is at best debatable, administrative and legal decision makers should give substantial weight to the social importance, in a racially and culturally diverse nation, of making allocative choices in a manner that achieves some consistency in appearance and practice (Bloche, 2001).

**Recommendation 5-6: Promote the consistency and equity of care through evidence-based guidelines.**

**To the extent possible, medical care allocative decisions should be driven by evidence-based clinical guidelines to insure consistency of care. These guidelines should be published, along with their supporting evidence base, to allow public and professional scru-**

**tiny, and used to examine the quality of care for racial and ethnic minorities.**

*Financial Incentives in Healthcare*

As discussed in Chapter 3, financial factors, such as capitation and plan incentives to providers to practice frugally, can pose greater barriers to racial and ethnic minority patients than for whites, even among patients insured at the same level. Low payment rates inhibit the supply of physician (and other healthcare provider) services to low-income groups, disproportionately affecting ethnic minorities. Inadequate supply takes the form of too few providers participating in plans serving the poor, and provider unwillingness to spend adequate time with patients. In Chapter 4, the committee linked this time pressure to the underlying problem of poor information exchange between physicians and members of minority groups. Where employers have an interest in providing an attractive benefit package, market forces protect middle and upper income groups against health plans “going too far” in rationing care. These protections are not available to all low-income groups, who must rely on balanced public policy to induce adequate supply of care.

More finely crafted provider incentives can have a positive role in efforts to reduce disparities in care. Greater economic rewards for time spent engaging patients and their families can contribute to overcoming barriers of culture, communication, and empathy. Payment schemes that reward providers for high scores on measures of patient satisfaction would further encourage the bridging of barriers related to racial and ethnic difference. Incentives to adhere to evidence-based protocols for frugal practice and to engage in age- and gender-appropriate disease screening would generally encourage efficient, quality care and penalize deviations regardless of race or ethnicity. Further, payment linked to favorable clinical outcomes, where reasonably measurable (e.g. control of diabetes, asthma, and high blood pressure), would provide additional such encouragement. Industry movement toward more nuanced incentive schemes along these lines could be catalyzed by private accrediting bodies, encouraged by business and professional leaders, and even initiated by public payors. Again, this recommendation is consistent with the IOM *Quality Chasm* report, which called for healthcare organizations, clinicians, purchasers, and other stakeholders to “align the incentives inherent in payment and accountability processes with the goal of quality improvement” (IOM, 2001a, p. 10).

**Recommendation 5-7: Structure payment systems to enhance available services to minority patients, and limit provider incentives that may promote disparities.**

**Payment systems to providers should ensure an adequate supply of services to racial and ethnic minority patients. Financial incentives to restrict care and pass liability to providers should be limited, to reduce conditions in which racial and ethnic stereotypes and biases may be exacerbated or reinforced.**

**Recommendation 5-8: Enhance patient-provider communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.**

**Economic incentives should be considered for practices that enhance provider-patient communication and trust, and that reward appropriate screening, preventive, and evidence-based clinical care.**

#### *Interpretation Services*

As noted in Chapter 2, nearly 14 million Americans are not proficient in English. In 1995, the Commonwealth Fund estimated that language differences are problematic for 21% of racial and ethnic minority group members who receive healthcare (Commonwealth, 1995). This percentage is almost certainly higher today given recent increases in immigration to the U.S. from many parts of the world. Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision-making, and ethical compromises, such as difficulty obtaining informed consent (Woloshin et al., 1995). In addition, low English reading proficiency may disproportionately and negatively affect many racial and ethnic minority patients' ability to read and understand written material from health plans and healthcare providers if appropriate translation is not provided. As discussed in Chapter 3, there is significant evidence that language affects variables such as follow-up compliance and satisfaction with services (Carrasquillo et al., 1999). Linguistic difficulties may present a barrier to the use of healthcare services (Derose and Baker, 2000), decrease adherence with medication regimes and appointment attendance (Manson, 1988), and decrease satisfaction with services (Carrasquillo et al., 1999; David and Rhee, 1998). For example, a recent survey of Spanish-speaking Latinos and English speakers of varying ethnicities who used emergency department services found that among patients who reported at least one physician visit in the previous three months, Latinos with fair or poor English proficiency reported 22% fewer visits than English-speaking non-Latinos, after controlling for reason for the visit (Derose and Baker, 2000). These associations were similar for patients in poor health, those with no usual source of care, and those without insurance. Other investigators have found independent



effects of language concordance on health outcomes, such that having a physician who spoke Spanish resulted in higher ratings of physical and psychological well being, higher health perceptions, and lower perceptions of pain (Perez-Stable, Napoles-Springer, and Miramontes, 1997).

A few studies examining the effectiveness of interpretation services have been conducted, with mixed results. Although mostly uncontrolled, some studies suggest that the use of interpreters for patients with limited English skills results in greater satisfaction (as compared to patients who said an interpreter should have been used; Baker, Hayes, and Fortier, 1998) and better medical outcomes (Tocher and Larson, 1998). However, in the investigation by Baker and colleagues (1998), while patients who used interpretation services rated their care as better than patients who would have liked services and did not receive them, they still rated their provider as less friendly, less respectful, less concerned, and felt less comfortable than patients who did not need an interpreter. These results suggest that interpretation services are necessary, but that both interpreters and providers should be aware that the mere availability of the service may not be adequate to improve satisfaction and outcomes. It has also been suggested that the use of remote language services, in which the interpreter is not physically in the room, may be preferable (for both patients and providers) to in-person interpretation services (Hornberger et al., 1996). While outcomes are somewhat variable, it is generally agreed that professional interpreters are necessary for many patients and that the use of family members, minors, or friends should be avoided as it may represent a breach of confidentiality, inhibit the patient from fully expressing symptoms or difficulties, or lead to errors in transmitting medical information.

The importance of interpretation services is underscored in guidelines offered by the Office for Civil Rights of the Department of Health and Human Services (U.S. DHHS) to prevent discrimination against limited-English proficient persons (U.S. DHHS, 2000). These guidelines pertain to any entity that receives direct or indirect financial assistance from HHS. Four key elements for compliance with the guidelines include: an assessment of the needs of the population; comprehensive written policies on language access (including hiring of bilingual staff and interpreters, arranging for telephone interpreters); training of staff; and monitoring of programs to ensure people with limited English proficiency are adequately served. Further, if the covered entity/agency suggests, requires, or encourages the use family members, minors, or friends as interpreters, it may expose them to liability under Title VI. Similarly, as noted above, the Office of Minority Health's national standards on culturally and linguistically appropriate services (CLAS) in healthcare also emphasize the importance of language access services.

An important issue for future consideration is the establishment of minimum standards for training of translators and interpreters. Significantly, the U.S. DHHS and some accreditation bodies are beginning to assess the feasibility of establishing minimum standards for interpreters and interpretation services. Selected federal laws and regulations, such as the Disadvantaged Minority Health Improvement Act, require the development of interpreter programs to increase the access of limited English proficient individuals to healthcare services. In addition, associations such as the Massachusetts Medical Interpreter Association (MMIA) in conjunction with Education Development Center, Inc., have published standards of practice focused on areas of interpretation, cultural interface, and ethical behavior. The recently established National Council on Interpretation in Healthcare has charged its Standards, Training and Certification (STC) Committee to draft standards, recommendations and informational materials concerning the interpreter role and performance as well as interpreter services and programs of interpreter education and assessment. Similarly, the California Healthcare Interpreters Association (CHIA) has recently released draft standards of ethical principles, protocols, and guidance for healthcare interpreters within the state.

**Finding 5-1: As a result of the increasing linguistic diversity in the United States, professional interpretation services are increasingly needed to assist low-English proficient racial and ethnic minority patients in healthcare settings.**

**Recommendation 5-9: Support the use of interpretation services where community need exists.**

**Professional interpretation services should be the standard where language discordance poses a barrier to care. Greater resources should be made available by payors to provide coverage for interpretation services for limited-English proficient patients and their families. Future research should identify best practices where the availability of interpretation services is limited.**

#### *Community Health Workers*

Community health workers have been acknowledged participants in healthcare systems since the 1960s (Witmer et al., 1995). These individuals, often termed lay health advisors, neighborhood workers, indigenous health workers, health aids, consejera, or promotora, fulfill multiple functions in helping to improve health outcomes. They have been defined as being “community members who work almost exclusively in community settings and who serve as connectors between healthcare consumers and

providers to promote health among groups that have traditionally lacked access to adequate care" (Witmer et al., 1995). The training of lay health workers varies and typically depends on the nature of services they will provide. Generally, the length of training varies from a few weeks to six months and includes lectures and supervised practical/field experiences (for review see Jackson and Parks, 1997; Witmer et al., 1995). One of the greatest assets of lay health programs is that they build on the strengths of community ties to help improve outcomes for its citizens.

In addition to increasing access to services, some evidence suggests that lay health workers can help improve the quality of care and reduce costs (Witmer et al., 1995). Lay workers can facilitate community participation in the health system, serve as liaisons between patients and providers, educate providers about community needs and the culture of the community, provide patient education, promote consumer advocacy and protection, contribute to continuity and coordination of care, assist in appointment attendance and adherence to medication regimens, and help to increase the use of preventive and primary care services (Brownstein et al., 1992; Earp and Flax, 1999; Jackson and Parks, 1997). Programs that utilize lay health workers have sought to improve healthcare delivery for a variety of conditions including stroke and hypertension (Richter et al., 1974), breast and cervical cancer screening (Brownstein et al., 1992; Dignan et al., 1998; Earp and Flax, 1999), and the use of prenatal services (Meister et al., 1992). Lay health workers have also been used to address broader issues such as improving healthcare organizations' ability to identify needs of the community (Baker et al., 1997) and improve general wellness through informing community members about resources and facilitating their access to and negotiation through services (Rodney et al., 1998).

During its inception, the concept of using lay health workers included collaborations between lay health workers and public health departments, homeless programs, and community health centers (Richter et al., 1974). More recently, partnerships have been formed with academic medical centers (see for example, Levine et al., 1994). This movement has been accompanied by increased efforts to evaluate the effectiveness of lay workers in improving patient satisfaction and increased use of services. Results indicate that use of lay health workers can increase awareness of and screening for breast cancer (Bird et al., 1998; Navarro et al., 1998; Slater et al., 1998) and cervical cancer (Bird et al., 1998; Dignan et al., 1998; Navarro et al., 1998). For example, among a population of Vietnamese-American women in California, the use of lay health workers significantly increased women's awareness of and utilization of Pap smear and mammography (Bird et al., 1998). The use of lay health workers in a diabetes education program improved completion, regardless of financial status or language

spoken, over conducting the education program without lay health workers (Corkery et al., 1997). However, the health workers did not have a significant effect on diabetes knowledge, self-care behavior, or glycemic control, although the small sample size ( $n = 64$ ) may have limited the investigators' ability to find statistically significant relationships with these outcomes.

In order for community health worker programs to be successful, they must be designed properly and workers must be adequately trained and supervised. Barriers to their effective use have included a lack of consistent, widely accepted definition of who they are and what services they can provide (e.g., scope of practice, qualifications), lack of consideration by degreed health professionals for their services, and lack of consistent funding for lay health programs (Witmer et al., 1995). Some literature provides guidance regarding the design of community health worker programs (Brownstein et al., 1992; Giblin, 1989; Jackson and Parks, 1997; Richter et al., 1974; Witmer et al., 1995), but rigorous evaluations of specific program components and their impact on service utilization are needed.

**Finding 5-2: Community health workers offer promise as a community-based resource to increase racial and ethnic minorities' access to healthcare and to serve as a liaison between healthcare providers and the communities they serve.**

**Recommendation 5-10: Support the use of community health workers. Programs to support the use of community health workers (e.g., as healthcare navigators), especially among medically underserved and racial and ethnic minority populations, should be expanded, evaluated, and replicated.**

#### *Multidisciplinary Teams*

Research demonstrates that multidisciplinary team approaches—utilizing physicians, nurses, dietitians, and others—have proven effective in optimizing risk reduction strategies. This effect is found in randomized controlled studies for patients with coronary heart disease (Multiple Risk Factor Intervention Trial Research Group, 1982), hypertension (Hypertension Detection and Follow-up Program Cooperative Group, 1979), and other diseases (SHEP Cooperative Research Group, 1991; Pedersen et al., 1994; Treatment of Mild Hypertension Study Research Group, 1993), and has extended to strategies for reducing risk behaviors such as smoking and sedentary lifestyle and managing obesity (Hill and Miller, 1996). Multidisciplinary teams coordinate and streamline care, enhance patient adherence through follow-up techniques, and address the multiple be-

havioral and social risks that patients face, particularly racial and ethnic minority patients. They may save costs and improve the efficiency of care by reducing the need for face-to-face physician visits and improve patients' day-to-day care between visits. Further, such strategies have proven effective in improving health outcomes of minorities previously viewed as "difficult to serve" (Hill and Miller, 1996). Multidisciplinary team approaches should be more widely instituted as strategy for improving care delivery, implementing secondary prevention strategies, and enhancing risk reduction.

**Recommendation 5-11: Implement multidisciplinary treatment and preventive care teams.**

**Multidisciplinary teams offer promise as a means to improve and streamline care for racial and ethnic minority patients, and therefore should be more widely implemented.**

#### PATIENT EDUCATION AND EMPOWERMENT

Skill-building and training for providers of healthcare has been a traditional avenue for helping to improve outcomes (see for example Roter and Hall, 1994; Roter et al., 1995; Williams and Deci, 2001), increase patient satisfaction with care (Roter et al., 1996), and decrease the incidence of lawsuits (Levinson et al., 1997; Mock, 2001). However, as issues of improved patient-provider communication/relationship have moved to the forefront, patient education, participation, activation, and empowerment have received more attention. Information that flows in both directions is deemed important for increasing patient cooperation, engagement, and adherence to medical regimes (Korsch, 1994).

Patient education has taken many forms including provision of books, pamphlets, in-person instruction, CD-ROM, and Internet-based information. Books such as that by Korsch and Harding (1998) help guide patients through typical office visits and provide information about asking the right questions, communicating with the provider when instructions are not understood or cannot be followed, and being an active participant in decision making. The guide also helps patients understand the nature of medical training and its impact on provider behavior. Other mediums such as entertainment television (Cooper, Roter, and Langlieb, 2000) and computer-based education programs (McRoy, Liu-Perez, and Ali, 1998) have been initiated. In addition, private and academic institutions offer information systems to assist patients in navigating healthcare systems. For example the Bayer Institute has developed a program called PRE-PARE, a six-step program using a self-administered audiotape and guidebook to help patients prepare for office visits. Complementary materials

were also developed for use by providers of healthcare to support and encourage use of the program. In addition, some medical institutions, such as the Ohio State University Medical Center and Cincinnati Children's Hospital Center, have established Internet-based programs to help answer patient questions about topics such as pain management, medications, medical procedures, nutrition, and health promotion.

As patient education approaches become more widely used, efforts to evaluate their effectiveness have increased, and have demonstrated positive results. In one of the earliest papers examining the beneficial effects of patient education, Roter (1977) assessed the effects of a health education intervention to increase patient question-asking during office visits. In this study, which was conducted with an urban and predominantly black population, patients were randomly assigned to intervention and non-intervention groups. There were also two non-randomized control groups. Results indicated that patients in the intervention group asked more direct questions and fewer indirect questions than did non-intervention group patients. However, within the intervention group, there was more negative affect, anxiety, and anger in the patient-provider interaction, while in the placebo group, patient-provider interaction was characterized as mutually sympathetic. In addition, the intervention group patients were less satisfied with care received in the clinic on the day of their visit than were placebo patients, but they demonstrated higher appointment-keeping (accounting for average number of appointments made) during a 4-month prospective monitoring period. These results suggest that efforts directed at increasing patient activation must also target physician behavior and how providers receive and respond to patients' increased participation.

A recently developed CD-ROM reproductive health education program for adolescents with diabetes has been evaluated for its effectiveness in altering knowledge, attitudes, skills, and behaviors. Initial results indicate that the use of the CD-ROM was associated with changes in knowledge, attitudes, and beliefs over the use of a self-instruction packet or standard care. Similarly, an individual education and coaching program in pain self-management for cancer patients was demonstrated to improve ratings of pain severity over patients who did not receive the intervention. However, no changes were observed in functional impairment resulting from pain, frequency of pain, or pain-related knowledge.

In a review article, Roter and colleagues (1998) summarized results of 153 studies evaluating the effectiveness of interventions to improve patient compliance. Many of these studies were patient education-based and included strategies such as individual and group teaching, use of written and audiovisual materials, mailed materials, and telephone instructions. Overall, the most striking results were seen for behavior strat-

egies (e.g., skill building, practice activities, modeling and contracting, rewards, mail and telephone reminders) and those that combined education and behavior strategies. In general, interventions that combined strategies were more successful than single-focus interventions. Significant results, though varied in magnitude, were found for refill records, pill counts, utilization, and improved health outcomes. While most studies cited were not specifically targeted toward communities of color, positive results from patient education programs offer promise for their use with racial and ethnic minority patients. However, it is crucial that interventions be adapted with cultural and linguistic considerations in mind and also address physician responses to their patients' increased activation, to ensure collaborative interactions.

**Finding 5-3: Culturally appropriate patient education programs offer promise as an effective means of improving patient participation in clinical decision making and care-seeking skills, knowledge, and self advocacy.**

**Recommendation 5-12: Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.**

**Culturally appropriate patient education programs tailored to specific racial and ethnic minority populations should be developed, implemented, and evaluated.**

## 6

# Interventions: Cross-Cultural Education in the Health Professions

### BACKGROUND

The 2000 U.S. Census confirmed what demographers had been predicting all along—our country has become more diverse than ever before (U.S. Census, 2000). Our expansion has been fueled by growth of our minority populations, in addition to significant immigrant influx (Immigration Statistics, 2001). How will the United States respond to this increasing diversity? Ultimately, our success as a nation hinges on how we meet the challenges diversity poses, while capitalizing on the strengths it provides. Many sectors have responded proactively to our demographic evolution, understanding that there are financial and market imperatives to better understanding, communicating, servicing, and partnering with those from diverse backgrounds. This has resulted in major educational efforts, through training and corporate development, as to how better to “manage” diversity at the workplace and in business/service relations (Chin, 2000).

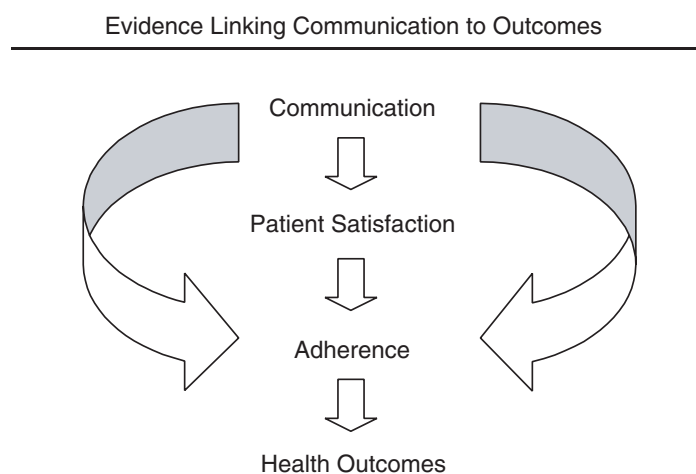
How will one of our largest industries—healthcare—respond? There is a growing literature that delineates the impact of sociocultural factors, race, and ethnicity on clinical care (Berger, 1998; Hill et al., 1990). Clinicians aren’t shielded from diversity, as patients present varied perspectives, values, beliefs, and behaviors regarding health and well-being. These include variations in patient recognition of symptoms, thresholds for seeking care, ability to communicate symptoms to a provider who understands their meaning, ability to understand the management strategy, expectations of care (including preferences for or against diagnostic



and therapeutic procedures), and adherence to preventive measures and medications (Einbinder and Schulman, 2000; Flores, 2000; Betancourt et al., 1999; Denoba et al., 1998; Gornick, 2000; Coleman-Miller, 2000; Williams and Rucker, 2000).

### CROSS-CULTURAL COMMUNICATION: LINKS TO RACIAL/ETHNIC DISPARITIES IN HEALTHCARE

Sociocultural differences between patient and provider influence communication and clinical decision-making (Eisenberg, 1979). Evidence suggests that provider-patient communication is directly linked to patient satisfaction, adherence, and subsequently, health outcomes (Figure 6-1) (Stewart et al., 1999). Thus, when sociocultural differences between patient and provider aren't appreciated, explored, understood, or communicated in the medical encounter, the result is patient dissatisfaction, poor adherence, poorer health outcomes, and racial/ethnic disparities in care (Flores, 2000; Betancourt et al., 1999; Stewart et al., 1999; Morales et al., 1999; Cooper-Patrick et al., 1999; Langer, 1999). And it is not only the patient's culture that matters; the provider "culture" is equally important (Nunez, 2000; Robins et al., 1998b). Historical factors for patient mistrust, provider bias, and its impact on physician decision-making have also been documented (Gamble, 1997; Schulman et al., 1999; van Ryn and Burke, 2000). Failure to take sociocultural factors into account may lead to stereotyping, and in the worst cases, biased or discriminatory treatment of pa-



**FIGURE 6-1** Evidence linking communication to outcomes.

tients based on race, culture, language proficiency, or social status (Schulman et al., 1999; van Ryn and Burke, 2000; Donini-Lenhoff and Hedrick, 2000). Two studies for physicians highlight these points.

First, Schulman et al. (1999) showed that differential referral to cardiac catheterization was based on race and gender. Second, van Ryn and Burke (2000) illustrated that physicians have different attitudes about patients based on race, as well. Similarly, one study involving 116 nursing students found that negative attitudes about racial/ethnic minorities was related to the absence of prior exposure, suggesting that these issues are not limited to physicians (Eliason, 1998).

### THE FOUNDATION AND EMERGENCE OF CROSS-CULTURAL EDUCATION

The meaning of “culture” has been widely debated and broadly defined, with certain common themes emerging. To summarize, culture can be seen as an integrated pattern of learned beliefs and behaviors that can be shared among groups and include thoughts, styles of communicating, ways of interacting, views on roles and relationships, values, practices, and customs (Robins et al., 1998b; Donini-Lenhoff and Hedrick, 2000). Culture shapes how we explain and value our world, and provides us with the lens through which we find meaning (Nunez, 2000). It should not be considered “exotic” or about “others” (Shapiro and Lenahan, 1996; Like et al., 1996), but as part of all of us and our individual influences (including socioeconomic status, religion, gender, sexual orientation, occupation, disability, etc.). We all are influenced by and belong, to multiple cultures that include, but go beyond, race and ethnicity.

Sociocultural factors are critical to the medical encounter, yet cross-cultural curricula have been incorporated into undergraduate, graduate and continued health professions education only to a limited degree (Carrillo et al., 1999). Their goal is to enhance learners’ awareness of sociocultural influences on health beliefs and behaviors, and to equip them with skills to understand and manage these factors in the medical encounter (Carrillo et al., 1999; Culhane-Pera et al., 2000; Zweifler and Gonzalez, 1998). This includes understanding population-specific disease prevalence and health outcomes and ethnopharmacology (Lavizzo-Mourey, 1996; Zweifler and Gonzalez, 1998).

Although cross-cultural medicine has gained recent attention, it has been discussed in the literature since the 1960’s during the advent of the community health and civil rights movement. There was a clear call then for responsiveness to cultural differences in health attitudes, beliefs, behavior, and language (Chin, 2000). In the 1970’s, the seminal work of Kleinman et al. solidified the important link between culture, illness and

healthcare (Kleinman et al., 1978). In the 1980's and 1990's, the focus shifted from "cultural sensitivity" to a demand for "cultural competence," a more skill-focused paradigm (Rios and Simpson, 1998; Welch, 1998; Lavizzo-Mourey 1996). Early work in the field is found in the literature of nursing, mental health, and family medicine (Shapiro and Lenahan, 1996; Kai et al., 1999; Kristal et al., 1983). An international interest in the intersection between culture and health has arisen, with work done in Australia, Great Britain, and Canada, among others (Louden et al., 1999).

Looking at undergraduate medical education over this time, we see interesting parallels. Since 1978, four surveys/literature searches have been conducted to determine whether medical schools were teaching cross-cultural issues in their curriculum (Louden et al., 1999; Wyatt et al., 1978; Lum and Korenman, 1994; Flores et al., 2000) (Table 6-1). Although each study was limited by not determining curriculum specifics (whether a course was required, contact hours, approaches, etc.), the trend shows a decrease in specific cross-cultural courses, and an increase in incorporation of these issues into the overall curriculum. This last finding is deceiving, as it's unknown to what extent cross-cultural issues are dealt with in other courses. This could simply mean that there are optional noon lectures or electives that cover cross-cultural issues during some part of the standard health professional academic year. Experts in the field remain skeptical about the results, which show a "mainstreaming" of cross-cultural education, and are concerned about how effectively these issues are addressed during medical education (Kai et al., 1999; Flores et al., 2000). There is no literature to document the extent to which these issues are covered in graduate or continuing medical education for either residents or practicing providers. The literature in nursing education is similarly sparse. Although material related to cultural diversity is considered an

**TABLE 6-1** Cross-Cultural Curricula in Undergraduate Medical Education

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1978 (Wyatt):
20% med schools offered specific "sociocultural courses"
40% covered issues within other courses, 40% offered none
1992(Lum):
13% offered separate "sociocultural course" (only 1 required)
60% integrated sociocultural factors into broader curriculum
1998(Flores):
8% offered separate course
87% integrated sociocultural factors into curriculum
1999(Loudon)
17 programs teaching "cultural diversity" identified (US, UK, Canada, Australia).

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NOTE: Cultural competence or cross-cultural medicine not used as search terms.

important part of baccalaureate curricula, there is virtually no information published on the extent to which cultural competence is included in undergraduate courses or the specifics of the material that is included (Clinton, 1996; Janes and Hobson, 1998).

Cross-cultural education for health professionals has emerged because of three major factors. First, cross-cultural education has been deemed critical in preparing our providers to meet the health needs of our growing, diverse population (Welch, 1998). Second, it's been hypothesized that cross-cultural education could improve provider-patient communication and help eliminate the pervasive racial/ethnic disparities in medical care seen today (Einbinder and Schulman, 2000; Williams and Rucker, 2000; Brach and Fraser, 2000). Third, in response to the Institute of Medicine Report on Primary Care which states that "there should be an understanding of cultural belief systems of patients that assist or hinder effective healthcare delivery," and in response to the Pew Health Professions Commission, which states that "cultural sensitivity must be a part of the educational experiences of every student," accreditation bodies for medical training (i.e., Liaison Council on Medical Education, Accreditation Council on Graduate Medical Education) now have standards that require cross-cultural curricula as part of undergraduate and graduate medical education (Liaison Committee on Medical Education, 2001; Accreditation Council for Graduate Medical Education, 2001; Committee on the Future of Primary Care, 1994; Pew Health Professions Commission, 1995). Although these standards are general in their language, they are being expanded in detail and remain enforceable. Similarly, leaders in nursing education recognize the importance of culture in the health of populations and patients. As early as 1977, the National League for Nursing required cultural content in nursing curricula and in 1991, the American Nursing Association published standards specifically indicating that culturally and ethnically relevant care should be available to all patients.

### APPROACHES TO CROSS-CULTURAL EDUCATION

Training in cross-cultural medicine can be divided into three conceptual approaches focusing on *attitudes*, *knowledge*, and *skills*. Like the proverbial three-legged stool, each approach plays a crucial role, but is unable to support any weight when not fully supported by the other two.

#### *A Focus on Attitudes: The Cultural Sensitivity/Awareness Approach*

The foundation of cross-cultural care is based in the *attitudes* central to professionalism—humility, empathy, curiosity, respect, sensitivity, and awareness of all outside influences on the patient (Bobo et al., 1991;

**TABLE 6-2** Conceptual Approaches to Cross-Cultural Education

Sensitivity/Awareness Approach

- Primary focus on provider **attitudes**
  - Goal is to increase provider awareness of impact of sociocultural factors on individual patients' health values, beliefs, behaviors, and ultimately quality of care and outcomes
- Exploration and reflection on culture, racism, classism, sexism, etc.
  - Discussion of these factors as they relate to the provider and the patient culture, and what impact they may have on clinical decision-making
  - Importance of curiosity, empathy and respect in the medical encounter highlighted
- Approach primarily taught in early in medical school and in certain residencies

Gonzalez-Lee and Simon, 1987). The added importance of these attitudes in cross-cultural medical encounters, where the desire to explore and negotiate divergent health beliefs and behaviors is paramount, has given rise to curricula designed to build or shape them within providers. The cultural sensitivity/awareness approach (see Table 6-2) incorporates educational exercises and techniques that promote self-reflection, including understanding one's own culture, biases, tendency to stereotype, and appreciation for diverse health values, beliefs, and behaviors (Culhane-Pera et al., 1997). Examples include open conversations exploring the impact of racism, classism, sexism, homophobia, and other types of discrimination in healthcare; determining how providers have themselves dealt with feeling "different" in some way; attempting to identify, using patient descriptors or vignettes, hidden biases we may have based on subconscious stereotypes; determining our reaction to different visuals of patients of different races/ethnicities; and discussing ways in which our family members have interacted with the healthcare system (Berlin, 1998; Donnini-Lenhoff, 2000; Tervalon and Murray-Garcia, 1998).

From a practical perspective, efforts to change attitudes are labor intensive, difficult, charged, complex to evaluate, and can seem abstract to those who are more clinically oriented (Kai et al., 1999). Nevertheless, attitudes such as curiosity, empathy, respect, and humility are critical to engaging in effective communication during the clinical encounter, whether the patient is from a similar or a distinct cultural background.

*A Focus on Knowledge: The Multicultural/Categorical Approach*

Traditionally, cross-cultural education has focused on a "multicultural" or "categorical approach," providing *knowledge* on the attitudes, values, beliefs, and behaviors of certain cultural groups (Paniagua, 1994). For

example, methods to care for the “Asian” patient or the “Hispanic” patient would present a list of common health beliefs, behaviors, and key practice “do’s and don’ts.” With the huge array of cultural, ethnic, national, and religious groups in the United States, and the multiple influences such as acculturation and socioeconomic status that lead to intra-group variability, it is difficult to teach a set of unifying facts or cultural norms (such as “fatalism” among Hispanics, or “passivity” among Asians) about any particular group (Chin, 2000; Hill et al., 1990). These efforts can lead to stereotyping and oversimplification of culture, without a respect for its fluidity (Donini-Lenhoff and Hedrick, 2000; Carrillo et al., 1999). Research has shown that teaching “cultural knowledge” can be more detrimental than helpful if it is not done carefully (Shapiro and Lenahan, 1996).

There are two instances where focusing on a knowledge-based approach can be effective. First, following the basic tenets of community-oriented primary care and community assessment, students and practitioners can learn about the surrounding community in which they train or practice. Some important factors include the social and historic context of the population (new immigrants or longstanding residents), the predominant socioeconomic status, the immigration experience (was the immigration chosen or forced), nutritional habits (diet high in protein, fiber, or fat), common occupations (i.e., blue collar or service industry), patterns of housing (i.e., housing development), folk illnesses and healing practices (i.e., *empacho*, “coining”), and disease incidence and prevalence. Several such models are described in the literature focusing on communities in U.S.-Mexican border towns, communities with a new influx of a specific immigrant group, and Native-American reservations (Kristal et al., 1983; Nora et al., 1994).

The second instance of an effective knowledge-based approach is knowledge that has a specific, evidence-based impact on healthcare delivery. Examples include ethnopharmacology; disease incidence, prevalence, and outcomes among distinct populations; the impact of the Tuskegee Syphilis Study and segregation as the cause of mistrust in African Americans; the effect of war and torture on certain refugee populations and how this shapes their interaction with the healthcare system; and the common cultural and spiritual practices that might interfere with prescribed therapies (such as Ramadhan—the sunup-to-sundown fast observed by Muslims—and how this might affect people with diabetes), to name a few.

When learning facts about “cultural groups,” it’s important for providers to ask themselves several questions to avoid falling prey to ecologic fallacy. How accurate and generalizable are these group assumptions? How current are they, given the fluidity of culture and diversity among groups? What are the limitations? How can I use this knowledge

**TABLE 6-3** Conceptual Approaches to Cross-Cultural Education

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Multicultural/Categorical Approach
<ul style="list-style-type: none"><li>• Primary focus on increasing provider <b>knowledge</b> of cross-cultural issues<ul style="list-style-type: none"><li>◦ Previous focus on teaching unifying cultural characteristics of cultural groups (patients of culture x believe. . . and behave . . .)</li></ul></li><li>• New focus on teaching methods of community assessment and evidence-based factors<ul style="list-style-type: none"><li>◦ These include disease incidence/prevalence among groups, ethnopharmacology, and historical factors that might shape health behaviors</li></ul></li><li>• Taught in undergraduate, graduate, and continuing medical education</li></ul>

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to deliver better care? (Shapiro and Lenahan, 1996). In summary, if a knowledge-based approach (see Table 6-3) is taught, it should focus on community oriented or specific, evidence-based factors. Absent this, learning as much as possible about the patient's own sociocultural context and perspectives while minimizing the reliance on generalizations is ideal.

*A Focus on Skills: The Cross-Cultural Approach*

The cross-cultural approach teaches providers *skills* that meld those of medical interviewing with the ethnographic tools of medical anthropology (Shapiro and Lenahan, 1996; Carrillo et al., 1999). These framework-based approaches focus on communication skills, and train providers to be aware of certain cross-cutting cultural issues, social issues, and health beliefs, while providing methods to deal with information clinically once it is obtained (Nunez, 2000; Berlin and Fowkes, 1998; Clinton, 1996). Curricula have focused on providing methods for eliciting patients' explanatory models (what patients believe is causing their illness) and agendas, identifying and negotiating different styles of communication, assessing decision-making preferences, the role of family, determining the patient's perception of biomedicine and complementary and alternative medicine, recognizing sexual and gender issues, and being aware of issues of mistrust, prejudice, and racism, among others (see Table 6-4) (Carrillo et al., 1999; Hill et al., 1990; Zweifler and Gonzalez, 1998; Culhane-Pera et al., 1997). For example, providers are taught that while it is important to understand all patients' health beliefs, it may be particularly crucial to understand the health beliefs of those who come from a different culture or have a different healthcare experience. As such, frameworks including questions to obtain this and other information are taught. Instead of applying a deductive approach that applies broad rules and generalizations about cultures to the individual, this inductive approach

**TABLE 6-4** Conceptual Approaches to Cross-Cultural Education

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Cross-Cultural Approach
<ul style="list-style-type: none"><li>• Primary focus on developing <b>tools and skills</b> for providers</li><li>• Process-oriented instruction that melds medical interviewing and communication skills with sociocultural and ethnographic tools of medical anthropology<ul style="list-style-type: none"><li>• Approaches to elicit patient's explanatory model (patient's conceptualization of illness)</li><li>• Methods to assess patient's social context</li><li>• Strategies for provider-patient negotiation and facilitation of participatory decision making</li></ul></li><li>• Foundation to care for diverse populations through development of interviewing frameworks</li><li>• Practical approach for clinical years; taught in undergraduate, graduate, and continuing medical education</li></ul>

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focuses on the patient, rather than theory, as the starting point for discovery (Shapiro and Lenahan, 1996). With the individual patient as teacher, providers are encouraged to adjust their practice style accordingly to meet their patients' specific needs. The cross-cultural approach has gained favor among educators who see its clinical applicability as a framework in caring for either diverse or targeted populations.

#### *Teaching Methods and Opportunities*

There have been a variety of teaching methodologies utilized for cross-cultural education at different levels of training (Table 6-6). In general, interactive, experiential, practical, case-based approaches that address cognitive, affective, and behavioral aspects of the learner are most effective (Welch, 1998). At the level of undergraduate and graduate medical education, strategies such as self-reflection (particularly for cultural sensitivity/awareness approach), focused didactics (especially for multicultural approach), and the use of vignettes, problem-based learning cases, medical encounter videos, and individual case-based discussion (usually for cross-cultural approach) are most common (Nunez, 2000; Carrillo et al., 1999; Loudon et al., 1999; Culhane-Pera et al., 1997). Innovative educational strategies include learner community immersion (whereby students or residents rotate through community-based healthcare facilities), role-play (whereby students or residents practice interviewing techniques using scripted cases), patient narratives, video interviews of patients, and the use of patients or actors for faculty facilitated, simulated medical encounters (Gonzalez-Lee and Simon, 1987; Rubenstein et al., 1992). Continuing education for practicing providers has focused more on "cultur-



ally competent” approaches to treating specific clinical conditions in targeted populations (i.e. “Hypertension in African Americans,” or “Managing Diabetes in Latinos”). In these instances, a knowledge-based approach is most commonly employed, in which disease incidence and prevalence of a specific condition in a target population is presented, along with focused strategies for managing said condition. These strategies may include evidence for the use of specific medications in certain populations or methods for incorporating community based resources for clinical support. Although other “provider-patient communication” continuing education courses focus more specifically on the process of improving understanding in the medical encounter, few have “cross-cultural communication” as a central theme.

There are various opportunities to incorporate cross-cultural issues in health professions education. In undergraduate and graduate medical education, courses have been taught during orientation, as part of established courses or electives, during retreats, as part of weekly conferences, or less frequently, as an optional or required stand-alone (see Table 6-5). Since there is currently no clear focus on cross-cultural issues within undergraduate and graduate health professions curricula, stand-alone courses are favored for the time being, although integration into the standard curricula would be optimal (Kai et al., 1999).

For practicing providers, integration of cross-cultural curricula as part of continuing education, or as part of the grand rounds series, or as part of faculty development, has been attempted. Certain states are considering requiring a standard number of continuing education credits in cross-cultural communication as part of professional licensure. Similarly, the Na-

**TABLE 6-5** Methods and Opportunities for Cross-Cultural Education

<b>Methods</b>	<b>Opportunities</b>
<p><i>Undergrad/Graduate Medical Education</i></p> <ul style="list-style-type: none"> <li>• Facilitated reflection</li> <li>• Didactics</li> <li>• Vignettes</li> <li>• Individual Cases</li> <li>• Problem-Based Learning</li> <li>• Videos</li> <li>• Simulated Patients</li> <li>• Community Immersion</li> </ul>	<p><i>Undergrad/Graduate Medical Education</i></p> <ul style="list-style-type: none"> <li>• Orientation</li> <li>• Electives</li> <li>• Retreats</li> <li>• Rounds</li> <li>• Conferences</li> <li>• Introduction to Clinical Sciences</li> <li>• Stand Alone Course</li> </ul>
<p style="text-align: center;"><b>Continuing Education</b></p> <ul style="list-style-type: none"> <li>• Didactics</li> <li>• Problem-Based Learning</li> <li>• Case-Based Discussion</li> </ul>	<p style="text-align: center;"><b>Practicing Providers</b></p> <ul style="list-style-type: none"> <li>• Continuing Education</li> <li>• Faculty Development</li> <li>• Licensure/Exams</li> </ul>

tional Board of Medical Examiners is exploring methods of incorporating questions that address cross-cultural issues in medical care on licensing exams. Certain medical malpractice insurers are offering premium discounts to providers who complete provider-patient communication courses, and are now considering applying the same discounts to providers who complete cross-cultural communication courses. Regardless of the setting, it is felt that cross-cultural education should be linked to the level of the learner's training, with more theoretical approaches in the pre-clinical years and more practical approaches during the clinical years (Nunez, 2000).

### *Evaluation*

To date, there has been limited evaluation published on the impact of cross-cultural education. Building on the three-legged stool model of attitudes, knowledge, and skills described above, we see some studies that have primarily shown improvements in cross-cultural knowledge (the type of knowledge has varied relative to the individual curricula taught). For example, Rubenstein et al. used pre- and post-test methodology to demonstrate that students who completed a "Culture, Communication, and Health" course displayed an increase in knowledge regarding:

1. The way in which a physician's ignorance of a patient's health beliefs and practices can adversely affect the clinical encounter;
2. The pervasiveness of non-conventional health beliefs and practices; and
3. The types of resources available for learning about patients' health beliefs and practices. (Rubenstein et al., 1992).

Similarly, Nora et al. used multiple-choice question methodology to show that an experimental group of students who completed a "Spanish Language and Cultural Competence Curriculum" had greater knowledge of Hispanic health and cultural issues, including disease prevalence, cultural perceptions of illness, and traditional health practices, compared with a control group (Nora, 1994). In addition, when compared with the control group, the experimental group was found to be less ethnocentric and more comfortable with others after the curricular intervention, based on the "Misanthropy Scale." In the area of graduate medical education, one published study found that family practice residents exposed to a three-year, multi-method cross-cultural curriculum displayed an increase in cultural knowledge and cross-cultural skills via self-report and faculty corroboration (Culhane-Pera et al., 1997). Research on continuing medical education courses for practicing providers targeted at improving commu-

nication skills (without a focus on cross-cultural communication) have shown mixed results (Haynes et al., 1984; Davis et al., 1992; Davis et al., 1995). Joos et al. showed no significant improvement in patient satisfaction for providers who had completed such courses versus those who hadn't (Joos et al., 1996). Levinson et al. did show a moderate increase in patient satisfaction and a significant increase in provider satisfaction for those who completed a course on improving doctor-patient communication (Levinson et al., 1993). It is difficult to know whether one can extrapolate these results to continuing medical education focusing on cross-cultural communication as there is yet no evaluative data in this area.

Cross-cultural education poses significant challenges for evaluation. For example, it's difficult to evaluate change in provider attitudes given the potential for social desirability bias on surveying, and the difficulty in observing encounters in real time. Assessing knowledge is perhaps easier, and can be assessed with standard evaluation tools such as pretest-post-tests and essays (Louden et al., 1999; Nora et al., 1994; Rubenstein et al., 1992). Skills can be evaluated in undergraduate and graduate health professions education using techniques such as the objective structured clinical examination, or videotaping actual clinical encounters (Nunez, 2000; Robins et al., 1998a; Robins et al., 2001). For practicing providers, one might assess patient satisfaction improvements among those who have completed cross-cultural communication courses. All in all, we should be able to evaluate some dimensions of attitudes, knowledge, and skills.

Another approach to evaluation asks three questions about the impact of curricula, building towards the link to outcomes. First, do providers learn what is taught? Second, do they use what is taught? And third, does what is taught have an impact on care?

These questions can be assessed using mixed methodologies that include both quantitative and qualitative techniques (Table 6-6) (Nunez, 2000; Like et al., 1996). These include pre- and post-tests, unknown clinical cases, qualitative physician and patient interviews, medical chart review, audio or videotape of medical encounter, objective structured clinical exams, patient and provider satisfaction, and processes of care (i.e. completion of health promotion/disease prevention interventions). It's important that we not hold cross-cultural curricula to unfair evaluation standards, as detractors have asked for a direct link between curricula and the improvement of hard clinical outcomes. Any assessment should match the educational objectives and be carried out in a careful, step-wise fashion, controlling for all possible confounders and focusing first on process measures (such as patient and provider satisfaction).

**TABLE 6-6** Evaluation of Cross-Cultural Curricula

Key Question	Evaluation Strategy
Do providers learn what is taught?	Pre-, Post -Test Unknown Clinical Cases Objective Structured Clinical Exam
Do they use what is taught?	Qualitative physician and patient interviews Medical Chart Review Audio or Videotape of medical encounter Patient, Provider Satisfaction
Does what is taught have an impact on care?	Processes of Care (i.e., completion of health promotion/ disease prevention interventions)

*Challenges and Opportunities*

There are several challenges ahead for cross-cultural education (Table 6-7). First, given the biomedical focus of health professions education, there is significant resistance to curricula that are viewed as “soft” or lacking an evidence base (Culhane-Pera et al., 1997). Second, given that providers are accustomed to factual, practical learning, they are often disappointed when specific group cultural knowledge (“Hispanic patients believe . . . or behave . . .”) is not presented (Kai et al., 1999). Third, providers feel that they don’t have the time needed to explore and negotiate complex sociocultural issues with patients, due to the short length of today’s medical encounter. Fourth, there is lack of consensus on fundamental, conceptual approaches and teaching methodologies, and lack of institutional support (both formal and informal) (Shapiro and Lenahan, 1996; Kai et al., 1999). Fifth and finally, although there is circumstantial

**TABLE 6-7** Challenges for Cross-Cultural Education

Challenges: Provider Perspectives	Challenges: Developing the Field
<ul style="list-style-type: none"> <li>• Provider resistance to curricula in this area</li> <li>• Limited awareness of impact of cross-cultural factors on healthcare and presence of health disparities</li> <li>• Desire for categorical approach to cross-cultural education</li> <li>• Time constraints for implementation of skills</li> </ul>	<ul style="list-style-type: none"> <li>• Varying fundamental approaches without consensus</li> <li>• Multiple teaching methodologies</li> <li>• Limited time, resources, faculty, and institutional support</li> <li>• Hypothetical link between cross-cultural education and the elimination of disparities that must be strengthened</li> </ul>

evidence that would substantiate the claim that improving provider cross-cultural communication will help eliminate disparities in healthcare, there are yet to be published studies to support this hypothesis.

Despite these challenges, several opportunities exist for the field. First, since the government has realized the importance of educational initiatives in this area (U.S. DHHS, 1999), there are broadening funding streams for cross-cultural education and research. Given the evidence linking provider-patient communication to patient satisfaction, adherence, and outcomes, cross-cultural education holds promise as one effort of a multi-pronged approach towards eliminating racial/ethnic disparities in healthcare. Research that would help to solidify this link should be developed. Second, expanded cross-cultural curricula that include teaching specific data on racial/ethnic disparities in healthcare, in addition to exploration and discussion of potential causative factors, are being piloted. Given the limited awareness of disparities on the part of providers and the public (The Henry J. Kaiser Family Foundation, 1999), this seems to be a worthy strategy. Finally, with growing acknowledgement as to the impact of social cognitive factors (including stereotyping) on provider decision-making, cross-cultural curricula are now reviewing the normal processes by which clinical decisions are made, and what negative impact they might have on minority populations.

Ultimately, cross-cultural curricula should focus on securing provider buy-in by introducing evidence on how sociocultural barriers affect medical care and lead to racial/ethnic disparities in health, and how specific cross-cultural strategies can help ameliorate them. Curricula should balance their approaches between addressing attitudes, knowledge, and skills in a way that offers providers multiple approaches to address the problems they face.

### SUMMARY

This chapter reviews evidence that sociocultural differences between patient and provider influence communication and clinical decision-making (Eisenberg, 1979). Evidence suggests that provider-patient communication is directly linked to patient satisfaction, adherence, and subsequently, health outcomes (Stewart et al., 1999). When sociocultural differences between patient and provider aren't appreciated, explored, understood, or communicated in the medical encounter, the result may be patient dissatisfaction, poor adherence, poorer health outcomes, and racial/ethnic disparities in care (Flores, 2000; Betancourt et al., 1999; Stewart et al., 1999; Morales et al., 1999; Cooper-Patrick et al., 1999; Langer, 1999).

There is a body of literature defining and supporting the importance

of cross-cultural education in the training of health professionals. Despite this, curricula in this area have been implemented to a limited degree in health professions education. There are several theoretical approaches to cross-cultural education that vary in their relative emphasis on attitudes, knowledge, and skill building. Current published evaluations do not support conclusive statements about the effectiveness of particular approaches. However, the approaches that focus on skill building are likely more effective in providing clinicians with the clinical acumen to diagnose and treat diverse populations of patients.

There are various opportunities in which cross-cultural communication courses could be integrated into the health professional curricula, including during undergraduate, graduate, and continuing medical education. A set of core competencies for cross-cultural education should be developed. These should include achievement of certain attitudes, knowledge and skills from which learners will benefit and that they will utilize in the medical encounter. Improving quality of care and developing a strategy to eliminate racial/ethnic disparities in the medical encounter should be the goal. Research to date supports implementing a combination of each of the conceptual approaches presented here to develop efficient, solution-oriented ways of introducing cross-cultural principles to guide physician-patient interactions (Shapiro and Lenahan, 1996). Inductive frameworks should focus on individualized, patient-centered care (Donini-Lenhoff, 2000). While there is no one “right” way to teach cross-cultural medicine, and interventions should be tailored to the specific learning environment, there are some guiding principles that can be followed and disseminated—some of which exist in the literature today (Betancourt et al., 1999; Nunez 2000; Like et al., 1996; Carrillo et al., 1999; Kristal et al., 1983). There should be some determination as to how best to incorporate cross-cultural education into the health professional’s curricula as part of a multipronged effort to eliminate racial/ethnic disparities in healthcare. Research suggests that required, full integration into the standard undergraduate and graduate medical curricula should be the gold standard. Yet in the absence of the capacity to do this, we should be including the teaching of cross-cultural medicine as a stand-alone (Flores, 2000; Nunez, 2000; Like et al., 1996; Bobo et al., 1991; Clinton, 1996). For practicing providers, continuing medical education—as part of licensure, as part of faculty development, and as part of obtaining medical malpractice insurance—all remain promising areas of integrating cross-cultural curricula and assessing cross-cultural communication skills.

Appropriate evaluation strategies and monitoring that directly assess the attitudes, knowledge and skills taught to providers should be devised. Careful attention should be given to the complexities of evaluation and

measurement in these types of curricula, with a strategic, step-wise, mixed-method, process-driven approach as a starting point for future research.

**Finding 6-1: Sociocultural differences between patient and provider influence communication and clinical decision making.**

Evidence suggests that provider-patient communication is directly linked to patient satisfaction, adherence, and health outcomes. Ineffective communication in the medical encounter may lead to patient dissatisfaction, non-adherence, poorer health outcomes, and subsequently, racial and ethnic disparities in healthcare.

**Finding 6-2: A significant body of literature defines and supports the importance of cross-cultural education in the training of health professionals.**

Despite several approaches and various opportunities for integration, curricula in this area have been implemented to a limited degree in undergraduate, graduate, and continuing health professions education.

**Finding 6-3: Cross-cultural education offers promise as a tool to improve healthcare professionals' ability to provide quality care to diverse patient populations and thereby reducing healthcare disparities.**

**Recommendation 6-1: Integrate cross-cultural education into the training of current and future health professionals.**

Strategies should be developed to fully integrate cross-cultural curricula into undergraduate, graduate, and continuing education of health professionals. These curricula should be expanded to include modules documenting the existence of racial and ethnic disparities in healthcare, and the impact of social cognitive factors and stereotyping on clinical decision-making. Required, practical, case-based curricula based on a set of core competencies, amenable to evaluation, should be the desired standard of training.

## 7

# Data Collection and Monitoring

The preceding chapters illustrate the complexity and variety of factors—including healthcare financing arrangements, institutional and organizational characteristics of healthcare settings, aspects of the clinical encounter, and the attitudes, perceptions, and beliefs of healthcare providers and their patients—that influence healthcare disparities. The complexity of these factors, coupled with the fact that disparities in care are not always apparent to patients or providers in clinical encounters, increases the need for data to better understand the extent of disparities and the circumstances under which disparities are likely to occur. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. Federal, private, and state-supported data collection efforts are scattered and unsystematic, and many health plans, with a few notable exceptions, do not collect data on enrollees' race, ethnicity, or primary language, pointing to significant obstacles to the collection and analysis of such data (Perot and Youdelman, 2001).

Standardized data collection, however, is critically important in the effort to understand and eliminate racial and ethnic disparities in healthcare. Having data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities. In addition, collecting appropriate data related to racial or ethnic differences in the process, structure and outcomes of care can help to identify discriminatory practices, whether they are the result of intentional behaviors and attitudes, or unintended—but no less harmful—biases or policies that result in racial or ethnic differences in care that cannot be justified by patient preferences or clinical need. Data collection



and monitoring therefore provides critically needed information for civil rights enforcement. Further, collecting and analyzing patterns of care by patient race, ethnicity, and other demographic data can help health plans to monitor plan performance. Such monitoring can help to ensure accountability to enrolled members and payors, improve patient choice, and allow for evaluation of intervention programs. Such evaluations are likely to improve service delivery for racial and ethnic minority populations, and therefore may result in cost savings that would offset the costs of data collection.

The collection of racial and ethnic data in health systems poses special challenges, however. Traditionally, the practice of healthcare has been dominated by individual practitioners who delivered care in settings relatively unaffected by regulation, oversight, or government intervention. Hospitals enjoyed little external monitoring, and their professionally dominated and autonomous organizational structure was rarely challenged prior to the emergence of the federal government as the largest healthcare payor. Today's cost-conscious healthcare systems present an opportunity for greater healthcare practice accountability, but medicine's traditional autonomy and self-government presents little history of oversight, particularly with regard to civil rights, that can be expanded upon (Smith, 1998).

Specific recommendations regarding the types of healthcare data that should be collected, and how this information should be analyzed and reported has been the subject of intensive study and debate by governmental (U.S. DHHS, 1999) and private groups (National Quality Forum, 2001; Perot and Youdelman, 2001), and is beyond the scope of this report. Selecting indicators of healthcare disparities that can be readily measured, analyzed and reported, and developing methods to ensure reliable data collection will require careful consideration of costs, benefits, and other potential problems inherent in collecting and reporting patient care data (see discussion of obstacles to racial/ethnic data collection, below). These issues will be weighed by a forthcoming National Academies study committee that has been asked by Congress to assess the adequacy of racial and ethnic data within U.S. Department of Health and Human Services (DHHS) systems. Ideally, however, all patient encounters should be assessed for the quality of care and patient outcomes. This would enable the data to be aggregated to many different levels of the healthcare delivery system, including health plans, medical groups, and hospitals. Most of the information collected should be recorded as part of the patient's medical record, a task that in the future will be assisted greatly by the development of electronic patient records. These data should be stratified by race, ethnicity, as well as socioeconomic status and, where possible, primary language.

### OBSTACLES TO RACIAL/ETHNIC DATA COLLECTION

The need for data on patients' race and ethnicity and quality of care must be balanced against other significant considerations. Foremost, patient privacy must be protected. The confidentiality and security of patient information and data transactions must, at minimum, conform with standards set forth in the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Secondly, the costs of data collection must be weighed relative to its benefits. When and how such data are collected will have broad cost implications; collection of patient race and ethnicity data at the point of plan enrollment, for example, will likely be less expensive than data collection among members already enrolled in plans whose race or ethnicity is unknown. Similarly, administrative and paperwork burdens are likely to increase as the numbers of patient data elements are increased. Formal Congressional checks on such administrative burdens (e.g., the Paperwork Reduction Act) require that administrators of publicly-funded programs assess such costs and demonstrate the utility of additional data collection relative to costs.

Other legal constraints must be assessed, as well. While the vast majority of states do not prohibit collection of patients' race and ethnicity data, some may impose restraints on when and how such data may be collected (Perez and Satcher, 2001). The extent of these restraints must be assessed and this information provided to managed care organizations (MCOs) and payors to avoid confusion over what kinds of data collection are allowed, and under what circumstances.

Political concerns must be also addressed to ensure cooperation from all parties in data collection efforts. Resistance to data collection efforts may come from healthcare providers, institutions, plans, and patients, unless the purposes and benefits of data collection are clearly explicated. Providers, as noted earlier, may resent perceived intrusions on autonomy. Patients, particularly minority patients, may worry that racial or ethnic data collection will result in "redlining" of services, selection of enrollees, or rationing of services on the basis of race or ethnicity.

Efforts to enforce data collection from the federal level may also meet resistance from state authorities, who retain primary responsibility for determining data requirements of health plans with whom states contract for Medicaid MCO services. Federal efforts to require the collection of patients' racial and ethnic data would raise challenges from those who find federal reporting requirements already burdensome and the federal role in dictating the terms of managed care contracts too extensive. Finally, it should be noted that some individuals are broadly opposed to government involvement in monitoring race and ethnic trends among the U.S. population, and are mounting challenges to the notion that the gov-

ernment should collect any information about race or ethnicity. Ward Connerly, for example, the California businessman who led efforts to repeal affirmative action in that state, is spearheading a ballot initiative to prevent the state from collecting any information about race or ethnicity, except for a few limited circumstances (Jordan, 2001). This initiative would likely undercut efforts to assess racial and ethnic inequities in healthcare, as well as in other potentially discriminatory practices.

In addition, health plans have raised significant concerns regarding the collection of patient race and ethnicity information. Many plans, led by American Association of Health Plans (AAHP), increasingly see the collection of information on patient race and ethnicity as an important means to evaluate their own efforts to reduce disparities in care and develop better strategies to serve growing minority patient populations (Ignani and Bocchino, communication with Alan Nelson, M.D., March 19, 2001). However, some plans have operated under the erroneous assumption that federal and/or state law prohibits the collection of patient race and ethnicity information. Efforts by the U.S. Department of Health and Human Services Office for Civil Rights (OCR) and Office of Minority Health (OMH) to clarify federal law (Perez, 2000; Perez and Satcher, 2001) have helped to dismiss this assumption.

Many health plans, however, remain concerned that their ability to serve minority patients could be hampered should data collection efforts be seen by these populations as an effort to ration care. In addition, plans that serve disproportionately minority and lower-income populations could be hurt by the release of "report card" information that reveals their enrolled members to be less healthy or to require more services than the majority population. In such instances, information about the health status of plans' enrolled populations and case-mix may largely reflect conditions of poverty and the generally higher incidence of morbidity and mortality among lower-income and minority populations, and may not necessarily reflect poor service on the part of health plans. This kind of information might unfairly hurt health plans' efforts to expand their market share among minority populations, and should be taken into account (Fiscella et al., 2000).

Other challenges include the accuracy of racial and ethnic data. As noted earlier, "race" and "ethnicity" are fluid, socially defined concepts that are not consistently understood or applied in data collection efforts. Racial or ethnic identity is determined by multiple factors and may vary depending on the contexts in which these constructs are defined and the manner in which data are collected. Observers recording race and ethnicity data are notoriously inaccurate, particularly with regard to Hispanic or American-Indian populations (e.g., death certificates commonly misreport the race of American Indians). Further, a small but increasing

proportion of individuals define themselves using two or more racial and ethnic categories, making simple classification difficult. Finally, efforts to address disparities in care must acknowledge the significant heterogeneity within each of the federally defined racial and ethnic groups (whites, African Americans, Native Americans, Asian Americans, Pacific Islanders, and Hispanics). Wide variations within each of these groups can be found in health status, health practices and behaviors, and healthcare resources. It is therefore important that data be collected on subgroups within these categories (e.g., Cuban American, Puerto Rican, Mexican American, Central American among the “Hispanic” ethnic group). Where possible and appropriate, data collected over several years can be combined to achieve sufficient analytic sample sizes (U.S. DHHS National Committee on Vital and Health Statistics, 1999).

These challenges underscore the need for consensus among health plans, providers, and consumers regarding data collection policies, and best practices regarding how data will be analyzed and to whom it will be presented. To this end, the committee believes that efforts by public and private groups, such as the National Quality Forum (NQF), the National Committee on Vital and Health Statistics (NCVHS), and the Agency for Healthcare Research and Quality (AHRQ), to convene experts and provide specific recommendations regarding the collection and analysis of data on patients’ race and ethnicity will prove fruitful to help achieve broad consensus on best policies and practices. Development of a full, national database of healthcare quality that can be analyzed by race and ethnicity will take time, however, and it is clear that a sequence of steps must be undertaken to reach this goal. An important first step would involve an assessment of existing data sets within public and private plans that allows for an analysis of patient care by race and ethnicity.

#### **THE FEDERAL ROLE IN RACIAL, ETHNIC, AND PRIMARY LANGUAGE HEALTH DATA**

Several agencies of the DHHS, recognizing the importance of racial, ethnic, and primary language healthcare data, have attempted to promote data collection and monitoring efforts, particularly to address the challenges noted above. Despite these efforts, federal data collection remains unsystematic and lacks an overall guiding structure to ensure accountability and cooperation by HHS agencies, states, and private sector partners involved with federal health programs (Perot and Youdelman, 2001).

The Summit Health Institute for Research and Education, Inc. (SHIRE) and the National Health Law Program (NHeLP), with support from The Commonwealth Fund, analyzed an array of statutes, regulations, federal

agency policies, practices, and data collection vehicles related to race, ethnicity, and primary language in healthcare settings. This analysis included an assessment of the extent to which federal policies mandate or encourage collection and reporting of race, ethnicity, and primary language data and an assessment of how current law is understood, interpreted, and implemented by federal officials. SHIRE and NHeLP analyzed 80 program-specific statutes and over 100 data collection vehicles, and developed 25 findings and 10 recommendations regarding federal data policies (Perot and Youdelman, 2001). These recommendations are listed in Box 7-1.

**BOX 7-1**

**Recommendations, Racial, Ethnic, and Primary Language Data Collection in the Healthcare System: An Assessment of Federal Policies and Practices (Perot and Youdelman, 2001)**

1. Ensure that Medicare data, as well as other data regarding individuals who are served by HHS programs or who participate in HHS research activities, are readily available and accurate by race, ethnicity, and primary language. Independent analysts have estimated that the Medicare beneficiary eligibility file compiled by the Social Security Administration is less than 60 percent accurate for all racial/ethnic classifications other than black or white.
2. Enforce state collection and reporting of data by race, ethnicity, and primary language for enrollees in Medicaid and the State Children's Health Insurance Program (SCHIP). Currently, data collection and reporting by states are often inconsistent and incomplete.
3. Revise the standards for implementation of the Health Insurance Portability and Accountability Act (HIPAA) to designate the code set for race and ethnicity data as mandatory for both claims and enrollment standards. Racial and ethnic categories used under HIPAA must be compliant with OMB standards.
4. Recommend that quality measurement and reporting tools such as the Health Plan Employer Data and Information Set (HEDIS) should collect and report health data by race, ethnicity, and primary language.
5. Ensure access to quality healthcare for people with limited English proficiency by effective monitoring of adherence to guidelines and collection of requisite data.
6. Include statutory conditions in new program initiatives, including block grants, stating that data must be collected and reported by race, ethnicity, and primary language, and that programs should allocate adequate resources to promote compliance, address technological dif-

SHIRE and NHeLP draw four principle conclusions regarding the federal role in racial, ethnic, and primary language data collection. First, the collection of such data is legal and authorized under Title VI of the Civil Rights Act of 1964. Second, a growing number of federal policies emphasizes the need for the collection of race, ethnicity, and primary language data. Third, such data is an indispensable tool for the assessment of progress toward federal goals of eliminating health disparities (U.S. Department of Health and Human Services, 1999). SHIRE and NHeLP found broad consensus within U.S. DHHS on this point, but a fourth conclusion of the investigators is that DHHS policies and practices fail to reflect this

facilities, ensure privacy and confidentiality of data collected, and implement effective educational strategies to maximize beneficiary and provider cooperation with data gathering efforts.

7. Encourage public and private agencies to participate in the development and implementation of approaches to improve data availability and promote data collection and reporting. In support of agencies, HHS should:
  - create a “tool kit” containing information on effective data-related techniques, technologies, and privacy safeguards currently in use;
  - bolster the HHS Data Council’s efforts to identify and document the benefits of collecting and reporting; and
  - support national policies to facilitate data-sharing among all federal and state agencies.
8. Expand or create public and private educational efforts to:
  - inform insurers, health plans, providers, private/public agencies, and the general public that data collection and reporting by race, ethnicity, and primary language are legal and in many instances required by federal law and regulations;
  - raise public awareness that the collection and reporting of these data are prerequisites for the achievement of Healthy People 2010 goals and essential to demonstrate compliance with the nondiscrimination requirements of Title VI; and
  - inform decision-makers that effective strategies exist for achieving compliance with data collection and reporting policies, including risk-adjustment, and make such compliance a condition for receiving government resources.
9. Provide states and healthcare providers with greater access to aggregated and disaggregated racial, ethnic, and primary language data acquired at the federal level, subject to privacy and confidentiality regulations.
10. Support research on existing best practices for data collection.

consensus, as data requirements and methods for collection and reporting vary across federal agencies, and no single HHS blueprint exists to provide a framework and rationale for the department's activities. Further, no department-wide mandate exists for racial, ethnic and primary language data collection and reporting, leaving only a patchwork of efforts across agencies to promote data collection and reporting (Perot and Youdelman, 2001).

The SHIRE-NHeLP report notes that two significant developments in early 2001 illustrate the "disconnect" between federal consensus and practice. In one instance, HHS finalized regulations regarding standard data elements for the electronic transmission of health information authorized under HIPAA, yet these rules failed to identify race or ethnicity as a required code, an omission that many HHS officials saw as a "lost opportunity." In another instance, HHS published regulations for Medicaid Managed Care and the State Child Health Insurance Program (SCHIP) that would require states to report the race, ethnicity, and primary language of enrollees on a quarterly basis, yet these regulations were suspended for further review following the change of presidential administrations in 2001 (Perot and Youdelman, 2001). Notably, the National Committee on Vital and Health Statistics (NCVHS), which serves to advise the federal government on health information and data policy, warned in a 1999 report that the limited data-collection practices of MCOs who serve Medicaid beneficiaries threatened to inhibit HHS's ability to monitor the quality of care provided by Medicaid MCOs. NCVHS urged that HHS develop more specific guidance about the manner and format in which Medicaid MCO data should be collected and reported by states (Mays, 2001).

Despite the lack of a framework or mandate for systematic data collection at the federal level, data on enrollee race and ethnicity is available to a limited degree for the two largest federal healthcare programs, Medicaid and Medicare. The Centers for Medicare and Medicaid Services (CMS—formerly the Healthcare Financing Administration [HCFA]) has generally required states to report patient encounter data for Medicaid enrollees, but has not required that states report data by race and ethnicity. Most states have voluntarily supplied CMS with data on Medicaid beneficiaries' race and ethnicity, and cumulative totals of beneficiaries' race and ethnicity are available from all states. As noted above, however, the proposed rule requiring all states to report the race and ethnicity of Medicaid and SCHIP recipients has yet to be implemented. Further, states would be expected, via CMS's proposed rule issued in August, 2001, to provide Medicaid MCOs with information regarding enrollees' race or ethnicity, but these data are often incomplete or inconsistent, and the rule did not require that this data be reported back to the agency (Perot and Youdelman, 2001). Medicare enrollees' race or ethnicity has been typically

extracted from the Medicare Enrollee Database, which is based on Social Security Administration (SSA) information. Enrollment data is available for all Medicare beneficiaries, but SSA data are limited, particularly for data obtained prior to 1994, as SSA only identified beneficiaries' race or ethnicity as "white," "black," "other," and "unknown." Efforts by HCFA to reconstruct this data by surveying the 2.1 million beneficiaries whose race was listed as "other" or "unknown" reduced the number of unidentified race codes significantly, but accuracy of these data for beneficiaries identified as other than "black" or "white" is estimated to be less than 60% (Perot and Youdelman, 2001).

### OTHER DATA SOURCES TO ASSESS HEALTHCARE DISPARITIES

Several other federal, state, and private data sources currently exist or are planned that can be tapped to assess racial and ethnic disparities in care. As will be noted later in this chapter, data from these sources can be used to help identify sources of disparities in care and/or monitor changes in racial and ethnic disparities in care over time. The following summary of data collection systems is not intended as an exhaustive listing of federal, state, or privately funded data sets that may be used to assess racial and ethnic healthcare disparities. For a more exhaustive listing of federal data collection systems, see the HHS *Directory of Health and Human Services Data Resources* (U.S. DHHS, 2001).

Several relevant national-level data sources that can be used to assess aspects of racial and ethnic healthcare disparities include:

#### *Consumer Assessment of Health Plans Survey (CAHPS)*

The Consumer Assessment of Health Plans Survey (CAHPS), supported by the AHRQ, provides information to healthcare consumers, purchasers, health plans, and others regarding the quality of healthcare plans and services. CAHPS surveys ask consumers about their experiences with health plans, such as the quality of communication with providers, the provision of translation services for patients with limited English proficiency, and the timeliness and quality of care provided for a variety of medical conditions and procedures. CAHPS survey data can be analyzed by respondents' race or ethnicity to assess group differences in patient experiences.

#### *Medical Expenditure Panel Survey (MEPS)*

The Medical Expenditure Panel Survey (MEPS), the most recent of a



series of federal surveys of medical care costs, was initiated by the AHRQ in 1996 for the purpose of assessing the types, frequency of use, and costs of healthcare services used in the United States. MEPS data yield information on health services expenditures and how they are paid for, as well as the extent of health insurance coverage among the U.S. population. MEPS consists of four components: the Household Component, which samples families and individuals to assess health status, insurance coverage, healthcare use and expenditures, and sources of payment for health services; the Nursing Home Component, which samples nursing homes and residents to assess characteristics of facilities and services offered, costs, and sources of payment of these services; the Medical Provider Component, which supplements information from the Household Component by surveying hospitals, physicians, and home healthcare providers; and the Insurance Component, which assesses the amount, types, and costs of health insurance available to employees. The Household Component collects data on respondents' race/ethnicity, and while the Nursing Home Component has racial and ethnic data available, only the African-American and white samples are large enough to permit analysis (U.S. DHHS, 2001). These data can be assessed by race and ethnicity, as well as other socio-demographic indicators, such as level of education, income and assets, and employment. Several of the studies summarized in Chapter 1 utilize MEPS data to assess patterns of disparities in care.

#### *Medicare Beneficiary Enrollment Database*

Medicare's Enrollment Database (EDB), supported by the CMS, is the principal database for Medicare beneficiary services, including access to and use of services covered under Medicare. The primary source for EDB beneficiary information, however, is the Social Security Administration's Master Beneficiary Record database. As noted above, these data are unreliable with respect to racial and ethnic populations other than black and white beneficiaries.

#### *Medicare Current Beneficiary Survey*

The Medicare Current Beneficiary Survey (MCBS), supported by CMS, is a continuing sample of Medicare beneficiaries to assess healthcare use, costs, and who pays for it. A variety of demographic data are collected from respondents during an initial interview, including race/ethnicity, health and insurance status, and education level. Data can be used to assess racial and ethnic differences in costs and utilization of care, and costs paid by Medicare as well as other public and private insurance sources.

Public and privately funded healthcare plans can take advantage of survey instruments developed as part of broader quality improvement initiatives, such as the Health Plan Employer Data and Information Set (HEDIS).

*Health Plan Employer Data and Information Set (HEDIS)*

The Health Plan Employer Data and Information Set (HEDIS), developed by the National Committee for Quality Assurance (NCQA) in conjunction with public and private purchasers, health plans, researchers, and consumer advocates, is a set of standardized performance measures that assesses the quality of healthcare and services provided by managed care plans. HEDIS was developed to ensure that purchasers and consumers have access to information to compare the performance of managed healthcare plans. HEDIS measures the effectiveness and availability of care in areas such as childhood immunization, breast cancer screening, cholesterol management, and treatment of heart attack. In addition, HEDIS offers information on structural attributes of health plans, such as practitioner turnover and rates of board certification and residency completion. HEDIS also includes a standardized survey of consumers' experiences that evaluates plan performance in areas such as customer service, access to care and claims processing.

At the state level, new data sets being developed, such as the California Health Interview Survey (CHIS), may allow researchers to explore regional and subpopulation variation in healthcare access and use.

*California Health Interview Survey (CHIS)*

The California Health Interview Survey (CHIS) is a collaboration of the UCLA Center for Health Policy Research, the California Department of Health Services, and the Public Health Institute to assess the health status, health behavior and risks, and healthcare access and utilization of the state's diverse population. Data from its survey of 55,000 California households will be available in early 2002 and will be made available through published reports, public-use files, and an Internet-based system that will allow requestors to gather information tailored to particular health topics, population groups, and geographic areas. In particular, CHIS asks respondents to provide information about their usual source of care, access to and use of specific services, experiences of discrimination in healthcare settings, and recall of provider advice, among other items. Results will be analyzed by respondents' race and ethnicity, with particular attention to racial and ethnic subgroups. Funding for CHIS has been

provided by the California Department of Health Services, The California Endowment, the National Cancer Institute (NCI), California Children and Families Commission, the U.S. Centers for Disease Control and Prevention (CDC), and the Indian Health Service (IHS).

### MODELS OF MEASURING DISPARITIES IN HEALTHCARE

Many models of healthcare “report cards” have been developed over the past few years, as healthcare consumers and purchasers of plans have expressed great interest in timely and accurate information about the quality of care delivered by plans, hospitals, and individual providers. Few such “report cards,” however, have focused exclusively or in part on racial and ethnic disparities in care. This paucity of information on disparities in care is likely to change in the near future, as federal and private initiatives are increasing visibility and attention to the problem. In one instance, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services (U.S. DHHS) has recently commissioned a review of measures of discrimination in healthcare settings. In another federal initiative, AHRQ has initiated plans to develop a national report on racial and ethnic disparities in healthcare, and plans to incorporate measures of racial and ethnic disparities in care in a national report of quality of care. Within the private sector, the National Quality Forum (NQF), with support from The Commonwealth Fund, has produced a report on measuring and reporting the quality of care for minority populations. These activities are likely to spur efforts to increase information available to consumers and purchasers of plans and promote greater choice when selecting plans, to promote accountability to consumers and purchasers, and to spark action on the part of plans, providers, and legal and regulatory bodies to reduce disparities in care.

Two models of “report cards” that specifically address racial and ethnic disparities in healthcare are reviewed below.

#### *“Health Accountability 36”*

Smith (1998) proposes a report card to assess racial and ethnic disparities consisting of 36 consensus indicators that have been developed and utilized in other settings by a range of public and private entities. The indicators were selected based on the availability of data, sensitivity of the indicators to key health conditions for vulnerable populations, and their amenability to public health and healthcare intervention. The first 12 indicators include measures adapted from the U.S. DHHS initiative *Healthy People 2000*, and are routinely collected and reported by the Na-

tional Vital Statistics report system to evaluate the health of geographically defined populations. The second 12 indicators include measures of managed care plans to provide consumers and purchasers with information about plan performance. Of these, the first six were developed by the National Committee for Quality Assurance for HEDIS, while the subsequent six indicators were selected by the former Agency for Healthcare Policy and Research (now AHRQ). The third set of 12 indicators was developed by the Joint Committee on Accreditation of Health Care Organizations (JCAHO) as part of its accreditation process to measure hospital performance, and reflect measures of obstetrical, oncologic, and cardiovascular outcomes. Smith (1998) notes that data for these indicators are currently available and can be analyzed using the standard categories for race and ethnicity adapted by the Office of Management and Budget (see Chapter 1, Table 1). A goal for public health agencies and health systems, Smith suggests, would be to bring racial and ethnic disparities to within 80%. These measures are listed in Table 7-1.

Several of the measures proposed by Smith can be criticized on the grounds that as indicators of population health, they are influenced to a far greater extent by social and economic forces such as income inequality, residential segregation (and subsequent substandard living conditions, especially for lower-income minority groups), environmental risks, and other social problems. As such, they are less amenable to health system intervention. Further, health systems that disproportionately enroll lower-income and minority patients will have a greater challenge in improving the health of a generally sicker population with higher rates of co-morbidities, and thus, may not demonstrate improvement on many of the measures. Smith (1998) notes, however, that the impact of plans' case-mix can be adjusted statistically. In addition, he notes, some health plans, such as not-for-profit integrated delivery systems, recognize the impact of social and economic forces on the health of their enrolled populations and attempt to address these forces by improving screening and primary and preventive healthcare services, and by addressing housing and other social service needs of their patients.

### *Integrated Approaches*

LaVeist and Gibbons (2001), in their report to U.S. DHHS<sup>1</sup> on poten-

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<sup>1</sup>U.S. DHHS commissioned LaVeist to "summarize the literature on racial/ethnic discrimination within healthcare settings, with the primary goal of describing how discrimination has been measured" (LaVeist and Gibbons, 2001, p. 1). In this review, the authors note that the existence of racial and ethnic disparities in healthcare does not necessarily reflect discrimination, but focus their analysis on indicators that may detect patterns of discrimination apart from disparities that are not inherently discriminatory.

**TABLE 7-1** “Health Accountability 36” Report Card Indicators

Unit of Analysis	Source	Indicators
Geographically Defined Population	Healthy People 2000	<ol style="list-style-type: none"> <li>1. Total age-adjusted death rate</li> <li>2. Automobile death rate</li> <li>3. Suicide death rate</li> <li>4. Lung cancer death rate</li> <li>5. Breast cancer death rate</li> <li>6. Cardiovascular death rate</li> <li>7. Homicide death rate</li> <li>8. Teen births</li> <li>9. Inadequate prenatal care</li> <li>10. % Low birthweight births</li> <li>11. Infant death rate</li> <li>12. Children in poverty</li> </ol>
Health Plan Covered Lives	HEDIS AHCPR	<ol style="list-style-type: none"> <li>1. % Women for whom prenatal care began in the first trimester</li> <li>2. % Children receiving all childhood immunizations by 24 months</li> <li>3. Cholesterol screening age 40-64 once in 5-year period</li> <li>4. % Women 51-64 continuously enrolled for 2 years who received mammogram breast cancer screening</li> <li>5. % Women 21-64 continuously enrolled for 3 years who received a Pap test</li> <li>6. % Members 2-19 with one or more asthma admissions</li> <li>7. % Diabetics 31-64 who had retinal exam during the preceding calendar year</li> <li>8. % Members 23-39 who visited a health practitioner in the past year</li> <li>9. % Rating how well the doctor listened as excellent</li> <li>10. % For whom last visit to doctor fully met their needs</li> <li>11. % Choice of doctors not a problem</li> <li>12. % Satisfied with overall plan</li> </ol>
Hospital Patient Clinical Population	JCAHO	<p>Obstetrical Indicators:</p> <ol style="list-style-type: none"> <li>1. % Low birthweight infants</li> <li>2. % Term infants admitted to NICU within one day of delivery</li> <li>3. % Neonates with an Apgar of 3 or less at 5 minutes and a birthweight &gt; 1,500 grams</li> <li>4. % Neonates with a discharge diagnosis of significant birth trauma</li> </ol> <p>Oncology Indicators:</p> <ol style="list-style-type: none"> <li>5. Survival of patient with primary cancer of the lung, colon/rectum, by state and histologic type</li> <li>6. Use of test critical to diagnosis, prognosis, and treatment</li> <li>7. Use of treatment approaches that have an impact on quality of life</li> <li>8. Interdisciplinary treatment and follow-up</li> </ol> <p>Cardiovascular Indicators:</p> <ol style="list-style-type: none"> <li>9. Intrahospital mortality as a means of assessing multiple aspects of CABG care</li> <li>10. Extended postoperative stay as a means of assessing multiple aspects of CABG care</li> <li>11. Intrahospital mortality as a means of assessing multiple aspects of PTCA care</li> <li>12. Intrahospital mortality as a means of assessing multiple aspects of acute MI care</li> </ol>

SOURCE: Smith (1998).

tial measures of discrimination in healthcare settings, note that such measures must not only address structural differences in receipt of care (e.g., the proportion of women receiving prenatal care in the first trimester, as suggested by Smith [1998]), but should also assess the quality of interpersonal interactions in healthcare settings. Structural differences shape the parameters of care provided to different populations, they note, but individual, subjective factors affect the quality of care in clinical interactions. They argue for an integrated approach that includes multiple measures, and meets the following criteria:

1. *Applicable to multiple racial/ethnic groups*—the indicators must be applicable to all racial and ethnic groups that make up the U.S. population.
2. *Produce unique scores for individual healthcare facilities*—the report card must be producible for individual healthcare facilities and not merely produce scores for the nation or a particular region.
3. *Data sources must be accessible*—the report card must be easily understandable to a broad audience of healthcare consumers and the indicators must have high “face validity.”
4. *No confounding*—indicators must not be confounded with other variables such as health insurance, patient preferences or larger societal factors. If there is confounding, there must be a way to adjust for it.
5. *Longitudinality*—the indicators must have the ability to be replicated over time (LaVeist and Gibbons, 2001, p. 7).

LaVeist and Gibbons weigh the merits of four potential approaches to measuring discrimination in care, including Smith’s (1998) “Health Accountability 36,” patient assessments, administrative claims audits, and assessments of substandard care. The “Health Accountability 36” measures draw largely upon existing data, and can be applied to geographically defined populations, individuals in health plans, and hospital and clinic patients. LaVeist and Gibbons note, however, that many of the measures, particularly those assessing racial differences in health status, are confounded with larger social and economic factors.

Several measures of patient satisfaction have been extensively evaluated, according to LaVeist and Gibbons, and several studies have assessed racial and ethnic differences in patients’ perceptions of the quality of care they receive (reviewed earlier). Few of these measures, however, have explicitly assessed patients’ perceptions of racial discrimination in care settings (the Seattle-King County survey of patient perceptions of discrimination in care, reviewed earlier, is a notable exception). Such measures have the potential of providing unique scores for individual healthcare facilities and can be used to assess changes over time. Patient perceptions of care, however, can be influenced by a wide range of fac-

tors, and may not reflect whether patients are receiving care appropriate to their needs. Nonetheless, such perceptions form an important component of a multi-pronged assessment profile, particularly if measures can assess the degree of patient participation in treatment decisions and understanding of their diagnosis and course of treatment.

Administrative claims data have been used extensively in prior research to audit care and demonstrate racial disparities in access to diagnostic and therapeutic procedures (much of this research is reviewed in Chapter 1). Well-controlled studies using claims data have adjusted for many potentially confounding factors, such as co-morbid conditions and insurance status, to isolate the influence of patient race on receipt of care. LaVeist and Gibbons (2001) suggest that administrative audits can produce unique scores for individual hospitals and healthcare facilities. Such data often fail, however, to illuminate process-of-care variables, such as referral patterns or participation in treatment decisions (e.g., whether providers present all treatment options and whether patients accept or refuse them). Prospective studies are therefore needed to supplement typically retrospective analyses of administrative claims data (see Chapter on “Research Needs”).

Measures of adverse events due to practitioner or healthcare setting error are also an important component of assessing disparities in care, according to LaVeist and Gibbons (2001). Increasingly, healthcare providers and consumers have focused on the problem of medical errors and patient safety, and at least two methodologies have been developed to evaluate adverse events. Both involve an initial screening of potentially problematic cases, typically by two trained healthcare professionals, but screening methods differ in that one approach utilizes actual medical records, while the other uses administrative claims data. Such analysis could indicate whether minority patients are differentially more or less likely to face substandard care. This method has the advantage of yielding objective data on the quality of care provided, relative to standard criteria. Data are free of confounding, and the accuracy and validity of these methods has been demonstrated, the authors note.

LaVeist and Gibbons (2001) conclude that a two-tiered, multi-assessment approach may be useful to assess discrimination in healthcare settings. In the first tier, routine monitoring of healthcare facilities can be accomplished by audits of administrative data and analyses of data on substandard care. This initial “screen” could identify facilities that should be investigated more closely. In the second assessment tier, facilities are informed of the disparities and are given a period of time to address them. If progress has not been made, LaVeist and Gibbons suggest, a method used more commonly to assess housing and employment discrimination—paired testing—may be used to further assess the possibility of ra-

cial or ethnic discrimination. In this strategy, individuals are trained to present the same needs and background information to targeted health-care facilities, but vary only in race or ethnicity (see Chapter on “Racial Attitudes and Discrimination”). The purpose of such testing, according to the authors, is to enhance awareness and to facilitate voluntary efforts to address racial disparities in care. Should these efforts fail, judicial remedies could be explored if clear violations of civil rights laws are found (LaViest and Gibbons, 2001). Unlike paired testing in housing and employment, however, the use of such strategies in healthcare settings poses unique legal and ethical challenges that should be addressed before such strategies are adopted.

#### *Reporting of Racial and Ethnic Disparities Using Existing Data Sets*

As noted earlier, the HEDIS data sets developed by NCQA offer a ready set of measures of plan performance that are widely used and accepted by health plans, purchasers, and consumers. Health plans voluntarily report this information to NCQA, which then disseminates data as part of its Quality Compass database in regular publications such as the NCQA *State of Managed Care Quality* report. Quality Compass 2000 contains measures of plan performance in several clinical areas, such as cancer screening, childhood and adult immunization, timely outpatient care, and evidence-based treatments for hypertension, cardiovascular disease, asthma, diabetes, and depression. Approximately half of the nation’s HMOs participate in Quality Compass, with another 90% participating in NCQA’s Accreditation and HEDIS programs.

Some researchers and plan administrators have raised concerns that health plan performance on these or other quality measures is affected by the sociodemographic mix of plan enrollees. According to this view, plans that enroll a high percentage of low-income or racial and ethnic minorities (who tend to be sicker, face a greater number of barriers to accessing care, and are less likely to utilize preventive and primary care services) may tend to face poorer health plan performance scores as a result of factors exogenous to the health system (Zaslavsky et al., 2000). Zaslavsky et al. (2000) tested this hypothesis by studying the relationship between plan performance on HEDIS measures and sociodemographic mix, including enrollee age, gender, and area of residence as an indicator of race/ethnicity and household income. The authors found that plan performance was negatively associated with the percentage of individuals receiving public assistance and the percentage of African Americans and Hispanics in enrollees’ area of residence, and positively associated with the percentage of college-educated and Asian-American residents. Adjusting for these demographic



variables, however, had a limited effect on plan performance, as most plans changed by less than 5% in performance measures.

Romano (2000) argues that even if case-mix differences could be adequately adjusted statistically, such adjustment does not necessarily improve analysis of the quality of care that plans deliver. To the contrary, he argues that statistical adjustment may hamper accurate assessment of plan performance by failing to identify the direction of the relationship between case-mix and plan performance—in other words, does the plan's case-mix result in poor performance, or does poor performance lead to the observed case-mix? In addition, statistical adjustment may “excuse” health plans for failing to address socioeconomic and racial/ethnic health disparities. Adjustment for case-mix may inadvertently remove plans' incentive to reduce disparities, according to Romano, by masking differences in the level of care provided to racial and ethnic minorities and low-income enrollees. He argues for reporting of data stratified by race, ethnicity, and socioeconomic status, which would offer the advantage of highlighting, rather than masking, sociodemographic disparities, and would allow consumers to make better informed choices about plans based on their own sociodemographic profile. In addition, by presenting performance data stratified by race, ethnicity, and socioeconomic status, plans could be rewarded for efforts to reduce disparities (Romano, 2000; Fiscella et al., 2000).

### DATA NEEDS AND RECOMMENDATIONS

The preceding discussion illustrates that despite the many challenges inherent in efforts to collect data on patients' race and ethnicity and monitor the quality of their care, data collection and monitoring are a feasible, critically important step in understanding and eliminating disparities in care. As Tom Perez (this volume) notes, “Effective data collection is the linchpin of any comprehensive strategy to eliminate racial and ethnic disparities in health.”

Currently, data collection efforts are unsystematic and inadequate to monitor the quality of care provided to racial and ethnic minorities. These efforts must be improved to ensure accountability of plans and providers to healthcare payors and consumers, to track disparities and assess the impact of quality improvement efforts, and to identify best practices that may be replicated by other plans and health systems. Federal leadership is needed to spearhead data collection efforts; for this reason, the committee advocates that the Secretary of the U.S. Department of Health and Human Services produce periodic studies to assess progress in eliminating racial and ethnic disparities in healthcare. The private sector, however, also shares a role in encouraging data collection and reporting of

patient care data by race, ethnicity, and where possible, primary language. Accreditation bodies, such as JACHO and NCQA, should require the inclusion of data on patient race, ethnicity, and highest level of education attained (in case of children, highest level of education attained by mother) in performance reports of public and private providers as part of health-care performance measurement. Such an emphasis would help to ensure that addressing healthcare disparities is seen by plans, providers, and purchasers as central to broader healthcare quality improvement efforts.

Data collection should be accomplished using a standard racial/ethnic classification scheme. Current OMB standards can be used, but data categories must go beyond the existing minimum standards to reflect the diversity within racial and ethnic populations, particularly at the local level (e.g., subgroups of Hispanics, African Americans, Asian Americans, etc.). In addition, information is needed on patients' socioeconomic status and primary language. These data should be stratified, where possible, to better understand the relative contributions of race/ethnicity, socioeconomic status, and other demographic variables to variations in care.

In the future, a standardized, central database is needed, with safeguards for privacy and confidentiality, which can be merged with other data systems. This database should be consistent with efforts to develop electronic patient medical records, and should be compatible to merge with other data systems. Such a long-term goal will require federal leadership and financial support.

**Recommendation 7-1: Collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.**

Standardized data should be collected on the race, ethnicity, and highest level of education (in case of children, highest level of education attained by mother) of all patients enrolled in publicly funded health programs and reported to Congress. Collection of data on patients' primary language should be encouraged, where feasible, as part of this effort. Data on healthcare access, use, and outcomes should be reported by race, ethnicity (including subgroups, and primary language where possible), and adjusted for highest level of education.

**Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.**

JACHO and NCQA should require the inclusion of data on patient race, ethnicity, and highest level of education attained (in case of children, highest level of education attained by mother) in performance reports of public and private providers as part of health care perfor-

mance measurement, such as NCQA's HEDIS indicators. The collection of data on patients' primary language should be encouraged. These performance reports should make elimination of healthcare disparities a focus of quality improvement efforts.

**Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.**

The secretary of HHS should conduct periodic studies to monitor the nation's progress toward eliminating racial and ethnic healthcare disparities, to provide insight into the root causes of these disparities, and to assess opportunities for intervention and improvement.

**Recommendation 7-4: Report racial and ethnic data by OMB categories, but use subpopulation groups where possible.**

Current OMB categories for race and ethnicity should be used in all reporting and monitoring efforts, but data categories must go beyond the existing minimum standards to reflect the diversity within racial and ethnic populations (e.g., subpopulations), particularly at the local level.

## 8

# Needed Research

In previous chapters, the committee has reviewed extensive evidence of racial and ethnic disparities in care, and has assessed potential sources of these disparities, as well as promising strategies to eliminate them. In the process, the committee notes that the evidence base to better understand and eliminate disparities in care remains less than clear. In this chapter, several broad areas of research needs are outlined. Some of this research is already underway or planned as a result of leadership and support from the federal Agency for Healthcare Research and Quality (AHRQ) and several private foundations (for a more thorough description of ongoing federal and private research and intervention efforts to address racial and ethnic disparities in care, see *Federal and Private Initiatives to Reduce Healthcare Disparities* in the appendix of this volume). The committee urges greater support from a range of federal and private sources, however, for a more ambitious research agenda aimed at disentangling the many influences on the process, structure, and outcomes of care for minority Americans.

This chapter is divided into several sections. The first three sections highlight research opportunities that should better illuminate the ways in which race and ethnicity influence the delivery of healthcare. To date, far greater research attention has been directed to documenting racial and ethnic disparities in care than in understanding how these disparities emerge in the structure and process of care, as these recommendations illustrate. The latter sections discuss areas where research has been minimal or notably absent. This includes intervention research; research on disparities in care among non-African-American racial and ethnic minor-

ity populations, such as Native Americans, Asian Americans, Pacific Islanders, Hispanics, and subgroups of these populations; and research on the role of non-physician healthcare professionals, such as nurses, physician assistants, occupational and rehabilitation therapists, mental health care providers, and others in eliminating racial and ethnic disparities in care. Finally, the last section offers suggestions for strategies to carry out this research.

### **UNDERSTANDING CLINICAL DECISION-MAKING AND THE ROLES OF STEREOTYPING, UNCERTAINTY, AND BIAS**

Much of the research cited in previous chapters relies on retrospective analyses of administrative claims or hospital discharge data. While these data sets have proven useful in identifying racial and ethnic disparities in a range of hospital and clinic-based services (from relatively routine diagnostic and treatment services through specialized surgical procedures), they pose a number of inherent limitations. Hospital discharge records yield only limited data regarding patients' interactions with the range of healthcare professionals with whom they come into contact and the race or ethnicity of these providers. Further, such data are often limited with regard to clinical decision-making processes and the information that clinicians must consider when recommending a course of treatment. For example, administrative data sets often contain only crude information regarding co-morbid conditions, diagnostic test data, and specific treatments.

Prospective studies are needed to focus on decision-making by patients and providers, to assess care management at different points along the continuum of care, and to assess the impact of patient-provider interactions on diagnosis and treatment. More complete records of patients' co-morbid conditions, as well as results of diagnostic tests, will help in the context of prospective research to assess the appropriateness of treatment. Such data will also assist in determining if physicians experience greater uncertainty in assessing presenting complaints of cultural or linguistic minority patients, or if their treatment decisions for these patients fail to correspond to accepted standards of care.

Beyond prospective studies of healthcare service delivery, additional research is needed on provider decision-making, heuristics employed in diagnostic evaluation, and how patients' race, ethnicity, gender, and social class may influence these decisions. As noted in earlier chapters, some experimental research has been conducted to assess the extent to which physicians' treatment recommendations differ by patient race and gender (e.g., Schulman et al., 1999). This research should be expanded to both replicate these findings and explore how social cognitive processes may

operate to influence patients' and providers' conscious and unconscious perceptions of each other and affect the structure, processes, and outcomes of care.

As noted in Chapters 3 and 4, it is likely that clinical uncertainty and discretion with regard to diagnostic and treatment options may play a role in healthcare disparities. When clinicians are uncertain about a patient's presenting symptoms, or when multiple treatment options are available but "best" practices among racial and ethnic minorities are unclear, treatment may be less well matched to patients' needs, because such conditions increase the likelihood that biases and implicit stereotypes may affect clinicians' decisions. Alternatively, when empirically-based practice guidelines offer evidence of the effectiveness of specific interventions among minority patients, uncertainty may be lessened. Future research should therefore assess whether disparities are reduced when clinicians are provided with and make use of evidence of treatment efficacy.

#### **UNDERSTANDING PATIENT-LEVEL INFLUENCES ON CARE**

As noted earlier, patient mistrust of providers may affect decisions to seek care, and may negatively influence the quality of the patient-provider relationship. Investigators should assess patients' attitudes and preferences toward healthcare providers and services, and examine the extent of these influences on the quality of care and treatment decisions. Research should also evaluate appropriate means of addressing and modifying negative cultural beliefs about care-seeking and mistrust of healthcare systems. Further, strategies to increase minority patients' ability to participate in treatment decisions and empower them as self-advocates within healthcare systems should be evaluated. It is important that these research efforts be conducted in active collaboration with racial and ethnic minority communities, both to avoid the perception that patients are to blame for unequal or poor treatment in healthcare settings, as well as to tap into cultural knowledge and traditions that may serve as sources of strength in the effort to "activate" patients.

#### **UNDERSTANDING THE INFLUENCE OF HEALTHCARE SYSTEMS AND SETTINGS ON CARE FOR MINORITY PATIENTS**

##### *Studies Within Healthcare Plans*

There is considerable variation across healthcare plans in the type and extent of coverage that beneficiaries receive. Even among those insured by public programs such as Medicare, some beneficiaries may hold a variety of types of supplemental insurance that enhances coverage for specific

services, thereby increasing their access to care. Many studies of racial and ethnic differences in healthcare, however, fail to account for these differences, often collapsing the privately-insured or publicly-insured into broad categories that mask differences in coverage. Future research should better account for these differences by assessing racial and ethnic disparities in care among similarly-insured patients within the same plan.

#### *Studies of DoD and VA Systems*

The committee's analysis revealed that for some healthcare services and under some conditions, racial and ethnic disparities in care are less pronounced. These findings are somewhat more consistent in studies of healthcare provided to active-duty personnel and their families through the U.S. Department of Defense healthcare system, which provides universal access to care, and are inconsistent among studies of the "equal-access" Veterans Administration healthcare system. Future research should seek to illuminate the conditions of health systems, including factors such as co-payment and accessibility that may be associated with racial and ethnic disparities in care.

#### *Type of Hospital or Clinic and Racial and Ethnic Disparities in Care*

Several studies find differences as to where racial and ethnic minorities receive care, even when holding insurance status constant. Lillie-Blanton, Martinez, and Salganicoff (2001) found that independent of sociodemographic factors, health status, and insurance status, African-American and Latino patients are more likely than white patients to have a hospital-based provider and are less likely to have an office-based provider as a usual source of care. Lillie-Blanton et al. (2001) note that these differences could reflect geographic or sociocultural barriers to care, patient preferences, or some combination of these factors. Structural, institutional, and organizational aspects of healthcare settings can affect the cost, content, and quality of care, as well as patient satisfaction. The contribution of these factors to healthcare disparities must be more thoroughly assessed. In addition, research should determine whether structural, institutional and organizational factors of healthcare settings affect the content of care or quality of communication for racial and ethnic minority patients.

Similarly, little is known about the healthcare providers that tend to serve racial and ethnic minority patients. Research indicates that racial and ethnic minority physicians, particularly those who are African American and Hispanic, disproportionately serve poor, underserved and minority patients (Komaromy et al., 1996). However, these providers re-

main a small fraction of the overall healthcare workforce. More must be understood about the racial and ethnic composition of providers who tend to serve minority patients, and the impact of racial concordance/discordance on care. In particular, little is known about the impact of international medical graduates working in minority communities. As noted earlier in this report, these providers disproportionately serve racial and ethnic minority patients, yet little is known about the quality of their interactions with minority patients, despite the apparent greater likelihood of cultural and linguistic misunderstanding. To better understand sources of racial and ethnic disparities in care, future research should analyze the experience, qualifications, specialties, and other attributes of providers who disproportionately serve racial and ethnic minority patients and to assess whether these factors may in part explain racial and ethnic disparities in care.

#### UNDERSTANDING THE ROLES OF NON-PHYSICIAN HEALTH PROFESSIONALS

The vast majority of research that documents racial and ethnic disparities in care and patient-provider communication in racially concordant and discordant dyads has focused on the role of the physician. This research has been important in illuminating key processes and decision points that may contribute to healthcare disparities. The disproportionate focus of research on physicians, however, unfairly places the locus of attention regarding disparities primarily on physicians. This fails to reflect the reality that much of healthcare is provided by non-physician professionals, including nurses, physician assistants, occupational and rehabilitation therapists, mental health professionals (including psychologists, social workers, and marital and family therapists), pharmacists, and allied health professionals. Further, with a few exceptions, research on racial and ethnic disparities in care has failed to consider the roles of other hospital and clinic staff—such as receptionists, admitting clerks, translators, and others—in contributing to the “climate” in which care is delivered. These individuals play at least as significant a role as physicians (if not more so) in conveying messages of respect and dignity to patients and in influencing how patients feel about the healthcare setting. Research is critically needed to assess how these individuals communicate with racial and ethnic minority patients, and in turn, how patients respond to them. Further, research should assess how educational programs can best improve these staffs’ attitudes, behaviors, and communication with racial and ethnic minority patients. In this regard, the committee notes that many corporations and organizations (and indeed, some health plans) have developed extensive training programs to assist their workforce in



better serving and addressing needs of culturally and linguistically diverse customers; these training programs offer potentially valuable models for healthcare institutions wishing to become more “customer-friendly” and improve service.

### **ASSESSING HEALTHCARE DISPARITIES AMONG NON-AFRICAN AMERICAN MINORITY GROUPS**

A central concern throughout the committee’s review of the literature on racial and ethnic disparities in healthcare has been the relative paucity of research on non-African-American racial and ethnic minority groups. While a number of important studies have sought to assess the extent of disparities among diverse racial and ethnic populations (e.g., Carlisle et al., 1995), the extent of disparities in care faced by Asian-American, Pacific Islander, Native American, and Hispanic populations remains unclear. Furthermore, barriers to care experienced by various subgroups of these populations must be better assessed. As noted earlier, focus group data and other information gathered by the committee suggest that linguistic and cultural mismatches pose greater challenges for recent immigrant minorities than for African Americans. There is tremendous cultural, linguistic, and socioeconomic variation within the “racial” populations noted above, and their historic and contemporary experiences in the United States—as noted by Byrd and Clayton (see appendix)—vary considerably, all of which significantly influence the context by which care is delivered to these populations.

### **ASSESSING THE EFFECTIVENESS OF INTERVENTION STRATEGIES**

The committee’s analysis suggests several promising avenues for interventions to eliminate racial and ethnic disparities in healthcare. To date, however, relatively less research attention has been devoted to assessing intervention efforts than to understanding the extent and sources of disparities in care. Several promising strategies have been identified that should continue to be the focus of research efforts, such as comprehensive cross-cultural education and communication training for healthcare providers. Research should assess not only the effectiveness of these interventions in reducing racial and ethnic gaps in appropriate care, but also their cost-effectiveness and the extent to which these interventions result in organizational and institution-level changes to improve care for minority patients. Research should also assess the benefits of other intervention strategies described earlier in this report, including language translation and interpretation services, lay health navigators, patient edu-

cation and “activation” strategies, and efforts to make healthcare services more culturally and linguistically accessible.

### **DEVELOPING METHODS FOR MONITORING HEALTHCARE DISPARITIES**

As discussed in the chapter on data collection and monitoring, the collection and reporting of healthcare information by patient race and ethnicity is an important step in monitoring the nation’s progress in eliminating racial and ethnic disparities in healthcare. Such efforts will assist consumers and purchasers in making better-informed choices about health plans, will help plans and providers to identify effective intervention strategies, and will identify practice settings where disparities occur and assist efforts to monitor compliance with civil rights laws. Data collection and monitoring efforts, however, will face several significant challenges to implementation, as noted earlier. Among these challenges are the need to ensure the privacy of medical records, problems posed in analyzing data from small population groups, the inconsistent use of and understanding of the federally-defined “race” and “ethnicity” categories, and the effect of differences in enrollee case-mix among plans on plan performance. Future research must address these challenges and identify efficient means for such data to be collected that do not pose undue bureaucratic burdens on healthcare providers, consumers, and plans.

### **UNDERSTANDING THE CONTRIBUTION OF HEALTHCARE TO HEALTH OUTCOMES AND THE HEALTH GAP BETWEEN MINORITY AND NON-MINORITY AMERICANS**

As noted earlier in this report, health status disparities observed between many minority and non-minority populations in the United States likely reflect a complex interplay of social, economic, biologic, and environmental factors. While some evidence suggests that preventive and primary care services can have a greater impact on improving health status for low-income than middle- and higher-income individuals, the contribution of healthcare disparities to health status differences between minority and non-minority populations remains unknown. Future research must assess this contribution, and identify how and why healthcare disparities play a role in poorer health outcomes for minorities relative to non-minorities. In addition, future research is needed to determine whether new medical services and technologies are implemented among minority patient populations at the same rates as the general patient population. New medical breakthroughs are occurring at staggering rates, and

promise to improve the quality of life and mitigate disease in ways never previously imagined. To the extent that these new technologies are made available and are within economic reach, research must assure that racial and ethnic minorities who have the ability to pay for such care are not disadvantaged in their efforts to receive it.

### MECHANISMS TO IMPROVE RESEARCH ON HEALTHCARE DISPARITIES

Research on racial and ethnic disparities in healthcare has grown significantly over the past two decades, and continues to offer new insights into the causes of and possible solutions to care disparities. To strengthen this research, however, and stimulate new insights and perspectives that may lead to innovative intervention strategies, the research enterprise may be strengthened in a number of ways. Much of the research reviewed earlier in this report has been conducted in specific departments of academic or research institutions, and has not taken full advantage of opportunities for interdisciplinary collaboration. Such collaboration will be necessary to address the complexities and multiple causal dimensions of healthcare disparities, as discussed earlier. Therefore, rather than dispersing research throughout the various departments of academic hospitals or other research institutions, researchers may seek to establish multidisciplinary units that encourage collaboration between departments as well as institutions (e.g., law, public health, sociology). In addition, federal and private research sponsors should encourage the conduct of research in a variety of settings (inner city; other urban; community health centers; etc.), and should encourage the participation of researchers from ethnic and racial minority groups.

#### **Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.**

Research is needed to illuminate how and why racial and ethnic disparities in care occur and to test intervention strategies to eliminate them. Specifically, research is needed to:

- Better understand the relative contribution of patient, provider, and institutional characteristics to healthcare disparities;
- Further illuminate provider decision-making, heuristics employed in diagnostic evaluation, and how patients' race, ethnicity, gender, and social class may influence these decisions;
- Assess the relative contributions of provider biases, stereotyping, prejudice, and uncertainty in producing racial and ethnic disparities in diagnosis, treatment, and outcomes of care;

- Understand the role of non-physician healthcare professionals, including nurses, physician assistants, occupational and rehabilitation therapists, mental health professionals (including psychologists, social workers, and marital and family therapists), pharmacists, allied health professionals, as well as non-professional staff in contributing to healthcare disparities;
- Assess healthcare disparities among non-African-American minority groups and subgroups;
- Assess the impact of international medical graduates (IMGs) on healthcare service delivery in racial and ethnic minority communities;
- Develop and test the utility for healthcare improvement of patient-based measures of (1) trust in providers and systems and (2) exposure to discriminatory practices by providers or systems;
- Develop methods for monitoring progress toward eliminating racial and ethnic disparities in healthcare; and
- Understand the relationship between healthcare disparities and the health gap between minority and non-minority Americans.

Finally, it is apparent that efforts to eliminate healthcare disparities will benefit from efforts to better address barriers to research and intervention. As noted earlier, these include ethical issues and data-related concerns, such as the need to protect patient privacy. At minimum, research and intervention efforts must conform to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations regarding the protection of patients' medical records and other confidential data. The Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) have already begun to address some of these concerns through ongoing research and data management, and should be encouraged to continue addressing barriers to data collection and research.

**Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.**  
AHRQ, CDC, and NIH should conduct research on barriers to eliminating racial and ethnic disparities in care, including data-related concerns (especially those related to HIPAA privacy regulations) and ethical issues.

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# Appendixes



# A

## Data Sources and Methods

In an effort to provide a comprehensive response to the study charge, the study committee examined various sources of data to assess the scope of disparities in healthcare, explore sources of these disparities, and generate strategies to eliminate them. These data sources included a review of recent scientific literature, commissioned papers, public input from professional societies and organizations, input from technical liaison panels, and focus group/roundtable input. The committee received these data over the course of the 17-month study period. The study timeline is depicted in Figure A-1.

### **Study Committee**

A 15-member study committee was convened to assess these data. Membership of the committee included individuals with expertise in clinical medicine, economics, healthcare services research, health policy, health professions education, minority health, psychology, anthropology and related fields. The committee was convened for five two-day meetings held in December 2000, February 2001, May 2001, July 2001, and September 2001.

### **Literature Review**

The literature review included, but was not limited to, seminal articles published in peer-reviewed journals within the last ten years, with an emphasis on the most recent publications. In selecting literature to re-



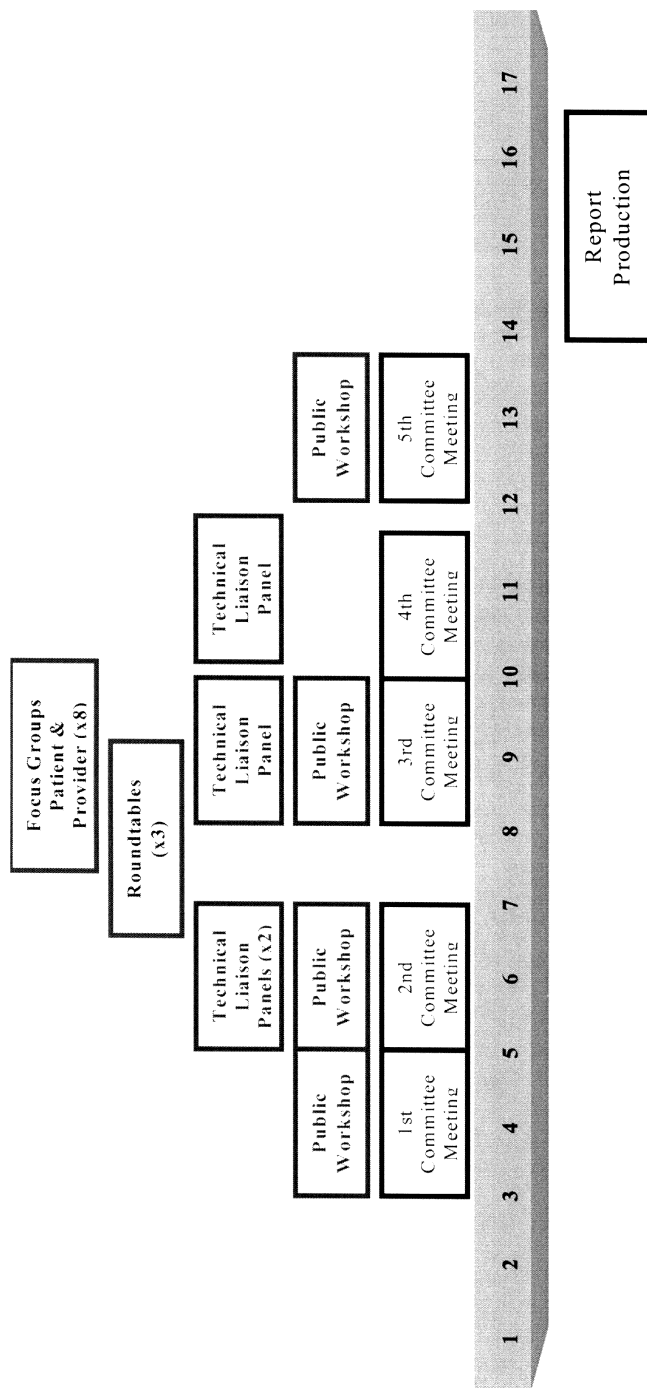


FIGURE A-1 Study components and timeline.

view, the committee identified only peer-reviewed studies that assessed racial and ethnic variation in healthcare while controlling for differences in access to healthcare (either by studying similarly insured patients or by statistically adjusting for differences in insurance status) and socioeconomic differences. This body of literature, however, represents only a fraction of the published studies that investigate racial and ethnic differences in access to and use of healthcare services.

### **Commissioned Papers**

The study committee commissioned seven papers. These papers were intended to provide in-depth information on selected topic areas (e.g., legal aspects of healthcare discrimination, studies on patient-provider interaction, extensive literature review). Topics and paper authors were determined by the study committee. It should be noted that the commissioned paper contributions do not serve to substitute for the committee's own review and analysis of the literature, as described above and in Chapter 1. Much of the committee's own analysis was conducted independently, prior to receiving the draft commissioned papers.

### **Public Workshops**

The study committee hosted four workshops to gain additional information from the public on aspects of the study charge. These workshops occurred during open portions of the committee's scheduled meetings. The topics and nature of the workshops were determined by the study committee. They were intended to allow the committee to gain additional perspectives on potential sources of bias in clinical settings; institutional or system-based obstacles that may differentially affect service provision to racial and ethnic minority patients; other potential sources of healthcare disparities; and explore potential interventions to eliminate disparities in health service delivery. Content included the perspectives of racial and ethnic minority and non-minority health professions organizations (e.g., American Medical Association), and government agencies, as well as programs and strategies employed by organizations to address disparities. In addition, at the fourth workshop selected commissioned papers served as topic areas for a discussion of legal and ethical perspectives. At each public workshop meeting, individuals and groups were invited to present information to the study committee in a roundtable setting to facilitate discussion and interaction. Agendas from public workshops and lists of participants are listed in Boxes A-1 through A-4.

**BOX A-1**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES,  
2101 CONSTITUTION AVENUE, NW  
ROOM 150**

**AGENDA  
TUESDAY, DECEMBER 19, 2000**

- 1:00 p.m. **WELCOME AND INTRODUCTIONS**  
***Alan Nelson, M.D.***  
Chair  
IOM Committee on Understanding and Eliminating Racial  
and Ethnic Disparities in Healthcare
- 1:15 p.m. **OVERVIEW FROM STUDY SPONSOR**  
***Nathan Stinson Ph.D., M.D., M.P.H.***  
Deputy Assistant Secretary for Minority Health,  
U.S. Department of Health and Human Services
- 1:35 p.m. **CONGRESSIONAL PERSPECTIVE**  
***Charles Dujon***  
Legislative Assistant, Office of the Honorable Jessie Jack-  
son, Jr. U.S. House of Representatives
- 2:00 p.m. **PRESENTATIONS FROM OTHER INTEREST GROUPS  
AND STAKEHOLDERS**  
***Rodney Hood, M.D.***, National Medical Association  
***Adolph Falcon, M.P.P.***, National Alliance for Hispanic Health  
***Jeanette Noltenius, Ph.D.***, Latino Council on Alcohol and  
Tobacco, Representing the Multicultural Action Agenda for  
Eliminating Health Disparities  
***Yvonne Bushyhead, J.D., & Beverly Little Thunder, R.N.***  
Indian Health Board
- 3:00 p.m. **UNDERSTANDING AND ELIMINATING RACIAL AND  
ETHNIC DISPARITIES IN HEALTHCARE — WHAT IS  
KNOWN AND WHAT NEEDS TO BE KNOWN?**  
***H. Jack Geiger, M.D.***  
City University of New York
- 4:00 p.m. **ADJOURN**

**BOX A-2**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES  
CECIL AND IDA GREEN BUILDING, 2001 WISCONSIN AVENUE, NW  
ROOM 126**

**AGENDA  
TUESDAY, FEBRUARY 20, 2001**

- 9:00 a.m. **WELCOME AND INTRODUCTIONS**  
***Alan Nelson, M.D.***  
Chair  
IOM Committee on Understanding and Eliminating Racial  
and Ethnic Disparities in Healthcare
- 9:15 a.m. ***Deborah Danoff, M.D.***  
Assistant Vice President, Division of Medical Education  
American Association of Medical Colleges
- 9:45 a.m. ***Paul M. Schyve, M.D.***  
Senior Vice President  
Joint Commission on Accreditation of Healthcare  
Organizations
- 10:15 p.m. ***Sindhu Srinivas, M.D.***  
President  
American Medical Student Association
- 10:45 a.m. ***Mary E. Foley, R.N., M.S.***  
President  
American Nurses Association
- 11:15 a.m. ***Randolph D. Smoak, Jr., M.D.***  
President  
American Medical Association
- 11:45 a.m. ***Terri Dickerson***  
Assistant Staff Director  
U.S. Commission on Civil Rights
- 12:15 p.m. **PUBLIC WORKSHOP ADJOURNS**

**BOX A-3**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES  
CECIL AND IDA GREEN BUILDING, 2001 WISCONSIN AVENUE, NW  
ROOM 126**

**AGENDA  
TUESDAY, MAY 15, 2001**

- 1:00 p.m. ***Carolyn Clancy, M.D.***  
Agency for Healthcare Research and Quality
- 1:45 p.m. ***James Youker, M.D.***  
President, American Board of Medical Specialties
- 2:15 p.m. ***Ray Wertz***  
Consumer Health Education Council
- 2:45 p.m. ***Vickie Mays, Ph.D., Chair***  
National Committee on Vital and Health Statistics  
Subcommittee on Populations
- 3:15 p.m. **QUESTIONS AND COMMENTS**
- 3:30 p.m. **PUBLIC WORKSHOP ADJOURNS**

**WEDNESDAY, MAY 16, 2001**

- 9:00 a.m. ***Robyn Nishimi, Ph.D.***  
Chief Operating Officer, National Quality Forum
- 9:30 a.m. ***Lovell Jones, Ph.D.***  
Intercultural Cancer Council
- 10:00 a.m. **PUBLIC WORKSHOP ADJOURNS**

**BOX A-4**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES,  
2101 CONSTITUTION AVENUE, NW  
MAIN BUILDING—LECTURE ROOM**

**PUBLIC WORKSHOP  
“RACE, THE MEDICAL MARKETPLACE, AND HEALTHCARE DISPARITIES”**

**AGENDA  
THURSDAY, SEPTEMBER 6, 2001**

8:30 a.m. **WELCOME AND INTRODUCTIONS**  
**Alan Nelson, M.D.**  
Chair, IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Healthcare

8:35 a.m. **OPENING REMARKS**  
**David Satcher, M.D., Ph.D.**  
U.S. Surgeon General

8:55 a.m. **PANEL DISCUSSION**  
**M. Gregg Bloche, J.D., M.D.**  
Moderator, IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Healthcare

**PARTICIPANTS:**

**Richard Epstein, J.D.**  
James Parker Hall Distinguished Service, Professor of Law,  
University of Chicago Law School

**Clark C. Havighurst, J.D.**  
Wm. Neal Reynolds Professor of Law, Duke University School of Law

**Marsha Lillie-Blanton, Dr. P.H.**  
Vice President in Health Policy, The Henry J. Kaiser Family Foundation

**June O'Neill, Ph.D.**  
Director, Center for the Study of Business and Government,  
Baruch College of Public Affairs

**Thomas Perez, J.D., M.P.P.**  
Assistant Professor and Director of Clinical Law Programs,  
University of Maryland Law School

**Thomas Rice, Ph.D.**  
Professor and Vice-Chair, Department of Health Services, UCLA  
School of Public Health

11:00 a.m. **ADJOURN**

### **Technical Liaison Panels**

Four liaison panels were assembled to serve as a resource to the committee, to provide advice and guidance in identifying key information sources, to provide recommendations to the study committee regarding intervention strategies, and to ensure that relevant consumer and professional perspectives were represented. Liaison panels were composed of individuals with relevant experience or expertise on the study charge. Nominations for individuals invited to the panels were sought from over 100 stakeholder groups. Panel members included patient advocates, providers of health-care services, payer groups, as well as representatives from ethnic minority professional organizations and federal agencies. Each liaison panel was convened by study staff in Washington, D.C. for a half-day meeting. Panelists were asked to provide recommendations regarding potential sources of data, intervention strategies, and other recommendations relevant to the study charge. Discussion content and recommendations from the liaison panels were presented by staff to the study committee at its meetings. The agenda for panel meetings is presented in Box A-5. Lists of participants for each of the four panels are presented in Boxes A-6 through A-9.

### **Focus Groups and Roundtable Discussions**

A series of focus groups were conducted by the Westat Corporation, Rockville, MD, for the study committee (see Appendix E). Information gathered at focus group discussions was intended to afford the study committee greater insight into the experiences and perceptions of patients and providers, supplementing data from the empirical literature, and providing a richer context for data interpretation. Qualitative data gathered during focus group discussions were used to illustrate and expand upon findings and recommendations provided in the committee report.

Six groups, composed of 8-10 individuals each, were conducted with healthcare consumers with participants from various racial and ethnic backgrounds. Two groups were conducted with African Americans: one in Los Angeles, CA, and the other in Rockville, MD. The third group was conducted in Los Angeles with Hispanics who were fluent in English, and the fourth was conducted in Washington, DC, with Hispanics who identified themselves as primary Spanish-speaking with little or no English fluency. The fifth group was conducted with American Indians in Albuquerque, New Mexico. The final group was conducted in Los Angeles with Chinese Americans who identified themselves as primarily Mandarin-speaking with little or no English fluency. Participants were asked to comment on the quality of healthcare they received and experiences encountered when seeking medical care in a variety of public and private

**BOX A-5**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**AGENDA—LIAISON PANEL**

- 12:00 p.m. **LUNCH**
- 12:15 p.m. **INTRODUCTIONS**  
*Daniel J. Wooten, M.D.*  
IOM Scholar in Residence  
Panel Chair
- 12:30 p.m. **OVERVIEW OF IOM STUDY**  
*Brian Smedley, Ph.D.*  
*Adrienne Stith, Ph.D.*  
IOM study staff
- 12:45 p.m. **CURRENT INITIATIVES AND RESOURCES FOCUSED ON  
REDUCING HEALTHCARE DISPARITIES**
- 1:30 p.m. **BREAK**
- 1:45 p.m. **DISCUSSION OF FACTORS THAT CONTRIBUTE TO  
INEQUITIES IN HEALTHCARE**
- 2:30 p.m. **PANEL INPUT—RECOMMENDATIONS TO STUDY  
COMMITTEE**
- Recommendations for Intervention Strategies
  - Policy Recommendations
  - Research Recommendations
- 4:00 p.m. **ADJOURN**



**BOX A-6**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**TECHNICAL LIAISON  
FEDERAL PANEL**

**FEBRUARY 12, 2001**

***Jonca Bull, M.D.***, Food and Drug Administration

***Denice Cora-Bramble, M.D.***, Health Resources and Services  
Administration

***Marsha Davenport, M.D.***, Center for Medicare and Medicaid Services

***Carole Brown***, Office for Civil Rights, Office of the Secretary of Health  
and Human Services

***LTC Willie L. Hensley***, Department of Veterans Affairs

***\*Joan Jacobs***, Office of Minority Health, Office of the Secretary of Health  
and Human Services

***Camara Phyllis Jones, M.D., M.P.H., Ph.D.***, Centers for Disease Control  
and Prevention

***Raynard Kington, M.D., Ph.D.***, National Institutes of Health

***Yvonne T. Maddox, Ph.D.***, National Institutes of Health

***Beverly Malone, Ph.D.***, Office of Public Health and Science, Office of  
the Secretary of Health and Human Services

***George A. Mensah, M.D.***, Centers for Disease Control and Prevention

***Leo J. Nolan III***, Indian Health Service

***Delores L. Parron, M.D.***, Planning and Evaluation Program, Department  
of Health and Human Services

***Capt. Adam M. Robinson, Jr., M.D.***, Department of Defense

***Craig Vanderwagen, M.D.***, Indian Health Service

\*observer from sponsoring office

**BOX A-7**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**TECHNICAL LIAISON PANEL**

**FEBRUARY 14, 2001**

*Joseph A. Berry, M.D.*, United Healthcare

*Zora Brown*, Breast Cancer Resource Committee

*Gina Gregory-Burns, M.D.*, Kaiser Permanente

*Mary Lou de Leon Siantz, R.N., Ph.D.*, National Association of Hispanic Nurses

*Gary C. Dennis, M.D.*, Howard University Hospital

*Richard Levinson, M.D., DPA*, American Public Health Association

*Joseph Quash, M.D.*, Association of Black Cardiologists

*Rene F Rodriguez, M.D.*, Interamerican College of Physicians and Surgeons

*Cynthia A. Warrick, Ph.D.*, Howard University

*Donald A. Young, M.D.*, Health Insurance Association of America

**BOX A-8**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**LIAISON PANEL**

**MAY 4, 2001**

*David Baines, M.D.*, Seattle Indian Health Board

*Henry Chung, M.D.*, Pfizer Pharmaceuticals Groups

*Tom Chung, Ph.D.*, Commonwealth of Massachusetts, Executive Office  
of Elder Affairs

*Carolyn M. Clancy, M.D.*, Agency for Health Research & Quality

*Gem P. Daus, M.A.*, Asian and Pacific Islander American Health Forum

*Lucille Davis, Ph.D., R.N.*, Southern University School of Nursing, Baton  
Rouge, LA

*Pete Duarte, M.D.*, Thomason Hospital, El Paso, TX

*Alicia C. Georges, Ed.D.*, Department of Nursing, Herbert H. Lehman  
College, Bronx, NY

*Robert D. Gibson, Pharm.D., Sc.D.*, American Pharmaceutical Association

*Miya Iwataki*, Los Angeles County Department of Health Services

*Anita Moncrease, M.D., M.P.H.*, Health Resources and Service  
Administration

*Tom Perez, J.D.*, Maryland University School of Law

*Elena Rios, M.D., M.S.P.H.*, National Hispanic Medical Association

*Richard Allen Williams, M.D.*, University of California at Los Angeles  
and Minority Health Institute

\**Violet Ryo-Hwa Woo, M.S., M.P.H.*, Office of Minority Health

\* observer from sponsoring office

**BOX A-9**

**INSTITUTE OF MEDICINE  
COMMITTEE ON UNDERSTANDING AND ELIMINATING  
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**LIAISON PANEL**

**JUNE 21, 2001**

**Dennis Andrulis, Ph.D., M.P.H.**, State University of New York Downstate Medical Center

**Deborah Bohr, M.P.H.**, Health Research and Educational Trust

**Cindy Brach, M.P.P.**, Agency for Healthcare Research and Quality

**Deborah Danoff, M.D.**, Association of American Medical Colleges

**Leonard G. Epstein, M.S.W.**, Bureau of Primary Health Care, Health Resources Services Administration

**George Flouty, M.D.**, Pfizer, Inc.

**Candice Mathew Healy, M.P.A.**, State University of New York Downstate Medical Center

**Laura Hernandez, M.P.I.A.**, Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration)

**Charlene Landis, M.A.**, Pfizer, Inc.

**Ed Martinez, M.S.**, National Association of Public Hospitals

**\*Guadalupe Pacheco, M.S.W.**, Office of Minority Health, DHHS

**Rea Panares, M.H.S.**, Washington Business Group on Health

**Carlos Vidal, Ph.D.**, State University of New York Stonybrook

**Malcom Williams, M.P.P.**, Grantmakers in Health

**VIDEO CONFERENCE PARTICIPANTS**

**Niels Agger-Gupta, Ph.D.**, California Healthcare Interpreters Association

**Sakinah Carter, M.P.H.**, The California Endowment

**Tessie Guillermo**, Asian and Pacifica Islander Health Forum

**Melba Hinojosa, M.A., RN**, MediCal Managed Care, California Department of Health Services

**Vivian Huang**, California Primary Care Association

**Wendy Jameson, M.P.P., M.P.H.**, California Health Care Safety Net Institute

**Beatriz Solis, M.P.H.**, LA Care Health Plan

**Jai Lee Wong**, The California Endowment

\* observer from sponsoring office

settings, either for themselves or for a child or other family member. All participants had private health insurance, Medicare, Medicaid/MediCal, or Indian Health Service coverage.

In addition, two focus groups were conducted by telephone with African American and Hispanic healthcare providers throughout the United States: one was conducted with nurses, the other with physicians. Participants were asked to provide their opinions and comments on the quality of healthcare services that minority patients receive. They also discussed how their race or ethnicity affected their medical training or professional careers. Providers' perspectives added a rich content for understanding patients' experiences with racism in healthcare, addressing some of the institutional factors that affect quality of care.

An experienced facilitator, who possessed knowledge of cultural and linguistic differences of ethnic minority groups, led each of the nine groups. Facilitators for the consumer groups were matched with regard to race, ethnicity, and primary language. Study staff were present at Washington, DC area and phone-based focus groups.

To supplement qualitative information on the experiences and perceptions of racial and ethnic minority patients, advocates, and their healthcare providers, roundtable discussions were held at two national conferences (the Asian American and Pacific Islander Health Forum [AAPIHF] conference in Alameda, CA and the Indian Health Service [IHS] Research conference in Albuquerque, NM) where racial and ethnic minority health issues were discussed. At both conferences, study staff solicited participants from among conference attendees and invited them to participate in small group discussions (up to 20 people) to discuss participants' perceptions of racial and ethnic healthcare disparities and strategies to eliminate them. At the Indian Health Service Research Conference, a member of the study committee (Dr. Jennie Joe) facilitated a small group discussion that including American Indian tribal leaders, healthcare providers, and IHS staff. At the AAPIHF conference, study staff facilitated three small discussion groups, including representatives of advocacy and community groups, healthcare providers, and others.

## B

# Literature Review

The study committee conducted an extensive review of literature on racial and ethnic disparities in healthcare (discussed in Chapter 1). In this appendix, summary tables of this literature are presented, along with criteria used in the conduct of this review.

To assess the evidence regarding racial and ethnic differences in health care, the committee conducted literature searches via PUBMED and MEDLINE databases to identify studies examining racial and ethnic differences in medical care for a variety of disease categories and clinical services. Searches were performed using combinations of following keywords:

- Race, racial, ethnicity, ethnic, minority/ies, groups, African American, Black, American Indian, Alaska Native, Native American, Asian, Pacific Islander, Hispanic, Latino.
- Differences, disparities, care.
- Cardiac, coronary, cancer, asthma, HIV, AIDS, pediatric, children, mental health, psychiatric, eye, ophthalmic, glaucoma, emergency, diabetes, renal, gall bladder, ICU, peripheral vascular, transplant, organ, cesarean, prenatal, hip, hypertension, injury, surgery/surgical, knee, pain, procedure, treatment, diagnostic.

This search yielded over 600 citations. To further examine this evidence base and address the study charge that called for an analysis of “the

extent of racial and ethnic differences in health care that are not otherwise attributable to known factors such as access to care," only studies that provided some measure of control or adjustment for racial and ethnic differences in insurance status (e.g., ability to pay/insurance coverage or comorbidities) were included in the literature review. Other "threshold" criteria included:

- Publication in past 10 years (1992-2002; this criterion was established because more recent studies tend to employ more rigorous research methods and present a more accurate assessment of contemporary patterns of variation in care);
  - Publication in peer-reviewed journals;
  - Elimination of studies focused on racial and ethnic differences in health status (except as it is affected by the quality of health care) and health care access, as well as publications that were editorials, letters, published in a foreign language, were non-empirical, or studies that controlled for race or ethnicity; and
  - Inclusion only of studies whose primary purpose was to examine variation in medical care by race and ethnicity, contained original findings, and met generally established principles of scientific research (e.g., studies that stated a clear research question, provided a detailed description of data sources, collection, and analysis methods, included samples large enough to permit statistical analysis, and employed appropriate statistical measures).

In addition, to ensure the comprehensiveness of the review, the committee examined the reference lists of major review papers that summarize this literature (e.g., van Ryn, 2002; Geiger, this volume; Kressin and Petersen, 2001; Bonham, 2001; Sheifer, Escarce, and Schulman, 2000; Mayberry, Mili, and Ofili, 2000; Ford and Cooper, 1995). Articles not originally identified in the initial search were retrieved and analyzed for appropriateness of inclusion in the committee's review. Finally, to ensure that the committee's search was not limited to studies with "positive" findings of racial and ethnic differences in care, searches were conducted for studies that attempted to assess variations in care by patient socioeconomic status and geographic region. These studies were included if the researchers assessed racial or ethnic differences in care while controlling, as noted above, for patient access-related factors.

To assess the quality of this evidence base, the committee ranked studies on several criteria:

- Adequacy of control for insurance status (studies of patients covered under the same health system or insurance plan were considered to be more rigorous than studies that merely assessed the availability of health insurance among the study population);
- Use of appropriate indicators for patient socioeconomic status (e.g., studies that measured patients' level of income, education, or other indicators of socioeconomic status);
- Analysis of clinical data, as opposed to administrative claims data (see limitations of administrative claims data noted below);
- Prospective or retrospective data collection (prospective studies were considered to be more rigorous than retrospective analyses);
- Appropriate control for patient co-morbid conditions;
- Appropriate control for racial differences in disease severity or stage of illness at presentation;
- Assessment of patients' appropriateness for procedures (e.g., studies that provide primary diagnosis and include well-defined measures of disease status, as in studies of cardiovascular care that assess racial differences in care following angiography) or that compare rates of service use relative to standardized, widely-accepted clinical guidelines; and
- Assessment of racial differences in rates of refusal or patient preferences for non-invasive treatment.

Studies that met the committee's "threshold" criteria are summarized in Table B-1.

As a "second level" analysis of the quality of evidence regarding racial and ethnic disparities in cardiovascular care, the committee identified a subset of studies that permit a more detailed analysis of the relationship between patient race or ethnicity and quality of care, while considering potential confounding variables such as clinical differences in presentation and disease severity. Several criteria were established to identify these studies, using generally accepted criteria of research rigor and quality. To begin, the committee identified only studies using clinical, as opposed to administrative data, for the reasons cited above. Secondly, the committee identified studies that provided appropriate controls for likely confounding variables, and/or employed other rigorous research methods. These



criteria included the use of adequate control or adjustment for racial and ethnic differences in insurance status; prospective, rather than retrospective data collection; adjustment for racial and ethnic differences in comorbid conditions; adjustment for racial and ethnic differences in disease severity; comparison of rates of cardiovascular services relative to measures of appropriateness; and assessment of patient outcomes.

Several caveats should be noted in undertaking this approach. One, studies using clinical data allow researchers to better assess whether disparities in care exist and are significant after potential confounding factors such as clinical variation and the appropriateness of intervention are taken into account, but these studies often are limited to small patient samples in one or only a few clinical settings, therefore sacrificing statistical power and potentially underestimating the role of institutional variables as contributing to healthcare disparities. Second, assessments of racial and ethnic differences in patients' clinical outcomes following intervention must be made with caution. Patients' outcomes following medical intervention reflect a wide range of factors, some of which are unrelated to the intervention itself (e.g., the degree of social support available to patients following treatment) and may vary systematically by race or ethnicity. In addition, a finding of no racial or ethnic differences in patient outcomes (e.g., survival) despite disparate rates of treatment should not be interpreted as demonstrating that disparities in the use of medical intervention are inconsequential. In such instances, researchers should ask whether equivalent rates of intervention might be associated with better patient outcomes among minorities. Finally, this second level of analysis should not be interpreted as suggesting that the larger literature presented above is insufficient to draw conclusions regarding disparities in healthcare. Almost all of the individual studies reviewed earlier possess limitations, but the collective body of this evidence is robust.

Despite these caveats, this second review afforded an opportunity to assess whether racial and ethnic disparities in care remain when racial differences in clinical presentation and other potentially confounding variables are controlled. Studies were considered in this second review only if they met four of six criteria noted above, in addition to the "threshold" criteria that studies employ clinical databases. Thirteen studies were identified through this process (see Table B-2). Of these, only two (Leape et al., 1999; Carlisle et al., 1999) found no evidence of racial and ethnic disparities in care after adjustment for racial and ethnic differences in insurance status, co-morbid factors, disease severity, and other potential confounder

as noted above. The remaining studies found racial and ethnic disparities in one or more cardiac procedures, following multivariate analysis. Almost all studies found that adjustment for one or more confounding factors reduced the magnitude of unadjusted racial and ethnic differences in care. Among the five studies that collected data prospectively, however, all found racial and ethnic disparities remained after adjustment for confounding factors.

**TABLE B-1** Summary of Selected Literature—Racial and Ethnic Disparities in Health Care

**Analgesia**

Source	Procedure/Illness	Sample	Analyses
Todd, Deaton, D'Adamo, and Goe, 2000	Assessed racial differences in receipt of analgesia among patients seen for extremity fractures in emergency departments.	Retrospective cohort study of 217 patients (127 African American, 90 white) seen in an emergency department in an urban hospital.	
Bernabei, Gambassi, Lapane et al., 1998	Assessed adequacy of pain management among elderly and minority cancer patients admitted to nursing homes.	13,625 cancer patients (12,038 white, 1,041 African American, 163 Hispanic, 107 Asian, 276 American Indian) discharged from hospitals to any of 1,492 Medicare-certified/Medicaid-certified nursing homes in five states.	

Analyses	Findings	Limitations
Multiple logistic regressions to predict use of analgesia by race, controlling for time since injury, total time in the emergency department, payer status, and need for fracture reduction.	Nearly three-fourths of white patients (74%) received analgesia, compared to 57% of African American patients. The crude risk of receiving no analgesia was 66% higher for black patients than white. After controlling for covariates, whites remained significantly more likely to receive analgesia (risk ratio = 1.7, 95% CI 1.1 to 2.3).	<ul style="list-style-type: none"><li>-Moderate sample size.</li><li>-Racial/ethnic groups other than white and African American not sampled.</li><li>-One site sampled.</li><li>-Retrospective study.</li><li>-Other relevant confounds such as alcohol and drug use not considered.</li><li>-Few racial/ethnic minority physicians in sample.</li></ul>
Logistic regression to predict unresolved daily pain, adjusting for gender, cognitive status, communication skills, and indicators of disease severity (e.g., explicit terminal prognosis), being bedridden, number of diagnoses, and use of other medications.	More than a quarter of patients in daily pain (26%), as assessed by self-report and independent raters, received no pain medication. After adjustment, African Americans had 63% greater probability of being untreated for pain relative to whites (odds ratio = 1.63, 95% CI 1.18 to 2.26). Older age, low cognitive performance, and increased number of other medications were also associated with failure to receive any analgesic agent.	<ul style="list-style-type: none"><li>-Small numbers in racial/ethnic groups.</li><li>-Retrospective, cross-sectional study.</li><li>-Data set not specifically focused on pain.</li><li>-Pain assessed by observational evaluation.</li><li>-Family members involved in collection of information to varying degrees.</li><li>-No data regarding analgesic dose or frequency of administration.</li></ul>

TABLE B-1 Continued

<b>Analgesia</b>			
Source	Procedure/Illness	Sample	Analyses
Cleeland, Gronin, Baez et al., 1997	Assessed adequacy of pain management among minority patients receiving care in settings that primarily serve minorities vs. patients who receive care in settings where few minority patients are treated.	281 minority outpatients (106 African American, 94 Hispanic, 16 other minority) with recurrent or metastatic cancer at 9 university cancer centers, 17 community hospitals and practices, and 4 centers that primarily treat minority patients.	
Ng, Dimsdale, Rollnik, and Shapiro, 1996	Assessed racial/ethnic differences in physicians prescription of patient-controlled analgesia for post-operative pain.	454 (314 white, 37 Asian, 73 Hispanic, 30 African American) consecutive patients receiving patient-controlled analgesia in post-operative period.	

Analyses	Findings	Limitations
<p>Compared treatment of pain among this sample with a larger, primarily white sample from a previous study where participants were treated in settings where fewer than 10% of patients were ethnic minorities. Pain assessed by independent ratings of patients and physicians. Adequacy of analgesia estimated by widely accepted measure of treatment of pain.</p>	<p>Sixty-five percent of patients who reported pain received inadequate pain medication. Patients treated in settings where the patient population was primarily black or Hispanic and those who were treated at university centers were more likely to receive inadequate analgesia (77%) than those who received treatment in settings where patient population was primarily white (52%; <math>p &lt; 0.003</math>). In addition, minority patients were more likely to be undermedicated for pain than white patients (65% vs. 50%; <math>p &lt; 0.001</math>), and were more likely to have the severity of their pain underestimated by physicians.</p>	<ul style="list-style-type: none"><li>-Data regarding race/ethnicity not available for comparison group.</li><li>-Data collected immediately after data on the non-minority comparison group collected.</li><li>-No data collected on ability to pay.</li></ul>
<p>Analysis of variance and post-hoc LSD-tests using ethnicity as independent variable. Dependent variables include amount of narcotic prescribed and amount of narcotic self-administered.</p>	<p>No significant differences found in patient rating of pain or amount of analgesia self-administered.</p> <p>Significant differences in the amount of narcotic prescribed among Asians, blacks, Hispanics, and whites (<math>F = 7.352</math>; <math>p &lt; 0.01</math>). Whites and African Americans were prescribed more narcotic than Hispanics and Asians.</p> <p>After adjustment for age, gender, pre-operative use of narcotics, health insurance, and pain site, ethnicity persisted as independent predictor of amount of narcotic prescribed.</p>	<ul style="list-style-type: none"><li>-Relatively small numbers of African Americans and Asians.</li><li>-Sample located at one site.</li><li>-Retrospective study.</li><li>-Analyses did not control for patient size or primary language.</li></ul>

TABLE B-1 Continued

**Analgesia**

Source	Procedure/Illness	Sample	Analyses
Todd, Lee, and Hoffman, 1994	Assessed racial/ethnic differences in physician's perceptions of pain in patients with isolated extremity trauma.	Prospective study of 207 patients (138 white, 69 Hispanic) admitted to ED at UCLA Medical Center between 1992-1993.	
Todd, Samaroo, and Hoffman, 1993	Assessed ethnic differences in receipt of emergency department analgesia for isolated long-bone fractures.	139 patients (108 white, 31 Hispanic) admitted to emergency department at UCLA. Patients with recorded alcohol or drug use excluded.	

Analyses	Findings	Limitations
<p>Analysis of Covariance to evaluate influence of confounding variables on the relationship between ethnicity and differences in patient and physician pain assessment. Independent variables included occupational injury, injury location, patient pain assessment, physician sex, injury type, insurance status, and patient ethnicity.</p>	<p>No differences found between non-Hispanic and Hispanic patients in patient pain assessment, physician pain assessment, or disparity between patient and physician pain assessment. Differences remained non-significant after controlling for confounds.</p>	<ul style="list-style-type: none"><li>-Patients enrolled study primarily in early evening and weekends.</li><li>-Moderate samples size.</li><li>-Racial groups other than Hispanic and white not sampled.</li><li>-Single site sampled.</li></ul>
<p>Logistic regression to evaluate independent influence of race/ethnicity on probability of analgesic administration. Independent variables included race/ethnicity, gender, language, insurance status, occupational injury, fracture reduction, time of presentation, total time in ED, hospital admission.</p>	<p>55% of Hispanic patients and 26% of white patients received no analgesic (crude relative risk = 2.12, 95% CI 1.35 to 3.32, <math>p = 0.003</math>). After simultaneously controlling for covariates Hispanic ethnicity was strongest predictor of no analgesia (odds ratio = 7.46, 95% CI 2.22 to 25.04, <math>p &lt; 0.01</math>).</p>	<ul style="list-style-type: none"><li>-Retrospective study.</li><li>-No control for covariates such as precise injury, presence of translators.</li><li>-Single site.</li><li>-Small sample size.</li><li>-Small number of Hispanics in sample.</li><li>-Racial/ethnic groups other than white and Hispanic not sampled.</li></ul>



TABLE B-1 Continued

<b>Asthma</b>			
Source	Procedure/Illness	Sample	Analyses
Krishnan et al., 2001	Race/ethnicity and gender differences in consistency of care with national asthma guidelines within managed care organizations.	5,062 patients (4,328 white, 734 African-American) who participated in the Outcomes Management System Asthma Study between 9/93 and 12/93.	
Zoratti, Havstad, Rodriguez et al., 1998	Assessed racial/ethnic differences in treatment for asthma in a managed care setting.	464 African-American and 1,609 white patients treated for asthma in a Southeast Michigan managed care system (27 ambulatory care clinics).	

Analyses	Findings	Limitations
<p>Multivariate logistic regression to determine whether race/ethnicity and sex were associated with five indicators of National Asthma Education and Prevention Program (NAEPP) guidelines (medication, self-management education, control of factors related to asthma severity, periodic assessment, and asthma specialist care).</p>	<p>After controlling for age, education, employment, and symptom frequency there were no significant race/ethnicity or sex differences in the use of medication regimen consistent with NAEPP recommendations for patients with moderate or more severe asthma.</p>	<p>-Results may not apply to patients with mild asthma. -Bias in self-report data. -Racial/ethnic groups other than white and African-American not sampled.</p>
<p>Regression analysis to predict use of services, adjusting for age, gender, marital status, and income (as assessed by average income of patients' community of residence).</p>	<p>African-American patients were more likely than whites to access care in emergency rooms (<math>p &lt; 0.001</math>), were hospitalized more often (<math>p = 0.023</math>), and were less likely to be seen by an asthma specialist (<math>p = 0.027</math>), after controlling for income, marital status, gender, and age. Among only low-income patients, African Americans were more likely to be treated in emergency rooms than whites, although no significant differences were found in access to specialty care and hospitalization rates. After adjusting for age, gender, marital status and income, African Americans were more likely to use oral corticosteroids (<math>p = 0.026</math>) and were less likely to use inhaled anticholinergic medications (<math>p = 0.016</math>).</p>	<p>-Racial/ethnic groups other than African American and white not assessed. -Use of administrative database. -Retrospective cross-sectional study. -Number prescriptions filled used as estimate of actual use. -No adjustment for co-morbidities.</p>

TABLE B-1 Continued

Cancer			
Source	Procedure/Illness	Sample	Analyses
Elston Lafata, Cole Johnson, Ben-Menachem, Morlock et al., 2001	Assessed sociodemographic differences in the receipt of colorectal cancer surveillance care.	251 patients (157 white, 94 minority [largely African American]) treated for colorectal cancer in a managed care organization.	
Farley, Hines, Taylor et al., 2001	Racial differences in cervical cancer survival in military health system.	Retrospective examination of 1,553 patient records (65% white, 10% African-American, 8% Filipino, 4% Korean, remaining percentages Japanese, Hawaiian, Indian, Asian, Pacific Islander, unknown, or other) from the Automated Central Tumor Registry for the U.S. Military Health Care System between 1988 and 1999. Patients included were diagnosed with invasive cervical carcinoma.	
Merrill, Merrill, and Mayer, 2000	Receipt of surgery or radiation therapy among white and African-American women with cervical cancer.	Data from 8,119 patients (86% white, 14% African-American) with invasive cervical cancer, as obtained from 11 tumor registries in Surveillance, Epidemiology, and End Results (SEER) program.	

Analyses	Findings	Limitations
<p>Kaplan-Meier survival analysis to determine cumulative incidence of service receipt; Cox Proportional Hazard models to quantify the effects of baseline clinical and sociodemographic characteristics on risk of service receipt. Analyses adjusted for age, race, gender, site and stage of original disease, type of treatment, comorbidity index, estimated income.</p>	<p>Within 18 months of treatment, over half of the total cohort received a colon examination (55%), nearly three-fourths had received carcino-embryonic antigen (CEA) testing, and nearly six in ten (59%) received metastatic disease testing. Whites were more likely than African Americans, however, to receive CEA testing (RR = 1.47, 95% CI 1.12 to 2.14) and displayed a slight but non-significant trend toward higher rates of colonic examination (RR = 1.43, 95% CI 0.94 to 2.18).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Retrospective study.                      -Use of claims data.</p>
<p>Survival analysis performed with Kaplan-Meier survival curves and log rank tests to determine significant differences. Cox proportional hazards regression to assess factors influencing survival. Data regarding age at diagnosis, histology, grade, stage, SES, treatment modality obtained.</p>	<p>No significant difference between the distribution of age, stage, grade or histology between African Americans and whites. No difference between these groups found in type of treatment. Differences in five- and 10-year survival rates were also not statistically significant.</p>	<p>-Small numbers in racial/ethnic minority groups.                      -Retrospective study.                      -Administrative data.</p>
<p>Logistic regression to predict receipt of therapy after adjusting for stage and grade of cancer, patient age, nodal status, histology, and presence of multiple cancer primaries.</p>	<p>Overall, 8.03% of whites and 11.64% of blacks did not receive either radiation therapy or surgery. For both blacks and whites, the odds of not receiving treatment increased with older age and distant and unstaged disease (vs. localized disease). Blacks were more likely to be diagnosed unstaged and were less likely to have localized disease; once stage was accounted for, racial differences in treatment status became insignificant. Among those not treated, blacks were more likely to have treatment not recommended than whites (53.68% vs. 40.32 %). Of those cases not</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -No controls for hospital characteristics, appropriateness, SES.</p>

TABLE B-1 Continued

<b>Cancer</b>			
Source	Procedure/Illness	Sample	Analyses
Bach, Cramer, Warren, and Begg, 1999	Early stage lung cancer.	10,984 patients (10,124 white, 860 African Americans) age 65 and older with resectable stage I or stage II non-small-cell lung cancer. Patients resided in one of 10 study areas of the Surveillance, Epidemiology, and End Results (SEER) program.	
McMahon, Wolfe, Huan et al., 1999	Assessed use of diagnostic and screening procedures among Medicare Part B eligible population.	All Medicare Part B transactions in the state of Michigan from 1986 to 1989 in which procedures were used to diagnose colorectal disease.	
Dominitz, Samsa, Landsman, and Provenzale, 1998	Assessed racial/ethnic differences in receipt of treatment and survival among patients with colorectal cancer in Veterans Administration (VA) health system.	3,176 patients (17.9% African American) with a new diagnosis of colorectal cancer.	

Analyses	Findings	Limitations
<p>Kaplan-Meier method used for constructing survival curves with log-rank statistic used for comparisons. Cox proportional-hazards method used to adjust for confounding variables. Analyses controlled for sex, income, age, stage of disease, type of Medicaid insurance, and comorbidity.</p>	<p>receiving therapy, few were due to patient refusal (3.76% among whites, 5.88% among blacks).</p> <p><i>Rate of surgery:</i> 64% for black patients vs. 76.7% for white patients (<math>p &lt; 0.001</math>). <i>Five-year survival rate:</i> 26.4% for black patients vs. 34.1% for white patients (<math>p &lt; 0.001</math>). However, there was a nonsignificant difference in survival rates b/w black and white patients who underwent surgery and similar rates for those who did not. This suggests that lower survival rates among black patients is largely explained by the lower rate of surgical treatment.</p>	<p>-Relatively small sample of African Americans.                      -Racial/ethnic groups other than white and African American not examined.                      -Retrospective study.                      -Administrative data.</p>
<p>Series of stepwise logistic regression analyses to predict association between procedure utilization and patient sociodemographic characteristics and residence characteristics.</p>	<p>Assessed contribution of patient age, sex, race, urbanicity of patients' community, per capita income of community, education level of community, and availability of physicians, internists, and gastroenterologists per 100,000 population to prediction of diagnostic procedures. African Americans were more likely than whites to receive barium enema only (odds ratio = 1.38, 95% CI 1.34 to 1.41), were less likely to receive a combination of barium enema and sigmoidoscopy (odds ratio = 0.80, 95% CI 0.78 to 0.83), and were less likely to receive any colonoscopy (odds ratio = 0.83, 95% CI 0.81 to 0.85).</p>	<p>-Racial/ethnic groups other than white and African American not examined.                      -Administrative data.                      -Retrospective study.</p>
<p>Logistic regression to predict likelihood of surgical resection, chemotherapy, or radiation therapy, after adjusting for patient demographic characteristics, comorbidities, distant metastases, and tumor location.</p>	<p>No significant racial differences found in rates of receipt of surgical resection (70% among blacks, 73% among whites; odds ratio = 0.92, 95% CI 0.74 to 1.15), chemotherapy (23% for both blacks and whites; odds ratio = 0.99, 95% CI 0.78 to 1.24), or radiation therapy (17% among blacks, 16% among whites; odds ratio = 1.10, 95% CI 0.85 to 1.43). Five-year relative survival rates were similar for black and white patients (42% vs. 39% respectively, <math>p = 0.16</math>).</p>	<p>-Racial/ethnic groups other than African American and white not assessed.                      -Administrative data.                      -Lack of data on SES.</p>

TABLE B-1 Continued

<b>Cancer</b>			
Source	Procedure/Illness	Sample	Analyses
Howard, Penchansky, and Brown, 1998	Assessed racial/ethnic differences in survival of breast cancer.	246 women (89 African American, 157 white) who sought care for breast cancer in one of three health maintenance organizations (HMOs).	
Ball and Elixhauser, 1996	Colorectal cancer.	20,634 discharges b/w 1980 and 1987 from 500 acute care hospitals in the U.S.	
Imperato, Nenner, and Will, 1996	Assessed variation by race/ethnicity in rates of radical prostatectomy among male	Pattern analysis of 4,154 Medicare claims for radical prostatectomy to treat pros-	

Analyses	Findings	Limitations
<p>Logistic regression to predict stage of disease at time of diagnosis and Cox survival analysis to assess determinants of survival.</p>	<p>No significant racial differences were found in stage of disease, utilization of health services before diagnosis of breast cancer, or receipt of breast examination. African-American patients were more likely to die than whites (30% vs. 18%, <math>p &lt; 0.04</math>) and experienced shorter average survival (1.63 years vs. 2.77 years, <math>p &lt; 0.024</math>). Two percent of whites and eight percent of African Americans missed two or more appointments following diagnosis; after adjusting for the number of appointments made, African Americans were more likely than whites to miss appointments. Missed appointments and stage of diagnosis were strongly associated with survival, and reduced the impact of race on survival.</p>	<p>-Relatively small sample.                      -Racial/ethnic groups other than African American and white not examined.                      -Retrospective review.</p>
<p>Logistic regression to predict diagnostic subgroups, procedure types, in-hospital mortality. Semilogarithmic ordinary least squares regression for length of stay.  <i>Covariates:</i> patient demographics, insurance status, clinical factors, and provider characteristics.</p>	<p>Black and white rates of inpatient mortality were equivalent only for the most severely ill. Otherwise, odds of inpatient mortality were 59% to 98% higher for black patients (odds ratio = 1.59 to 1.982, <math>p &lt; 0.05</math> to <math>p &lt; 0.01</math>).                      Procedure type was equivalent only for the sickest patients. Black patients with primary tumor and no evidence of oncologic sequelae were 41% less likely than whites to receive a major colorectal therapeutic procedure (odds ratio = 0.59, <math>p &lt; 0.001</math>). When metastasis was recorded black patients with primary tumor were 27% less likely to received a major colorectal therapeutic procedure (odds ratio = 0.726, <math>p &lt; 0.05</math>).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Use of discharge data.                      -Retrospective study.</p>
<p>Pattern analysis of rates of prostatectomy, relative to incidence of prostate cancer</p>	<p>Rates of radical prostatectomy were lower among African Americans than among whites (b/w ratio ranged from</p>	<p>-Rates for racial/ethnic groups other than white and</p>



TABLE B-1 Continued

Cancer	Source	Procedure/Illness	Sample	Analyses
		Medicare patients in New York state.	Prostate cancer between 1991 and 1993.	
Harlan, Brawley, Pommerenke et al., 1995		Assessed variations in the use of radical prostatectomy and radiation to treat prostate cancer by geographic area, age, and race/ethnicity.	Data for 67,693 men (9.4% African American) with localized and regional cancer, as obtained from Surveillance, Epidemiology, and End Results (SEER) program database between 1984 and 1991.	
Optenberg, Thompson, Friedrichs et al., 1995		Assessed long-term survival of black and white prostate cancer patients in Department of Defense (DoD) medical facilities.	1,606 prostate cancer patients (7.5% African American, 92.5% white) who were active duty personnel, dependents, or retirees eligible for care in the military medical system.	

Analyses	Findings	Limitations
and Medicare claims for both black and white males.	0.59 in 1991 to 0.86 in 1993; no confidence intervals provided).	African American not examined. -Retrospective study. -Administrative data. -Analyses did not control for income/SES, comorbidities or other potential confounds.
Chi-square test of association between race and receipt of treatment. Tests for trends calculated using Mantel-Haenszel test.	Black men aged 50 to 69 years were less likely than similarly aged white men to receive prostatectomy. For black and white men aged 70 to 79 years, rates of prostatectomy were similar in 1984, but became significantly divergent by 1991, as a larger proportion of white men received the procedure ( $p < 0.01$ ). In 1991, a significantly higher proportion of black men aged 50 to 59 years received radiation. For all age groups in 1991, twice as many blacks as whites (12.5% vs. 6.6%) received no treatment.	-Racial/ethnic groups other than white and African American not examined. -Administrative data. -Retrospective study. -Adjustment not made for comorbidities, SES or other potential confounds.
Multiple life-table regression analysis to determine if stage and grade of cancer, wait time, age or race affect patient survival. Cox proportional hazard function used to compute mortality risk ratios for black and white patients.	Blacks presented at a significantly higher stage of cancer development than whites (26.4% of blacks presenting with distant metastases compared to 12.3% of whites, $p < 0.001$ ), and demonstrated a greater percentage of recurrence (30.6% vs. 21.4%, $p = 0.02$ ). There were no significant racial differences in wait time to receive treatment, and no significant differences were found in the type of treatment when stratified by stage of presentation. Overall, stage, grade, and age were found to affect survival, but not race. When analyzed by stage, blacks demonstrated longer survival for distant metastatic disease (mortality risk ratio = 0.644, 95% CI 0.396 to 1.036).	-Racial/ethnic groups other than white and African American not examined. -Administrative data. -Retrospective study.

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
Petersen et al., 2002	Assessed racial differences in treatment for AMI.	Analysis of 606 black and 4,005 white VA patients with diagnosed AMI discharged from one of 81 VA hospitals.	
Bell and Hudson, 2001	Racial and gender differences in emergency room treatment of chest pain.	Analysis of 379 records of patients (229 white, 150 African American) presenting to ER with chest pain during one calendar year at two county hospitals in North Carolina.	
Okelo et al., 2001	Rates of recommendation for coronary revascularization when race/ethnicity were unknown by physicians.	Data reviewed for 938 consecutive cardiac catheterizations in 882 patients (26.5% African American, 73.5% white) performed between 1993 and 1995. Cardiologists and cardiothoracic surgeons provided with all clinical and angiographic data without racial identifiers and were asked for revascularization recommendations.	

Analyses	Findings	Limitations
<p>Logistic regression to assess use of guideline-based medications, invasive cardiac procedures, and all-cause mortality at 30 days, 1 year, and 3 years.</p>	<p>No differences between African-American and white patients in receipt of beta blockers, but African Americans were more likely to receive aspirin and were less likely to receive thrombolytic therapy at time of arrival and were less likely to receive bypass surgery, even when only high-risk coronary anatomic subgroups were assessed. No racial differences found in rates of refusal of invasive treatment.</p>	<p>-Racial/ethnic groups other than white and African American not examined.                      -Retrospective data collection.                      -Physician, hospital characteristics not assessed.</p>
<p>Logistic regression to assess whether treadmill testing, cardiac catheterization (CC), and echocardiogram (Echo) were recommended or performed. Analysis of covariance to assess wait time to first EKG. Models tested main effects of clinic, gender, race, and insurance, and interactions between gender and race and between insurance and race. Number of cardiovascular related co-morbid conditions also included in models.</p>	<p><i>Treadmill:</i> no significant differences.                      CC: Whites more likely to receive cardiac catheterization (adjusted odds ratio = 2.8317, 95% CI 1.7833 to 4.4963).                      Echo: African Americans more likely to receive Echo (adjusted odds ratio = 0.5927, 95% CI 0.377 to 0.931).                      Time to first EKG: African-American patients waited longer than whites for EKG.</p>	<p>-Racial/ethnic groups other than white and African American not examined.                      -Relatively small sample.                      -Retrospective.                      -Results from diagnostic procedures (e.g., treadmill stress tests) that may have explained variance in CC not available.</p>
<p>Revascularization recommendations compared between African-American and white patients and correlated with clinical data. Logistic regression analyses performed for CABG and PTCA. Independent variables included age, African-American ethnicity, co-morbid disease, LV dysfunction, number of coronary arteries with significant stenosis, and involvement of specific arteries.</p>	<p>After adjustments, African Americans more likely to have a recommendation for PTCA (odds ratio = 1.42, 95% CI 0.96 to 2.11, <math>p = 0.08</math>) and less likely to have recommendation for CABG (odds ratio = 0.59, 95% CI 0.37 to 0.94, <math>p = 0.02</math>).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Physician, hospital characteristics not assessed.</p>

TABLE B-1 Continued

Cardiovascular Disease

Source	Procedure/Illness	Sample	Analyses
Schneider, Leape, Weissman et al., 2001	Assess whether racial differences in cardiac revascularization are due to “overuse” of the procedure in white patients.	Stratified weighted random sample of 3,960 Medicare beneficiaries in 173 hospitals (in five states) who underwent coronary angiography in 1991 and 1992.	
Watson, Stein, Dwamera et al., 2001	Influence of race and gender on use of invasive procedures in patients with acute myocardial infarction (AMI).	Prospective study of 838 patients (443 white men, 264 white women, 79 African-American men, 49 African-American women) with AMI seen between January 1994 and April 1995 in five community hospitals in Michigan.	
Canto, Allison, Kiefe et al., 2000	Reperfusion therapy for acute myocardial infarction (AMI).	26,575 Medicare patients (25,044 white, 1,531 African American) meeting eligibility criteria for reperfusion therapy.	

Analyses	Findings	Limitations
<p>RAND criteria used to determine proportion of coronary artery bypass graft (CABG) and percutaneous transluminal coronary angioplasty (PTCA) procedures that were appropriate, uncertain, or inappropriate.</p> <p>Multivariable logistic regression analysis to assess odds of receiving inappropriate PTCA or inappropriate CABG surgery. Analyses controlled for age, income, clinical characteristics, and state procedure performed.</p>	<p>Rates of inappropriate PTCA ranged from 4% to 24% among study states, and 0% to 14% for CABG surgery.</p> <p>White men had significantly higher adjusted odds than African American men of receiving inappropriate PTCA (odds ratio = 2.42, 95% CI 1.02 to 5.76). No significant differences were found among white women, African-American women, and African-American men. Adjusting for between-hospital effect of race and gender somewhat reduced higher odds of inappropriate PTCA among white men.</p> <p>Inappropriate CABG surgery did not differ by race.</p>	<p>-Retrospective study examining medical record and claims data.</p> <p>-Racial/ethnic groups other than African American not examined.</p>
<p>Multiple logistic regression to identify predictors of cardiac catheterization (CC). Of those undergoing CC, analyses to predict coronary artery bypass grafting (CABG), percutaneous transluminal coronary angioplasty (PTCA), or atherectomy. Analyses adjusted for age, hospital of admission, insurance, severity of AMI, and comorbidity. Coronary artery anatomy added as covariate in analyses conducted among patients receiving CC.</p>	<p>Rate of being offered CC (with white men as reference group), was 0.88 (95% CI 0.60 to 1.29, <math>p = 0.502</math>) for white women, 0.79 (95% CI 0.41 to 1.5, <math>p = 0.465</math>) for black men, and 1.14 (95% CI 0.53 to 2.45, <math>p = 0.733</math>) for black women.</p> <p>For those receiving CC, the rate of being offered angioplasty was 1.22 (95% CI 0.75 to 1.98, <math>p = 0.416</math>) for white women, 0.61 (95% CI 0.29 to 1.28, <math>p = 0.192</math>) for black men, and 0.4 (95% CI 0.14 to 1.13, <math>p = 0.084</math>) for black women. The rate of being offered CABG was 0.47 (95% CI 0.24 to 0.89, <math>p = 0.021</math>) for white women, 0.36 (95% CI 0.12 to 1.06, <math>p = 0.065</math>) for black men, and 0.37 (95% CI 0.11 to 1.28, <math>p = 0.118</math>) for black women.</p>	<p>-Racial/ethnic groups other than African American and white not examined.</p> <p>-Small sample of African Americans.</p> <p>-Single geographic location.</p> <p>-No controls for appropriateness or SES.</p>
<p>Bivariate and multivariate analyses of prevalence ratios to predict use of reperfusion therapy by race and gender. Statistical adjustments for age, medical history, clinical</p>	<p>White men were most likely to receive reperfusion therapy (59%), followed by white women (56%), black men (50%), and black women (44%). Prevalence ratios (after statistical adjustment):</p>	<p>-Study excluded patients who were not white or African American.</p> <p>-No controls for socioeconomic status.</p>

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
Carlisle, Leape, Bickel, Bell et al., 1999	Underuse and overuse of diagnostic testing for coronary artery disease.	356 patients (43% white, 27% African American, 19% Latino, 9% Asian or Pacific Islander) presenting to ER in one of five Los Angeles area hospitals. Patients completed questionnaire asking whether they had received diagnostic testing for coronary artery disease. Patient medical records were also reviewed.	
Daumit, Hermann, Coresh, and Powe, 1999	Ethnic differences in use of cardiovascular procedures in patients with end-stage renal disease as they transition to Medicare health insurance.	4,987 patients (3,152 white, 1,835 African American) with end-stage renal disease from 303 dialysis facilities between 1986 and 1987. Patients were followed for up to seven years. Data obtained from the Case Mix Severity Study of the US Renal Data System.	

Analyses	Findings	Limitations
<p>presentation, and hospital characteristics.                      Logistic regression to assess whether education, insurance status, gender, age, and race/ethnicity were independent predictors of underuse or overuse.</p>	<p>WW/WM – 1.00 (95% CI 0.98 to 1.03);                      BW/BM – 1.00 (95% CI 0.89 to 1.13);                      BW/WM – 0.90 (95% CI 0.82 to 0.98);                      BM/M – 0.85 (95% CI 0.78 to 0.93).                      Only level of education was associated with underuse, or inappropriate use of diagnostic testing. Underuse more likely to occur among patients without a college education (odds ratio = 2.2, 95% CI 1.0 to 4.4).</p>	<p>-Retrospective cohort study.                      -Study limited to patients presenting to ER.                      -Approximately 50% of potential subjects did not respond or could not be contacted.                      -Issues of colinearity among education, insurance, and race/ethnicity.</p>
<p>Logistic regression to assess effect of race on receipt of a cardiovascular procedure at baseline. Covariates include age, type insurance at baseline, type of employment, employment status, marital status, region of country, coronary artery disease, history of smoking, cholesterol level, triglyceride level, history diabetes, obesity, cerebrovascular disease, congestive heart failure, history malignant condition, low serum albumin level, and type of dialysis.                      Logistic regression also used to identify receipt of procedure during follow-up.                      Cox proportional hazards model used to assess time to receipt of procedure during follow-up for white compared to African American patients.</p>	<p>After adjustment, odds of having a cardiac procedure at baseline were nearly three times greater for white patients than for African-American patients (odds ratio = 2.92, 95% CI 2.04 to 4.18).                      During follow-up white patients were 1.4 times more likely to have a procedure (adjusted relative risk = 1.41, 95% CI 1.13 to 1.77).                      In patients with Medicare before end-stage renal disease, the baseline difference in procedure use was eliminated over follow up (odds ratio = 1.05, 95% CI 0.56 to 1.6).                      Among patients who already had Medicare at baseline, the adjusted odds ratio of procedure use for white compared to African-American patients was 3.0. At follow-up, no difference between ethnic groups seen in procedures after hospitalization for myocardial infarction or coronary disease.</p>	<p>-No controls for hospital characteristics and availability of procedures.                      -Data obtained from administrative records.                      -Racial/ethnic groups other than white and African American not included.</p>



TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
Gregory, Rhoads, Wilson et al., 1999	Assess racial differences in rates of cardiac procedures, relative to availability of hospital-based invasive cardiac services.	13,690 New Jersey residents (1,217 African American, 12,473 white) hospitalized with a primary diagnosis of AMI.	
Hannan, van Ryn, Burke et al., 1999	Coronary artery bypass graft (CABG) surgery.	1,261 post-angiography patients (680 white non-Hispanic, 314 African American, 267 white Hispanic), stratified by race and gender, who would benefit from CABG in New York state, according to RAND appropriateness and necessity criteria. Patients identified and tracked for three months. Data obtained from clinical data, telephone and mail surveys of patients and physicians, and information from NY Cardiac Surgery Reporting System.	
Leape, Hilborne, Bell et al., 1999	Assessed use of CABG or PCTA for patients for whom revascularization procedures	631 patients (44% white, 27% African American, 29% Hispanic) at 13 New York City	

Analyses	Findings	Limitations
<p>Logistic regression to predict receipt of catheterization and PTCA/CABG, after controlling for patient clinical and demographic factors and availability of cardiac procedures in hospital where patients were first admitted.</p>	<p>For all patients, the likelihood of receiving catheterization within 90 days of AMI was significantly greater among those hospitalized in facilities that provided cardiac services. Blacks were less likely to receive catheterization than whites (b/w odds ratio = 0.74 for those younger than age 65 [95% CI 0.61 to 0.90], 0.68 for those age 65 years and older [95% CI 0.56 to 0.83]) controlling for age, sex, health insurance status (for those younger than age 65), anatomic location of primary infarct, co-morbidities, and the availability of cardiac services. Similarly, blacks were less likely than whites to receive revascularization procedures within 90 days of admission (b/w odds ratio = 0.63 for those younger than age 65 [95% CI 0.52 to 0.76], 0.69 for those age 65 years and older [95% CI 0.54 to 0.86]), controlling for patient demographic and clinical factors and availability of cardiac services.</p>	<p>-Ethnic/racial groups other than African American and white not examined.                      -Retrospective cohort study.                      -Use of hospital records.                      -No controls for SES.</p>
<p>Stepwise logistic regression to predict use of CABG within three months. Statistical adjustments for age, gender, vessels diseased, risk status (low, medium, high), type of insurance, and other clinical characteristics.</p>	<p>African-American and Hispanic patients were significantly less likely to undergo CABG than white non-Hispanics. Odds ratios: white/African-American – 0.64 (95% CI 0.47 to 0.87); white/Hispanic – 0.60 (95% CI 0.43 to 0.84).</p>	<p>-Results may not be representative of NYS (in terms of access by race/ethnicity and gender in the state).                      -No controls for SES.</p>
<p>Logistic regression to assess</p>	<p>No significant variations found in rates of revascularization among African-American patients, (72%), Hispanic patients (67%) and white patients (75%).</p>	<p>-Moderate sample size.</p>

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
	were deemed clinically necessary.	hospitals who met RAND criteria for necessary revascularization. Data obtained by hospital record review.	
Scirica, Moliterno, Every, Anderson et al., 1999	Racial/ethnic differences in care of patients with unstable angina.	2,948 (77% white, 14% black, 4% Hispanic, 1% Asian, 3% unknown race/ethnicity) consecutive patients with unstable angina admitted to 35 U.S. hospitals in 1996 (GUARANTEE registry). Medical records were reviewed and questionnaire was completed for each patient.	
Canto, Herman, Williams, Sanderson et al., 1998	Racial/ethnic differences in presenting characteristics, treatment, and outcomes in patients with myocardial infarction.	275,046 consecutive AMI patients (86% white, 3% Hispanic, 1% Asian and Pacific Islander, < 1% Native American) enrolled in the National Registry of Myocardial Infarction 2 from 1994 to 1996. African-American patients not included in analyses.	

Analyses	Findings	Limitations
probability that a patient would receive revascularization as a function of demographic characteristics and type of hospital.	Rates of revascularization were significantly lower, however, among hospitals that did not provide revascularization services (and therefore had to refer patients to other hospitals) than those that did provide revascularization (59% to 76%, difference = 17% [95% CI 8% to 35%]).	-Retrospective study. -Data obtained by record review. -No controls for SES.
Logistic regression to assess independent contribution of demographic, insurance, and clinical factors in distinguishing white from nonwhite patients.	Nonwhites had higher incidence of hypertension and diabetes. Cardiac catheterization was performed less often in nonwhites as compared to whites (36% vs. 53%, $p = 0.001$ ). In patients meeting criteria for appropriate catheterization (by AHRQ guidelines), fewer nonwhites underwent the procedure (44% vs. 61%, $p = 0.001$ ) and among these fewer nonwhites had significant coronary stenosis (72% vs. 90%, $p = 0.001$ ). Angioplasty and CABG received equally often in white and nonwhite patients, among those catheterized who had indications for revascularization.	-Relatively small number of minorities. -Collapse of minorities into one category. -No controls for SES.
Logistic regression to assess factors predicting acute reperfusion strategies, invasive cardiac procedures, and mortality. Variables include demographics, medical history, cardiac risk factors, chest pain, symptom onset to hospital arrival, Killip class, pulse, systolic blood pressure, electrocardiogram, and hospital characteristics.	Hispanics were as likely as whites to receive thrombolytic therapy. Asian and Pacific Islanders were less likely to receive this therapy (odds ratio = 0.84, 95% CI 0.72 to 0.99). Native Americans more likely than whites to receive thrombolytic therapy (odds ratio = 1.18, 95% CI 0.90 to 1.54).  All minority groups as likely as whites to receive coronary arteriography. Hispanics were as likely as whites to undergo revascularization procedures, however Asian and Pacific Islanders were less likely to undergo angioplasty (odds ratio = 0.82, 95% CI 0.64 to 1.04) and more likely to have bypass surgery (odds ratio = 1.23, 95% CI 0.96 to 1.57). Native Americans were less likely to undergo both angioplasty	-NRMI-2 not randomized sample of patients. -No available information on SES. -Retrospective study.

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
Taylor, Canto, Sanderson, Rogers, and Hilbe, 1998	Racial/ethnic differences in management and outcome in patients with Acute Myocardial Infarction (AMI).	Patients from National Registry of Myocardial Infarction 2 (NRMI-2). 275,046 patients included (86% white, 6% black).	
Laouri, Kravitz, French et al., 1997	Assessed use of CABG and/or PTCA for patients for whom procedures are deemed clinically necessary following coronary angiography.	671 patients (55% white, 21% Latino, 12% African-American) at six hospitals (four public and two academically affiliated private hospitals) who met explicit clinical criteria for coronary revascularization. Data abstracted from medical records and from patient interviews.	
Peterson, Shaw, DeLong et al., 1997	Assessed racial/ethnic differences in use of coronary angioplasty and bypass surgery among patients with	Prospective study of 12,402 white and African-American patients at Duke University Medical Center (10.3% Afri-	

Analyses	Findings	Limitations
<p>Logistic regression to assess variables independently predicting utilization of acute reperfusion strategies, invasive cardiac procedures, and mortality. Variables included age, race, sex, payer status, history, chest pain, ST elevation, MI location and type, symptom onset to hospital arrival, Killip class, pulse, systolic BP, contraindications to thrombolysis, census region, and hospital characteristics.</p>	<p>(odds ratio = 0.72, 95% CI 0.50 to 1.05) and bypass surgery (odds ratio = 0.63, 95% CI 0.38 to 1.04) than whites.</p> <p>Mortality similar among whites, Hispanics, Asian and Pacific Islanders, and Native Americans.</p> <p>Black patients were less likely to receive intravenous thrombolytic therapy (odds ratio = 0.76, 95% CI 0.71 to 0.80), coronary arteriography (odds ratio = 0.85, 95% CI 0.77 to 0.95), and coronary artery bypass surgery (odds ratio = 0.66, 95% CI 0.58 to 0.75). No significant differences were found in hospital mortality.</p>	<p>-NRMI-2 not randomized sample of patients.                      -No available information on SES.                      -Retrospective study.</p>
<p>Assessed underuse of coronary revascularization relative to RAND/UCLA criteria for necessity of revascularization procedure. Logistic regression analyses evaluated the effect of gender, ethnicity and type of hospital on CABG or PCTA, or any revascularization, controlling for age, clinical presentation, angiographic findings, and ejection fraction.</p>	<p>African Americans were significantly less likely than whites to undergo necessary CABG (b/w odds ratio = 0.49, 95% CI 0.23 to 0.99), and were less likely to undergo necessary PTCA (odds ratio = 0.20, 95% CI 0.06 to 0.72). Patients at public hospitals were less likely to undergo PTCA than those at private hospitals (odds ratio = 0.10, 95% CI 0.02 to 0.44).</p>	<p>-Moderate sample size.                      -Retrospective study.                      -No controls for SES, or hospital characteristics.</p>
<p>Logistic regression models to predict the likelihood that a patient would undergo angioplasty or</p>	<p>African Americans were 13% less likely than whites to undergo angioplasty (odds ratio = 0.87, 95% CI 0.73 to 1.03) and 32% less likely to</p>	<p>-Racial/ethnic groups other than white and African</p>

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
	documented coronary disease. Also assessed whether differences were associated with differences in survival rates.	can American) with documented coronary disease.	
Ramsey et al., 1997	Assessed gender and ethnic differences in receipt of percutaneous transluminal coronary angioplasty (PTCA) and aortocoronary bypass surgery (ACBS).	1,228 Mexican-American and white patients hospitalized for myocardial infarction (MI). Data collection part of Corpus Christi Heart Project.	
Sedlis, Fisher, Tice et al., 1998	Assessed racial differences in receipt of cardiac procedures in a VA hospital.	1,474 white and 322 African-American patients who had undergone catheterization and were likely candidates for surgery or angioplasty.	
Taylor, Meyer, Morse, and Pearson, 1997	Assessed rates of cardiovascular procedures by race in	Abstracted chart reviews from 1,441 patients (1,208 white, 155 African American,	

Analyses	Findings	Limitations
<p>bypass surgery. Extension of life associated with bypass surgery calculated by use of proportional-hazards regression model. Risk ratios for black and whites compared after adjusting for base-line prognostic factors. Independent variables included age, sex, severity of disease, other clinical and co-morbid factors, and insurance.</p>	<p>undergo bypass surgery (odds ratio = 0.68, 95% CI 0.56 to 0.82). Racial differences were more marked among patients with severe disease (48% of African Americans with severe coronary disease underwent surgery vs. 65% of whites, <math>p &lt; 0.001</math>). Analysis of survival benefit of surgery also revealed racial differences; among patients expected to survive more than one year, 42% of African Americans underwent surgery, compared to 61% of whites (<math>p &lt; 0.001</math>). Finally, the adjusted five-year mortality rate among patients revealed that African-American patients were 18% more likely than whites to die (odds ratio = 1.18, 95% CI 1.05 to 1.32).</p>	<p>American not examined.                      -Single site.                      -No information about patient preferences.                      -No controls for SES.</p>
<p>Logistic regression to predict receipt of services, after adjusting for age, sex, previous diagnosis of coronary heart disease, MI, diabetes mellitus, hypertension, occurrence of congestive heart failure during MI, location and type of MI.</p>	<p>Among only patients who had received catheterization to determine extent of disease, Mexican Americans were less likely to receive PTCA, but not ACBS, than whites after adjusting for clinical and demographic characteristics (odds ratio = 0.65, 95% CI 0.43 to 0.99).</p>	<p>-Single geographic location.                      -No controls for SES, hospital characteristics.</p>
<p>Analyses were generated from surgical referral conference at VA hospital between 1988 and 1996. Racial differences in conference recommendation and patient compliance with recommendations were analyzed using Fisher's exact test.</p>	<p>Therapeutic cardiac procedures (surgery or PTCA) were offered more frequently for white patients (72.9%) than African-American patients (64.3%; odds ratio = 1.497, <math>p = 0.0022</math>). This difference could not be explained by simple clinical differences between the two groups. African-American patients, however, were more likely than whites to refuse invasive procedures (odds ratio = 2.026, 95% CI 1.311 to 3.130).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Single site.                      -Potential confounds such as SES not assessed.</p>
<p>Logistic regression to assess</p>	<p>No differences found in rates of catheterization procedures between white and "nonwhite" patients during AMI</p>	<p>-Retrospective study.                      -Potential con-</p>



TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
	military health services system.	78 other) with principle or secondary diagnosis of AMI in 125 military hospitals.	
Weitzman, Cooper, Chambless et al., 1997	Assessed rates of performance of cardiac procedures in relation to gender, race, and geographic location.	5,462 patients (815 of these African-American) in four states (North Carolina, Mississippi, Maryland, and Minnesota) hospitalized for myocardial infarction (MI).	
Allison, Kiefe, Centor et al., 1996	Assess variations in use of medications among African-American and white Medicare patients hospitalized with Acute Myocardial Infarction (AMI).	Retrospective medical record review of 4,052 patients (3,542 white, 510 African American) hospitalized in all acute care hospitals in Alabama with principle discharge diagnosis of AMI.	

Analyses	Findings	Limitations
differences by patient race in rates of catheterization or revascularization procedures, controlling for age, gender, cardiovascular risk factors, and clinical data relevant to admission for AMI.	admission (odds ratio = 0.96, 95% CI 0.69 to 1.34) or between white and black patients (odds ratio = 1.19, 95% CI 0.80 to 1.78). Similarly, no differences were found in rates of revascularization (PTCA or CABG) between white and “nonwhite” patients (odds ratio = 0.90, 95% CI 0.59 to 1.39) or between white and black patients (odds ratio = 1.11, 95% CI 0.65 to 1.89). No differences were found in mortality or rates of readmission within 180 days following initial discharge. However, white patients were significantly more likely than nonwhite patients to be considered for future catheterization (odds ratio = 1.77, 95% CI 1.20 to 2.61).	finds such as SES, disease severity, appropriateness not assessed.
Logistic regression to estimate odds of having diagnostic and therapeutic procedures performed during an MI event by race, gender, and type of hospital.	After controlling for severity of MI and co-morbid conditions, blacks admitted to teaching hospitals were significantly less likely to receive PTCA (b/w odds ratio = 0.4, 95% CI 0.2 to 0.6), CABG (b/w odds ratio = 0.4, 95% CI 0.2 to 0.9) or thrombolytic therapy (b/w odds ratio = 0.5, 95% CI 0.3 to 0.8). Similarly, blacks admitted to non-teaching hospitals were significantly less likely to receive PTCA (b/w odds ratio = 0.5, 95% CI 0.3 to 0.7), CABG (b/w odd ratio = 0.3, 95% CI 0.2 to 0.6) or thrombolytic therapy (b/w odds ratio = 0.5, 95% CI 0.3 to 0.7).	-Racial/ethnic groups other than African American and white not assessed. -Potential confounds such as SES, co-morbidities, appropriateness not assessed.
Logistic regression to assess rate of receipt of thrombolysis, beta-andrenergic blockade and aspirin, controlling for patient age, gender, clinical factors, severity of illness, algorithm-determined candidacy for therapy, and hospital characteristics	After controlling for patient appropriateness for therapy, age, gender, clinical characteristics, and hospital characteristics, white patients were more likely to receive thrombolytics than black patients (odds ratio = 0.51, 95% CI 0.38 to 0.78). No differences were found in receipt of beta-blockers (odds ratio = 1.18, 95% CI 0.91 to 1.53)	-Racial/ethnic groups other than white and African American not examined. -Relatively small sample of African Americans. -Retrospective study. -Data obtained

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
Herholz et al., 1996	Assessed gender and ethnic differences in receipt of cardiovascular medications on discharge from hospital following myocardial infarction (MI).	Discharge data for 982 patients hospitalized for definite or possible MI; data are from the Corpus Christi Heart Project.	
Blustein, Arons, and Shea, 1995	Assessed variations by race, payor, and gender in process of care leading up to revascularization procedures for patients with cardiovascular disease.	5,857 non-Medicare (less than 65 years of age) patients admitted to hospitals in California with a principal diagnosis of acute myocardial infarction (AMI).	
Carlisle et al., 1995	Assessed use of coronary artery angiography, bypass graft surgery, and angioplasty among Los Angeles	131,408 patients (89,781 white, 16,509 African American, 19,218 Latino, and 5,900 Asian) discharged from L.A. County	

Analyses	Findings	Limitations
(e.g., rural vs. urban, teaching vs. non-teaching).	or aspirin (odds ratio = 1.00, 95% CI 0.81 to 1.24) by patient race.	through record review. -No controls for SES.
Logit regression to predict receipt of medications by gender and ethnicity, after adjusting for age, diagnosis of diabetes mellitus, hypertension, congestive heart failure, serum cholesterol level, and cigarette smoking.	Mexican Americans received fewer medications than whites (odds ratio = 0.62, 95% CI 0.33 to 1.15), even after adjusting for clinical and demographic characteristics. Mexican Americans were less likely to receive almost all major medications, especially antiarrhythmics, anticoagulants, and lipid-lowering therapy.	-Single geographic region. -No controls for SES, hospital characteristics, appropriateness.
Series of chi square and regression analyses to determine likelihood of receipt of services during prehospital, intrahospital (duration of initial hospitalization), interhospital, and posthospital (readmission for revascularization following initial hospitalization) phases. African-American and Hispanic patients grouped together as "minority" due to small numbers.	Authors found differences in likelihood of receipt of procedures during nearly every phase of treatment for different racial and payor groups. Whites, those with private insurance, and those with more severe heart disease were more likely to gain initial admittance to hospitals providing revascularization services. Once hospitalized, whites, males, those with private insurance, and those with more severe disease were more likely to actually receive revascularization. These same patterns were observed among those patients not initially admitted to hospitals offering revascularization but who later received revascularization upon re-admittance or transfer. In logistic regression analyses to assess odds of receiving revascularization during any admission, whites were more likely to receive revascularization (odds ratio = 1.49 [no CI reported]), as were the privately insured.	-Relatively small number of minorities. -Administrative data, lack of clinical detail. -Retrospective study.
Series of logistic regression models to assess relationship between use of invasive procedures and ethnicity, controlling for primary	African Americans were less likely than whites to receive bypass graft (odds ratio = 0.62, 95% CI 0.56 to 0.69) and angioplasty (odds ratio = 0.80, 95% CI 0.72 to 0.88). Latinos	-Retrospective. -Administrative records used. -Proxy used for co-morbidity and income.

TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
	County residents with possible ischemic heart disease.	hospitals following angiography, CABG, or angioplasty. National Hospital Discharge Survey records of 10,348 patients (9,289 white, 159 African American) hospitalized with AMI.	
Giles et al., 1995	Assessed race and sex differences in rate of receipt of catheterization, PTCA, or coronary artery bypass surgery (CABS).		
Maynard, Every, Martin, and Weaver, 1995	Implications of less intensive use of revascularization in black patients on long-term survival.	420 black and 10,834 patients hospitalized for acute myocardial infarction in metropolitan Seattle from 1988 to 1994.	

Analyses	Findings	Limitations
<p>diagnosis, age, gender, insurance type, income (proxy), co-morbidities, and differences among hospitals in volume of invasive procedures.</p>	<p>were less likely to receive angiography (odds ratio = 0.90, 95% CI 0.85 to 0.95). Asian Americans did not differ from whites in invasive cardiac procedure rates, although all three ethnic groups were less likely to receive procedures than whites when hospital procedure volume was not controlled.</p>	
<p>Logistic regression analysis adjusting for age, type of health insurance, hospital size and type, region, in-hospital mortality, and hospital transfer rates to assess differences in rates of procedures by race. Analyses also performed to match individuals admitted to the same hospital and who did not undergo a procedure. Analyses limited to procedures occurring during initial hospitalization.</p>	<p>Significant differences by race and gender were found after statistical adjustment and patient matching procedure. With white males as the referent, black men were less likely to receive catheterization (odds ratio = 0.67, 95% CI 0.51 to 0.87) or CABS (odds ratio = 0.63, 95% CI 0.44 to 0.90), while black women were less likely to receive catheterization (odds ratio = 0.50, 95% CI 0.37 to 0.68), PTCA (odds ratio = 0.42, 95% CI 0.23 to 0.76) or CABS (odds ratio = 0.37, 95% CI 0.22 to 0.62). Among only those patients who underwent catheterization (and therefore had access to a cardiologist), black women were less likely to receive subsequent PTCA or CABS.</p>	<ul style="list-style-type: none"> <li>-Administrative data.</li> <li>-Retrospective.</li> <li>-No controls for SES.</li> <li>-May only be able to generalize to patients with more severe disease.</li> </ul>
<p>Logistic regression to assess racial differences in age-adjusted hospital mortality and use of revascularization. Log rank statistic used to determine differences in survival.</p>	<p>No significant differences found in proportion of black and white patients receiving thrombolytic therapy or cardiac catheterization. After adjusting for use of cardiac catheterization, percent professionals in census block, history of prior coronary surgery, history of angina, use of thrombolytic therapy, sex, and history of congestive heart failure, black patients 40% less likely to undergo revascularization (odds ratio = 0.60, 95% CI 0.45 to 0.81, <math>p = 0.0008</math>).</p> <p>After adjustment race was not associated with long-term survival.</p>	<ul style="list-style-type: none"> <li>-Relatively small sample of African-American patients.</li> <li>-Racial/ethnic groups other than African American and white not assessed.</li> <li>-SES estimated by census blocks.</li> </ul>

TABLE B-1 Continued

<b>Analgesia</b>			
Source	Procedure/Illness	Sample	Analyses
Peterson, Wright, Daley, and Thibault, 1994	Racial differences in procedure use and survival following acute myocardial infarction (AMI) within Department of Veterans Affairs.	33,641 (29,119 white, 4,522 African American) male veterans discharged with diagnosis of AMI from January 1988 to December 1990.	
Ayanian, Udvarhelyi, Gatsonis et al., 1993	Assessed racial differences in rates of coronary revascularization following angiography and relationship of these differences to hospital characteristics.	27,485 Medicare Part A enrollees (26,389 white, 1,096 African American) who underwent inpatient coronary angiography in 1987.	
Whittle, Conigliaro, Good, and Lofgren, 1993	Racial differences in use of cardiovascular procedures in Department of Veterans Affairs.	Retrospective study of 428,300 male veterans (74,570 African American, 353,730 white) discharged from VA hospitals with diagnoses of cardiovascular disease or chest pain between 1987 and 1991.	

Analyses	Findings	Limitations
<p>Logistic regression to assess effect of race on use of cardiac catheterization, coronary angioplasty, coronary bypass surgery, and overall coronary revascularization. Likelihood ratios calculated for 30-day, 1-year, and 2-year survival. Analyses adjust for age, cardiac complications, number of secondary diagnoses, previous hospitalization, hospital location, on-site availability of cardiac catheterization and bypass surgery, and year of admission.</p>	<p>After adjustment, as compared to white patient, African Americans 33% less likely to undergo cardiac catheterizations within 90 days of AMI (odds ratio = 0.67, 95% CI 0.62 to 0.72); 54% less likely to undergo coronary bypass surgery within 90 days of AMI (odds ratio = 0.46, 95% CI 0.40 to 0.53), and 42% less likely to undergo angioplasty within 90 days of AMI (odds ratio = 0.58, 95% CI 0.48 to 0.66). The black/white ratio for any cardiac revascularization procedure within 90 days of AMI was 0.46 (95% CI 0.41 to 0.52). African Americans more likely to survive 30 days following AMI compared to whites (adjusted odds ratio = 1.18, 95% CI 1.07 to 1.31). No differences found between races for 1 or 2-year survival rates.</p>	<p>-Racial ethnic groups other than white and African American not included.                      -Administrative database.                      -Retrospective study.                      -No controls for SES.</p>
<p>Logistic regression analyses to predict revascularization, controlling for age, sex, region, Medicaid eligibility, principal diagnosis, secondary diagnoses, and hospital characteristics.</p>	<p>African Americans were less likely than whites to receive a revascularization procedure (w/b adjusted odds ratio = 1.78, 95% CI 1.56 to 2.03). Greater use of revascularization occurred in public, private, teaching, nonteaching, and urban/suburban hospitals, and in hospitals where revascularization procedures were available, as well as in hospitals where such procedures were not available, after controlling for patient demographic and clinical factors. No significant black/white differences in rates of revascularization were found in rural hospitals.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Relatively small sample of African-American patients.                      -Administrative data set.                      -Retrospective study.</p>
<p>Logistic regression to assess association of race with use of procedures controlling for diagnosis, region, age, co-morbidity, marital status, year of diagnosis, whether CABG performed at hospital where diagnosis made.</p>	<p>After adjustment, white patients more likely than African American patients to undergo cardiac catheterization (odds ratio = 1.38, 95% CI 1.34 to 1.42), angioplasty (odds ratio = 1.50, 95% CI 1.38 to 1.64), and CABG (odds ratio = 2.22, 95% CI 2.09 to 2.36).</p>	<p>-Racial/ethnic groups other than African American not examined.                      -Retrospective study of administrative data set.                      -No controls for admission practices.</p>



TABLE B-1 Continued

Cardiovascular Disease			
Source	Procedure/Illness	Sample	Analyses
<b>Cerebrovascular Disease</b>			
Mitchell, Ballard, Matchar et al., 2000	Assessed rates of tests and treatment for cerebrovascular disease: noninvasive cerebrovascular tests, cerebral angiography, carotid endarterectomy, anticoagulant therapy, and probability of receiving care from a neurologist.	Inpatient hospital records of 17,437 Medicare patients (15,929 white and 1,508 African American) with a principal diagnosis of transient ischemic attack (TIA).	
Oddone, Horner, Sloane et al., 1999	Racial differences in use of carotid artery imaging in Veterans Affairs Medical Centers.	803 patients (389 African American, 414 white) hospitalized in one of four VA Medical Centers between April 1991 and January 1995	

Analyses	Findings	Limitations
<p>Computed state age- and sex-adjusted rates of CABG for whites and African Americans and evaluated relative to need for care (as indicated by myocardial infarction rate) and supply of physicians (as indicated by the number of thoracic surgeons and cardiologists per 10,000 persons).</p>	<p>Nationally, CABG rate was 27.1 per 10,000 for whites, 7.6 per 10,000 for African Americans. Racial differences were greater in the Southeast, particularly in non-metropolitan areas. Correlation of CABG rates was significantly associated with the density of thoracic surgeons and location in the Southeast for whites, but physician availability and location was not correlated with CABG rates for African Americans.</p>	<p>-Some veterans in study obtained care outside of VA.                      -Administrative data set.                      -Racial/ethnic groups other than white and African American not examined.                      -Retrospective study.                      -Limited information on demographic factors.</p>
<p>Logistic regression adjusting for comorbid illness (including hypertension and prior history of stroke), ability to pay (proxy based on dual Medicaid-Medicare eligibility and area of residence), and other clinical and demographic variables.</p>	<p>After adjusting for patient, illness, and provider characteristics, African Americans were 83% as likely as whites to receive noninvasive cerebrovascular testing (95% CI 0.73 to 0.93). Among those receiving noninvasive testing, African Americans were 54% as likely to receive cerebral angiography (95% CI 0.36 to 0.80), and among those receiving angiography, the odds of African Americans receiving carotid endarterectomy was 0.27 (95% CI 0.09 to 0.78). African Americans were 62% as likely to receive anticoagulant therapy, but this difference not statistically significant given small number of African-American subjects. African-American patients were 21% less likely to receive care from a neurologist (95% CI 0.69 to 0.90).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Retrospective study.                      -Administrative data.</p>
<p>Logistic regression to determine adjusted odds ratios for receiving any carotid artery imaging. Models adjust for age, comorbidity,</p>	<p>African American patients were less likely to have an imaging study of their carotid arteries (22% vs. 45%, <math>p = 0.001</math>). Race remained an independent predictor of imaging after adjusting</p>	<p>-Retrospective study reviewing medical records.                      -Very small number of African Ameri-</p>

TABLE B-1 Continued

<b>Cerebrovascular Disease</b>			
Source	Procedure/Illness	Sample	Analyses
		with ICD-9 diagnoses of either transient ischemic attack, ischemic stroke, or amaurosis fugax. Record review of clinical data.	
<b>Children's Health Care</b>			
Weech-Maldonado et al., 2001	Parents' ratings and reports of pediatric care under Medicaid Managed Care by race, ethnicity, and primary language.	Responses for over 9,000 children (842 Hispanic, 1,344 African American, 131 Asian, 330 American Indian, 6,329 white, 111 other) from the National Consumer Assessment of Health Plans Benchmarking Database 1.0 Data from 33 HMOs from Arkansas, Kansas, Minnesota, Oklahoma, Vermont, and Washington state.	

Analyses	Findings	Limitations
<p>linical presentation, anticipated operative risk, and hospital.</p>	<p>for clinical factors (odds ratio = 1.50, 95% CI 1.06 to 2.13). Whites were significantly more likely to be assessed as appropriate candidates for surgery using RAND criteria (18% vs. 4%, <math>p = 0.001</math>) because of higher prevalence of significant carotid artery stenosis. RR of carotid endarterectomy for whites compared to African Americans was 1.34 (95% CI 0.70 to 2.53).</p>	<p>cans received procedure.                      -Study limited to hospitalized patients.                      -No controls for SES.</p>
<p>Ordinary least squares regression to assess the effect of race/ethnicity, Hispanic language, and Asian language on ratings and reports of care, controlling for parent age, gender, education, and child's health status. Care domains examined include doctor/nurse rating, health care rating, health plan rating, timeliness of care, provider communication, staff helpfulness, and plan service.</p>	<p>Compared with whites, Asian/other reported worse care across several domains [getting needed care (<math>\beta = -8.11, p &lt; 0.05</math>), timeliness of care (<math>\beta = -18.65, p &lt; 0.001</math>), provider communication (<math>\beta = -17.19, p &lt; 0.001</math>), staff helpfulness (<math>\beta = -20.10, p &lt; 0.001</math>), plan service (<math>\beta = -10.95, p &lt; 0.001</math>)]. English-speaking Asian parents did not differ significantly from whites on any reports of care. Spanish-speaking Hispanic parents reported more negative care than whites on timeliness of care (<math>\beta = -9.24, p &lt; 0.01</math>), provider communication (<math>\beta = -4.37, p &lt; 0.05</math>) staff helpfulness (<math>\beta = -6.09, p &lt; 0.05</math>), and plan service (<math>\beta = -6.93, p &lt; 0.001</math>). English-speaking Hispanic parents did not differ from whites on any reports of care. African-American parents scored lower than whites on reports of getting needed care (<math>\beta = -3.52, p &lt; 0.05</math>), timeliness of care (<math>\beta = -4.53, p &lt; 0.01</math>), and plan service (<math>\beta = -4.29, p &lt; 0.001</math>). American Indians had worse reports of care than whites for getting needed care (<math>\beta = -9.12, p &lt; 0.05</math>), timeliness of care (<math>\beta = -3.52, p &lt; 0.01</math>), provider communication (<math>\beta = -3.27, p &lt; 0.05</math>), and plan service (<math>\beta = -4.12, p &lt; 0.01</math>).</p>	<p>-No controls for other SES characteristics such as income, occupation                      -No examination of clinical meaningfulness of differences in reports and ratings of care.                      -Mail and telephone surveys, data did not identify surveys administered in English vs. Spanish.</p>

TABLE B-1 Continued

Children's Health Care

Source	Procedure/Illness	Sample	Analyses
Furth et al., 2000	Access to kidney transplant list.	3,284 patients < 20 years of age (1,122 black, 2,162 white) with ESRD who had first dialysis between January 1, 1988, and December 31, 1993.	
Hampers et al., 1999	Assess whether language barriers between patients and physicians were associated with differences in diagnostic testing and length of stay.	Prospective investigation of 2,467 patient visits to Emergency Department between September and December 1997 (413 white, 557 African American, 1,284 Hispanic, 124 other, 89 NA). 286 families did not speak English, representing a language barrier for the physician in 209 cases.	
Zito, Safer, dosReis, and Riddle, 1998	Psychotropic medication use.	99,217 African-American (60,868) and white (38,349) youths ages five through 14, who were Medicaid recipients in the state of Maryland seen in ambulatory settings.	
Hahn, 1995	Use of prescription medications.	Two samples of children: 1) ages one to five ( $n = 1,347$ ), and 2) ages 6 to 17 ( $n = 2,155$ ) who had at least one ambula-	

Analyses	Findings	Limitations
<p>Cox proportional hazard analysis to examine independent effect of race on the time from first dialysis for ESRD until first activation on cadaveric transplant waitlist for index transplant controlling for confounding factors (age, gender, cause of ESRD, SES, incident year of ESRD, ESRD network, facility characteristics).</p>	<p>Controlling for confounders, black patients were 12% less likely than white patients to be activated on the kidney transplant wait list (relative hazard = 0.88, 95% CI 0.79 to 0.97). In addition, after controlling for confounders, the relative hazard for black patients in the lowest SES quartile being activated on the wait list was 0.84 (95% CI 0.70 to 1.01) compared to relative hazard of 1.0 (95% CI 0.8 to 1.3) for black patients in the highest SES quartile.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -Potential confounds such as co-morbidities, appropriateness not examined.</p>
<p>Mann-Whitney U tests used to compare total charges among groups. Analysis of covariance used to assess predictors of total charges and length of ED stay. Race/ethnicity, insurance status, provider training, patient care setting, and triage category, patient age, patient vital signs, included in models to isolate effect of language barrier.</p>	<p>The presence of a language barrier accounted for a \$38 increase in charges for testing (<math>F = 14.1, p &lt; 0.001</math>) and 20 minute longer ED stay (<math>F = 9.1, p = 0.003</math>).</p>	<p>-No independent or family verification of language barrier.                      -No full control for complexity of cases                      -No controls for use of professional interpreter or ad hoc interpreter                      -Single site</p>
<p>Logistic regression to estimate the probability of psychotropic medication use as a function of race and region. The effect of race controlling for region and interaction of race and region were analyzed.</p>	<p>Caucasians were twice as likely to receive psychotropic prescriptions compared with African Americans after adjusting for geographic region (odds ratio = 1.97, 95% CI 1.84 to 2.12). The interaction of race and region was significant (<math>\chi^2 = 23.3, df = 7, p &lt; 0.001</math>), such that the odds of receiving psychotropic medications differed by geographic region (range 1.23 to 2.60).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -One geographic location.                      -Administrative data.                      -Retrospective study.                      -Potential confounds such as income, service use, and provider specialties not assessed.</p>
<p>Logistic and multiple regression used to assess the probability of receiving a prescription medication and</p>	<p><i>For children ages one to five:</i>                      1) Black children (odds ratio = 0.532) were half as likely to receive prescription medication compared with white</p>	<p>-Administrative data.</p>

**TABLE B-1** Continued

**Children's Health Care**

Source	Procedure/Illness	Sample	Analyses
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tory care visit in 1987. Data were obtained from the Household Component of the National Medical Expenditure Survey (NMES).

Analyses	Findings	Limitations
	<p>children (odds ratio = 1.0) (<math>p &lt; 0.001</math>). Adding health factors to the model did not change relationships. However, addition number of physician visits reduced differences, such that they were no longer significant. There was no difference in the probability of receiving medication for Hispanic children compared with white children.</p> <p>2) After controlling for age, maternal education, insurance, poverty status, source of care, geographic location, health status, # bed days, # reduced activity days, and physician visits, black children received the fewest number of medications. The average number of medications for black children was 86.5% compared to that of white children, while Hispanic children averaged 94.1% compared to that of white children.</p> <p><i>For children ages six to 17:</i></p> <p>1) Black (odds ratio = 0.536) and Hispanic (odds ratio = 0.621) children were less likely to receive any prescription medication compared to white (odds ratio = 1.0) children. The addition of health factors, and number of physician visits did not change these relationships (odds ratio = 0.601, <math>p &lt; 0.001</math>, odds ratio = 0.697, <math>p &lt; 0.01</math> respectively).</p> <p>2) After controlling for age, maternal education, insurance, poverty status, source of care, geographic location, health status, # bed days, # reduced activity days, and physician visits, black children received the fewest number of medications. The average number of medications for black children was 89.7% compared to that of white children, and 92.1% for Hispanic children compared to that of white children.</p>	



**TABLE B-1** Continued

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**Diabetes**

Source	Procedure/Illness	Sample	Analyses
Chin, Zhang, and Merrell, 1998	Assessed quality of care and resource utilization among African-American and white patients with diabetes.	1,376 African-American and white Medicare beneficiaries with diabetes (14% African Americans).	

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**Emergency Services**

Lowe et al., 2001	Assessed racial differences in denial of authorization for emergency department (ED) care by managed care gatekeepers.	15,578 African-American and white patients who sought care in an urban hospital emergency department.	
Baker, Stevens, and Brook, 1996	Assessed racial differences in emergency department use.	1,049 patients (295 African American, 237 white, 517 Hispanic) registered for non-emergency medical problems in the Harbor-UCLA Medical Center Emergency Department.	

Analyses	Findings	Limitations
<p>Linear and logistic regression to assess independent contribution of race to health status, quality of care, and resource utilization, controlling for sex, education, and age. Measures included patient survey, ADA and RAND criteria for quality of care, and Medicare reimbursement.</p>	<p>African-American patients were less likely to have measurement of glycosylated hemoglobin (adjusted odds ratio = 0.65, 95% CI 0.48 to 0.88) lipid testing (odds ratio = 0.66, 95% CI 0.48 to 0.89), ophthalmological visits (odds ratio = 0.72, 95% CI 0.56 to 0.93), and influenza vaccinations (odds ratio = 0.26, 95% CI 0.19 to 0.36).                      African-American patients were more likely to use the ED (39% vs. 29%, <math>p &lt; 0.01</math>) and had fewer physician visits (8.4 vs. 9.7 visits per year, <math>p &lt; 0.05</math>). In addition, African-American patients had higher reimbursement for home health services, however, once adjusting for case-mix variables race was not associated.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Confounds such as hospital characteristics, appropriateness, and comorbidities not examined.</p>
<p>Multiple logistic regression to assess racial differences in authorization for emergency department services.</p>	<p>After adjusting for patients' age, gender, day, and time of ED visit, type of Managed Care Organization (MCO) and triage category, African Americans were more likely to be denied authorization for care (odds ratio = 1.52, 95% CI 1.18 to 1.94). Patients who were covered by a Medicaid MCO (odds ratio = 1.50, 95% CI 1.19 to 1.90) or those covered with MCOs with mixed Medicaid and commercial patient populations (odds ratio = 2.05, 95% CI 1.41 to 2.98) were more likely than those covered by purely commercial MCOs to be denied authorization for care.</p>	<p>-Racial groups other than African American and white not assessed.                      -Single site.</p>
<p>Logistic regression to assess independent effect of race/ethnicity on ED use.</p>	<p>19% of African Americans, 13.2% of whites and 11.3% of Hispanic patients reported two or more previous ED visits (in preceding three months) (<math>p = 0.01</math> across groups) (unadjusted odds ratio 1.82 for</p>	<p>-Sample obtained at one site, selective enrollment.                      -Cross-sectional survey.</p>

TABLE B-1 Continued

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Emergency Services

Source	Procedure/Illness	Sample	Analyses
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Eye Care

Devgan, Yu, Kim, and Coleman, 2000

Surgical treatment of glaucoma in African-American Medicare beneficiaries.

Retrospective cohort analysis of 30,495 African-American and 160,792 white patients over 65 years of age undergoing argon laser trabeculoplasty or trabeculectomy surgery between 1991 and 1994.

Wang, Javitt, and Tielsch, 1997

Glaucoma and cataract treatment.

642,048 Medicare beneficiaries (606,069 white, 35,979 black) age 65 and older who used eye care services. Patients with physician-diagnosed glaucoma or cataract who underwent surgical treatment.

Analyses	Findings	Limitations
	<p>African Americans compared with Hispanics). After adjusting for age, insurance status, regular source of care, and transportation difficulties, ethnicity was not significantly associated with two or more ED visits in the preceding three months (adjusted odds ratio for Hispanics compared with African Americans 1.48, 95% CI 0.95 to 2.3 and adjusted odds ratio for Hispanics compared with whites was 1.22, 95% CI 0.74 to 2.00).</p>	
<p>Age and sex adjusted rates of argon laser trabeculoplasty and trabeculectomy surgery were obtained and compared with surgery rates expected based on disease prevalence.</p>	<p>For each age and age-sex subgroup, the rate of surgical procedures is higher in African Americans compared to whites. The age-sex-adjusted rate ratio was 2.14 (95% CI 2.11 to 2.16). Assuming treatment should be performed in proportion to age-race prevalence, African Americans underwent glaucoma surgery at 47% below expected rate (expected rate: 5.52 procedures per 1,000 person-year of enrollment, adjusted rate: 2.95 procedures per 100 person-year enrollment).</p>	<ul style="list-style-type: none"> <li>-Administrative data base.</li> <li>-Data does not contain information on beneficiaries who may be enrolled in HMOs or VA hospitals.</li> <li>-Racial/ethnic groups other than African American and white not analyzed.</li> </ul>
<p>Black-white relative risk of having a physician-diagnosed condition and surgical treatment were compared to the expected value based on population survey data for each specific disease.</p>	<p>Black patients used eye care services at two-thirds the rate of white patients (age gender adjusted RR = 0.67, 95% CI 0.66 to 0.68). Black women were 73% as likely to use services as white women, while black men were 56% as likely to use services. Among users of eye care services, black patients were 2.2 times more likely than whites to be diagnosed with glaucoma, after adjusting for age and gender (RR = 2.17, 95% CI 2.12 to 2.22). In addition, among users of eye care services, blacks had lower than expected rates of treatment for glaucoma (observed RR = 3.2, 95% CI</p>	<ul style="list-style-type: none"> <li>-Administrative database.</li> <li>-Differential presentation for care based on severity can not be ruled out.</li> <li>-Other clinical confounds may exist.</li> </ul>

TABLE B-1 Continued

Eye Care			
Source	Procedure/Illness	Sample	Analyses
<b>Gallbladder Disease</b>			
Arozullah, Ferreira, Bennett et al., 1999	Racial variation in rate of adoption of laparoscopic cholecystectomy procedure in Department of Veterans Affairs Medical System. Mortality and length of hospital stay also examined.	16,181 patients (14,249 Caucasian and 1,932 African American) diagnosed with gall bladder or biliary disease who underwent either open cholecystectomy or laparoscopic cholecystectomy. Data were collected through: a) record review of claims files, and b) prospectively compiled clinical data from records and interview, for the year before the new procedure was introduced and the first four years of use of the procedure (1991-1995).	

Analyses	Findings	Limitations
	<p>3.1 to 3.4 vs. expected RR of 4.3, 95% CI 3.5 to 5.4), but a higher treatment rate for cataract (RR = 1.2, 95% CI 1.2 to 1.3). Among patients with physician diagnosed glaucoma and cataract, black patients were more likely to undergo surgical treatment for these diagnoses than white patients (RR = 1.5 for glaucoma, 95% CI 1.4 to 1.5; RR = 1.2 for cataract, 95% CI 1.2 to 1.3).</p>	
<p>Modified multiple logistic regression model to predict the use of laparoscopic versus open cholecystectomy. Predictors included race, age, marital status, hospital geographic location, co-morbid illnesses, and year of surgery. To examine mortality and length of stay, multiple logistic regression equations used. Predictors included age, gender, marital status, coexisting medical condition, geographic region, year of care, and type of cholecystectomy.</p>	<p><i>Claims data</i> indicate that after controlling for confounding variables, African-American patients who underwent cholecystectomy were 25% less likely as white patients to undergo the laparoscopic procedure (adjusted odds ratio = 0.74, 95% CI 0.66 to 0.83). The shortening of postoperative length of hospital stay (from 9 to &lt; 4.5 days with new procedure) occurred in the first year for white patients and in the fourth year for African-American patients (<math>p &lt; 0.001</math>).</p> <p><i>Clinical data</i> indicate that after adjustment, African-American patients were 0.68 times as likely to undergo the laparoscopic procedure (95% CI 0.55 to 0.84).</p>	<ul style="list-style-type: none"><li>-Administrative data set.</li><li>-Racial/ethnic groups other than African American not examined.</li></ul>

TABLE B-1 Continued

HIV/AIDS

Source	Procedure/Illness	Sample	Analyses
Shapiro, Morton, McCaffrey et al., 1999	Assessed racial/ethnic, gender, and other sociodemographic variations in care (number of care-seeking visits and use of protease inhibitors [PI] or nonnucleoside reverse transcriptase inhibitors [NNRTI]) for persons infected with HIV.	Multistage probability sample of 2,846 individuals, including African-American and Hispanic patients, using data from the HIV Costs and Services Utilization Study.	
Bennett, Horner, Weinstein et al., 1995	Assessed quality of care for pneumocystis carinii pneumonia (PCP) among white, Hispanic and African-American patients with HIV receiving care in either Veterans Administration (VA) hospitals or non-VA systems.	Retrospective chart review of a cohort of 627 VA patients and 1,547 non-VA patients with treated or cytologically confirmed PCP who were hospitalized from 1987 to 1990.	
Moore, Stanton, Gopalan, and Chaisson, 1994	Assessed use of anti-retroviral drugs and prophylactic therapy to treat pneumocystis carinii pneumonia (PCP) in an urban population infected with HIV.	838 African-American, Hispanic, and white patients presenting at an urban HIV clinic from March 1990 through December 1992. Data obtained through interview and record review with six-month follow-up.	

Analyses	Findings	Limitations
<p>Logistic regression to predict use of PI and NNRTI, prophylaxis against pneumocystis carinii pneumonia (PCP), use of antiretroviral medication, hospitalizations, ambulatory visits, and emergency department visits.</p>	<p>Adjusting for insurance status, CD4 cell count, sex, age, method of exposure to HIV, and region of country, African-American and Hispanic patients were 24% less likely than whites to receive PI or NNRTI at initial assessment, although this disparity declined to 8% at the final assessment stage, a difference that remained statistically significant (<math>p = 0.016</math>). On average, blacks waited 13.5 months to receive these medications, compared to 10.6 months for whites (<math>p &lt; 0.001</math>).</p>	<p>-Potential confounds such as co-morbidities, SES not assessed.</p>
<p>Logistic regression to predict diagnostic procedures (use and timing of bronchoscopy) and use and timing of PCP medications, controlling for insurance status, age, sex, risk group status, severity of PCP illness at admission, use of medications prior to admission, type of hospital, and hospital volume of patients with AIDS.</p>	<p>For all patients, regardless of the type of hospital in which they were treated, use of anti-PCP medications was initiated within two days of admission for 70% to 77% of patients. Approximately 60% of patients underwent a bronchoscopy at some point during hospitalization. Black and Hispanic patients at non-VA hospitals were more likely to die during hospitalization, and were less likely to undergo bronchoscopy in the first two days of admission. No racial differences were found in use of bronchoscopy, receipt of anti-PCP medications within two days of admission, or mortality in VA hospitals.</p>	<p>-Retrospective study.                      -No controls for SES, co-morbidities.</p>
<p>Logistic regression to predict receipt of antiviral agents or PCP prophylaxis, adjusting for patient income, insurance status, mode of HIV transmission, and place of residence.</p>	<p>No racial differences were found in the stage of HIV disease at the time of presentation. However, 63% of eligible whites, but only 48% of eligible blacks received antiretroviral therapy, and PCP prophylaxis was received by 82% of eligible whites and only 58% of eligible blacks. African-American patients were significantly less likely than whites to receive antiretroviral therapy (odds ratio = 0.59, 95% CI 0.38 to 0.93) or PCP prophylaxis (odds ratio = 0.27, 95% CI 0.13 to 0.56). Whites were more likely to report a usual source of care (59%) than African Americans (34%, <math>p &lt; 0.001</math>).</p>	<p>-Single site.                      -Confounds such as comorbidities not assessed.</p>



TABLE B-1 Continued

Maternal and Infant Health

Source	Procedure/Illness	Sample	Analyses
Aron, Gordon, DiGiuseppe et al., 2000	Cesarean delivery rates.	25,697 women (19,996 white, 5,701 nonwhite) with no prior history of cesarean delivery admitted to 21 northeast Ohio hospitals from January 1993 through June 1995. Data were obtained from Cleveland Health Quality Choice.	
Barfield, Wise, Rust et al., 1996	Civilian vs. military outcomes in prenatal care utilization, birth weight distribution, and fetal and neonatal mortality rates.	2,171,147 births for African- American and white mothers [79,154 in military hospitals (16.2% AA), 2,091,993 in civilian hospitals (9.5% AA)] recorded from 1981 to 1985 in the Maternal and Child Health database compiled by the Community and Organi- zation Research Institute of the University of California – Santa Barbara.	

Analyses	Findings	Limitations
<p>Nested (to account for clustering of patients in individual hospitals and provide more robust estimates of variance of group effects) logistic regression used to yield odds ratios for cesarean delivery in non-white patients relative to whites and for patients with government insurance or who were uninsured relative to patients with commercial insurance. Analyses were adjusted for 39 risk factors.</p>	<p>Overall rates of cesarean delivery were similar in white and nonwhite (over 90% African-American) patients. After adjusting for clinical risk factors, non-white women were more likely to deliver via cesarean (odds ratio = 1.34, 95% CI 1.14 to 1.57, <math>p &lt; 0.001</math>). Analysis also indicated that insurance status independently influences use of cesarean delivery.</p>	<p>-Results may reflect regional characteristics.                      -Retrospective study.                      -No assessment of appropriateness or necessity of cesarean.</p>
<p>Relative risks and Mantel-Haenszel Chi-square analyses for stratified comparisons were calculated.</p>	<p><i>Prenatal care utilization:</i> utilization was lower for black patients than white patients in both military (RR = 0.79, 95% CI 0.75 to 0.82) and civilian (RR = 0.51, 95% CI 0.50 to 0.52) populations. However, the magnitude of the disparity was lower in the military population (<math>p &lt; 0.001</math>).</p> <p><i>Birth weight:</i> for military and civilian groups black patients had higher rates of very low birth weight and moderately low birth weight, however, rates were significantly lower in the military group. For example in the very low-birth-weight category, the rate for black births was lower than the rate for black civilian births (RR = 0.68, 95% CI 0.56 to 0.82). For white patients the military rates of very low birth weight (RR = 0.75, 95% CI 0.65 to 0.87) were also significantly lower than their civilian counterparts.</p> <p><i>Fetal and neonatal mortality:</i> For military and civilian groups, mortality was significantly higher for black patients. While fetal mortality rates for white</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -Observational study, no control for insurance in civilian group, SES, co-morbidities.</p>

TABLE B-1 Continued

Maternal and Infant Health

Source	Procedure/Illness	Sample	Analyses
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Braveman, Egerter, Edmonston, and Verdon, 1995	Cesarean delivery rates.	217,461 singleton first live births (15,529 African American, 19,142 foreign-born Asian, 62,303 foreign-born Latina, 26,802 U.S.-born Latina, 93,685 white) among women in California in 1991.	
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Brett, Schoendorf, and Kiely, 1994	Use of prenatal care technologies (ultrasonography, tocolysis, amniocentesis).	Births among non-Hispanic black and non-Hispanic white women in 1990 (3.1 million available for ultrasonography, 3.2 million for tocolysis, 37,000 for amniocentesis). Data were obtained from the National Center for Health Statistics.	
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Analyses	Findings	Limitations
Multiple logistic regression to determine adjusted odds ratios of cesarean delivery by race/ethnicity.	<p>patients were similar for military and civilian groups, rates for black military groups were significantly lower than their civilian counterparts (RR = 0.80, 95% CI 0.65 to 0.99).</p> <p>After adjusting for covariates (insurance, personal, community, medical, and hospital characteristics), African-American women were 24% more likely to undergo cesarean than whites (adjusted odds ratio = 1.24, 95% CI 1.18 to 1.31). U.S.-born Latinas were also at an elevated risk compared to whites (adjusted odds ratio = 1.07, 95% CI 1.03 to 1.12). Among women residing in 25% or more non-English speaking communities, who delivered high-birth weight babies or who gave birth at for-profit hospitals, cesarean delivery was more likely among nonwhites and was over 40% more likely among black women than white women (odds ratio = 1.51, 95% CI 1.20 to 1.89; odds ratio = 1.42, 95% CI 1.21 to 1.67; odds ratio = 1.42, 95% CI 1.20 to 1.68, respectively).</p>	<p>-Data collected in single region.                      -Retrospective study.</p>
Logistic regression was used to estimate likelihood of tocolysis and Mantel-Haenszel to estimate use of ultrasonography and amniocentesis. Confounders controlled for include: maternal age, education, marital status, location of residence, birth order, timing of first prenatal care visit, and plural births.	<p>Amniocentesis was used substantially less frequently by black women (adjusted RR = 0.58, 95% CI 0.56 to 0.60). Ultrasonography was received by black women slightly less frequently than white women (adjusted RR = 0.88, 95% CI 0.87 to 0.88). Black women with singleton births were slightly more likely to receive tocolysis than white women (adjusted RR = 1.06, 95% CI 1.04 to 1.09), although the risk of idiopathic pre-term delivery is estimated to be three times higher in black women. Women with plural births received tocolysis two thirds as often as white women (adjusted RR = 0.69, 95% CI 0.62 to 0.75).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -No controls for hospital characteristics, many prenatal care details (e.g., time of procedure), regional differences in practices, appropriateness of procedure.</p>

**TABLE B-1** Continued

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**Maternal and Infant Health**

Source	Procedure/Illness	Sample	Analyses
Kogan, Kotelchuck, Alexander, and Johnson, 1994	Self-reported receipt of prenatal care advice from providers.	8,310 women (6,782 white non-Hispanic and 1,532 black women) who participated in the 1988 National Maternal and Infant Health Survey conducted by the National Center for Health Statistics.	

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**Mental Health**

Kales, Blow, Bingham et al., 2000	Impact of race on mental health care utilization among veterans.	Retrospective study of 23,718 patients (859 Hispanic, 3,529 African American, 19,330 white) age 60 and older hospitalized for psychiatric diagnoses treated in Department of Veterans Affairs inpatient facilities in 1994.	
Melfi, Groghan, Hanna, and Robinson, 2000	Antidepressant treatment.	13,065 Medicaid patients diagnosed with depression treated between 1989-1994.	

Analyses	Findings	Limitations
<p>Logistic regression to assess contribution of race to mothers' report of receipt of advice or instructions during any of their prenatal visits on: breast-feeding, alcohol consumption, tobacco, and use of illegal drugs. Analyses controlled for age, marital status.</p>	<p>After adjustment for covariates, more white women reported receiving advice for alcohol (odds ratio = 1.29, 95% CI 1.10 to 1.51) and smoking cessation (odds ratio = 1.20, 95% CI 1.01 to 1.39). Breast-feeding promotion just missed significance with a trend toward more advice for white women. A significant interaction between race and marital status emerged, such that black single women were 1.4 times more likely than single white women to not receive advice on drug cessation, while there were no racial differences among married women.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Data self-report.</p>
<p>ANCOVA to test for group differences in inpatient psychiatric variables. Covariates included age, medical co-morbidity, psychiatric co-morbidity, and survival months. Analyses also performed for outpatient variable (outpatient visits).</p>	<p>After adjustment, African-American patients had significantly fewer outpatient psychiatric visits (least-squares means: H = 15.9 visits, AA = 15.3 visits, W = 22.3 visits, <math>W &gt; AA</math>, <math>p &lt; 0.02</math>). Similarly, African-American patients with substance abuse disorders had significantly more outpatient psychiatric visits than white patients (least-squares means: H = 19.4 visits, AA = 23.2 visits, and W = 13.2 visits, <math>AA &gt; W</math>, <math>p &lt; 0.0001</math>).</p> <p>No significant differences found in inpatient care.</p>	<p>-Administrative database.                      -Potential confounds such as medication dosing/response, treatment compliance, illness course, personal resources not measured.                      -Relatively few Hispanics in sample.</p>
<p>Bivariate tests between those who did and did not receive antidepressants and between racial categories. Logistic regressions to examine determinants of receiving antidepressants. Covariates included age, gender, Medicaid eligibility status, year of initial depression, if initial care received</p>	<p>44% of whites and 27.8% blacks received antidepressant treatment within 30 days of 1st indicator of depression (<math>p &lt; 0.001</math>). Whites were more likely to receive antidepressants than black patients (odds ratio = 0.495, 95% CI 0.458 to 0.536, <math>p = 0.0001</math>) and other/unknown racial category patients (odds ratio = 0.749, 95% CI 0.627 to 0.880, <math>p = 0.0006</math>). Blacks were less likely than whites to</p>	<p>-Racial/ethnic groups other than African Americans and whites not assessed.                      -Administrative database.                      -Retrospective study.</p>

TABLE B-1 Continued

Mental Health			
Source	Procedure/Illness	Sample	Analyses
Segal, Bola, and Watson, 1996	Prescription of antipsychotic medications by physicians in psychiatric emergency services.	442 patients (256 white, 107 African American, 47 Hispanic, 10 Asian, 22 "other") seen in psychiatric emergency rooms. Data were obtained through observation of evaluations and record review. Evaluators were primarily psychiatrists (80%) and white (88%).	
Chung, Mahler, and Kakuma, 1995	Inpatient psychiatric treatment.	164 adults (76 African American, 88 white) admitted to acute inpatient setting with Axis I diagnosis of major mood or psychotic disorders.	

Analyses	Findings	Limitations
from mental health provider, number of comorbid conditions.	receive SSRIs (odds ratio = 0.844, 95% CI 0.743 to 0.959, $p = 0.0093$ ) when prior clinical research suggests that blacks are more susceptible than whites to side effects of Tricyclics and therefore should be more likely to receive SSRIs.	-Information not available on severity of depressive disorder.
Analysis of covariance models constructed using least-squares regression or logistic regression to assess the influence of race on five prescription practice indicators. Models controlled for presence of psychotic disorder, severity of disturbance (GAS score), dangerousness, psychiatric history, if physical restraints used, hours spent in the emergency service, clinician's efforts to engage patient in treatment, if optimum time was spent on the evaluation.	More psychiatric medications were prescribed to African Americans than other patients ( $\beta = 0.99, p < 0.005$ ).  African-American patients received more oral doses ( $\beta = 1.21, p = 0.02$ ) and injections ( $\beta = 0.54, p = 0.04$ ) of antipsychotic medications. The 24-hour dosage of antipsychotic medication given to African Americans was significantly higher than for other patients ( $\beta = 862, p < 0.001$ ).  The tendency to overmedicate African-American patients was lower when clinician's efforts to engage the patients in treatment were rated as being higher. Models predicting number of medications, number of oral and injected antipsychotic and 24-hour dosage became non-significant.	-Small number of minorities. -Sites all urban public hospitals in single geographic area. -No controls for SES, hospital characteristics.
ANOVA and Logistic regression to assess effects of race, diagnosis (psychotic vs. nonpsychotic), and socioeconomic status (insurance status) on treatment. Data were obtained through record review.	After controlling for diagnosis and SES, African-American patients had shorter length of stay ( $F = 9.12, df = 1, 150, p = 0.003$ ). In addition, white patients were 3.8 times more likely than African-American patients to be on one-to-one observational status (95% CI 1.6 to 8.9). Analysis of interactions indicated that among high SES patients, African Americans were 3.5 times more likely to receive urine drug screens, regardless of diagnosis ( $n = 109, 95\% \text{ CI } 1.2 \text{ to } 10.1$ ).	-Relatively small sample. -Single site. -Retrospective study. -No assessment of diagnostic validity between the two groups.



**TABLE B-1** Continued

<b>Mental Health</b>			
Source	Procedure/Illness	Sample	Analyses
Padgett, Patrick, Burns, and Schlesinger, 1994	Use of inpatient mental health services.	7,768 persons insured by Blue Cross and Blue Shield Association's Federal Employees Plan in 1983, who had at least one inpatient psychiatric day and random sample of 5,000 nonusers of mental health services.	
<b>Peripheral Vascular Disease</b>			
Guadagnoli, Ayanian, Gibbons et al., 1995	Amputation and leg-sparing surgery for peripheral vascular disease of the lower extremities.	19,236 Medicare patients who underwent amputation or leg-sparing surgery at 3,313 hospitals in the U.S.	

Analyses	Findings	Limitations
<p>Logistic regression developed for each ethnic group to predict probability of at least one day of psychiatric hospitalization and number of inpatient days. Predictors included predisposing factors (education, family size, percentage of county black, Hispanic, or white), enabling factors (region of country, salary, high or low option selected for insurance coverage), and need factors (annual medical expenses, family's annual medical expenses, other family member receipt of inpatient psychiatric care).</p>	<p>No significant differences were found among blacks, whites and Hispanics in the probability of a psychiatric hospitalization or in number of inpatient psychiatric days.</p>	<p>-Administrative data. -Retrospective study. -No assessment of diagnostic validity.</p>
<p>Logistic regression to assess odds of amputation and surgery for black relative to white patients, controlling for case-mix, region, and hospital characteristics.</p>	<p>Black patients were more likely to undergo all forms of amputation than were white patients (unadjusted odds ratio = 1.47 to 2.24). White patients were twice (unadjusted odds ratio = 0.51) as likely to undergo lower-extremity arterial revascularization and almost three times (unadjusted odds ratio = 0.35) more likely to undergo angioplasty than black patients.</p>	<p>-Racial/ethnic groups other than African American and white not examined. -Administrative data. -Retrospective study. -No controls for potential confounds such as SES, disease severity, appropriateness.</p>
	<p>Among patients with diabetes, black patients were 58% more likely than white patients to undergo above the knee amputation (adjusted odds ratio = 1.58, 95% CI 1.32 to 1.90). Black patients who did not have diabetes were twice as likely to undergo the procedure (adjusted odds ratio = 2.13, 95% CI 1.87 to 2.41).</p>	

**TABLE B-1** Continued

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**Peripheral Vascular Disease**

Source	Procedure/Illness	Sample	Analyses
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**Pharmacy**

Morrison, Wallenstein, Natale et al., 2000	Differences in white and nonwhite neighborhoods in pharmacy stocking of opioid analgesics.	Random sample of 30% (347) of New York City pharmacies. Pharmacists surveyed via telephone.	
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**Physician Perceptions**

Thamer, Hwang, Fink et al., 2001	Racial and gender differences in nephrologists recommendations for renal transplantation using hypothetical patient scenarios.	271 nephrologists (72% white, 14% Asian, 5% African American) surveyed as part of the Choices for Health Outcomes in Caring for ESRD (CHOICE) Study. Survey administered between	
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Analyses	Findings	Limitations
	<p>Among patients with diabetes, blacks were 48% and 32% less likely to undergo percutaneous transluminal angioplasty (adjusted odds ratio = 0.52, 95% CI 0.40-0.67) and lower-extremity bypass surgery (adjusted odds ratio = 0.68, 95% CI 0.59 to 0.79), respectively. Among those who did not have diabetes, black patients were 71% less likely to undergo angioplasty (adjusted odds ratio = 0.29, 95% CI 0.23 to 0.37) and 44% less likely to undergo lower-extremity bypass surgery (adjusted odds ratio = 0.56, 95% CI 0.50 to 0.63).</p>	
<p>Generalized linear model to assess relationship between racial/ethnic composition of neighborhoods and opioid supplies of pharmacies. Analyses controlled for proportion of elderly persons at census-block level and crime rates at the precinct level.</p>	<p>Overall, two-thirds of pharmacies that did not carry any opioids were in predominantly nonwhite neighborhoods. After adjustment pharmacies in predominantly nonwhite neighborhoods (&lt; 40% of residents white) were significantly less likely to have adequate opioid supplies than were pharmacies in predominantly white neighborhoods (at least 80% residents white) (odds ratio = 0.15, 95% CI 0.07 to 0.31). Among 176 pharmacies with inadequate stock, reasons were as follows: 54%—little demand for medications, 44%—concern about disposal, 20%—fear of fraud and illicit drug use, 19%—fear of robbery, 7%—other (e.g., problems with reimbursement).</p>	<ul style="list-style-type: none"> <li>-No controls for differences in pharmacy supplies across neighborhoods.</li> <li>-Sample from one site.</li> <li>-Possible reporting errors by pharmacists.</li> <li>-Pharmacists only questioned about opioids recommended as appropriate first-line medications.</li> </ul>
<p>Scenarios presented patient's age, race (white, African American, Asian), gender, living situation, treatment compliance, diabetic status, residual renal function status, HIV</p>	<p>Asian males less likely than white males to be recommended for transplantation (odds ratio = 0.46, (95% CI 0.24 to 0.91). Females were less likely than males to be recommended (adjusted odds ratio = 0.41, 95% CI 0.21 to 0.79). No differences between African-American and white patients were found.</p>	<ul style="list-style-type: none"> <li>-Survey data in lieu of treatment data.</li> <li>-Potential bias in response rate.</li> <li>-No controls for patient SES.</li> </ul>

TABLE B-1 Continued

Physician Perceptions

Source	Procedure/Illness	Sample	Analyses
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June 1997 to June 1998. Response rate 53%.

Weisse, Sorum,  
Sanders, and Syat, 2001

Racial and gender differences  
in pain management.

111 surveyed primary care physicians from Northeast regions of U.S. who were presented vignettes depicting patients with medical complaints, two painful (kidney stone, back pain) and one control (sinusitis). Race and gender of fictitious patients varied. Questions following vignettes assessed physicians' aggressiveness in treating symptoms.

Effect of race and SES on

Analyses	Findings	Limitations
<p>status, weight, and cardiac ejection fraction. Responding physicians asked if they would recommend transplantation given presence of certain criteria. Multiple logistic regression to assess independent effect of nephrologist and patient factors on decision to recommend transplantation. Analyses adjust for patient and neurologist demographics, clinical characteristics, nephrologist training, and organizational affiliations.</p>	<p><i>Kidney stone pain:</i> Decision to treat with hydrocodone did not vary by race. Among physicians who opted to treat with medication, dose of hydrocodone selected did not differ by patient race (white = 308 mg, African American = 271 mg), patient gender, or physician gender. Interaction between physician gender and patient race was found (<math>F_{1,85} = 9.65, p = 0.003</math>). Male physicians prescribed higher doses to white patients than to African Americans, while female physicians prescribed higher doses to African-American patients.</p> <p><i>Back pain:</i> Decision to treat with hydrocodone did not vary by race. Similarly, dose selected did not differ by patient race (white 188 = mg, African American = 233 mg), patient gender, or physician gender. No interactions were observed.</p> <p><i>Sinus Infection:</i> Decision to treat with antibiotic did not differ by patient race or gender. White patients were prescribed a longer course of antibiotics (<math>X = 13.7</math> vs. <math>9.2</math> days, <math>F_{1,87} = 4.90</math>,</p>	<ul style="list-style-type: none"> <li>-Small sample size.</li> <li>-Convenience sample.</li> <li>-Physicians in Northeast, limiting generalizability.</li> <li>-Approximately 50% of solicited physicians participated.</li> <li>-No controls for physician prescribing habits.</li> <li>-Racial/ethnic groups other than white and African American not investigated.</li> <li>-Few racial/ethnic minority physicians in sample.</li> </ul>

TABLE B-1 Continued

Physician Perceptions

Source	Procedure/Illness	Sample	Analyses
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van Ryn and Burke,  
2000

physician perceptions of  
patients.

618 patient encounters  
at eight New York state  
hospitals.

Assessed physicians' recom-  
mendations for managing  
chest pain, using vignettes of  
"patients" that varied only in  
gender and ethnicity.

Patients Perceptions

Doescher et al., 2000

Racial and ethnic differences  
in patients' perceptions of  
their physicians (trust and  
satisfaction).

32,929 patients surveyed  
through the Community  
Tracking Survey, a nationally  
representative sample sur-  
veyed 1996-1997.

Analyses	Findings	Limitations
<p>Logistic regression used to regress physician perception variables on patient race and SES, controlling for each other and patient age, sex, sickness, depression, mastery, social assertiveness, as well as physician age, sex, race, and specialty.</p>	<p><math>p = 0.03</math>) and were prescribed refills more often (<math>X_1^2 = 107</math> vs. <math>4.05</math>, <math>p = 0.04</math>).</p> <p>Black patients rated less positively than white patients on several dimensions including physicians' assessment of patient intelligence (odds ratio = <math>0.51</math>, <math>p \leq 0.01</math>), feelings of affiliation toward the patient (odds ratio = <math>0.68</math>, <math>p \leq 0.05</math>) and beliefs about patient's likelihood of risk behavior (odds ratio = <math>0.58</math>, <math>p \leq 0.02</math>) and adherence with medical advice (odds ratio = <math>0.62</math>, <math>p \leq 0.01</math>).</p>	<ul style="list-style-type: none"> <li>-Potential for social desirability in responses.</li> <li>-Finding limited to one state and narrow sample of patients.</li> <li>-Use of single-item measures.</li> <li>-Differences in care not measured.</li> </ul>
<p>Logistic regression analysis to assess the effects of "patient" race and gender, while controlling for physicians' assessment of the probability of coronary</p>	<p>Physicians were less likely to recommend cardiac catheterization for women than men (odds ratio = <math>0.60</math>, 95% CI <math>0.4</math> to <math>0.9</math>) and African Americans than whites (odds ratio = <math>0.60</math>, 95% CI <math>0.4</math> to <math>0.9</math>). Analysis of race-sex interaction revealed that African-American women were significantly less likely to be referred for catheterization than white men (odds ratio = <math>0.4</math>, 95% CI <math>0.2</math> to <math>0.7</math>).</p>	<ul style="list-style-type: none"> <li>-Representativeness of sample: participants recruited at national meeting.</li> <li>-Hospital characteristics where physician's practiced unknown.</li> <li>-Underemphasis of subgroup analysis.</li> </ul>
<p>Analyses adjusted for socioeconomic factors.</p>	<p>After adjustment, patients from minority groups reported less positive perceptions of physicians than white patients on both scales.</p>	<ul style="list-style-type: none"> <li>-Racial/ethnic subgroups not assessed.</li> <li>-Physician race/ethnicity or other characteristics not assessed.</li> <li>-Potential for response bias.</li> </ul>



TABLE B-1 Continued

<b>Radiographs</b>			
Source	Procedure/Illness	Sample	Analyses
Selim, Gincke, Ren, Deyo et al., 2001	Racial and ethnic differences in use of lumbar spine radiographs.	401 patients (315 white, 22 African American, 4 non-white Hispanic, 1 "other") with low back pain (LBP) receiving ambulatory care services in VA clinics in Boston area. Patients completed Medical Outcome Study Short Form Health Survey (SF-36), LBP questionnaire, comorbidity index, and straight leg raising (SLR) test.	
<b>Rehabilitative Services</b>			
Harada, Chun, Chui, and Pakalniskis, 2000	Assessed sociodemographic and clinical characteristics associated with use of physical therapy (PT) in acute hospitals, skilled nursing facilities, or both.	Records of 187,900 hip fracture patients (94% white, 4% African American, 3% "other") derived from Medicare administrative databases.	
Horner, Hoenig, Sloane et al., 1997	Assessed racial differences in utilization of inpatient rehabilitative services among elderly stroke patients.	2,497 African-American and white Medicare patients hospitalized following stroke at any of 297 acute-care hospitals in five states.	

Analyses	Findings	Limitations
<p>Logistic regression to assess race, age, education, income, comorbidities, pain intensity, radiating leg pain, SLR, 2 summary scores from the SF-36 (physical component summary, mental component summary) as predictors of obtaining lumbar spine radiographs during 12 months of follow-up.</p>	<p>At higher levels of back pain, non-white patients received more spine films than did white patients (74% vs. 50%, <math>p &lt; 0.01</math>). Among patients with positive straight leg raising test, nonwhite patients had more spine films than white patients (23% vs. 11%, <math>p &lt; 0.01</math>).</p> <p>After controlling for clinical characteristics, race was no longer an independent predictor of lumbar spine radiograph use.</p>	<ul style="list-style-type: none"> <li>-Relatively small sample.</li> <li>-Small number of African-American and Hispanic participants.</li> <li>-Potential bias in self-report data.</li> <li>-Nonwhite patients combined in analyses.</li> <li>-Generalizability of population—elderly male veterans in Boston area.</li> </ul>
<p>Logistic regression to predict PT by pattern of use. Independent variables included age, gender, comorbidity index, surgery type, fracture type, urinary incontinence, and hospital characteristics.</p>	<p>African-American patients were less likely than whites to receive acute physical therapy only (b/w odds ratio = 0.81, 95% CI 0.73 to 0.89), were less likely to receive therapy in both acute care and skilled nursing facilities (b/w odds ratio = 0.70, 95% CI 0.65 to 0.76), and were more likely to receive no physical therapy at all (b/w odds ratio = 1.30, 95% CI 1.18 to 1.43).</p>	<ul style="list-style-type: none"> <li>-Relatively few minority patients.</li> <li>-Administrative data.</li> <li>-Retrospective study.</li> <li>-Analysis limited to acute hospitalization.</li> </ul>
<p>Logistic regression to predict utilization of physical and occupational therapy by race.</p>	<p>After adjusting for clinical and socioeconomic factors associated with use of physical and occupational therapy, no racial differences were found in the likelihood of use of therapy (RR = 1.06, 95% CI 0.89 to 1.27) or time to initiate therapy (African Americans = 6.6 days, whites = 7.4, <math>p = 0.42</math>). Similarly, no racial differences were found in length of physical or occupational therapy in days or as a proportion of hospital stay.</p>	<ul style="list-style-type: none"> <li>-Administrative data.</li> <li>-Retrospective study.</li> </ul>

TABLE B-1 Continued

<b>Rehabilitative Services</b>			
Source	Procedure/Illness	Sample	Analyses
Hoening, Rubenstein, and Kahn, 1996	Racial and other sociodemographic and geographic differences in use of physical and occupational therapy in elderly Medicare patients with acute hip fracture.	2,762 African-American and white Medicare patients (9% African American) treated in 297 randomly-selected hospitals from five states.	
<b>Renal Care and Transplantation</b>			
Ayanian, Cleary, Weissman, and Epstein, 1999	Effect of patient preferences on access to renal transplantation.	1,392 patients (384 African-American women, 354 white women, 337 African-American men, 317 white men) with end-stage renal disease who had recently begun to receive maintenance treatment with dialysis in Southern California, Alabama, Michigan, and the mid-Atlantic region of the U.S.	

Analyses	Findings	Limitations
<p>Multivariate logistic regression to predict utilization of physical or occupational therapy by race, socio-demographic variables, severity of hip fracture, geographic region, and other factors. Data obtained through record review.</p>	<p>After controlling for clinical factors, African-American patients (odds ratio = 1.56, 95% CI 1.04 to 2.34) and dual eligible Medicare/Medicaid patients (odds ratio = 1.36, 95% CI 1.05 to 1.76) were less likely to receive high-intensity physical or occupational therapy. No racial differences were found in time to initiation of therapy.</p>	<p>-Small number African Americans.                      -Retrospective study.</p>
<p>Measures included interviews and data from the renal networks and the United Network for Organ Sharing. Logistic regression to estimate: 1) the adjusted relative odds of referral for evaluation at a transplant center; and 2) placement on a waiting list for a transplant or receipt of transplant within 18 months after start of dialysis, for African-American and white men and women. Analyses control for patient preference and expectations, perceptions of care, region, age, education, income, insurance, employment, marital status, car ownership, type facility, cause of renal failure, health status, and co-morbidities.</p>	<p>African-American patients were slightly less likely than white patients to report wanting a kidney transplant (76.3% African-American women vs. 79% of white women, <math>p = 0.13</math>; 80.7% African-American men vs. 85.5% white men, <math>p = 0.04</math>). However, compared to preferences, African-American patients were much less likely than white patients to have been referred to a transplant center for evaluation (50.5% of African-American women vs. 70.7% of white women; and 53.9% for African-American men vs. 76.2% for white men; <math>p &lt; 0.001</math> for each comparison), and to have been placed on a waiting list or to have received a transplant within 18 months after initiating dialysis (31.9% African-American women vs. 56.5% for white women, and 35.3% for African-American men vs. 60.6% for white men, <math>p &lt; 0.001</math> for each comparison).</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Potential bias in patient recall.</p>

TABLE B-1 Continued

**Renal Care and Transplantation**

Source	Procedure/Illness	Sample	Analyses
Kasiske, London, and Ellison, 1998	Racial/ethnic differences in early placement on kidney transplantation waiting list.	41,596 patients registered with 238 UNOS centers on the national OPTN kidney and kidney-pancreas waiting list between April 1, 1994, and June 30, 1996.	

Barker-Cummings, McClellan, Soucie, and Krisher, 1995	Use of peritoneal dialysis as initial treatment for end-stage renal disease (ESRD).	10,726 patents who began treatment for end-stage renal disease at dialysis centers in North Carolina, South Carolina, and Georgia and who reported to ESRD Network between January 1, 1989, and December 31, 1991.	
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**Use of services and procedures—General**

Jha, Shlipak, Hosmer et al., 2001	Hospital mortality.	39,190 male patients (28,934 white and 7,575 black) admitted to 147 VA hospitals nation-wide for one of six diagnoses (pneumonia, angina, congestive heart failure, chronic obstructive pulmonary disease, diabetes, chronic renal failure).	
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Analyses	Findings	Limitations
<p>Logistic regression to assess patient and center characteristics on listing before dialysis or registration after being placed on maintenance dialysis.</p>	<p>White patients more likely to be placed on waiting list before vs. after initiating maintenance dialysis than non-white patients. Independent predictors of listing before dialysis included being African American (odds ratio = 0.465, <math>p &lt; 0.001</math>, reference: white), Hispanic (odds ratio = 0.588, <math>p &lt; 0.001</math>, reference: white) and Asian/other (odds ratio = 0.548, <math>p &lt; 0.001</math>, reference: white), in addition to factors including age, prior transplant, level of education, employment status, insurance status, receiving insulin, listed for kidney-pancreas vs. kidney only, and listed in a center with high volume.</p>	<p>-Retrospective study utilizing administrative data.                      -Analyses did not include measures for hospital characteristics of appropriateness.</p>
<p>Logistic regression (backward stepwise procedure) to assess relationship between ethnicity and initial dialysis modality, controlling for patient characteristics.</p>	<p>African Americans were 57% less likely than whites to be initially treated with peritoneal dialysis (odds ratio = 0.43, 95% CI 0.39 to 0.47). After controlling for confounding characteristics (age, education, social support, home ownership, functional status, albumin level, hypertension, history of MI, peripheral neuropathy, and comorbid diabetes) the odds ratio of initial treatment for African Americans compared with whites was 0.45 (95% CI 0.38 to 0.52).</p>	<p>-Racial/ethnic groups other than African American and white not assessed.                      -Potential confounds such as hospital characteristics, appropriateness not examined.</p>
<p>Principle outcome was mortality at 30 days. Secondary outcomes were in-hospital and 60-day mortality. Analysis included logistic regression for inpatient mortality and Cox Proportional hazard models for 30-day and 6-month mortality to estimate the</p>	<p>Mortality at 30 days was 4.5% in black patients and 5.8% in white patients (RR = 0.77, 95% CI 0.69 to 0.87, <math>p = 0.001</math>). Mortality for black patients was lower for each of the six diagnoses. Adjustments for patient and hospital characteristics had a small effect (RR = 0.75, 95% CI 0.66 to 0.85, <math>p &lt; 0.001</math>). Black patients also had lower in-hospital and 6-month mortality.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -Confounders such as illness severity,</p>

**TABLE B-1** Continued

Use of services and procedures—General			
Source	Procedure/Illness	Sample	Analyses
Tai-Seale, Freund, and LoSasso, 2001	Effect of mandatory enrollment in managed care (MC) on service use among African American compared to white Medicaid beneficiaries.	Data from Medicaid eligibility, claims, and MC encounter data from two counties in one state where one county implemented “freedom-of-choice” waiver enrolling its Medicaid beneficiaries in MC, and one county not involved in the waiver. In the waiver county, 3,490 adults and 3,414 children from pre-period (12 months prior to enrollment); 4,082 adults and 3,834 children in post-period. In non-waiver county, 2,087 adults and 2,093 children in pre-period and 1,200 adults and 1,200 children in post-period. Approximately half sample in each group was African American.	
Andrews and Elixhauser, 2000	Ethnic differences in receipt of major therapeutic procedures during hospitalization.	Data from 1.7 million (88% white, 12% Hispanic) hospital discharges. Data from 1993 discharge abstracts from Healthcare Cost and Utilization Project State Inpatient Database for California, Florida, and New York.	
Weinick, Zuvekas, and Cohn, 2000	Racial and ethnic magnitude of disparities in use of health care services from 1977 to 1996.	Data from three national databases (1977 National Medical Care Expenditure Survey, 1987 National Medical Expenditure Survey, 1996 Medical Expenditure Panel Survey).	

Analyses	Findings	Limitations
<p>independent association of race with mortality.</p>		<p>admissions practices not assessed.</p>
<p>Count data models adjusted for nonrandom selection within difference-in difference (DD) econometric approaches. Services assessed include physician visits, emergency department visits, and inpatient admissions. Difference-in difference method used to identify the program effect of mandatory enrollment in managed care on use of services.</p>	<p>African-American beneficiaries had fewer visits to physicians than white beneficiaries after mandatory enrollment. This held for both adults (DD = -1.937, <math>p &lt; 0.01</math>) and children (DD = -0.813, <math>p &lt; 0.01</math>). No differences found for inpatient admissions. African-American children had a significant increase in use of emergency rooms (DD = 0.116, <math>p &lt; 0.01</math>).</p> <p>In analyses controlling for racial differences in trends of service use that were unrelated to managed care, but may have biased difference-in-difference estimates, results indicate that African-American adults (DD = -2.463, <math>p &lt; 0.01</math>) and children (DD = -1.098, <math>p &lt; 0.01</math>) had lower levels of relative service use. Increases in emergency department visits for African-American children not evident. Decrease inpatient service use found for African-American adults (DD = -0.039, <math>p &lt; 0.05</math>).</p>	<p>-Racial/ethnic groups other than African American and white not assessed.                      -Use of administrative data.                      -Using different samples in pre- and post-waiver periods.                      -Data from two counties in one state.                      -Disproportional enrollment of African Americans in HMOs.</p>
<p>Logistic regression to assess effect of ethnicity on likelihood of receiving therapeutic procedure for 63 conditions. Analyses controlled for age, gender, disease severity, health insurance, income of patient's community, and hospital characteristics.</p>	<p>Hispanics less likely than non-Hispanics to receive major procedures for 38% of 63 conditions and more likely to receive procedures for 6.3% of conditions.</p>	<p>-Administrative database.                      -Data could not examine differences between Hispanic subgroups.</p>
<p>Outcomes analyzed included usual source of care, probability of having at least one ambulatory care (AC) visit, and average number of visits for those indicating AC services. Other variables</p>	<p>In 1996, blacks were 2.1 percentage points more likely than whites to lack a usual source of care (<math>p &lt; 0.10</math>) and Hispanics were 9.9 percentage points more likely than whites to lack a usual source of care (<math>p &lt; 0.001</math>). Disparities increased from 1977 to 1996,</p>	<p>-Administrative data bases.                      -Retrospective study.                      -Need and appropriateness of services not examined.</p>



TABLE B-1 Continued

Use of services and procedures—General

Source	Procedure/Illness	Sample	Analyses
White-Means, 2000	Use of services (paid caregiver, therapist, mental health, dentist, foot doctor, optometrist, chiropractor, ER visit, doctor visits, prescription medications) by disabled elderly.	Data are from the National Long Term Care Survey. 527 black and 4,007 white disabled elderly Medicare recipients.	
Khandker and Simoni-Wastila, 1998	Prescription drug utilization.	487,922 black and 341,274 white Georgia Medicaid enrollees in 1992. 76% of black and 84% of white enrollees received prescriptions through Medicaid on an outpatient basis.	
Harris, Andrews, and Elixhauser, 1997	Influence of race (African American and white) and gender on likelihood of hav-	Discharge abstract data on 1,727,086 discharges (87.9% white, 12.1% African American, 63.6% female, 36.4%	

Analyses	Findings	Limitations
<p>examined included insurance coverage, family income, age, sex, marital status, education, health status, region of country, and residence in or outside of metropolitan area. Used regression-based difference-indifference approach to examine change in disparities over time, controlling for variables listed above.</p>	<p>particularly among Hispanics. Adjusted analyses indicate that the disparity for Hispanics increased by 6.5 percentage points (<math>p &lt; 0.01</math>). The disparity for blacks decreased 3.2 percentage points (<math>p &lt; 0.05</math>) during this time period.</p> <p>50-75% of disparities would remain if disparities in income and insurance coverage were eliminated.</p>	
<p>Regression analysis to estimate relative influence of health conditions and financial resources on racial patterns of community long-term care services. Models include measures of medical conditions and disabilities, income, insurance status, regional and rural residence, whether unpaid caregivers provide in-home services, and sociodemographic characteristics (gender, education).</p>	<p>Given similar medical conditions, black patients are less likely to use services, particularly prescription medications and physician services. Black patients who live in rural areas, small cities, and western states or who have more joint and breathing problems are more likely to use services. Differences in personal attributes (i.e., income, health) do not fully explain racial differences in use of prescriptions and physician services.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.</p>
<p>Model estimating black-white differences in use and level of use of prescription drugs controlling for age, sex, and Medicaid eligibility characteristics.</p>	<p>Black children used 2.7 fewer prescriptions compared to white children. Black adults used 4.9 fewer prescriptions, and black elders used 6.3 fewer prescriptions than white elders (all significant at the 99% level). White Medicaid enrollees had higher use and spending than black enrollees across most high-volume therapeutic drug categories.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -SES and clinical factors not examined as potential confounds.</p>
<p>Logistic regression to assess independent effect of race and gender on likelihood of having a major procedure</p>	<p>African Americans were less likely than whites to receive major therapeutic procedures in 37 of 77 (48.1%) conditions. They were more likely</p>	<p>-Racial/ethnic groups other than white and African</p>

TABLE B-1 Continued

Use of services and procedures—General

Source	Procedure/Illness	Sample	Analyses
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ing a major therapeutic or diagnostic procedure.

male) from the Hospital Cost and Utilization Project (HCUP-2) for 1986. Hospitals include national sample of 469 facilities.

Giacomini, 1996

Gender and ethnic differences in hospital-based procedure utilization.

Retrospective analysis of data on 7,249 hospital discharges in California between 1989 and 1990.

Analyses	Findings	Limitations
<p>(identified using ICD-9-CM codes). Analyses controlled for influence of personal (age, expected pay source, indicators of clinical condition) and hospital-level characteristics (e.g., bed size, public ownership, teaching hospital, urban location).</p>	<p>than whites to receive a major therapeutic procedure in 9.1% of conditions. There was no significant difference in 42.8% of disease categories (<math>\alpha = 0.05</math>). Similarly, African Americans were less likely to receive a major diagnostic, without therapeutic, procedure in 20.8% of conditions, more likely to receive diagnostic procedure in 13% of disease categories. There were no significant differences between races in 66.2% of categories.</p> <p>Females were less likely than males to receive major therapeutic procedures for 32 of 62 (52%) conditions. Females were less likely to receive a major diagnostic, without therapeutic, procedure in 26% of conditions.</p> <p>Patterns emerged with respect to conditions for which there were race and gender differences. For example, African Americans had lower rates than whites and women had lower rates than men for many trauma categories.</p>	<p>American not examined.                      -Retrospective study.                      -Administrative data.</p>
<p>Logistic regression to estimate likelihood of obtaining procedure as function of ethnicity and gender. Analyses controlled for insurance status, age, principal diagnosis, and number of co-morbidities. Odds ratios calculated for following procedures: heart transplant, kidney transplant, extracorporeal shockwave lithotripsy, hip replacement, carotid endarterectomy, CABG, PTCA, pace-</p>	<p>White patients were more likely than African Americans to receive kidney transplantation (odds ratio = 3.05, 95% CI 2.27 to 4.17), defibrillator implant (odds ratio = 2.86, 95% CI 1.28 to 6.25), CABG (odds ratio = 2.44, 95% CI 2.08 to 2.78), endarterectomy (odds ratio = 2.27, 95% CI 1.41 to 3.70), and angioplasty (odds ratio = 2.00, 95% CI 1.79 to 2.22).</p> <p>Whites were more likely than Latino patients to receive angioplasty (odds ratio = 1.72, 95% CI 1.56 to 2.22), kidney transplantation (odds ratio = 1.58, 95% CI 1.20 to 2.08), and CABG</p>	<p>-Administrative data.                      -Retrospective study.                      -Potential confounds including measures of SES, appropriateness of services, hospital characteristics not assessed.</p>

TABLE B-1 Continued

Use of services and procedures—General

Source	Procedure/Illness	Sample	Analyses
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Gornick, Eggers, Reilly et al., 1996	Assessed racial differences in mortality and use of services among a Medicare population.	26.3 million Medicare beneficiaries (24.2 million whites, 2.1 million African Americans) aged 65 years or older.	
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Phillips, Hamel, Teno et al., 1996	Assessed racial differences in use of: operation, dialysis, pulmonary artery catheterization, endoscopy, bronchoscopy, and hospital charges.	9,105 hospitalized adults (79% white, 16% African American, 3% Hispanic, 1% Asian) in five geographically diverse teaching hospitals, with one of nine illnesses associated with average 6-month mortality of 50%. Data collected through chart review and interviews with patients and physicians.	
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Analyses	Findings	Limitations
maker implant, and automatic cardioverter-defibrillator implant.	<p>(odds ratio = 1.49, 95% CI 1.35 to 1.67).</p> <p>Whites were more likely than Asian patients to receive endarterectomy (odds ratio = 2.08, 95% CI 1.18 to 3.85) and angioplasty (odds ratio = 1.30, 95% CI 1.15 to 1.47).</p> <p>Asians were more likely than whites to receive hip replacement (odds ratio = 0.47, 95% CI 0.29 to 0.77).</p> <p>Males' odds of receiving most procedures exceeded those of females.</p>	
Multiple regression to predict utilization rates by race-specific median income, age, gender, and interaction of race and income.	<p>B/w differences found in:</p> <p><i>mortality</i>: 1.19 men (<math>p &lt; 0.001</math>), 1.16 women (<math>p &lt; 0.001</math>)</p> <p><i>hospital discharges</i>: 1.14, <math>p &lt; 0.001</math></p> <p><i>ambulatory care visits</i>: 0.89, <math>p &lt; 0.001</math></p> <p><i>bilateral orchiectomy</i>: 2.45, <math>p &lt; 0.001</math></p> <p><i>amputations of lower limbs</i>: 3.64, <math>p &lt; 0.001</math></p> <p>Adjusting for differences in income reduced differences, but not significantly.</p>	<p>-Racial/ethnic groups other than African American and white not examined.</p> <p>-Administrative data.</p> <p>-Retrospective study.</p> <p>-Factors such as clinical, hospital characteristics not assessed as potential confounds.</p>
Logistic regression to assess independent effect of race on procedure use, controlling for age, gender, education, income, type insurance, severity of illness, functional status, study site, and other confounding variables	<p>Black patients utilized significantly fewer resources than patients of other races (odds ratio = 0.70, 95% CI 0.6 to 0.81). The median adjusted difference in hospital cost was \$2,805 lower for black patients (95% CI \$1,672 to \$3,883 less). Results remained significant after adjusting for physician's perceptions of patients' prognosis.</p>	<p>-Highly selective sample.</p> <p>-Data on SES variables not available for all subjects.</p>

**TABLE B-1** Continued

**Use of services and procedures—General**

Source	Procedure/Illness	Sample	Analyses
Wilson, May, and Kelly, 1994	Assessed racial differences in receipt of total knee arthroplasty among older adults with osteoarthritis.	Records of nearly 300,000 Medicare recipients who underwent total knee arthroplasty between 1980 and 1988.	
Escarce, Epstein, Colby, and Schwartz et al., 1993	Racial differences in use of medical procedures among Medicare enrollees.	1986 physician claims data for 1,204,022 Medicare enrollees (1,109,954 whites and 94,068 African Americans). Individuals enrolled in HMOs excluded.	

**Vaccination**

Schneider et al., 2001	Magnitude of racial differences in influenza vaccination in managed care vs. fee-for-service insurance.	Data from 1996 Medicare Current Beneficiary Survey. 13,674 Medicare beneficiaries (12,414 white, 1,260 African American).	
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Analyses	Findings	Limitations
<p>Natural logarithm transformation method to estimate confidence intervals for white-to-black ratios of rates of total knee replacement.</p>	<p>The prevalence of symptomatic osteoarthritis of the knee was lower among whites than blacks, although this difference was non-significant. African Americans, however, were less likely than whites to receive total knee arthroplasty (odds ratios ranged from 1.5 to 2.0 for women, 3.0 to 5.1 for men). This disparity persisted at each of five levels of income strata.</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Administrative data.                      -Retrospective study.                      -Clinical, SES, hospital factors, appropriateness not explored as confounds.</p>
<p>Mantel-Haenszel method to calculate white-black relative risks, adjusting for age and sex.</p>	<p>Whites more likely than African Americans to receive 23 of 32 services (white-black RR &gt; 1.0, <math>p &lt; 0.05</math>). For example, whites were 1.5 to 2.0 times as likely to receive eight of the study services, 2.0 to 3.0 times as likely to receive three of the services, and more than 3.0 times as likely to receive coronary bypass, coronary angioplasty, and carotid endarterectomy.</p> <p>African Americans were more likely than whites to receive seven services (white-black RR &lt; 1.0, <math>p &lt; 0.05</math>). For example, African Americans more than 1.5 times as likely to receive laser trabeculoplasty, glaucoma surgery, and retinal photocoagulation.</p>	<p>-Racial/ethnic groups other than African American and white not assessed.                      -Administrative data.                      -Retrospective study.                      -Potential confounds such as SES and clinical and hospital characteristics not assessed.</p>
<p>Percentage of respondents (adjusting for SES, clinical comorbidities, and care-seeking attitudes) who received vaccination and magnitude of racial disparity in vaccination was calculated, comparing patients with managed care.</p>	<p>Both whites and African Americans had higher rates of vaccination under managed care, however racial disparity was not reduced under managed care.</p> <p>After adjustment, the racial disparity in fee for service was 24.9% (95% CI 19.6% to 30.1%). The disparity in managed care was 18.6% (95% CI 9.8% to 27.4%). Both disparities were statistically significant, however the</p>	<p>-Racial/ethnic groups other than African American and white not examined.                      -Potential bias in self-report data.</p>



TABLE B-1 Continued

Use of services and procedures—General

Source	Procedure/Illness	Sample	Analyses
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Women's Health

Brown, Perez-Stable, Whitaker, Posner et al., 1999	Hormone Replacement Therapy (HRT).	8,986 women (50% white, 20.2% Asian, 14.7% African American, 8.6% Latina, 6.3% Soviet immigrant) seen in the general internal medicine, family medicine, and gynecology practices at UCSF between January 1, 1992, and November 30, 1995.
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Marsh, Brett, and Miller, 1999	Hormone replacement therapy (HRT).	25,203 sampled visits made by women (age 45-64, 16.4% by black and 83.6% by white women). Data were obtained from the National Health Care survey.
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Analyses	Findings	Limitations
and those with fee-for-service insurance.	absolute percentage point difference in racial disparity between the managed care and fee-for-service groups (6.3%, 95% CI -4.6% to 17.2%) was not.	
Logistic regression was used to calculate odds of prescribing HRT for each ethnic group using whites as the reference group. Predictor variables were age, income, and clinical diagnosis.	Compared to white women, all other groups were less likely to be prescribed HRT after adjusting for age, income, diabetes, hypertension, CHD, and osteoporosis. Asians (odds ratio = 0.56, 95% CI 0.49 to 0.64), African Americans (odds ratio = 0.70, 95% CI 0.60 to 0.81), Latinas (odds ratio = 0.70, 95% CI 0.58 to 0.84), and Soviet immigrants (odds ratio = 0.14, 95% CI 0.10 to 0.20) were each less likely to receive a prescription for HRT than were white women. Women with osteoporosis were also more likely to receive HRT.	<ul style="list-style-type: none"> <li>-Single site.</li> <li>-Retrospective review.</li> <li>-Data not available on variables such as education, menopausal symptoms, hysterectomy status, etc.</li> <li>-Physician recommendations or patient characteristics not assessed.</li> </ul>
Logistic regression used to examine whether any previously identified racial differences in HRT could be attributed to known confounders (age, source of payment for visit, drugs other than HRT, whether physician had previously seen patient, physician or clinic specialty type, site of care, region of practice, obesity, duration of visit, physician sex).	While physician visit rates were equal for black and white women, the rate of visits per year in which HRT was prescribed to white women (odds ratio = 0.38, 95% CI 0.32 to 0.45) was more than twice the rate for black women (odds ratio = 0.17, 95% CI 0.12 to 0.23) in this age group.	<ul style="list-style-type: none"> <li>-Racial/ethnic groups other than African American and white not examined.</li> <li>-Retrospective study.</li> <li>-Limited information on patient characteristics.</li> </ul>

TABLE B-1 Continued

<b>Women's Health</b>			
Source	Procedure/Illness	Sample	Analyses
Burns, McCarthy, Freund, Marwill et al., 1996	Mammography.	3,187,116 women (7% black, 93% white) ages 65 and older receiving Medicare who resided in one of the following states, Alabama, Arizona, Connecticut, Georgia, Kansas, New Jersey, Oklahoma, Pennsylvania, Oregon, or Washington. Women had received bilateral mammography. Data were obtained from HCFA database for 1990.	

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Analyses	Findings	Limitations
Logistic regression to predict mammography use according to age, number of primary care visits, income, state of residence for black and white women in each state.	In every state, at each primary care visit level (one, two, or three or more visits) black women had mammography less often than white women (even across income levels). Age, income, and state adjusted logistic models reveal that among white women, primary care use has a significant effect on use of mammography: <i>for one visit</i> odds ratio = 2.73, 95% CI 2.70 to 2.77, <i>for two visits</i> odds ratio = 3.98, 95% CI 3.93 to 4.03, <i>for three or more visits</i> odds ratio = 4.62, CI 4.58 to 4.67. Results for black women reveal an analogous, but weaker effect: <i>for one visit</i> odds ratio = 1.77, CI 1.67 to 1.87, <i>for two visits</i> odds ratio = 2.49, CI 2.36 to 2.63, <i>for three or more visits</i> odds ratio = 3.15, CI 3.04 to 3.25.	-Racial/ethnic groups other than African American and white not examined. -Administrative data. -Retrospective study.

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**TABLE B-2** Selected Studies Exerting Control Over Key Clinical Characteristics

Author	Year	Type of Data	Insurance	Prospective/ Retrospective	Adjust for: Comorbidities?	Disease Severity
Petersen et al.	2002	Clinical	VA healthcare system	Retrospective	Yes	
Conigliaro et al.	2000	Clinical	VA healthcare system	Retrospective	Yes	
Carlisle et al.	1999	Clinical records and ED logs	Statistical adjustment for type of insurance	Retrospective	No	
Daumit et al.	1999	Clinical	ESRD Medicare	Prospective	Yes	
Hannan et al.	1999	Clinical	Statistical adjustment for type of insurance	Prospective	Yes	
Leape et al.	1999	Clinical and laboratory data from medical records	Statistical adjustment for type of insurance	Retrospective	No	
Scirica et al.	1999	Clinical	Statistical adjustment for type of insurance	Prospective	Yes	
Canto et al.	1998	Clinical	Statistical adjustment for payor status	Retrospective	Yes	

Just for: morbidity?	Disease Severity	Appropriateness	Assessed Outcomes?	Find Disparities?
	Yes	Yes	Yes – no overall differences in mortality found.	Yes, black patients with AMI were equally likely as whites to receive beta-blockers, more likely than whites to receive aspirin, but were less likely to receive thrombolytic therapy at time of arrival and were less likely to receive bypass surgery, even when only high-risk coronary anatomic subgroups were assessed. No racial differences in refusal rates for invasive treatment.
	Yes	Yes	No	Yes, especially when CABG was deemed “necessary.”
	No	Yes	No	No, only lack of post-high school education was significant predictor of underuse.
	Yes	Yes	Yes	Yes, but diminished with insurance eligibility.
	Yes	Yes	No	Yes, African-American patients less likely to undergo CABG than whites, considering RAND criteria.
	Yes	Yes	No	No significant racial or ethnic differences after accounting for hospital type and necessity of revascularization.
	No	Yes	No	Yes, among patients meeting criteria for appropriate catheterization, fewer nonwhites received catheterization.
	Yes	No	Yes	Non-African-American minorities less likely to receive beta-blocker TX at discharge, but as likely to receive intravenous thrombolytic therapy (except Asian/Pacific Islanders) and undergo coronary arteriography and revascularization procedures as whites. No differences in hospital mortality.

**TABLE B-2** Continued

Author	Year	Type of Data	Insurance	Prospective/ Retrospective	Adjust for: Comorbidities?	Disease Severity
Taylor et al.	1998	Clinical	Statistical adjustment for payor status	Retrospective	Yes	
Laouri et al.	1997	Clinical and laboratory data from medical records	Not assessed, but patients sampled from both public (where patients are likely insured) and private hospitals (patients likely uninsured).	Retrospective with patient follow-up	Yes	
Maynard et al.	1997	Clinical	Statistical adjustment for payment by Medicaid	Prospective	Yes	
Peterson et al.	1997	Clinical data	Statistical adjustment for type of insurance	Prospective	Yes	
Taylor et al.	1997	Clinical data	Statistical adjustment for payment type of insurance	Prospective	Yes	

Just for: morbidity?	Disease Severity	Appropriateness	Assessed Outcomes?	Find Disparities?
	Yes	No	Yes	Yes, African Americans less likely to receive intravenous thrombolytic therapy, coronary arteriography, and CABG than whites. No differences in hospital mortality.
	Yes	Yes	No	Yes, significant underuse of revascularization procedures among African Americans and patients at public hospitals.
	Yes	No	Yes	Despite less intensive use of revascularization procedures in African Americans, long-term survival after AMI was similar to whites.
	Yes	Yes	Yes	African Americans less likely than whites to receive bypass surgery, but no differences found in angioplasty. Differences in treatment most pronounced among patients with severe disease. Differences in treatment associated with lower survival among African Americans.
	Yes	Yes	Yes	African Americans less likely than whites to receive bypass surgery, but no differences found in angioplasty. Differences in treatment most pronounced among patients with severe disease. Differences in treatment associated with lower survival among African Americans.



## C

### Federal-Level and Other Initiatives to Address Racial and Ethnic Disparities in Healthcare

The following list represents a sample of Federal and non-Federal programs, initiatives, and collaborations related to racial/ethnic disparities in healthcare. This list is not intended to represent a comprehensive inventory of Federal programming; rather, it presents some examples of efforts intended to reduce and/or eliminate disparities.

#### EXECUTIVE OFFICE OF THE PRESIDENT

##### Office of Management and Budget

*Guidance on Aggregation and Allocation of Data on Race for Use in Civil Rights Monitoring and Enforcement.* Purpose of these guidelines is to: a) establish guidance for agencies that collect or use aggregate data on race, and b) establish guidance for the allocation of multiple race responses for use in civil rights monitoring and enforcement. The guidelines do not mandate the collection of race data, but standardize its collection if agencies choose to gather it.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

##### HHS-Wide Initiatives

*Minority HIV/AIDS Initiative.* This initiative, in collaboration with the Congressional Black Caucus, seeks to improve the nation's effectiveness in preventing and treating HIV/AIDS in African American, Hispanic, and other minority communities. This initiative began in 1999 with \$156 million and

was increased to \$251 million in 2000. The funds are distributed in the following areas: 1) providing technical assistance and infrastructure support, 2) increasing access to prevention and care, and 3) building stronger linkages to address the needs of specific populations. Grants are provided to community-based organizations, research institutions, minority-serving colleges and universities, healthcare organizations, and state and local health departments. Agencies involved include Centers for Disease Control and Prevention, Health Resources and Services Administration, Indian Health Services, National Institutes of Health, Office of Minority Health, Office of Minority Health-Resource Center, Office on Women's Health, and the Substance Abuse and Mental Health Services Administration.

HHS and the American Public Health Association announced in 2000 a partnership to eliminate racial and ethnic health disparities. The partnership includes a three-phase plan to develop guidelines for collaboration to develop a detailed, comprehensive national plan, and to implement the plan by 2002.

### Office of the Secretary

#### *Office of Minority Health*

*Healthy People 2010.* A set of health objectives for the nation to achieve over the next decade. The first goal of Healthy People 2010 is to help individuals of all ages increase life expectancy and improve their quality of life. The second goal of Healthy People 2010 is to eliminate health disparities among different segments of the population. Products of the initiative include, for example, the publication *A Community Planning Guide Using Healthy People 2010*, a guide for building community coalitions, creating a vision, measuring results, and creating partnerships dedicated to improving the health of a community.

*The Cross Cultural Health Care Program (CCHCP)* was created in 1992 to serve as a bridge between communities and healthcare institutions to ensure access to healthcare that is culturally and linguistically appropriate. This program facilitates cultural competency training for providers and medical staff, interpreter training for community interpreters and bilingual healthcare workers, outreach to underrepresented communities, community-based research, interpreter services, translation services, and publications and videos relating to cross-cultural healthcare.

#### *Office for Civil Rights*

The Office has engaged in a number of efforts related to disparities in care. It has addressed redlining issues (limiting or eliminating services in

specific geographic areas), conducted compliance review of home health-care agencies nationwide to ascertain compliance with civil rights statutes, and investigated how managed care plans establish their service area and how they target their marketing activities. For example, Region II (New York) has developed a self-assessment tool for providers to assist them in ensuring that their facility is able to meet the challenge of servicing a diverse population. The New York Regional Office is also investigating allegations of racial disparities in the provision of healthcare services by some healthcare providers in two counties in New York (e.g., poor quality of care for minorities, lack of access to more prominent medical facilities, language barriers to healthcare), and is collecting and analyzing data pertaining to specific healthcare facilities in an effort to gain a better understanding of the root causes of disparities. In addition, Region V (Chicago) has conducted investigations focused on disparities in kidney transplant programs.

#### **Agency for Healthcare Research and Quality**

*Measures of Quality of Care for Vulnerable Populations.* This initiative will develop and test new quality measures for use in the purchase or improvement of healthcare services for priority populations. For example, one such project will develop a quality of care measure for hypertension in a population of Hmong refugees and pilot test the instrument.

*Assessment of Quality Improvement Strategies in Health Care.* A recently funded study will create a partnership of six health providers to evaluate the effectiveness of nurse management compared to usual care for congestive heart failure patients in Harlem.

*Translating Research into Practice (TRIP).* Initiated in 1999, this funding is aimed at generating knowledge about approaches that effectively promote the use of empirically derived evidence in clinical settings that will lead to improved healthcare practice and sustained practitioner behavior change. A priority for the FY2000 TRIP initiative is to determine to what extent general strategies need to be modified to improve quality of care for minority populations.

*Understanding and Eliminating Minority Health Disparities Initiative* will support the development of Centers of Excellence that will conduct research to provide information on factors that influence quality, outcomes, costs, and access to healthcare for minority populations.

#### **Centers for Disease Control and Prevention**

*Racial and Ethnic Approaches to Community Health (REACH 2010).* This five-year demonstration project seeks to eliminate disparities in health in

the following priority areas: infant mortality, cervical cancer, cardiovascular disease, diabetes, HIV/AIDS, and immunizations. The two-phase project will support community coalitions in the design, implementation, and evaluation of community-driven strategies to eliminate health disparities. Phase I is a 12-month planning period during which needs assessments and action plans are developed. Phase II is a four-year period during which action plans will be carried out. An evaluation logic model will be used to guide the collection of data.

*National Program of Cancer Registries.* This program provides funding to states/territories to enhance existing registries and create new registries. FY2001 funding will focus on training and technical assistance to improve collecting race and ethnicity data and evaluating the completeness and accuracy of data for racial and ethnic minority populations.

*Alaska Native Colorectal Cancer Education Project* is being developed and will involve screening tests and the provision of specific language to Alaska Natives for use with healthcare providers when discussing colorectal cancer.

*Hispanic Colorectal Cancer Outreach and Education Project* is a partnership with the National Alliance for Hispanic Health to increase awareness and screening for colorectal cancer. The CDC is also investigating psychosocial and cultural influences that impact prevention attitudes, behaviors, and adherence to screening guidelines among Puerto Ricans and Dominicans.

*National Comprehensive Cancer Control (CCC) Program* seeks to develop coordinated efforts with health agencies to increase the number and quality of cancer programs and to reduce the burden of cancer in minority populations.

*National Breast and Cervical Cancer Early Detection Program (NBCCEDP)* is a 10-year-old program that funds all 50 state health agencies, DC, 12 tribal organizations, and 6 territories to conduct breast and cervical cancer early detection programs. The program works to ensure that women receive screening services, needed follow-up, and assurance that tests are preformed in accordance with current guidelines.

*National Training Center* initiative trains providers serving American-Indian women to enhance cultural sensitivity and client-provider interactions. The CDC is also developing a CD-ROM to educate Ohio providers about various cultural perspectives on breast care and interpersonal communication with patients.

Research on *prostate cancer screening behaviors* among African-American men, in collaboration with Loma Linda University, will examine the relationship between what primary care providers report telling their patients about prostate cancer and how the men perceive the messages.

The CDC has proposed the addition of questions on "reactions to race" to the *2002 Behavior Risk Factor Surveillance System*. As questions

regarding the effects of racism on disparities in health status are raised, the CDC has proposed the addition of race questions to the survey in order to begin to measure racism and its impact on health.

### **Centers for Medicare and Medicaid Services**

*Reducing Health Care Disparities National Project.* This project focuses on working at the state level to reduce disparities. Its objectives are to improve health status and outcomes in racial/ethnic populations and reduce disparity between healthcare received by beneficiaries who are members of a targeted racial and ethnic group and all other beneficiaries living in each state.

*Excellence Centers to Eliminate Ethnic/Racial Disparities (EXCEED) initiative* involves the awarding of grants that will help understand and address factors that contribute to ethnic and racial inequities in healthcare. For example, projects involve topics such as racial and ethnic variations in medical interactions, improving the delivery of effective care to minorities, and understanding and reducing native elder health disparities.

### **Health Resources and Services Administration**

*Measuring Cultural Competence in Health Care Delivery Settings.* This Project in coordination with the Lewin Group seeks to develop a measurement model of cultural competence for healthcare delivery settings. The objectives are to advance the conceptualization of measurement of cultural competence in healthcare settings, identify specific indicators and measures that can be used to assess cultural competence in healthcare, and assess the feasibility and practical application of these measures. Products of the project will include: a framework for measuring cultural competence in healthcare settings; a synthesis and assessment of existing measures; and a report recommending domains, indicators, measures, measurement uses, and data sources regarding competence measurement.

*Community Access Program (CAP).* The CAP helps healthcare providers develop integrated, community-wide systems that serve the uninsured and underinsured. CAP grants are designed to increase access to healthcare by eliminating fragmented service delivery, improving efficiencies among safety net providers, and by encouraging greater private sector involvement. Currently, CAP grants support 76 communities in urban and rural areas and on tribal lands. A new application competition in the fall of 2001 will support 40 more communities. Partners in the CAP coalitions include local health departments, public hospitals, community health centers, universities and state governments. The partners use CAP funds to create and expand collaboration in three main areas—coordi-

nated intake and enrollment systems, integrated management information systems, and referral networks and coordination of services. The agency also will use FY 2001 funds to provide training and technical assistance to all CAP grantees and to support a national evaluation of the program.

The *Provider's Guide to Quality and Culture* serves as a source for health professionals seeking resources on cultural issues within the context of quality of care. The Guide emerged out of the Quality Center of the Bureau of Primary Health Care and was developed by Management Sciences for Health, a nonprofit organization focused on the improvement of global health. The Guide responds to four of the six national aims articulated by the National Institute of Medicine's (IOM) *Crossing the Quality Chasm* report (safety, effectiveness, patient-centeredness, and equity).

The *Oral Health Initiative*, an initiative of HRSA and HCFA, seeks to eliminate disparities in access to oral healthcare and improvement of oral health. The goals of the initiative are to: a) integrate dental health activities within the two agencies; b) partner with public agencies and private dental professional educational and advocacy organizations; and c) promote the application of dental science and technology to reduce disparities.

### Indian Health Service

The Indian Health Service has a number of programs in place to improve healthcare access and quality, as well as increase community awareness of disease prevention and treatment. For example, the *Southwest Native American Cardiology Program* was developed in 1993. This program was developed to provide direct cardiovascular care to Native Americans at reservation clinics within the Navajo, Phoenix, and Tucson Areas as well as provide tertiary care for complex cardiovascular disease in Tucson. The *National Diabetes Program* was initiated to develop, document, and sustain a public health effort to prevent and control diabetes in American Indian and Alaska Native communities. Other programs, such as the *Elder Care Initiative*, serve to promote the development of high-quality care for American Indian and Alaska Native elders. The activities of the initiative are focused on information and referral, technical assistance and education, and advocacy. This is accomplished in partnership with a variety of tribal, state, federal, and academic programs.

### National Institutes of Health

A trans-NIH working group, consisting of each NIH institute and center director, was initiated in 1999 to develop a *strategic research agenda on*

*health disparities.* The objectives of the working group are to: develop a five-year Strategic Research Agenda; recruit and train minority investigators to advance community outreach activities; form new and enhance current partnerships with minority and other organizations that have similar goals to close health gaps; define, code, track, analyze, and evaluate progress more uniformly across the agency; and enhance public awareness.

The *National Center on Minority Health and Health Disparities (NCMHD)* at the National Institutes of Health was established in 2000. The new Center will conduct and support research, training, dissemination of information, and other programs about minority health conditions and about populations with health disparities. The goals of the Center are to assist in the development of an integrated cross-discipline national health research agenda; to promote and facilitate the creation of a robust minority health research environment; and to promote, assist, and support research capacity building activities in the minority and medically underserved communities.

#### **Substance Abuse and Mental Health Services Administration**

*Community Action Grant Program*—Hispanic priority. Awards are made to Hispanic community-based organizations to support the development and implementation of substance abuse prevention, addictions treatment, and mental health services for Hispanic adults and adolescents. For example, among the new grants is a program that is working toward a specialized dual-diagnosis model for Hispanic/Latino clients with co-occurring mental and addictive disorders.

*Specialized HIV/AIDS outreach and substance abuse treatment*, a grant program to support community-based substance abuse treatment programs targeted to minority populations at risk for HIV/AIDS.

SAMHSA developed a *pocket guide and desk reference* for clinicians, which has been translated into Spanish, to help providers assess and treat substance abuse conditions. Physicians and nurses serving these communities are being trained at regional meetings, an effort coordinated by the Interamerican College of Physician Surgeons.

SAMHSA established a multi-disciplinary panel to develop *standards of mental healthcare for Latinos*. The panel developed a report that includes Standards from the Consumer Perspective, Clinical Guidelines for Providers, and Provider and System Competencies for Training. The standards are being piloted to develop performance indicators and best practices.

SAMHSA has made available new funds to help improve access, addictions treatment, and mental health services in racial/ethnic minority communities in order to reduce disparities in services.

*American Indian and Alaskan Native Planning Grants* provide funds to communities to support the development of local substance abuse treatment system plans to deliver integrated substance abuse, mental health services, primary care, and other public health services.

Activities of *The Special Programs Development Branch* have included: the collection of data on access to and quality of mental health services within ethnic and minority communities; working with representatives of consumer, advocacy, professional, and provider organizations serving minority communities to improve mental health treatment; developing guidelines and measures to assist state and local governments in making services and systems of care responsive to diverse cultural needs; and examining the impact of managed care on access, quality, and cost of mental health services for ethnic and minority populations.

#### **DEPARTMENT OF VETERANS AFFAIRS**

The Department has instituted several *Centers for Excellence* in healthcare that focus on healthcare issues unique and prevalent in the minority community. For example, the Centers for Excellence in Hepatitis C, Treatment and Prevention have been established in California and Florida. The Center has developed culturally sensitive literature on hepatitis C for distribution in minority communities and has been translated into Spanish, Cherokee, and Navajo.

The Department has initiated several investigations to examine disparities in care in areas including prostate cancer, cardiac procedures, osteoarthritis care, and delivery of care to American Indians and Hispanic Americans.

#### **OTHER PROGRAMS/INITIATIVES TO ADDRESS HEALTHCARE DISPARITIES**

The *Cambridge Health Alliance* is a network of three hospitals, the Cambridge Public Health Department, community based programs, physician practices, neighborhood health centers, and a managed Medicaid health plan. The communities serviced by the Alliance have large and diverse minority populations, with 26% of residents living below 200% of the federal poverty line. Among the many intergrated services included are multilingual interpreter services, public health, and preventive services.



## D

# Racial Disparities in Healthcare: Highlights from Focus Group Findings

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### STORIES OF RACIAL DISCRIMINATION IN HEALTHCARE PRACTICE

Racial discrimination occurs on many levels, in a variety of contexts, intertwined with income, education level, and other sociodemographic factors. It can be subtle or disturbingly overt. During the eight focus groups, participants were asked to talk about their own personal experiences with racism in healthcare. When asked whether discrimination exists in receiving quality healthcare, one African-American participant summed up the collective response in this way: "The medical world just reflects the real world." Throughout the following section, participants' stories and opinions are presented in their own words, providing evidence of healthcare inequity that participants attributed directly or indirectly to racial or ethnic discrimination, their lack of English-language proficiency, or both.

#### **Effect of Stereotyping**

Participants often felt that the quality of health care services they received stemmed from misperceptions and stereotypes, not the reality of who they are. They said they often feel that health care providers treat them differently and assume they are less educated, poor, or deserving of less respect because of their race or culture. A Hispanic physician, speaking of the perceptions of his colleagues, corroborated participants' opinions that health care providers make assumptions about their patients based on race or ethnicity. "As soon as they look at the patient and see

he's African American or Latino, they assume automatically that he doesn't have insurance at all."

The following quotes provide examples of encounters that participants had with healthcare providers who made stereotypical assumptions about their education or culture.

*My name is . . . [a common Hispanic surname] and when they see that name, I think there is . . . some kind of a prejudice of the name. . . . We're talking about on the phone, there's a lack of respect. There's a lack of acknowledging the person and making one feel welcome. All of the courtesies that go with the profession that they are paid to do are kind of put aside. They think they can get away with a lot because "Here's another dumb Mexican." (Hispanic participant)*

*I've had both positive and negative experiences. I know the negative one was based on race. It was [with] a previous primary care physician when I discovered I had diabetes. He said, "I need to write this prescription for these pills, but you'll never take them and you'll come back and tell me you're still eating pig's feet and everything. . . . Then why do I still need to write this prescription." And I'm like, "I don't eat pig's feet." (African-American participant)*

*My son broke my glasses so I needed to go get a prescription so I could go buy a pair of glasses. I get there and the optometrist was talking to me as if I was like 10 years old. As we were talking, they were saying, "What do you do," and as soon as they found out what I did [professionally], the whole attitude of this person changed towards me. I don't know if they come in there thinking, "Oh this poor Indian does not have a clue." I definitely felt like I was being treated differently. (Native-American participant)*

One participant spoke about a relative who did not want to take her husband's name after marriage for fear of being negatively stereotyped.

*My granddaughter, she's a doctor herself. She graduated in Mexico and then she came here. She [studied here] so she could become a doctor here. She married a Mexican guy named [a common Hispanic surname]. You know what she did? She took off [a common Hispanic surname] and kept [another surname], her father's name. (Hispanic participant)*

### Language Barriers

Many participants in the Chinese- and Spanish-speaking focus groups voiced concern about being treated unfairly because of their lack of English-language proficiency. As a result, they perceived that healthcare providers treat them differently and were concerned that they receive lower quality care.

*If you speak English well, then an American doctor, they will treat you better. If you speak Chinese and your English is not that good, they would also kind of look down on you. They would [be] kind of prejudiced. (Chinese participant)*

*When they see he can't explain himself, they look at him as if [they are] belittling him. They treat him with a lot of inferiority... the doctor, nurses, receptionists. You can tell when the person is not liked by the doctors or the staff. I have seen a lot of discrimination in that manner. (Hispanic participant)*

*I have a desire to improve my English so I can go to an American doctor and get better treatment. (Chinese participant)*

Healthcare providers were also concerned about not being able to communicate adequately with their patients because of a language barrier. One African-American nurse spoke of “seeing the fear in their eyes” and knowing how upset and frustrated patients were in trying to communicate what was wrong with them. A Hispanic nurse acknowledged the language problem, stating that for “new immigrants that do not speak the language properly . . . it is the biggest obstacle they encounter.”

Non-English-speaking participants, especially those in the Hispanic group, recounted many examples of personal situations in hospitals and other settings where they were forced to deal with serious health conditions without the benefit of interpreters or patient healthcare staff willing to assist them. They said they encountered healthcare staff who ignored them and avoided trying to help them. Others pointed out instances where they or their family members have received poor quality healthcare services and have been treated disrespectfully because they speak little or no English.

*A long time ago my husband was in pain. I had to call an ambulance and they took him to the hospital. We waited three hours. I would ask the nurse to please treat him because he could not stand the pain. She would say, “We’re going to call him, we’re going to call him.” I saw black people being called in, but they never called him back. I asked for some medication in the meantime. They never came out with the medicine. . . . Well, we left. [My husband] told me it must have been because we are Hispanic and don’t speak English. They would call and call in black people. . . . I think if we would’ve been black or American we would have been treated faster. (Hispanic participant)*

*[My wife] was treated badly. They wouldn’t take care of her. They were changing her IV and the nurse was very rough in the way she would take the needle out and put it back in. I felt bad. I had to go and tell them with the little English I speak what was happening. So, they changed the nurse. That’s the way it is. All the situations we are experiencing are because we can’t communicate in English. (Hispanic participant)*

*My son was in a bed and another boy was with his mother. Of course, they didn’t speak English. The lady didn’t know . . . she wanted to know where they were taking the boy. She asked for the girl who was interpreting for her. One of the nurses said, “I don’t know why they send these people here without anybody to interpret for them. We’ll come back later,” and they left . . . but they*

*didn't do anything about finding out where the interpreter was. (Hispanic participant)*

*I had eye surgery two or three years ago. The specialist was black. There were Hispanics out front. I told them I had an appointment with the doctor. They asked me if I spoke English . . . one said to the other in Spanish, "Go inside with her." "No, you go." I asked them who was going to go with me because the doctor was waiting for me. Once we were inside, he would speak [only to the interpreter] directly. I felt rejected. (Hispanic participant)*

*Five years ago my son got double pneumonia. The doctors wanted to operate [on] him. . . . They called my husband and he said he had to talk with the specialist who was treating my son to see what he had to say about the surgery. We called . . . and the specialist said my son would not be able to resist that type of surgery. My husband called the hospital and told me not to sign any papers. I didn't speak English. I didn't know anything. They put the paper in front of me to sign. They insisted I sign the paper. My husband told me not to sign anything and [that] he was on his way [to pick us up]. In the end my son didn't have the surgery and he didn't die like they said he would. Three days after they said he needed the surgery he got better. The surgery was not necessary. (Hispanic participant)*

*I called a pharmacy to see if my daughter's medicine was ready and they put me on hold. They put the phone down and said, "She's a Spanish speaker," and they put me on hold. She left me waiting a long time until I hung up. (Hispanic participant)*

### **The Role of Economics**

Oftentimes, participants noted, a person's perceived or actual socioeconomic status can be an obstacle to obtaining quality healthcare services. Participants were concerned that they may receive a lower standard of care because healthcare providers make assumptions about the type of treatment or medication that they can afford because they are racial or ethnic minorities.

*I know there have been a couple of times the doctor wanted to prescribe a certain medication but because of how much it was, he prescribed something else. Not what was best, but what I could afford. (African-American participant)*

*Often times, the system gets the concept of black people off the 6 o'clock news, and they treat us all the same way. Here's a guy coming in here with no insurance. He's low breed. (African-American participant)*

*A lot of black people don't have money so I guess you would say that it's hard [to get quality healthcare.] A lot of black people don't have any insurance. (African-American participant)*

### Lack of Respect

Many participants unequivocally believed that the lack of respect healthcare providers have for them leads to lower quality healthcare services than persons of other ethnicities, especially whites, receive. They spoke of instances where the office staff would not “look them in the eye” when they spoke to them or greeted other patients with a more pleasant attitude. Others felt a lack of respect when they were rushed during appointments and sensed that providers or their staff did not want to take the time to help them, answer their questions, or explain medical procedures to them.

*They wouldn't accept the appointment over the phone; they just put me on hold. I went in there and she looked at me and I told her I'd been calling trying to make an appointment. She said, "Well, you see this stack of paper, you think you're the only one?" She either thought I was Mexican or she recognized I was Indian, but she would not make that appointment. She just got smart with me and all. I told my husband about it. He's big and white. She got to him just like that. No problem. She got the appointment and got him through. She wouldn't do it for me. (Native-American participant)*

*I felt that because of my race that I wasn't serviced as well as a Caucasian person was. The attitude that you would get. Information wasn't given to me as it would have [been given to] a Caucasian. The attitude made me feel like I was less important. I could come to the desk and they would be real nonchalant and someone of Caucasian color would come behind me and they'd be like, "Hi, how was your day?" (African-American participant)*

*I don't have a problem with taking more time to be able to understand each other, but they get really annoyed when you don't understand them. Basically, they get really annoyed if you talk too much because they know they don't understand your language. When I go to the doctor I ask a lot of questions, so they can get really aggravated with me. I don't know if they would do the same thing to a white person. (African-American participant)*

Others felt they must wait for long periods of time before receiving medications and other medical assistance, while whites are cared for first.

*I would call [for the nurse] when I was feeling pretty bad. They wouldn't come until I finally had to yell, "Help me, I'm in pain! I need something to calm the pain!" They had to call someone and she gave it to me. There were American [patients] there. They would even close the curtains for them. (Hispanic participant)*

*If your bell was on and the Caucasian lady, she doesn't even have to have her bell on. She was being attended to because they knew they better . . . do a certain quality [of service]. Whereas the same quality should have been given to the*

*black people, but their bell would be on and they still would have to wait.*  
(African-American participant)

### Improper Diagnosis or Treatment

More troubling are instances that participants mentioned where the quality of medical treatment was compromised by discriminatory attitudes or practices that participants believed led to either misdiagnosis or improper treatment.

*When I was growing up, my parents didn't have health insurance. We would go to the Indian Health Service. You'd go there to the clinic and I think sometimes you wonder about the quality of the medical personnel that was examining you. My younger sister had appendicitis. It burst, and they told her she had a stomach flu. I don't know how they were hiring the medical personnel at that time. It's changed now, but back then I don't think we had some of the best medical officers or nurses.* (Native-American participant)

*Being in a group practice seeing predominantly African-American patients, I have patients who have seen mainly white physicians in the past. When they come in to visit with us and speak with us, something as simple as [asking them to] sit up on a table and they got a question. "What are you going to do?" "I'm going to examine you." "Oh, my other doctor never did that."* (African-American physician)

*Of course, in psychiatry we see this [discrimination]. One area we see is in terms of diagnosis. Patients are inappropriately diagnosed and medications prescribed for the patients. We see errors in that. Minority patients will often be diagnosed inappropriately as being schizophrenic.* (African-American physician)

*When I ask [my Hispanic patients] if the other doctor ever examines you, they say, "No, they give me a prescription." It's amazing. A lot of times these patients have these problems that are missed by the other doctors.* (Hispanic physician)

In some instances, participants noted, racial and ethnic minority patients have difficulties gaining access to the specialists they need. One physician noted that specialists mistreat racial and ethnic minority patients to avoid having to provide treatment for them.

*I'm in private practice and we refer a lot. We kind of know what specialists to avoid because we hear the patients coming back and telling about what type of treatment they're getting from these specialists. A lot of the specialists in these institutions act like they don't want to see the minority patient at all. When the minority patient ends up there maybe because they're on [a particular] plan... they are mistreated.* (African-American physician)

In contrast to situations described by participants in which healthcare providers sought to limit their access to healthcare services, two female participants described being pressured to have surgical procedures that, in retrospect, were deemed unnecessary by other doctors.

*The first thing they wanted to do was a hysterectomy. I was 36 years old and they never really examined me. I was just telling them the symptoms and it scared me and I left. . . . I guess they were trying to stop the population birth, whatever, because [the hospital] back then was for people who didn't have insurance.* (African-American participant)

*My Ob-Gyn is Caucasian. I have fibroid tumors and the doctor I've been going to, he's been my Ob-Gyn for 14 years and for the last 2 years he told me I have to have this hysterectomy. I had a girlfriend at the office recommend me to a female African-American physician. . . . A week later she called me at home and said to me, "There's nothing wrong with you. The fibroid is there but if it's not bothering you, if it's not broke, don't fix it. You don't need to have a hysterectomy."* (African-American participant)

To overcome discriminatory attitudes from healthcare providers, one participant suggested that it is necessary for minorities to be "strong" and not "humble in your voice and tone" to have a better chance at getting the care they wanted.

*I believe that African Americans do get a lower quality of care. I think if you're educated, if somebody's not treating you right then you kind of push past some of the stuff, but for somebody that doesn't have a good feeling about themselves, whether it's because of race or literacy, that makes it very hard for them to get the care that they need.* (African-American nurse)

### CHALLENGE OF IDENTIFYING RACIAL AND ETHNIC DISCRIMINATION

Some participants found it difficult to identify obvious examples of discrimination they encountered in their healthcare experiences, although they were certain that discrimination exists in healthcare settings. As one African American participant aptly described, "It's hard to identify discrimination because they don't show it. They'll be sweet and smooth, all the way through it." Participants mentioned experiencing discrimination in many situations, but because of the subtleties often inherent in discrimination, it was challenging to identify overt examples. They often said, "You just know," or "You can feel it" when describing incidences of discrimination.

Overall, participants felt that racial discrimination could not easily be separated from other forms of discrimination. The quotes that appear in the following section illustrate participants' concerns about not receiving

appropriate healthcare services, but they also show that the link between one's race or ethnicity and poor treatment can be very complex. While the underlying issues (e.g., economics, improper diagnosis) mentioned here parallel those discussed in an earlier section, the claims made in the following quotes only *suggest* that a lower quality of healthcare stems from racial or ethnic discrimination. The evidence for this causal relationship tends to be circumstantial.

### Patients' Appearance

Some participants hinted that attention to appearance, (e.g., being well-dressed) might counteract discriminatory tendencies. One Hispanic participant said he felt it was important to "be presentable," otherwise the healthcare staff would likely make him wait for hours before helping him. Another said:

*I've noticed that, outward appearance has a lot to do with the rapport that you have with your provider. They talk to you a little different, they treat you a bit differently. You can walk in, you're all battered and crummy looking, and their whole personality changes. You walk in looking half-way decent, and they're very pleasant, and they react and act completely different. (African-American participant)*

### Patients' Economic/Insurance Status

Some participants provided examples of how they or their family members received poor healthcare services because of their lack of insurance or perceived inability to pay for these services. They believed that they were being treated differently by the healthcare system, although they did not make a direct link to race or ethnicity.

*I went back [to IHS] after I found out everything that needed to be done. I went back to the clinic and chewed out the doctor. Then she said, "Wait a minute. Wait a minute. Do you realize how much it's going to cost you? It's like buying a new car." I said "I don't care at this point. It's my life. I don't care how much money I have to pay out of my pocket." Then she says, "Wait a minute. Let's send you to a specialist." I said, "Why didn't you tell me this to begin with? Now that I'm making my move, now you're telling me, OK, now you can do this and that for me?" I said, "No thank you. This is it." (Native-American participant)*

*My niece went to this hospital and they wouldn't wait on her because she didn't have insurance. They told her she would have to go to the county hospital. So I had to take her to the county hospital. She was bleeding all the way. It was just terrible, because she didn't have insurance. (African-American participant)*



*It's almost like "Oh well, this person doesn't have insurance. Let's just give them the IHS treatment."* (Native-American participant)

*I have a son and he's considered disabled. He had MediCal before. I got it before I got insurance through my job, and I had to wait 100 days before I got the insurance through my job. So I noticed there's a longer waiting period... other people are coming in after me and have later appointments, but they have private insurance, so they're seen before me and my son. And it wasn't just the waiting period; the treatment was different. Now that I have private insurance, as soon as I get there, [they see me].* (Hispanic participant)

*An Ob/Gyn who had a large Medicaid population, not just black and Hispanic, but a large Medicaid population . . . they told the doctor they wanted him to have more deliveries at other hospitals. [He refused.] The hospital then, at that point, decided they would stop taking all Medicaid period because this doctor would not leave. For an entire year this hospital wouldn't pay Medicaid just so this doctor wouldn't deliver there anymore.* (African-American physician)

### Healthcare Setting

Native Americans, because of their unique access to healthcare through the Indian Health Service (IHS), spoke often about the poor quality of care at the IHS clinics. More than participants in the other groups, they defined their ability to get quality healthcare services by the setting in which they received care and not by their race. They did not blame poor healthcare on individual providers as much as they did on the IHS system.

*If you go into IHS for a problem, they don't investigate your problem to the extent that a private place does. [Private offices] go through everything like an ultrasound, blood work, the whole nine yards, and they pinpoint the problem. IHS, they give you a temporary solution or shot and it comes back up a month later.* (Native-American participant)

*I think the way that race plays into it is because we all go to the Indian Health Service because we're Indian. That's where we start out with our healthcare.* (Native-American participant)

*I've had experiences where I had no choice but to go to the Indian Health Service. You go in there, they rush through you. They misdiagnosed several things with me, and you're just rushed through. I've dealt with accidents, and to get your accidents paid for and stuff, IHS takes forever to get those reports through. It took like 2 years, and that's a very long time. I don't know where they get that, but I don't think that's right.* (Native-American participant)

### Attitude of Healthcare Providers

Some participants were surprised and disappointed by the uncaring attitude exhibited by some of their healthcare providers or administrative

staff. In some cases, they felt staff were unwilling to help them, and information about their health was delayed or not provided to them. In other situations, doctors seemed more interested in insurance payment issues and less concerned with providing appropriate care for their patients.

*The doctor comes in and says, "Why is he on oxygen?" I was recovering from surgery. He's looking at the chart and he says, "The insurance doesn't cover it. Take it off." Just like that. I'm right there, and I'm thinking "Wow, that's pretty harsh if it comes from a doctor." That was unfair I thought. (Hispanic participant)*

*First of all, they didn't send me back the results for 5-6 months. I can't get an answer on the phone when I call. I have to call like 10 times and they put me on hold and say they'll transfer me. They never transfer me. They hang up on me. (Hispanic participant)*

A few participants did not think their physicians took the time necessary to listen to them or examine them properly. They felt that their overall health needs were being ignored.

*[The doctor] just walks in and has other patients to see, [she asks] "What's wrong with you now?" and that's it. Sometimes I will go into other things that I have felt and it's like, "Oh, just take vitamins." What if there's something else wrong? They're not trying to find out what's wrong. Maybe I have cancer or something. (Hispanic participant)*

*They just come in, look at the chart, say, "OK, are you taking your medications? See you in 3 months." . . . if they find the chart. Sometimes they can't even find mine. (Hispanic participant)*

### **Other Stories About Misdiagnosis or Improper Treatment**

Some participants spoke of going to the hospital or doctor and receiving misinformation or improper service from healthcare providers. In some cases, participants said their healthcare providers misdiagnosed their condition or were too passive in their treatment approach. A few participants questioned whether some providers they went to were qualified to make an accurate diagnosis of their health problem. Again, the concerns expressed in these specific instances were linked to race and ethnicity by implication only.

*At the hospital, they sent me over to a doctor, who was not an [eye] specialist. He diagnosed me with cataracts and said I needed surgery the next day. Thanks to a miracle from God, I did not end up blind. [Afterwards] eight days went by that I was blind in that eye. . . . Jose took me to another doctor. The [second] doctor told us I needed surgery the next day. It's a miracle from God that I can see. The other doctor left me with silicone. They put the entire amount that comes in the*

*packet when they should have only put half. Why did the man who wasn't an eye specialist tell me I had cataracts, when what I had was a detached retina? (Hispanic participant)*

*My daughter was young and I took her to the hospital. She had stomach pains... I went to this private doctor and hospital and they sent us home with some medicines. . . . The next day I sent her to school. The school called me up and said, "You [have] got to come pick up this child because she can't even walk." So I said, "OK, I'm going to County General because they will make sure this child's taken care of." I'm not going back playing with these people [at the private office]. I took her to County General. They had her in there for 5 hours checking everything. I found out that she had walking pneumonia. (African-American participant)*

*In my country, if they find you have a fibroma they remove it. They don't wait for it to grow. Maybe if they had taken them out this wouldn't have happened to me. (Hispanic participant)*

#### INSTITUTIONAL DISCRIMINATION IN HEALTHCARE

In discussions with African-American and Hispanic physicians and nurses, they spoke not only about the discrimination their patients experience at the provider-patient level, but also cited examples of how health-care institutions perpetuate discrimination in their policies and methods of practice. Providers felt institutions mandate policies that have a significant negative impact on the provision or access to services for racial and ethnic minority patients.

*It's very difficult to recruit Hispanics [for clinical trials] who cannot understand the consent form. I felt there was some resistance [to spending extra time counseling Spanish-speakers]. [I was told] it was just not really necessary, that I can just give them a synopsis of what is in that consent form. I said, "Wait a minute. This is a very important piece of paper. Why should it be different? You don't give a synopsis to English-speakers." So you can see sometimes the double standard there. (Hispanic nurse)*

*They would not take certain doctors from certain ZIP codes, but we found out what was going on and that subsequently has changed a few years ago. Because they didn't want [minority] patients, they just excluded people from certain ZIP codes, from certain sections of the city. (African-American physician)*

Providers also cited examples of discrimination that they have had to contend with personally during their medical training or professional career.

*There are those that don't get promoted because of their race or whatever. The reason [may be because] they're not well liked by administration or it may be just that they don't want that person in that setting because of their race—that*

*is out there. Racism is alive and well, and those of us who think that it's not are living in some kind of dream world. (African-American nurse)*

*The local medical society . . . it's got the good old boy attitude. It's the same old doctors that have been running it, and they're still running it. The new guys kind of have trouble getting in. (Hispanic physician)*

*I heard an Anglo doctor complaining that his daughter is having trouble getting into medical school. Then another doctor jumps in, another Anglo, "Oh, don't worry about it. I know the admissions coordinator. . . I'll get her in. I'll give him a call and she'll be in." When does a Hispanic or black student have those advantages, the connections? I certainly didn't have any connections, and I still don't have any connections. I couldn't get my son into medical school if I tried. (Hispanic physician)*

### INCLUSION OF AND RESPECT FOR CULTURE IN HEALTHCARE EXPERIENCES

While some participants did not feel it was essential that providers and patients be of the same race or ethnic background, many participants felt that a cultural match between healthcare providers and patients is helpful in communicating more easily. One African-American physician summed up responses saying, "Basically, you're comfortable with what you're familiar with. That's the bottom line." Participants felt that it is easier to develop a rapport or discuss treatment options with healthcare providers of their own race who already understand their language and cultural idiosyncrasies.

*I don't think necessarily you have to be an African American to provide good care to African Americans, but if you're not you really need to be aware of the culture and some of the issues in that culture, and really look at how you feel about dealing with people from that culture. (African-American nurse)*

*For me, my doctor is a thin doctor, but she knows that I like Mexican food so she knows it's hard for me to lose weight. She understands the way my parents brought me up, the culture, the background, so she knows. In other words, we understand each other because we're both Hispanic. (Hispanic participant)*

*If someone, the doctor for example, is of the same ethnicity, Hispanic, he understands the idiosyncrasies more. For example, for women, in our country there are certain taboos. It is more difficult to talk about private things. So, a doctor of our same race will understand those things more. (Hispanic participant)*

*I feel I could relate better to the African American [doctor]. He knows black folks better. If you're talking about high blood pressure, diabetes, sometimes these are things that traditionally do not happen to white folks. To the extent with the ills that we suffer, I believe he would be better suited for me. (African-American participant)*

*I think there are just certain aspects of the culture that one may know a little bit more about by just being part of the culture. For example, with Hispanic patients, it's more of a touchy feely—especially my relationship with older women. There's always a lot of hugging or kissing, whereas with the men—none of that—there's only hand shaking. When it comes to my African-American women, there is some touchy feely stuff, but, again, there is more distance. I think just being aware of the cultural attitudes makes it slightly different. (Hispanic physician)*

In instances where healthcare providers or administrative staff are of a different race or ethnicity than the patients they are treating, participants expressed a desire for more patience and respect from their providers. They felt that doctors and nurses who are treating a high proportion of patients from a particular racial or ethnic group should be familiar with relevant customs that may impact patients' healthcare decisions.

*One thing—the elders—they're stubborn. You got to have a lot of patience with them because they think they're all right and they don't want to go to a doctor. It takes a lot just to get them to go. Have patience and be courteous towards them and respect them. (Native-American participant)*

*A lot of Native Americans are shy. I think that would be good for a doctor to make sure the patient understands the treatment they're going to provide or the cause of their illness and make sure they understand what's going on. (Native-American participant)*

*Our culture is very different. The Americans have a different way of treating people. We are more affectionate, sweet. We have a lot of time to give, they are very quick. (Hispanic participant)*

*I think if [doctors] have a basic knowledge of the culture and are sensitive of that, culture is just the traditional part of healing. There was one doctor at IHS. My brother injured his leg, went in, had an x-ray. . . . I remember at the end of the visit, and this was the only time I heard one of the doctors there say, "If you want to go visit your medicine man, feel free to do that." (Native-American participant)*

*Yeah, I had to have surgery and also my mom. In both cases this is the same doctor, a specialist, and when he explained about my mom, for example, he even took me in the room. He showed her and me, he even on a piece of paper showed how the liver and all this, what they had to do and this and that, and explained in language that we understood and took the time. It took him maybe a little more than 20 minutes, and that counts for something in my book you know. (Hispanic participant)*

*If they're going to practice in a Native-American setting, they should understand how traditional medicine can lead to healing the patient. (Native-American participant)*

*Understand what the past healthcare history has been to Native Americans. Maybe just having an understanding of how Native-American healthcare has been across the U.S., not just here in the Southwest, but everywhere. I think that would make [healthcare providers] effective because then they would know what's happened in the past and not repeat the same mistakes. (Native-American participant)*

## CONCLUSION

The stories and recollections of participants across the eight focus groups provide supporting evidence for the concern that racial and ethnic minorities are less likely to receive appropriate medical services, and that they experience a lower quality of healthcare than do nonminorities. While racial and ethnic discrimination is not always easy to recognize or recall, participants offered many concrete examples of discriminatory situations they encountered. This research adds to the growing body of literature examining racial and ethnic disparities in healthcare and provides evidence of both interpersonal and institutional discrimination. Perhaps, through continued research and awareness, healthcare delivery will become more respectful and culturally appropriate for racial and ethnic minority patients in the future.

## E

### Committee and Staff Biographies

**Alan Nelson, M.D., *Chair***, is an internist-endocrinologist who was in private practice in Salt Lake City, Utah until becoming chief executive officer of the American Society of Internal Medicine (ASIM) in 1992. Following the merger of ASIM with the American College of Physicians (ACP) in 1998, Dr. Nelson headed the Washington Office of ACP-ASIM until his semi-retirement in January 2000, and currently serves as Special Advisor to the EVP/CEO of the College. Dr. Nelson was appointed to the Medicare Payment Advisory Commission (MedPAC) in May 2000. He was president of the American Medical Association in 1989-90 and was president of the World Medical Association from 1991-1992. Dr. Nelson received his M.D. degree from Northwestern University. He is a Master of the American College of Physicians and a member of the Institute of Medicine.

**Risa Lavizzo-Mourey, M.D., M.B.A., *Co-Vice Chair***, is the Senior Vice President at the Robert Wood Johnson Foundation. Prior to joining the foundation, she was the Director of the Institute on Aging, Chief of the Division of Geriatric Medicine, and the Sylvan Eisman Professor of Medicine and Health Care Systems at the University of Pennsylvania as well as the Associate Chief of Staff for Geriatrics and extended care for the Philadelphia Veterans Administration Medical Center. Dr. Lavizzo-Mourey's research is at the interface of geriatric medicine and health policy, focusing specifically on disease and disability prevention as well as health care issues among persons of color. She earned her medical degree at Harvard Medical School followed by a Masters in Business

Administration at the University of Pennsylvania's Wharton School. Dr. Lavizzo-Mourey was formerly the Deputy Administrator of the Agency for Health Care Policy and Research, now known as the Agency for Health Care Research and Quality within the U.S. Department of Health and Human Services. She was also a member of the White House Health Care Policy team. Dr. Lavizzo-Mourey is a Master of the American College of Physicians-American Society of Internal Medicine and a member of the Institute of Medicine.

**Martha N. Hill, Ph.D.,** *Co-Vice Chair*, is Interim Dean, Professor, and Director, Center for Nursing Research, at The Johns Hopkins University School of Nursing. Her research has focused on hypertension care and control in urban African American Communities. Dr. Hill has also worked in the area of diabetes control in African Americans, patient and provider compliance with recommendations, strategies for patient education and behavior change, and health promotion and disease prevention. Her most recent work includes research on barriers to hypertension care and control, and dispelling myths about urban Black men with hypertension. Dr. Hill received her master's degree from the University of Pennsylvania and her doctorate degree in behavioral sciences from the Johns Hopkins School of Hygiene and Public Health. She is a fellow of the American Academy of Nursing, the Society of Geriatric Cardiology, the Society for Behavioral Medicine, and was the 1997-1998 president of the American Heart Association. Dr. Hill is a member of the Institute of Medicine.

**Joseph R. Betancourt, M.D., M.P.H.,** is Senior Scientist, Institute for Health Policy and Director for Multicultural Education, Multicultural Affairs Office at Massachusetts General Hospital-Harvard Medical School. Dr. Betancourt's primary interests include cross-cultural medicine, minority recruitment into the health professions, and minority health/health policy research. His research has focused on developing a framework for cultural competence as a health policy initiative and quality measure (funded by the Commonwealth Fund), and exploring root causes for racial/ethnic disparities in health (funded by HCFA and the NIH). Dr. Betancourt is a graduate of the New Jersey Medical School, Cornell Medical Center, and the Harvard School of Public Health. He serves on the New York Academy of Medicine's Racial/Ethnic Disparities Working Group and the Greater New York Hospital Association's Steering Committee on Racial/Ethnic Disparities.

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### IOM Staff Biographies

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On a personal note, Dr. Smedley would like to acknowledge his godfather, Dr. Charles H. Wright of Detroit, Michigan. Dr. Wright was an obstetrician whose tireless efforts to increase awareness of the rich history of African peoples and their descendants in America and throughout the world resulted in the creation of the Charles H. Wright Museum of African-American History in Detroit, among many other such institutions. Dr. Wright died on March 7, 2002, shortly before this report was released.

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## Paper Contributions





# Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and a Consideration of Causes

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## INTRODUCTION

At no time in the history of the United States has the health status of minority populations—African Americans, Native Americans and, more recently, Hispanics, and several Asian subgroups—equaled or even approximated that of white Americans. The health of all American racial and ethnic groups has improved dramatically, particularly over the last six decades, but the paired burdens of excess morbidity and decreased life expectancy for people of color have been noted over several centuries and have proved, even recently, to be stubbornly resistant to substantial change (Byrd and Clayton, 2000; National Center for Health Statistics, 1998). Two observations, some four decades apart, illustrate this persistence of inequality. In his classic 1944 study of the role of race in American life, Gunnar Myrdal noted that “Area for area, class for class, Negroes cannot get the same advantages in the way of prevention and care of disease that whites can” (Myrdal, 1944). In 1985, the Report of the Secretary’s Task Force on Black and Minority Health concluded that “Despite the unprecedented explosion of scientific knowledge and the phenomenal capacity of medicine to diagnose, treat and cure disease, Blacks, Hispanics, Native Americans, and those of Asian/Pacific Islander heritage have not benefited fully or equitably from the fruits of science or from systems responsible for translating and using health sciences technology” (USDHHS, 1985). In 1995, the overall African-American mortality rate was 60 percent higher than that of whites—precisely what it had been in 1950 (Williams and Rucker, 2000; Williams, 1999).

Classic public health doctrine holds that the major determinants of population health status and the primary explanations of disparities among population groups lie in the social, physical, and economic environments, which in turn are determined by the larger society's norms, values, social stratification systems and political economy (King, 1996; Menefee, 1996). The causes of these minority/white disparities in health status have consistently been attributed to such variables as socioeconomic status (especially income, lack of education, and unemployment); lifestyle choices and behavioral risks; occupational and environmental hazards, inferior housing, poor nutrition, and different cultural beliefs about health and illness. There is evidence for all of these variables. Another explanation is lack of minority access to health care, particularly the lack of either public or private health insurance, which has persisted despite the introduction and expansion of such programs as Medicare and Medicaid (Blendon et al., 1989; Weinick, Zuvekas, and Cohen, 2000).

Two other variables frequently suggested as causative similarly reflect values and beliefs that are prevalent in the larger society and appear with considerable frequency in the medical literature on disparities. The first of these is the contention that there are biologically and genetically distinct human races, and that "racial" biologic differences in susceptibility to, manifestations of, or therapeutic responses to specific diseases are significant pathophysiologic contributors to health disparities. Such beliefs appeared frequently in 19th-century America as elaborate, pseudoscientific arguments for the inherent biological inferiority of African Americans (Cartwright, 1851). Today, however, despite the recognition that "race" is a social rather than a meaningful biologic concept (Marks, 1995; Cavalli-Sforza, Menozzi, and Piazza, 1994; Witzig, 1996), arguments about the medical importance of racial groupings continue to appear, without pejorative intent and in highly sophisticated form (Wood, 2001; Schwartz, 2001; Goodman, 2000).

The second suggestion is that racial and ethnic discrimination itself may be an important contributor to health disparities, not merely through the historic and persistent disadvantages it creates for minorities in the American social structure, but also specifically through health provider bias—conscious or unconscious, individual or institutional. A rich literature attests to the persistence and prevalence of racist beliefs and discriminatory behaviors in contemporary American society (Steinhorn and Diggs-Brown, 1999; Waller, 1998; Polednak, 1997; Massey and Denton, 1993; Hacker, 1992; Feagin, 1991; Farley and Allen, 1989). There was limited quantitative evidence, however, for the view that such racial/ethnic discrimination might occur frequently in medicine until the availability of large administrative databases from Medicare, the Health Care Financing Administration (HCFA), the Department of Veterans Affairs (VA) and

other sources initiated a growing stream of studies examining racial and ethnic disparities in diagnosis and treatment. These studies clearly established that whatever the causes, the experience of minorities *within* the health care system differed from that of comparable whites across a broad range of disease categories. The majority of these investigations focused on African-American patients; data on Hispanics, Native Americans, and Asian/Pacific Islanders were more limited.

In 1990, the American Medical Association (AMA) took formal note of black-white disparities in health care. While emphasizing the probable roles of socioeconomic status and sociocultural factors and noting the limitations of many studies, the AMA also acknowledged that “Disparities in treatment decisions may reflect the existence of subconscious bias. . . . The health care system, like all other elements of society, has not fully eradicated this [racial] prejudice” (Council on Ethical and Judicial Affairs, 1990). Intense discussions of the early evidence and its possible causes, however, were already underway. A search of the literature prepared for the AMA’s board of trustees covering only the articles, commentaries and letters that appeared in the *Journal of the American Medical Association* and the *New England Journal of Medicine* from 1984 to 1994, filled 66 single-spaced pages (Board of Trustees Report 50-1, 1995). The comments of many physicians were heavily weighted toward denial. As van Ryn has pointed out, such reluctance is understandable because the idea that racial/ethnic bias might be operative conflicts with most physicians’ conscious commitment to anti-discriminatory principles, their views of their own behaviors, that of their peers and the institutions within which they work, and the ethical commitments of medicine (van Ryn, 2001).

Studies of racial/ethnic disparities in diagnosis and treatment proliferated throughout the 1990s and were characterized by increasingly sophisticated control or adjustment for such confounding variables as health insurance status, income and education, severity or stage of disease, comorbidity, and hospital type and resources. They drew upon a wide variety of data sources, regional and multi-center collaborations, quality assurance investigations, and disease-specific investigations such as the Coronary Artery Surgery Study (CASS). Relatively few were based on detailed access to clinical records. The limitations of administrative databases and retrospective methodologies usually precluded any evidence-based identification of the causes of disparities. Explanations, which were necessarily speculative in most cases, were drawn from the same repetitive list of possibilities. They included patient choice or preference, unmeasured aspects of socioeconomic status, unmeasured clinical variables, biological differences in disease manifestation or response to treatment, minority cultural beliefs, lack of trust in the health care system, deficiencies in providers’ cultural competence, and difficulties in cross-racial/

ethnic physician-patient communication, in addition to the possibility of individual or institutional bias. In the late 1990s, concerns about racial/ethnic bias and stereotyping appeared with increasing frequency in the medical literature (Geiger, 1996, 1997; King, 1996; Smith, 1998; Williams and Rucker, 2000) and began to be presented as issues of social justice (McGary, 1999). Recently, local governments and public health departments have conducted studies of racial/ethnic disparities and discrimination in health care institutions in their own areas (Twin Cities Metro Minority Health Assessment, 2001; Seattle and King County Public Health Department, 2001). At the federal level, Congressional legislation has specifically addressed issues of discrimination in health care, and a new National Center on Minority Health and Health Disparities has been established at the National Institutes of Health. Clearly, the problem of racial/ethnic disparities in diagnosis and treatment is increasingly being viewed as an important subset of the issue of achieving equity in health status (Department of Health and Human Services, 2000) and as a particularly troubling component of the problems of race and ethnicity in the larger society.

It is in this context that systematic reviews of the relevant medical literature may help to illuminate three key questions. Does the cumulative weight of evidence establish that there are significant racial and ethnic differences in diagnostic investigation and therapeutic recommendations and actions, due at least in part to problems of bias and discrimination? If so, do such differences in health care in turn contribute to the excess burdens of morbidity, disability, impaired quality of life and premature mortality that are already so well documented in studies of the health status of minority populations? Finally, what can be determined about the multiple processes and causes of these differences? The answers may be helpful in addressing two additional questions: What are the needs for further research, and what steps might be taken now to reduce or eliminate such disparities?

### **The Present Review: Scope and Methods**

This paper will present a sampling of findings from an ongoing review of the medical literature on racial and ethnic differences in diagnosis and treatment. Relevant studies were identified by searching Medline and many other databases, including those maintained by HCFA, the Agency for Healthcare Research and Quality (AHRQ), and the HHS Office of Minority Health (OMH). Additional studies were identified through references in published articles. A substantial number of dedicated web sites relevant to issues of minority health, cultural competence and health workforce diversity were examined, as were a wide variety of

reports from the Henry J. Kaiser Family Foundation, the Commonwealth Fund, the Association of American Medical Colleges (AAMC), the National Medical Association (NMA), the Hispanic Medical Association (HMA), and other organizations. Editorials, commentaries, and workshop and conference reports were also reviewed. In all, more than 600 bibliographic citations have been accumulated and organized primarily by disease category. Topics include general medical care, coronary artery and other cardiac disease, cancer, cerebrovascular disease, asthma, HIV/AIDS, renal disease and renal transplantation, diabetes, mental health, maternal and child health, ophthalmic disease, prevention, and a small sampling of other disease categories. An effort was made to identify all relevant studies comparing diagnosis and treatment by race or ethnicity, including any that did not report significant disparities. Additional topics include research methods and clinical trials, issues of trust and communication in the healthcare system, and medical education and cultural competence.

A hard copy of each article was obtained from the library and examined for relevance, study design, appropriateness of data sources, analytic methods and control of potentially confounding variables, and originality. Each selected article was then reviewed by at least two people—a physician with epidemiologic training and a master's or doctoral level epidemiologist or health services researcher. A detailed one- or two-page annotation was then prepared, including not only the material usually presented in the abstracts—purpose, data sources, study design, methods and results—but also important details from the text such as the discussions, the offered explanations, the acknowledged limitations, and any statements of implications for policy or research. Initial support for this work was provided by the Robert Wood Johnson Foundation, and support for what is now an ongoing effort has been provided by the Josiah Macy, Jr., Foundation, the Commonwealth Fund, the Ford Foundation, and the W.K. Kellogg Foundation.

This effort substantiates and extends the pioneering work of Mayberry and his associates, who published the first detailed and comprehensive review of the relevant medical literature (Mayberry, Mili, and Ofili, 2000). As indicated by the list of topics, the scope of the present effort was somewhat broader, as was the time frame. A few studies and commentaries, mostly in the psychiatric literature, were found in the 1960s (Gross and Herbert, 1969; Pasamanick 1963) and a small number of relevant publications appeared in the 1970s. The majority of articles selected for this review, however, were published between 1980 and the first half of 2001.

Our purpose in the following sections is not to present an exhaustive account or description of each annotation in every topic category, a task that would require a much longer paper. Instead, a modest number of

studies, selected as representative of the most important findings, will be described and discussed in the following section on general medical and surgical care. This will give some sense of the data sources, study designs and methods that are typical of the entire research effort. In subsequent sections, an attempt will be made to present representative studies in each of five disease categories. These examples from the literature review are intended to document the multiplicity of factors, including but by no means limited to individual and institutional bias, that contribute to racial and ethnic disparities in diagnosis and treatment.

### General Medical and Surgical Care

Perhaps the most useful data come from large-scale studies that examine racial/ethnic differences in the adequacy, intensity and quality of diagnostic and therapeutic procedures for a wide range of clinical conditions, in different hospital types and health care systems. For example, Kahn and her colleagues examined the quality of care provided to a nationally representative sample of 9,932 elderly Medicare-insured beneficiaries. The sample included patients who were black or from poor communities and who had been hospitalized for congestive heart failure, pneumonia, acute myocardial infarction or stroke, in one of 297 acute care hospitals—urban teaching, urban nonteaching, or rural—in five states (Kahn et al., 1994). The study is noteworthy for its detailed examination of clinical records, and its use of explicit quality criteria to assess the most basic (not luxury) elements of care: history taking and physical examination, common diagnostic tests such as chemistries and chest X-rays, and standard therapies such as diuretics and antibiotics. Because the care of black and poor patients was found to be similar, the two groups were combined in the analysis. When the experience of these patients was compared with that of people who were white or more affluent, the quality of care as measured by these fundamental indicators was found to be significantly lower for the black and poor group. While quality of care was best in urban teaching hospitals, the magnitude of the quality gap was similar in all three hospital types. The authors noted that further research is necessary to clarify whether sociocultural and educational incongruity between providers and patients translates into misunderstandings about patients' preferences and expectations, and to evaluate the extent to which stereotyping, discrimination and bias exist in the hospital setting. They concluded that "racial characteristics and poverty status also influence the quality of care received by acutely ill, insured patients after they have gained access to the hospital."

A number of similar studies examined black-white differences in the use of selected specific procedures. Lee and colleagues reviewed the use

of both basic and sophisticated diagnostic tests and minor and major surgical procedures, using claims data for Medicare beneficiaries in 10 states and the District of Columbia who had both Part A and Part B coverage. A subset of this sample was created by matching beneficiaries on the basis of zipcode of residence to neutralize the effects of black-white differences in provider access and regional practice patterns. Despite the adequacy of health insurance coverage, black patients' utilization was substantially weighted toward lower-cost procedures. The authors concluded that "...providers appear to be giving less intensive care to otherwise similar black Medicare beneficiaries" (Lee et al., 1997). Similarly, McBean and Gornick studied the use of 17 major diagnostic and therapeutic procedures and found that black Medicare beneficiaries were much less likely than whites to receive "referral-sensitive surgeries" (McBean and Gornick, 1994).

One of the largest studies reviewed more than 1.7 million hospital discharge abstracts to examine use of major diagnostic and therapeutic procedures in 77 disease categories in some 500 acute care hospitals (Harris, Andrews, and Elixhauser, 1997). After controlling for patient age, severity of illness, health insurance and hospital type, blacks were significantly less likely than whites to receive a major therapeutic procedure in almost half of the 77 disease categories. Again, in a five percent sample of more than 1.2 million claims in a HCFA Medicare database, blacks were found less likely than whites to receive 23 of 32 services, and the disparities were found even when patients were insured by both Medicare and Medicaid, minimizing the confounding of race with financial barriers to care (Escarce and Epstein, 1993). In a study of racial variation in procedures characterized as low, moderate or high physician discretion (Mort, Weisman and Epstein, 1994), blacks were less likely to undergo even such low-discretion (i.e., clinically urgent) procedures as appendectomy and repair of an abdominal aortic aneurysm. Disparities are not limited to African Americans, however. After adjusting for socioeconomic status, a study comparing experiences of Hispanic with non-Hispanic patients in California, Florida, and New York found that Hispanics were less likely to undergo major procedures in 38 percent of 63 different disease categories (Andrews and Elixhauser, 2000). A similar pattern was found even when very basic in-hospital diagnostic and therapeutic procedures for such common conditions as congestive heart failure and pneumonia were examined (Ayanian et al., 1999a). Using explicit process criteria and after adjustment, black Medicare patients were significantly less likely than whites to receive adequate laboratory and other diagnostic tests or therapeutic drugs such as diuretics and antibiotics.

Most of the investigations described above are broad-brush studies. Despite the consistency of their findings, and the indications that dispari-



ties may occur at every level of disease severity and at every stage of the diagnostic and therapeutic process, they have the limitations described previously. Most are retrospective, and cannot report information gleaned directly from providers or patients. Most have limited access to detailed clinical records, and so estimates of variables such as stage and severity of disease are likely to be approximations. There are serious problems in controlling or adjusting adequately for socioeconomic status when data on individual patient income, education or occupation are limited or absent. Health insurance may fail to eliminate the financial barrier of out-of-pocket expenses, which may affect both patient and provider choices. And finally, these studies offer relatively little evidence on outcomes such as disability or subsequent mortality.

These limitations underlie both the wide range and tentative nature of the explanations that are offered for the findings of racial and ethnic differences in care. The list is extraordinarily varied, but strikingly similar across studies. As noted previously, researchers suggest patient choice or preference; unmeasured socioeconomic variables; unmeasured clinical variables; unspecified sociocultural factors and differences in health beliefs; and impaired physician-patient communication and interactions. Also frequently mentioned are financial barriers and procedure costs as disincentives to care; differences in provider type, practice patterns, referral patterns and hospital resources; and overuse of procedures for whites rather than underuse for blacks. Yet, almost all the investigators also raise the possibility of racial bias and discrimination by providers, sometimes referring explicitly to racial and ethnic stereotyping. And many call for further research specifically designed to resolve the unanswered questions of causation.

A number of general surgical and orthopedic studies present similar findings. Blacks hospitalized in Maryland from 1985 to 1987 had lower rates for discretionary orthopedic, vascular, and laryngeal surgeries; the more discretionary the procedure, the lower the incidence among blacks. The differences were particularly marked for vascular surgery and were attributed to lower rates of referral and access to specialty care (Gittelsohn, Halpern, and Sanchez, 1991). A large retrospective cohort study of amputation rates and leg-sparing surgery for peripheral vascular disease among African-American and white Medicare beneficiaries found that among both diabetics and nondiabetics, African Americans were significantly more likely than whites to undergo amputations and significantly less likely to receive lower-extremity arterial revascularization (Guadagnoli et al., 1995). A striking example of racially differential provision of advanced technology was reported in the free-care VA system, in which both providers' financial incentives and patients' financial barriers are irrelevant and the socioeconomic spectrum of patients is substantially narrowed.

Researchers examining a prospective clinical records file covering all VA hospitals with operating rooms studied the use of laparoscopic versus conventional open cholecystectomy (which has a much higher in-hospital death rate) in the first four years after the introduction of the newer method. After adjustment for age, coexisting disease, socioeconomic status, and potentially confounding clinical characteristics, African Americans were 32 percent less likely than whites to receive laparoscopic surgery (Arozullah et al., 1999). In several other studies, African Americans were significantly less likely to receive total hip or total knee replacements, although racial variation in disease incidence may account for some of the differences (Harris and Sledge, 1990; Wilson, May, and Kelly, 1994; Baron et al., 1996).

A few studies reported particularly troubling outcomes. Hispanic patients with long bone fractures in one teaching hospital emergency room were twice as likely as non-Hispanics to receive no medication for pain (Todd, Samaroo, and Hoffman, 1993). At least one study showed that minority outpatients with cancer were provided with inadequate analgesic medication (Cleeland et al., 1997). Elderly African-American, Hispanic, Native Americans and Asian nursing home residents with cancer were also less likely to receive pain medication (Bernabei et al., 1998). Finally, in a national sample of intensive care units (ICUs) in the United States, African-American patients were found to receive significantly less treatment, less technological monitoring, fewer laboratory tests and less life-supporting treatments than whites in the first 24 hours in the ICU, after adjusting for type and severity of illness, age, and hospital characteristics (Williams et al., 1995). However, the researchers noted no black-white difference in overall ICU and hospital death rates.

Finally, studies of hormone replacement therapy provide some insight into the contribution of physician-patient communication to differences in care. Post-menopausal African-American women were not only less likely than white women to receive such treatment, but also less likely to receive counseling from physicians or be offered the choice of replacement therapy (Marsh et al., 1999; McNagney and Jacobson, 1997; Ganeson and Norris, 2000).

### **Coronary Artery Disease**

Coronary artery disease (CAD) and acute myocardial infarction (AMI) are the most intensively and elaborately studied topics among all studies of racial and ethnic differences in care. In the last 20 years close to 200 studies, reviews, editorials and commentaries have investigated or discussed disparities in cardiac catheterization, angioplasty, coronary artery bypass surgery (CABG) and medical therapies such as the use of

beta-blockers, thrombolytic drugs, and aspirin. The reasons for the abundance of CAD-related studies are apparent. Coronary artery disease is a leading cause of death in all population groups. Its natural history, pathophysiology, risk factors and complications are well understood. There are relatively clear and standardized criteria for the appropriateness of invasive interventions and medical treatments. Utilization of these procedures and treatments is recorded in numerous databases, across all hospital types, and in many multicenter studies of specific diagnostic, treatment, or outcomes questions. Over the last decade, studies have been characterized by increasingly sophisticated control or adjustment for confounders. With only a relative handful of exceptions (usually based on smaller samples), the pattern of results is clear: African Americans with CAD or AMI are significantly less likely to receive appropriate cardiac procedures or therapies (Maynard et al., 1986; Hannan et al., 1991; Udvarhelyi et al., 1992; Ayanian et al., 1993; Franks et al., 1993; Whittle et al., 1993; Peterson et al., 1994; Giles et al., 1995; Carlisle et al., 1995; Stone et al., 1996; Gornick et al., 1996; Sedlis et al., 1997; Weitzman et al., 1997; Peterson et al., 1997; Hannan et al., 1999; Canto et al., 2000). They are less likely to be catheterized. If they are catheterized, African Americans are frequently 20 percent to 50 percent less likely to undergo a revascularization procedure. They are less likely than whites to receive beta blockers, thrombolytic drugs, or aspirin. These findings occur in both teaching and nonteaching hospitals. Cumulatively, the studies have accounted for age, sex, disease severity, symptom expression, comorbidity, health insurance or payor, and physician specialty, though each of these has some effect on its own. Roughly similar but less consistent disparities have been found for Hispanic patients (Goff et al., 1995; Mickelson et al., 1997; Canto et al., 1998; Hannan et al., 1999) but the documentation is less extensive; one study found no significant differences (Ramsey et al., 1997). Little difference in either invasive or medical treatment has been found between whites and Asians or Native Americans, but the number of studies is far too small to justify firm conclusions (Canto et al., 1998).

It is worth noting again that most of this large body of evidence on disparities in the diagnosis and treatment of cardiac disease does not reflect problems of primary *access* to health care, but are based on studies of persons already *in* the health care system.

There is less certainty about the causes of these differences as the same varied explanations offered for differential treatment in general medical and surgical care tend to be presented in every disease category. Recent experimental and prospective studies, however, have clearly identified racial and ethnic bias or stereotyping in clinical decision making as a contributing factor (Schulman et al., 1999; van Ryn and Burke, 2000). One especially useful review of more than 25 major studies argues that while

the causes of these inequalities in care remain to be fully elucidated, the studies have clarified what does *not* explain them (East and Peterson, 2000). Thus, these authors conclude, the disparities are not due to differences in disease prevalence because the treatment differentials are found in studies comparing black and white people with documented lesions or infarctions, and among those who have had access to cardiologists. They are not due to differences in clinical presentation, electrocardiographic findings, or size and distribution of coronary artery lesions. They are not fully explained by comorbidity or other clinical characteristics. They are not due to health insurance or payor type alone, since these disparities occur among equally insured Medicare patients and in VA hospitals where care is free. (Public hospital patients, however, who are disproportionately minority, are less likely to receive revascularization procedures unless they have in-hospital access to a cardiologist. In other hospitals, such differences are not explained by physician specialty). Any patient whose primary admission is to a hospital with the requisite catheterization and operative facilities, however, is more likely to receive revascularization. The racial and ethnic disparities are not due to regional variations, since they have been found in all areas of the country. They are not due to patient choice or refusal of procedures by minority patients; although a few studies of heart disease have found such an effect, more recent prospective studies have indicated that it is far too small to account for the large differences in treatment rates. The disparities are not due to overuse of appropriate treatments for whites and underuse for minorities, as inappropriate use does not vary by race.

A uniquely detailed perspective on the complex sequence of events leading to decisions on revascularization—and the role of race at each stage in the process—is offered by a study of white, black and Hispanic patients, *not* on Medicare, who were discharged from California hospitals with a principal diagnosis of AMI during an eight-month period in 1991. The investigators divided the process into four phases: pre-hospital (admission to a hospital offering revascularization); intra-hospital (initial admission); inter-hospital (immediate transfer to a hospital offering revascularization), and post-hospital (re-admission for revascularization during ensuing months). At every stage, both race and payor status were powerful predictors of revascularization (angioplasty and CABG). For example, within hospitals offering revascularization, whites and privately insured patients were most likely to receive revascularization; minority patients and the uninsured were least likely. Whites were also more likely to undergo transfer and revascularization than were minority patients. In the subgroup of patients who received a diagnostic cardiac catheterization, whites were almost 50 percent more likely than minority patients to have the procedure “converted” to a revascularization procedure. After ac-

counting for the strong association between race and payor status, as well as gender, disease severity and age, the baseline racial differences were not diminished in any phase (Blustein et al., 1995).

In general, the pattern is similar for medical therapy of CAD. Poor, black, or female patients with AMI were less likely to receive beta-blockers, thrombolytic therapy, or aspirin (Rathore et al., 2000a). In a Corpus Christi study, Mexican Americans with myocardial infarction were more than 40 percent less likely than comparable whites to receive thrombolytic therapy (Goff et al., 1995), and in a VA study Hispanics were more than 70 percent less likely to do so (Mickelson et al., 1997).

Although a few studies have found no racial difference in revascularization rates, or have implicitly questioned the existence of physician bias in decision making as an explanation for differences, such studies also have significant limitations. For example, Leape et al. found similar revascularization rates for whites and racial/ethnic minorities, but the study used broad diagnostic categories (including “suspected atherosclerosis”) and the sample size was small (Leape et al., 1999).

A recent study raises more important and troubling questions than its data can answer. Chen et al. examined a large sample of more than 18,000 Medicare patients admitted to the hospital for AMI. After adjustment for a wide variety of potential confounders, the researchers reported a significant deficit in the rate at which black patients received cardiac catheterization as compared with white patients—a finding consistent with many other investigations. Uniquely, however, this study compared the experience of patients by the race of their attending physicians, and found that the black-white gap in catheterization for the patients of black attending physicians was almost identical to the black-white gap for the patients of white attending physicians. Since the authors found no significant interaction between the patient’s race and the physician’s race, they concluded that “racial discordance between the patient and the physician does not explain differences between black patients and white patients in the use of cardiac catheterization” (Chen et al., 2001). The implication, fully articulated in an accompanying editorial, is that “overt racial prejudice did not account for racial differences in the rates of cardiac catheterization among black patients,” presumably on the assumption that black physicians cannot be racially prejudiced (Epstein and Ayanian, 2001).

In almost every hospital with the requisite facilities, however, it is a cardiologist—not the attending physician—who must make the initial decision to recommend or deny catheterization. We do not know how many of the black and white attending physicians, respectively, referred their patients to cardiologists for a requested catheterization. And among the small numbers of white and black patients whose attending physicians were cardiologists, the published data do not specify what decisions those

black and white cardiologists made for patients of either race. In a comment on Chen et al., Barr pointed out that as many as 70 percent of all the patients were likely to have had a cardiac consultation, and given that there are only a few hundred black cardiologists and more than 18,000 white cardiologists, it is likely that most black patients were seen by white cardiologists (Barr, 2001). If this is so, the study by Chen et al. essentially compared the decisions of white cardiologists with those of other white cardiologists, regardless of the race of the attending physician. While it is possible for an attending physician to overrule a cardiologist's negative recommendation and demand a catheterization, the study did not provide data by either physician race or patient race as to how often (if ever) this happened.

There are other troubling possibilities. Bias, as frequently noted, can be covert and unconscious rather than overt. Institutional racism—customs and practices in a hospital that produce racial inequalities, regardless of an individual physician's intentions—may play a role. As noted by Jacobs, there may be something in the process of medical education, professional acculturation or practice experience that subtly biases both black and white physicians, so that "racial prejudice . . . does not depend on the color of the perpetrator's skin" (Jacobs, 2001). In sum, these uncertainties underscore the need for prospective studies, with access to detailed clinical records, information on the *processes* of clinical decision-making, and interviews with both patients and physicians.

Several studies also merit specific mention because of the importance of their findings. A large study at Duke Medical Center found the common pattern of significantly lower rates of CABG among African Americans. Those who did not receive such treatment included patients who were at highest risk, had two- or three-vessel disease, and would have been expected to gain the greatest benefit. The five-year mortality rate for blacks was significantly higher than for whites (Peterson et al., 1997), in contrast to other studies that had found little difference in mortality outcomes. A study of revascularization procedures at major medical centers in New York State examined the care of patients who had been classified, by widely accepted criteria, as "inappropriate," "appropriate," or "necessary" for revascularization. Among all African-American patients, including those in the "necessary" category for whom the procedure is regarded as almost obligatory in the absence of contraindications, the rates of angioplasty and CABG were lower than those of comparable whites. In the "necessary" category, African Americans underwent angioplasty and CABG 37 percent fewer times than whites; there was no difference between Hispanics and whites in this same category. Patient choice accounted for only a very small amount of the variation, and in 90 percent of the cases in which patients did not receive bypass surgery, it was the

physician who made the decision not to recommend the procedure (Hannan et al., 1999). In an elegant follow-up study designed to conceal the fact that race was an important focus of inquiry, researchers interviewed the decision-making clinicians about their treatment decisions. The physicians believed that their recommendations to deny invasive treatment to many African-American patients were based on sound clinical criteria. The data suggested, however, that the physicians projected classic negative racial stereotypes onto those patients, and that their negative perceptions of race and class were in fact predictive of their treatment decisions (van Ryn and Burke, 2000).

Perhaps the single most impressive demonstration of the role of race in clinical decision-making comes from the VA hospital system, which is well represented in studies finding significant racial/ethnic disparities in care. At the Cleveland VA hospital between 1993 and 1995, decisions about angioplasty and CABG on 938 consecutive patients who had undergone catheterization were made by a committee of cardiologists and cardiothoracic surgeons on the basis of a presentation by a cardiology fellow; they did not see the patient. The presentation of each case included all of the customary clinical data, including the extent and distribution of coronary artery lesions, cardiac function, comorbidity, etc., but *race was not specified*. When the decision-makers were effectively blinded to race, overall rates of revascularization were similar for blacks and whites, but on the basis of clinical factors identified in this series of patients, blacks were more likely to receive angioplasty and whites were more likely to undergo CABG (Okelo et al., 2001).

A recent independent review of 61 studies published from 1966 to May 2000, examining racial variation in receipt of invasive cardiovascular procedures, reached conclusions strikingly similar to those in our own evaluations of the evidence. Among studies using administrative data, odds ratios extracted from the data by the authors for African-American patients compared with white patients ranged from 0.41 to 0.94 for cardiac catheterization, from 0.32 to 0.80 for angioplasty, and from 0.23 to 0.68 for CABG, and procedure rates were also found to be lower for Hispanic and Asian patients. Among studies using detailed clinical data, odds ratios for African-American patients compared with white patients ranged from 0.03 to 0.85 for catheterization, from 0.20 to 0.87 for angioplasty, and from 0.22 to 0.68 for CABG. Studies using survey methods found conflicting results regarding patient refusals as a cause of racial variation in receipt of invasive cardiovascular procedures, and the authors noted that “physician bias was also associated with racial variation in recommendations for treatment” (Kressin and Petersen, 2001).

The evidence from these many investigations supports the hypothesis that providers’ perceptions of race and ethnicity is one of the factors

that affect their clinical decisions. This effect may be a direct consequence of conscious bias (Finucane and Carese, 1990) or, more often, unconscious negative stereotyping (van Ryn and Burke, 2000; van Ryn, 2001). Such stereotyping may be indirect in that it is mediated by distortions or omissions in cross-racial/ethnic physician-patient communication that are, in turn, a consequence of providers' race- or class-based stereotypic judgments of patients' intelligence, likelihood of compliance with recommended regimens, or preferences. Both processes may contribute to the repeatedly documented disparities in the care of patients with coronary artery disease.

There is some evidence, however, that such racial and ethnic differences in the diagnosis and treatment of coronary artery disease are neither intrinsic nor immutable characteristics of all health care systems in the United States. Taylor et al. examined the experiences of 1,441 patients with AMI within the free-care, equal-access Department of Defense health care system, which is open to all active-duty and retired military personnel and their dependents in what is, effectively, a national staff-model managed care system. After controlling for age, gender, clinical characteristics, and other variables, they found no racial differences in the rates of catheterization or revascularization (Taylor et al., 1997).

### Cancer

Studies of racial and ethnic disparities in cancer incidence and prevalence, screening, stage at diagnosis, treatment and survival uniquely illustrate the complex and multifactorial nature of the causes of such differences. To explain them, investigators have invoked variation in tumor biology, genetic differences, cultural differences and folk beliefs, socioeconomic status, problems of access to and continuity of care, physician practice styles and communication with patients, and interactions among all of these factors. The possibility of racial bias is mentioned less frequently, although some studies have found a residual and unexplained effect of race after other variables are accounted for (Eley et al., 1994).

This complexity is illustrated by studies of breast cancer. While African-American and Hispanic women have a lower incidence, they are often first seen for treatment when they already have advanced disease and they have a worse prognosis and shorter survival times than comparable whites (Shinagawa, 2000; Institute of Medicine, 1999). Although early studies concluded that these differences were almost entirely attributable to racial/ethnic differences in socioeconomic status (Dayal, Power, and Chen, 1982; Bassett and Krieger, 1986), biological factors and cultural beliefs were also suggested as causative factors for both African Americans and Hispanics. Differences in income, education, and health insurance



were found to account for findings that elderly blacks had significantly lower experience of regular cancer preventive services such as mammograms, Pap tests, clinical breast examinations, rectal examination and fecal occult blood testing (Hegarty et al., 2000). In a North Carolina study, African-American women were three times more likely than whites to present with advanced stage disease, but when the analysis accounted for income, folk and religious beliefs about cancer, lack of a regular physician, and knowledge about breast cancer, the racial difference dropped to 20 percent (Lannin et al., 1998)

In data from National Health Interview Surveys, black and Hispanic women reported significantly lower rates than whites in having a screening mammogram in 1987, but by 1990 minority rates had improved so rapidly that all three groups were nearly equal (Breen and Kessler, 1994). When ethnic subgroups were considered, however, a different picture emerged. While overall, older black and Hispanic women have mammography and Pap smear rates similar to those of whites, the rates differed among Columbian, Dominican, Ecuadorian, Puerto Rican, Caribbean, Haitian, and U.S.-born black women (Mandelblatt et al., 1999; O'Malley et al., 1997). Similarly, a project focused on minority and underserved women found that rates of ever having had a mammogram were 93 percent for blacks and 90 percent for whites, but only 80 percent for Hispanics, 73 percent for Chinese and 46 percent for Vietnamese women (O'Malley et al., 1997).

Physician performance is an important factor in breast cancer diagnosis, and has been found to vary by patient race. Access to a regular provider is strongly associated with mammogram use (Bush and Langer, 1998) but cannot fully explain racial/ethnic variation. A study of 1990 HCFA billing files from 10 states accounting for patients' income levels and number of primary care visits found that older black women were consistently less likely than comparable white women to receive a mammogram, perhaps because physicians may be unwilling or unable to spend the additional time necessary to educate black women about the importance of the procedure (Burns et al., 1996). After an abnormal finding on a screening mammogram, African-American, Hispanic, and Asian women all had less timely follow-up than whites, and African-American women were much less likely than white women to undergo biopsy (Chang et al., 1996). Suggested explanations included patient preferences, insurance coverage, and discriminatory practices among providers.

Variation by race has also been found in patterns of treatment in some, but not all, studies. Black patients with breast cancer experienced "significantly different care" from whites on four of 10 treatment procedures, though they were not the most clinically important (Diehr et al., 1989). Later studies found similar rates and types of treatment among African-

American, Hispanic, and white women (Farrow, Hunt and Samet, 1992; Satariano, Swanson, and Moll, 1992). Among managed care organizations in which white and African-American women have equal access to health care, one study found equal survival rates after adjustment for stage of diagnosis and socioeconomic variables (Yood et al., 1999). Another study found that African-American women were less likely to receive breast conserving surgery, but the race effect disappeared after adjustment for stage at diagnosis, patients' educational level and rural or metropolitan residence. In a third such study, African Americans and whites received similar treatments (Velanovich et al., 1999). In contrast, two other studies have reported that even when universal access to medical care is assured, there are still racial disparities in breast cancer diagnosis and treatment (Katz and Hofer, 1994; Trock et al., 1993).

Similar patterns are found in treatment for men and women with colorectal cancer. In a study of discharge data from a nationally representative sample of more than 500 acute-care hospitals (Ball and Elixhauser, 1996), blacks were treated less aggressively than whites with similar disease, even after adjusting for insurance coverage, hospital type, and co-morbidities. Blacks were from 27 to 41 percent less likely (depending on tumor stage) to undergo major procedures such as colon resection and cholecystectomy. The authors could not determine whether these differences were social, cultural or economic. Similar treatment differences were found in a study of Medicare beneficiaries (Cooper et al., 1996; Cooper, Yuan, and Rimm, 1997). In marked contrast, there were no differences by race in surgical, radiation, chemotherapy treatments or five-year survival among patients treated in the free-care VA system (Dominitz et al., 1998) and no differences by race in treatment methods or survival rates in the equal-access Department of Defense health care system (Optenberg et al., 1995).

A striking difference in treatment has been found for early stage non-small-cell lung cancer, a condition treatable by surgery that can substantially increase the likelihood of surviving for five years or longer. Bach et al. examined the experience of nearly 11,000 black and white Medicare patients with this diagnosis. The two groups were similar in stage of disease, type of insurance, number of previous hospitalizations, and co-morbidity. After controlling for age, sex, stage of disease, co-morbidity, marital status, and income, blacks were only about half as likely as whites to undergo surgery. The authors estimated that 44 of the 77 excess black deaths were attributable to the difference in surgery rates, and suggested that either patient preference or physicians' decisions were responsible (Bach et al., 1999). In at least one other study, the absence of a physician's recommendation for surgery was more frequent for black than for white patients, and patients' refusal of surgery or contraindications for surgery were uncommon (Polednak, 2000).

### Stroke

African Americans suffer strokes at a rate as much as 35 percent higher than whites, and the death rate among those suffering strokes is twice as high among blacks as whites (Gillum, 1986; Gorelick, 1998; Ness and Aranow, 1999). Yet almost every major study has found that blacks receive the major diagnostic and therapeutic interventions—cerebral angiography and carotid endarterectomy—far less frequently than do whites (Gross et al., 1984; Gorelick et al., 1984; Gillum, 1995; Oddone et al., 1993; Hsia, Mosoe, and Krushat, 1998; Oddone et al., 1999). The variety of explanations offered for these differences include (1) the suggestion that stenosis of cerebral arteries in blacks is much more frequent in intracranial vessels that cannot be treated by carotid endarterectomy; (2) black and white patients present with different symptomatic expressions of this disease or with higher black risks due to hypertension or diabetes; (3) clinicians' beliefs about this suggestion lead them to refer black patients less frequently for invasive diagnostic and therapeutic procedures; (4) black patients refuse such invasive procedures at much higher rates than do whites and are much less willing to accept surgical risks; (5) there is racial bias in the selection of patients for invasive rather than medical treatment; (6) physicians present treatment options less fully to black patients, who may have less information about the disease and physicians make less enthusiastic recommendations to black patients for invasive procedures, among other differences in physician-patient communication; and (7) the differences are due to financial barriers and racial differences in ability to pay. There is reasonably good evidence for some of these explanations, no definitive evidence for others, and still others have been refuted.

Economic barriers seem least likely. These racial differences have been found in both private hospitals and in VA hospitals where care is free. Studies have shown that both with and without adjustment for patient income, whites are still three times as likely as blacks to receive these procedures (Horner, Oddone, and Matchar, 1995) and these authors concluded that "there is no documented study indicating that differences in patient preference explain racial disparities in carotid endarterectomy or other invasive procedures." A subsequent study specifically examined the willingness of black and white patients who had undergone a previous transient ischemic attack (TIA) to consider the possibility of carotid endarterectomy at different assumed levels of risk from the procedure. In other words, they were asked how much of a gamble they were willing to take to achieve a benefit. African Americans showed a much greater desire to avoid the procedure (Oddone et al., 1998). However, this finding was based on the complicated presentation of hypothetical situations via telephone interviews, a situation that the authors noted may be very dif-

ferent from that of a patient facing a real-world choice, and the sample size was small. In a 1993 VA study, black patients were found to be only one-third as likely as whites to receive carotid angiography, the essential diagnostic precursor to a decision regarding endarterectomy, and Hispanics were less than half as likely as whites to do so (Oddone et al., 1993). The authors noted that evidence regarding racial differences in the distribution of lesions was inconsistent, and that, despite higher black rates of hypertension, hypertensive blacks and whites received endarterectomy at the same rate. Much more definitive findings came from a 1999 VA study of stroke or TIA patients whose appropriateness for endarterectomy, by lesion distribution, degree of stenosis, and degree of operative risk had been determined according to standard guidelines (Oddone et al., 1999). Blacks with TIA were less likely than whites to receive any type of angiography, even by low-risk, non-invasive Doppler imaging techniques; after adjustment for all confounders, white patients were approximately 50 percent more likely to receive diagnostic imaging than blacks. More whites than blacks were found to be appropriate for endarterectomy (18 percent versus 4 percent); among the blacks and whites deemed appropriate, whites were 34 percent more likely to receive endarterectomy. The difference was even greater (24 percent versus 3 percent) between white and black patients whose appropriateness was less certain—a situation in which physician discretion in the presentation of options to patients is likely to be greater. These results could not be explained by differences in symptoms or other clinical factors. Instead, the authors called for further research “with emphasis on the physician-patient interaction surrounding decision-making for the procedure, and the determinants of physician recommendations.”

### **Renal Disease and Kidney Transplantation**

Among all minorities, African Americans and Native Americans suffer an excess risk of illness and death from end-stage renal disease (ESRD). Among Native Americans, for example, the rate of ESRD is four times that of whites. This is a consequence of the higher rates of hypertension, diabetes and sickle cell disease among blacks, diabetes among Native Americans, and less access to, or utilization of, early primary care intervention for both groups. The two life-saving or life-extending treatments for ESRD are dialysis and kidney transplantation. Although treatment of ESRD is specifically supported by a Medicare program, kidney transplantation is differentially distributed by race.

Compared with whites, blacks and Native Americans are less likely to receive transplants and are less likely to be put on a waiting list for transplants. If they are waitlisted, they wait longer before receiving a

transplant. If they do receive a cadaveric or donor kidney, they are more likely to suffer transplant failure. As long ago as 1981 to 1985, the most likely people (among those on dialysis) to receive a kidney transplant were white, male, young, non-diabetic and high-income (Held et al., 1988). A decade later, an HCFA study showed that time from renal failure to transplantation, time from renal failure to wait listing, and time from wait listing to transplantation were all longer for blacks than for whites, Asian Americans, or Native Americans (Eggers, 1995). A cohort study of more than 41,000 ESRD patients on the waiting lists of all the 238 renal transplant centers in the United Network for Organ Sharing from 1994 to 1996 used a measure of early wait listing and found that blacks, Hispanics and Asians, patients of any race or ethnicity who were less well educated, and those with fewer financial resources were much less likely to receive a transplant (Kasiske, London, and Ellison, 1998). In one dialysis center in which 67 percent of the patients were black, 64 percent of those who received a kidney transplant were white (Delano, Macey, and Friedman, 1997). In one of the relatively few studies of Native Americans with ESRD, rates of kidney transplantation in New Mexico and Arizona were sharply lower compared with whites, and waiting times were longer (Narva et al., 1996). A telephone survey of a representative national sample of ESRD patients showed that within the first year on dialysis, 30 percent of white respondents but only 13.5 percent of black respondents were placed on a waiting list, and three times as many whites as blacks received a kidney (Ozminkowski et al., 1997). The study also found that patients with annual incomes of more than \$40,000 a year were twice as likely to receive transplants as those with incomes under \$10,000.

Thus, the cumulative evidence for racial differences in access to and rate of transplantation is clear and powerful. As in other disease categories, however, the reasons for these disparities may involve many factors and are the subject of vigorous debate. Ozminkowski and his colleagues asserted that approximately 60 percent of the differences between black and white waiting list entry rates and roughly half of the differences in transplantation rates were due to race-related differences in socioeconomic status, biologic factors associated with the complicated immunologic problems of donor-recipient matching by human leukocyte antigens, disease severity and the presence of contraindications, and—of particular interest to our review—patient preferences or choices (Ozminkowski et al., 1997). In contrast, authors of a New York State study argued that differences in socioeconomic status were only minor contributors (Byrne, Nedelman, and Luke, 1994). Some researchers have argued that HLA-based allocation of kidneys has a disparate impact on minorities (Gaston, Dooley, and Diethelm, 1993; Butkus, Meydrich, and Raju, 1992), but others have asserted that these immunologic factors are less important (Chertow and Milford, 1997).

Many studies have provided evidence that African-American patient preferences, including refusal of or disinterest in the possibility of transplantation, is an important contributor. A number of recent investigations have cast light on the nuances and complexities of both patient and provider behavior. When a large sample of ESRD patients in four regions of the United States were interviewed about their preferences, black patients were less likely than whites to want a transplant (Ayanian, Cleary, Weissman, and Epstein, 1999). There were even larger racial differences, however, in the rates at which blacks and whites were fully informed of the options and referred for evaluation for a transplant, an essential step in offering a choice. These differences in referrals remained significant after adjustment for patients' preferences and expectations, sociodemographic characteristics, the presence or absence of co-existing illness, and other relevant variables. There is no evidence that the differences in referrals were motivated by providers' racial bias, conscious or unconscious, but the difference by race in provider behavior seems clear. An exploration of dialysis patients' behaviors in a prospective cohort study showed that black and poor patients were less likely to complete any of the steps involved in the process of seeking a transplant (Alexander and Schgal, 1998). In what is perhaps the most poignant finding, a recent study of dialysis patients in Maryland found that one of the factors associated with black disinterest in transplantation was what the authors described as fatalism based on lifelong experiences of perceived racial discrimination (Klassen, 2001). In an editorial comment on related studies, Sabatini urged physicians to "explain the procedure better or more clearly, allaying fears, anticipating questions, and providing a different kind of support than is currently offered. . . . We should examine our own attitudes and practices for the influence of social or cultural bias that could be affecting the delivery of health care" (Sabatini, 1997).

### HIV/AIDS

Over the past two decades, infection with the human immunodeficiency virus and clinical progression to AIDS have disproportionately affected African Americans and Hispanics and are now among leading causes of death for these groups. Rates for Asian/Pacific Islanders are much lower but are increasing in urban areas (Kanuha, 2000). Yet, among the hundreds of scientific papers published each year that describe the progression of the epidemic among minority groups there are relatively few (compared with other disease categories) that bear directly on racial disparities in diagnosis and treatment. One commentator has complained of "scientific silence" about AIDS and African Americans (Mackenzie, 2000).

Studies that have addressed such disparities have focused far more on patient behaviors than on possible provider contributions to such differences. Considerable attention has been paid to potential explanatory variables such as patient preferences and attitudes, lack of knowledge or understanding, and mistrust of the health care system, in addition to such familiar issues as differences in socioeconomic status, lack of health insurance, problems of access to care, and apparent biologic differences in response to medication. The overall pattern, however, is clear. African Americans and Hispanics are less likely than whites to receive a variety of medications or to undergo some diagnostic procedures, although the findings vary by source of care. In the period from 1987 to 1990, for example, blacks (and to a lesser extent, Hispanics) were less likely to undergo bronchoscopy and tended to receive less timely administration of prophylaxis against an opportunistic infection in many hospitals, but there were no such disparities in the free-care VA hospital system (Bennett et al., 1995). Black patients were less frequent recipients of prophylactic drugs and of AZT medication on first appearing for treatment and during a follow-up period (Easterbrook et al., 1991). Among gay and bisexual men with HIV infection, whites were approximately 60 percent more likely than blacks to be taking antiretroviral drugs (Graham et al., 1994), after adjustment for access to care and insurance status. The study design did not permit any determination of causes, but possible explanatory factors were identified as patient choice, differing social and cultural norms, or discriminatory practices of providers. In patients appearing for treatment at a teaching hospital, blacks were 40 percent less likely than whites to have previously received antiretroviral drugs or prophylaxis against opportunistic infection, regardless of income and insurance status (Moore et al., 1994). These disparities disappeared during their subsequent treatment. Possible causes were described as misconceptions about HIV/AIDS among blacks, distrust of health authorities, or "prescribing habits" of providers. Investigators who examined the use of more recently developed antiretroviral drugs among a large sample of Medicaid-insured patients with HIV or AIDS found that blacks were significantly less likely than whites to receive nucleoside antagonists and protease inhibitors; and blacks were 20 percent more likely than whites to die each month (Anderson and Mitchell, 2000).

Difficulties in physician-patient communication in HIV/AIDS cases have been reported in a number of studies, particularly in discussing choices about end-of-life care and resuscitation (Haas et al., 1993) and when there was racial/ethnic discordance between provider and patient. A small study of physicians at one teaching hospital found that they felt more confident about giving an overview of clinical trials to white patients than to those of other races or ethnicities (Stone et al., 1998). Patient

mistrust is also described as a factor. Among 520 black adults in 10 randomly selected census tracts, 27 percent agreed with the statement that “HIV/AIDS is a man-made virus that the federal government made to kill and wipe out black people,” and an additional 23 percent were undecided (Klonoff and Landrine, 1999). Conspiracy beliefs were not related to age or income but tended to occur among culturally traditional, college-educated men who had experienced considerable racial discrimination.

### The Overall Pattern of Evidence

The more than 150 studies reviewed above constitute only a modest—but representative—sample of the extensive literature in each of the six disease categories. The pattern of racial and ethnic disparities in diagnosis and treatment thus established is by no means limited to these diseases, but is similarly evident in all of the other major topics in our review. In psychiatric care, for example, African Americans are more likely than whites to be diagnosed as psychotic but are less likely to be given antipsychotic medications. They are also more likely to be hospitalized involuntarily, to be regarded as potentially violent, and to be placed in restraints or isolation—differences that are found at every age level and in both outpatient and inpatient services (Benson, 1983; Mukherjee, 1983; Rosenfield, 1984; Sleath, Svarstad, and Roter, 1998; Whaley, 1998; Kales et al., 2000a,b; DelBellow et al., 2001). Racial stereotyping or “labeling” is frequently invoked as a cause of these disparities (Strakowski et al., 1995; Abreu, 1999). In the case of asthma, a study of black and white Medicaid-insured children in Detroit found that African-American children were much more likely than their white counterparts to receive inadequate therapy—obsolete fixed-combination medications rather than the recommended single-entity prescriptions—and were less likely to receive steroids or an adrenergic inhaler (Bosco, Gerstman, and Tomita, 1993; Joseph et al., 1998), despite higher rates of health care visits and higher rates of hospitalization. In terms of prevention, Medicare-insured African Americans were less likely than whites to receive preventive services. The same study also found that African Americans were more likely to undergo bilateral orchiectomy (for prostate cancer) and more likely to undergo lower limb amputation (for diabetes and peripheral vascular disease), findings that are likely to reflect inadequate primary and preventive care (Gornick, Eggers, and Reilly, 1996). In these three disease categories, as in the six reviewed above, the suggested explanations include the full range of hypotheses listed previously, from minority mistrust to impaired communication to physician bias and stereotyping.

In summary, the preponderance of the evidence strongly suggests that among the multiple causes of racial and ethnic disparities in American



health care, provider and institutional bias are significant contributors—a possibility raised repeatedly, if reluctantly, by many researchers. This conclusion is explicitly supported by a number of studies in which providers' views have been assessed or in which decision-making physicians have been blinded to patient race or ethnicity. It is further supported by observations of physician-patient interactions and institutional cultures, and buttressed by experiments (described in both the medical and social psychology literatures) in which professional responses to white and non-white patients or subjects are found to differ significantly in diagnosis, prognosis and therapeutic recommendations, in the absence of change in any other variable.

Almost all studies have limitations of one sort or another. Limits on the ability to control for the effects of socioeconomic status are of particular concern, given the power of the associations between race and income, education and occupation in American society. But as Mayberry and his colleagues have observed, "The strength and weaknesses of each individual study vary. . . . The methodological inadequacy of an individual study may be a relatively moot point in the context of the body of literature that gives consistent findings and in which one study, often the more recent, may overcome the specific failing of a previous investigation" (Mayberry, Mili, and Ofili, 2000).

There is no scientifically sound way of quantifying the role of individual or institutional bias, as compared with other causes, in creating racial and ethnic disparities in care. However, non-clinical influences on decision making by clinicians—particularly the impact of race/ethnicity, social class, and culture—have been identified and discussed for many years in the medical and social science literature (Geiger, 1957; Bloom, 1965; Freidson, 1973; Eisenberg, 1979; Henderson, 1985). More recent contributions have explicitly linked the perceptions of providers at every level—from medical students to residents to experienced practitioners—to processes and decisions as varied as judgments of patients' quality of life (Rathore et al., 2000b), physician-patient communication during the medical encounter (Waitzkin, 1985; Levy, 1985; Cooper-Patrick et al., 1999), recommendations for cardiac catheterization (Schulman et al., 1999), and the management of pain (Weisse et al., 2001). It seems reasonable to conclude that neither the health care system as a whole nor individual providers are fully insulated from attitudes toward race, ethnicity, and social class that are prevalent (though often unacknowledged) in the larger society. Much less is known today about the processes by which these attitudes and perceptions are formed in the course of medical training and clinical experience and incorporated into clinical decision making. This might be called the natural history of social categorization in medicine and is an important subject for further research.

### Racial and Ethnic Disparities in Care: A Global Problem?

It is useful to note that differential treatment of minorities, particularly people of color, is not a uniquely American phenomenon. In the United Kingdom, published reports alleging racism in the National Health Service appeared as early as 1981. A local community health council report quoted in an article on “Racism, the National Health Service, and the Health of Black People” strikes themes that are familiar:

“What is perhaps most interesting is the similarity between the stereotypes being generated within the health service and those in other parts of the state. In the NHS the mythology is that Afro-Caribbean women are feckless and irresponsible, while Asian women are compliant but stupid. West Indian women are dubbed as having no culture; the problem for Asians *is* their culture...The similarity between the two sets of stereotypes is not remarkable, but it reminds us just how much what goes on in the health service reflects, is reinforced by and *itself* reinforces values. . . .” (Kushnick, 1988). More recently, social class and language other than English (an indicator of minority status) was associated with impaired continuity of care (Hemingway, Saunders, and Parsons, 1997). A little-noticed finding in a British study of coronary revascularization procedures was that non-white patients are referred for revascularization less often than white patients with similar severity of disease (Hemingway et al., 2001).

A recent editorial in the *British Medical Journal* on racism in the National Health Service prompted a torrent of supportive letters and commentaries, though—like the editorial itself—they focused far more on perceived discrimination against Indian, Pakistani, Bangladeshi, African, and other minority physicians than on differential treatment of patients from these population groups (Bhopal, 2001). Racial/ethnic prejudice and discrimination against minority physicians in the National Health Service is examined at length in *Racism in Medicine: An Agenda for Change*, a book published in June 2001 by the King’s Fund, a distinguished British foundation. A joint United States-United Kingdom Collaborative Initiative on Racial and Ethnic Health has been underway since 1997, but its work has focused more on differences in health status than on disparities in health care (Office of Minority Health, 1997).

The health care of Aboriginal people in Australia has drawn substantial critical attention in that nation during the past two decades. Among numerous papers on cultural competence, and health status, and differentials in care, one—titled “These sorts of people don’t do very well” to capture the flavor of some clinical discussions—considers the impact of racial stereotypes on the allocation of health care resources (Lowe, Keridge, and Mitchell, 1995). Similarly, numerous studies have examined

problems of differential treatment of the Inuit people in Canada and emphasized the need for greater cultural competence on the part of physicians (Masi, 1989; Hamilton, 1996; Young et al., 2000). A scattering of articles in English-language journals has considered the care of such minority groups as African immigrants in France and Russian immigrants in Israel.

In the extreme case of South Africa, apartheid and profound inequality in the availability and content of medical and public health services had particularly devastating consequences for the health of the non-white majority populations (Nightingale et al., 1990). Even five years after the establishment of a democratic government and the beginnings of health sector reform, evidence of discriminatory treatment persists, particularly in the private sector, and attests to the difficulty of changing some professional behaviors (Personal communication, N.D. Zuma, Minister of Health, July 15, 1996).

### Implications for Change

Earlier in this review it was noted that the major determinants of the deficits in health status of minority population groups in the United States were lack of access to care and differences in the social, physical and biological environments—incomes, education, occupation, housing and nutrition—which are themselves determined in part by persistent racism (Williams, 1998; Collins and Williams, 1999). Compared with those deeply entrenched causes, provider and institutional bias are far more directly (though not easily) remediable, and represent an opportunity for more rapid change.

To approach recommendations for change in provider behavior requires a recognition of the nature of racial and ethnic stereotyping. Numerous studies in social psychology have established that stereotyping is automatically triggered and operates below the level of conscious awareness. It is intensified by time pressure and complex cognitive tasks—the very hallmarks of much clinical practice—and functions as a convenient shortcut in the management of interpersonal relations, even when it conflicts with consciously held egalitarian views. It is resistant to disconfirmation—the recognition and acceptance of evidence that conflicts with the stereotype (Devine, 1989; Stangor and McMillan, 1992; Macrae, Milne, and Bodenhauser, 1994; Ryan et al., 1996; Hilton and von Hippel, 1996). Of particular consequence to physicians is the form of stereotyping called application error, in which epidemiologic information about a population group is inappropriately applied to any member of that group, without consideration of individual characteristics (van Ryn, 2001). Gamble has described the classic example of a middle-class and profes-

sional African-American woman who is assumed by an emergency room clinician to be an unemployed welfare recipient (Gamble, 1997). African-American males in painful sickle cell crisis are assumed to be drug addicts seeking opiates (Wailoo, 2001). Not all such bias is covert; openly pejorative racial comments on ward rounds have been described by many observers (Finucane and Carrese, 1990).

The first task, then, is to create increased recognition among providers of the existence and processes of stereotypical bias, and their role in the differential treatment of minority patients. Given the understandable difficulty of most physicians to recognize in themselves, their peers, and their health care workplaces that such disparities and biases exist and because such issues are in conflict with their consciously held egalitarian commitments, this will require a sustained long-term effort and a variety of strategies.

There are several mechanisms for attempting this. First, as suggested by Fiscella et al., the tracking of patterns of care by patient race and ethnicity can be added to the quality assurance systems of all organized settings of care (Fiscella et al., 2000). The ability to monitor systematically and regularly for disparities is a basic requirement for accountability. Of equal importance is that awareness that this aspect of clinical behavior is being monitored may facilitate change. Second, the problems and nature of stereotyping and bias need to be taught and discussed repeatedly at every level of the undergraduate and graduate medical curriculum, not merely as part of a cultural competency curriculum devoted to the beliefs and behaviors of different groups of patients, but also as efforts at self-awareness and recognition of the culture of medicine itself. It is important that faculty physicians, who are the preceptors of students and residents, be included in this process.

Recent suggestions have been made to change both the process and the meaning of racial and ethnic identification in everyday clinical practice. In a discussion of racism in the examination room, one clinician has pointed out that "labeling by race has been customary, expected, thought to clarify biologic risk for particular diseases, and considered critical for establishing an appropriate differential diagnosis" and as a proxy for socioeconomic status (South-Paul, 2001). Others have suggested that the place of race in the clinical presentation should be changed from its customary position in the initial description of the patient, whether or not such identification has any clinical relevance (Anderson and Moscou, 2001). Instead, they assert that if race or ethnicity are used at all they should be part of the social history, not the initial description. Such alterations may seem trivial, but small changes in the daily forms of practice, consistently adopted, can change the culture of medicine.

Finally, the limitations of much of the research on disparities in race and ethnicity underscore the need for prospective studies, with access to detailed clinical records. This may be particularly important in understanding the variations in verbal and nonverbal physician-patient communication in both race-concordant and race-discordant physician-patient dyads. Further research is essential, but implementation of corrective recommendations now should not be held in abeyance.

The raw discrimination and blatant racism described by Myrdal nearly six decades ago of relegating African Americans and other minority patients to all-black hospitals, charity wards, or the basement wards of white hospitals have disappeared, but the scars of those past experiences remain, and subtler forms of differential treatment have emerged (Myrdal, 1944). As in other sectors of American society, the elimination of race/ethnicity-based and class-based disadvantage in the health sector has always been an unsteady march, rather than a seamless record of uninterrupted progress. The documentation and further exploration of disparity is a step in an ongoing journey.

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# Racial and Ethnic Disparities in Healthcare: A Background and History

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## INTRODUCTION

Despite steady improvement in the overall health of the United States' population, the health of America's racial and ethnic minorities varies from the *mainstream*. For example, the health status of African Americans—a racial-ethnic group already burdened with deep and persistent history-based health disparities—has been recently characterized as stagnant or deteriorating (Byrd and Clayton, 2000, 2002; Collins, Hall, and Neuhaus, 1999; National Center for Health Statistics, 1998a; Sullivan, 2000; Williams, 1999). A body of nearly 600 scientific publications documenting racial and ethnic disparities in healthcare provides ample evidence of this problem (Geiger, 2000; Mayberry, Mili, and Ofili, 2000). Though it is well known that these disparities reflect socioeconomic differences and inadequate access to quality healthcare, contemporary evidence suggests that in addition to racial, ethnic, class, and gender *bias*, direct and indirect *discrimination* are also important factors (Geiger, 2000; Mayberry, Mili, and Ofili, 2000; U.S. Commission on Civil Rights, 1999a, 1999b; Williams, 1999).

Following the lead of the legislation and committee reports, this Institute of Medicine (IOM) study is one part of a multifaceted effort by the United States Congress to understand and eliminate racial and ethnic disparities in healthcare. The IOM report explores, analyzes, and offers corrective action for factors linked to racial and ethnic health and healthcare

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disparities, including American racial, ethnic, and immigrant relations; “racism;” “historic racial discrimination” and bias; biased clinical decision-making; a health system structured on the basis of race, *ethnicity*, and class; and access barriers caused by shortages of racial and ethnic *minority* providers (Byrd and Clayton, 2000, 2002; Section of House Committee Report to Accompany H.R. 3064, 2000; Sullivan, 2000).

Differences in population characteristics such as race, ethnicity, *class*, *culture*, and gender are at the root of many of the present health and health system problems in the United States. From the perspective of racial and ethnic relations, such differences have generated group identities and self-awareness, racial mythology, group interaction, stereotyping, competition, conflict, a corpus of critical theory, accommodation, and in some instances, *assimilation* and integration. A number of academic disciplines and formidable bodies of scientific literature have grown around each of these subjects and in many instances African Americans serve as surrogates for racial and ethnic minority groups in the United States. This is not only by design, but based on the fact the overwhelming majority of the research, published literature, and data on racial and ethnic disparities before 1985 was focused on that group. Moreover, the chronicle of African Americans, alongside Native Americans, epitomizes the depth, breadth, and intensity of the American racial and ethnic minority experience (Burns and Ades, 1995; Byrd and Clayton, 2000, 2001a, 2002; Feagin and Feagin, 1999; Outlaw, 1990; Smedley, 1999; Stuart, 1987).

Though viewed by many as recent occurrences, racial- and ethnic-based health disparities are centuries-old phenomena. They are outcomes that reflect medical-social values and policies in Western (and later U.S.) medicine and healthcare, which paralleled the values and policies in the larger societies. Could it be that these differences, and the biases and discrimination they both generated and reflected, have dictated or even distorted how the U.S. health system functions? If so, what are the characteristics and profile of this dysfunction? What are the origins, bases, and evolution of the biases and inequities that contribute to persistent racial and ethnic health and healthcare disparities? Their persistence represents a major challenge and an affront to the genius of the American health system, while serving as the driving force behind this IOM study. As we acquire the knowledge to begin answering these questions, we can start to understand the nature of the problems, to perform objective analyses, and, eventually, to craft fact-based, logical interventions and solutions for the problems (Byrd and Clayton, 2000, 2001a, 2002; Feagin and Feagin, 1999; Section of House Committee Report to Accompany H.R. 3064, 2000; Smedley, 1999; *The Healthcare Fairness Act of 1999*, 1999; U.S. Department of Health and Human Services, 1985a).

It is clear that health and healthcare in the United States are multi-racial, multi-ethnic, immigrant stories. A brief examination of racial and ethnic relations in this country from its colonial past to the present provides the context for the larger examination of health and healthcare as social processes and problems. And since virtually all modern health policy decisions are based on the collection of accurate demographic, health, and health-related data, it is essential to have a better understanding as to how data regarding America's various racial and ethnic groups are collected. An examination of the intricacies of the process, its standardization, and its evolutionary phases is both a prerequisite and a necessity, especially as it has related to health and healthcare. A factual chronology about data and its collection is provided in order to appreciate and learn from the past experiences, to dispel assumptions and mythologies, and as a preparation for future fact-based policy-making.

America is a nation of immigrants. A discussion built around appreciating the nation's health experience as an immigrant story, thus, provides a window on the present racial and ethnic health disparities. Following is an examination of the major U.S. racial and ethnic groups, both European and people of color, focusing on their health and the variables that affect their health. This lends a broader and much needed health policy perspective on where we have been and where we need to go.

Recurrent themes resonate throughout the document. For example, as racial and ethnic minorities become larger percentages of our total population, the health and healthcare of minority Americans become national public policy issues of the first rank—in both relative and absolute terms. Another theme is that healthcare is presently conceptualized as a human right.

Obtaining a background regarding the roles of race, ethnicity, gender, culture, and class in U.S. society and healthcare is requisite to deciphering the message inherent in the racial and ethnic health and healthcare disparities. In order to acquire a deeper understanding of the present racial and ethnic health and healthcare disparities, one must gain an understanding of the origins, evolution, and perpetuation of racial and ethnic bias, inequities, and disparities in health and healthcare in the United States and its earlier Western predecessor cultures. Because of the variation in opinions and usage of certain terms emanating from this wide range of disciplines, a glossary has been included that contains terms the IOM Committee thought would be useful to readers (Byrd and Clayton, 2000, 2001a; Feagin and Feagin, 1999; Fee, 1997; Fluss, 1997; Section of House Committee Report to Accompany H.R. 3064, 2000; *The Healthcare Fairness Act of 1999*, 1999).

### American Racial and Ethnic Relations: The Context

Racial and ethnic diversity is a basic tenet in the evolution of this society. Neither health nor healthcare is an exception. “The development of social and economic inequalities based on race and ethnicity has been a central theme—and a central dilemma—of the history of the United States [and the Western World], shaped over many generations by the European conquest of indigenous peoples and by massive waves of both coerced and uncoerced immigration from all over the world” (Pedraza and Rumbaut, 1996, xvi). Moreover, racial and ethnic relations have always been tumultuous in the United States. The use of terms such as *dominant group* and *subordinate group* in the study of American racial and ethnic relations suggest—and has often been linked to—racial and ethnic hierarchy, stratification and substantial inequality among groups. Disparate outcomes between European Americans and racial and ethnic minority Americans in many spheres of social life, health, and healthcare—as all are viewed as social processes—are not new and should not be unexpected (Byrd and Clayton, 2000, 2001a, 2002; Feagin and Feagin, 1999; Jaco, 1979; Kosa and Zola, 1975; Pedraza and Rumbaut, 1996; Smedley, 1999). Founded more than 200 years ago after a revolution that cut colonial ties with Europe, the creation of the United States was based on Enlightenment principles of freedom and equality. A vigorous nation of great racial and ethnic diversity emerged. However, racial and ethnic *prejudices*, biases, oppression, and conflict were embedded in the colonial antecedents, the founding period, and central documents of the new republic (Brinkley, 1993; Feagin, 2000; Omi and Winant, 1994). Further, as Rumbaut notes, “[I]mmigration and conquest—by hook or by crook—have been the originating processes by which American ethnic groups have been formed and through which, over time, the United States itself has been transformed into arguably the world’s most ethnically diverse society” (Pedraza and Rumbaut, 1996, xvi). The European (predominantly English) colonists often took land from Native Americans (American Indians) by force or collusion. By the late-seventeenth century, the colonists had established an economy strongly based in African-American chattel slavery in the South and on the slave trade in the North. Moreover, throughout succeeding centuries a tradition of oppressing non-English (e.g., Irish and Italian) and non-European (e.g., Chinese, Japanese, and Mexican American) immigrants was also established (Brinkley, 1993; Burns and Ades, 1995; Feagin, 2000; Feagin and Feagin, 1999; Stuart, 1987). At first, liberty and justice were provided only for males of British descent, and inequality in life chances along racial, gender and ethnic lines became a fundamental fact of the new nation’s institutions. As Flexner observed, “Whatever their social station,

under English common law, which became increasingly predominant in the colonies . . . women had many duties, but few rights" (1975, 7). Conflict between Anglo-Protestant Americans and Indians varied from outright warfare to separate coexistence. Though the promotion of non-English immigration had coincided with English mercantile and colonial aims and intensified in the nineteenth century, new white immigrants ("foreigners") often met hostility and found themselves less than equal socially or under law. Women struggled continuously for their rights (Flexner, 1975). Racial tension and conflict was a constant between Anglo-Protestant Americans and African Americans under 246 years of brutal and exploitive chattel slavery, followed by 100 years of social segregation, physical oppression, political subjugation, and economic exploitation. As English domination was modified over the next two centuries by the challenges and occasional ascendancy of other northern Europeans, southern, and eastern Europeans as well as other non-European groups trying to move up socially, economically, and politically, the United States became an unprecedented and uneasy mix of diverse peoples (Brinkley, 1993; Burns and Ades, 1995; Feagin, 2000; Feagin and Feagin, 1999; Omi and Winant, 1994; Shipler, 1997; Stuart, 1987).

Basic documents of the new republic reflect its patterns of racial subordination, ethnic discrimination, and gender difference. Neither the Articles of Confederation, nor the Declaration of Independence, nor the Naturalization Law of 1790 extended the doctrines of freedom and equality to African Americans (Brinkley, 1993; Feagin and Feagin, 1999; Omi and Winant, 1994). One provision of the Naturalization Law of 1790 was that only "white" persons could become citizens (Takaki, 1993, 273). After a failed campaign by southern slaveholders to count black slaves for apportioning states' legislative representation though not for direct taxation (Brinkley, 1993, 150), enslaved Americans were counted as three-fifths of a person in the U.S. Constitution. Women were not allowed suffrage until 1920, Native Americans until 1924, and most African Americans until 1965. First-generation Asian Americans could not become U.S. citizens until 1952 (Brinkley, 1993, 576-577, 816; Feagin and Feagin, 1999, 209, 391; Office of Research on Women's Health, 1998, 17). Slavery was not only legal with blacks designated as chattel, the slave trade was allowed to continue until 1808, and a fugitive slave provision was incorporated by the 1850s that required the return of runaways to their owners. Neither the Declaration of Independence's famous statement that "all men are created equal" nor the Constitution's Bill of Rights applied to African Americans (Higginbotham, 1978, 1996). The Alien, Sedition, and Naturalization Acts compromised the rights and citizenship status of immigrants as early as the late 1700s and early 1800s. The Page Act of 1875 restricted the immigration of Chinese women, while the Chinese Exclusion Act of 1882 pro-

hibited the group as a whole (Brinkley, 1993; Feagin, 2000; Feagin and Feagin, 1999; Takaki, 1993).

By adopting the English language and accommodating to English-oriented institutions, white non-British immigrant groups have gained substantial power and status in the United States. However, voluntary and involuntary immigrants from Africa, Asia, and Latin America, as well as Native Americans have remained subordinate to white Americans in political, cultural, and in most instances, economic terms. For example, despite their arrival as agricultural laborers recruited in the 1880s, Japanese Americans could not become naturalized citizens until the passage of the McCarran-Walter Act of 1952 (Omi and Winant, 1994, 81). Though racial and ethnic diversity, inequality, and oppression continue to be part of the foundation of U.S. society, Americans of color continue to challenge their subordinate status (Feagin and Feagin, 1999; Omi and Winant, 1994). In many ways, the continuing story of racial, ethnic, class, and gender biases and conflicts in the United States is evidence of the system's dynamism—the promises and sorrows of the American dream. America's troubled past has profoundly affected its health system. Likewise, the poor health status and outcomes of African American and other minority populations are inextricably linked to historical racial and ethnic discrimination (Byrd and Clayton, 2000, 2001b, 2002; Stuart, 1987; Williams, 1999). If current demographic trends continue and people of color become the majority of the U.S. population by the middle of the twenty-first century, dramatic institutional changes will be necessary—including changes within the nation's health system (Brinkley, 1993; Byrd and Clayton, 2000, 2001a, 2002; Collins, Hall, and Neuhaus, 1999; Feagin, 2000; Feagin and Feagin, 1999).

### **Racial and Ethnic Data Collection and Definitions**

Racial and ethnic minority groups are among the more difficult demographic categories to categorize because there is no simple scheme for defining these groups or classifying the categories' subgroups (U.S. Department of Health and Human Services, 1985a). As will be discussed later, attempts at categorization are further complicated by the complex histories and chronologic layers of definitions and classifications related to racial and ethnic concepts in Western culture (Byrd and Clayton, 2000, 2002; Smedley, 1999). Imprecise and changing definitions of race and ethnicity emanating from the federal government, anthropologists and other social scientists further complicate the issue of definitive categories or classifications (American Anthropological Association, 1997; Thernstrom, Orlov, and Handlin, 1980; Zenner, 1996). Nevertheless, in order to assess the health status, outcomes, and services utilization of vari-

ous racial and ethnic groups in the United States, data must be collected with some type of category system. Although current data collection systems are both imprecise and do not adequately collect data for all the important U.S. racial or ethnic minority groups, the federal government does attempt to perform this task in a systematic manner (U.S. Office of Management and Budget, 1997).

The U.S. government provides a standard classification system for record keeping, collection, and presentation of data on race and ethnicity in federal program administrative reporting and statistical activities. The five racial and two ethnic categories are: American Indian or Alaskan Native, Asian, Native Hawaiian or Pacific Islander, Black, White, Hispanic or Latino, Not Hispanic or Latino [Box 1-1, Introduction, this volume], and originate from a 1977 Office of Management report (Haynes and Smedley, 1999). Depending on the data source, these racial or ethnic classifications are based on self-classification or on observation by an interviewer or other person filling out the questionnaire (National Center for Health Statistics, 2000).

Before 1980, the National Vital Statistics System for newborn infants and fetal deaths tabulated the race of the fetus or newborn according to the race of both parents. If the parents were of different races and one parent was White, the child was classified according to the race of the other parent. When neither parent was White, the child was classified according to the father's race, with one exception: if either parent was Hawaiian, the child was classified as Hawaiian. Since 1989, newborn infants and fetal deaths are tabulated according to the race of the mother (National Center for Health Statistics, 1998a). In spite of these efforts, most existing sources of health data, with the exception of those derived from the census and from the vital registration system (birth and death certificates), permit examination of only the three largest racial and ethnic categories: non-Hispanic White persons, non-Hispanic Black persons, and persons of Hispanic or Mexican origin (National Center for Health Statistics, 2000).

The gathering of racial data by the U.S. Census Bureau is symbolic of its centrality in the nation's culture (Omi and Winant, 1994). As the U.S. health system developed, these data sets profoundly affected health policy and health services delivery. Race has been such an important characteristic in this country that census takers have tallied the racial composition of the population since the first U.S. Census taken in 1790: "[T]he U.S. Census has always included a question about race. Whites were normally distinguished from nonwhites" (Thernstrom, Orlov, and Handlin, 1980, 869). However, "[t]he racial categories used in census enumeration have varied widely from decade to decade" (Omi and Winant, 1994, 3). Until the 1850 census, African Americans were tabulated as either "Slave" or

"Free Colored," with the latter term sometimes including detribalized Native Americans. Though the 1850 and 1860 censuses collected data for free persons in "White," "Black," or "Mulatto" categories, the main tables continued to designate the overall population as "White," "Slave," and "Free Colored." The 1860 census also counted "Civilized Indians" (who were required to pay taxes because they did not live on reservations) and Chinese. In 1870, Japanese were added, and the "Civilized Indian" category was divided into "Pure Indians" and "Half-breeds" designations. The first reliable statistics tabulated for Native Americans "are those for 1890, the year in which the Bureau of the Census and Bureau of Indian Affairs made a concerted effort to report accurately the Indian population and the occurrence of vital events" (Stuart, 1987, 96). Census Bureau officials grouped mulattos with Negroes under "Colored" in 1880, but made finer distinctions in 1890, counting 6.3 million Negroes, 957,000 mulattos, 105,000 quadroons, and 70,000 octoroons. Finally admitting these divisions were valueless for analytical purposes, they grouped them all together with the Chinese, Japanese, and Indians under the general heading "Colored" (Thernstrom, Orlov, and Handlin, 1980).

In 1900, under the growing influence of anthropological notions of race, census officers were determined to assess the U.S. population in terms of the then-presumed four great races: Caucasian or White, Negro or Black, Mongolian or Yellow, and Indian or Red. Chinese and Japanese were designated subdivisions of Mongolian, and it was finally decided to use the term Negro and abandon the ambiguous term "Colored." By 1910 census officials reverted to "Black" and "Mulatto" but avoided the term "Colored." The main divisions were "White," "Negro," "Indian," "Chinese," "Japanese," and "All Other" (including subdivisions for Hawaiians, part-Hawaiians, and other races). The Indian population was treated separately in a special census recording both the "civilized" and those residing on reservations, and provided details on tribes, languages and geographic areas. This set many precedents for modern censuses. Mexicans were put in the "Other Races" category in 1930 but were later counted as Whites. Other Asian and Pacific Islander subgroups were tabulated, but appeared only in general tables. Enumerators in 1960 were instructed to consider how the person or family identified itself, and in 1970 self-identification was introduced into racial and ethnic tabulations (Thernstrom, Orlov, and Handlin, 1980).

*Ethnicity* is a much more recent concept. As a response to the general movement toward self-identification and the modern notions of a plural-

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\* While the 1890 Census had used the term "Colored" to mean all nonwhite persons, in the West Indies it meant part-European, part-Negro, and in the earlier censuses, in some southern states, and in some other countries it meant anyone with a Negro ancestor.

istic democratic society, the ethnic-origin category was introduced in the Current Population Survey in 1969 and included in the U.S. Census in 1980. However, there are difficulties with this mode of distinguishing races and ethnic origin, including sampling variation, changes in respondent fashion, and the difficulties of handling racial and ethnic mixtures. These issues are yet to be resolved (Haynes and Smedley, 1999; National Center for Health Statistics, 2000; Thernstrom, Orlov, and Handlin, 1980). The 1997 standards have five *racial groups*: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, and White, all of which continue to offer possibilities for confusion and complexity. Respondents are able to select more than one of the five groups, which sometimes diminishes sample size, creates ambiguous results, and increases the likelihood of not meeting the standards for statistical reliability or confidentiality. All federal data systems are required to be compliant with this system by 2003 (National Center for Health Statistics, 2000). Whether or not one is of Hispanic origin reflects another dimension, because the U.S. Census Bureau reiterates, "Hispanics are classified as an ethnicity, not as a race. People of Hispanic origin, therefore, may be of any race" (U.S. Census Bureau, 2001a). Therefore, the Office of Management and Budget outlines a more complex "combined format" whose minimum acceptable categories are: American Indian or Alaskan [sic] Native; Asian or Pacific Islander; Black, not of Hispanic origin; Hispanic; or White, not of Hispanic origin (Haynes and Smedley, 1999).

*Distinguishing racial and ethnic groups from one another is useful in medical, health services, and epidemiologic research, provided that researchers are clear on the nature and source of human variation (e.g., cultural and behavioral patterns, environmental influences) and their relationship to health outcomes. Race and ethnicity affect factors as varied as disease rates, health behaviors, conceptions of well-being and attitudes toward health maintenance and home treatment, illness behavior, utilization patterns, concepts of disease and illness, interactions with mainstream health professionals and organizations, and ethnic interest groups and medical delivery (Harwood, 1981). Using such information applicable to distinct groups could direct appropriate and efficient biomedical and health services research, focus health promotion disease prevention efforts, objectively redirect health services and restructure components of the health system, and guide diversity and cultural competence programs. However, if the "boundaries" of ethnic identity remain unclear, continue to be perceived as more flexible rather than rigid, become agents to defocus and fragment the nation's health policy and political mechanisms, all compounded by increased numbers of mixed ethnicity families in this country (where individuals claim two or more ethnicities), the challenge of pluralistic ethnic-oriented data collection, analysis, research, and program creation remains daunting. As we develop the methodology and*



science of tracking racial and ethnic health and healthcare outcomes, urgent efforts should be directed toward eliminating racial and ethnic bias in the caregivers and re-educating both caregivers and patients to eliminate stereotyping, conscious, and unconscious biases. In the interim, there can be no delay in making recommendations leading to: 1) patient and provider education to understand the existence and dynamics of racial and ethnic bias in the healthcare arena; 2) programs at all levels teaching the dynamics of the stereotyping and the bias-producing processes and how they affect healthcare; and 3) the development of measures to teach patients and providers the specific cultural competence, diversity and cross-cultural skills to maximize the benefits of the doctor-patient relationship (Haynes and Smedley, 1999; White, Rutledge, and Brown, 2000; Zenner, 1996).

### **Immigration, Racial and Ethnic Groups, Health and Healthcare**

Racial and ethnic groups are viewed today as by-products of social processes such as immigration, group interaction and conflict, group hierarchies and dominance, *acculturation*, and assimilation (Feagin and Feagin, 1999; Pedraza and Rumbaut, 1996). Acknowledgment of the effects of racial and ethnic problems on health and disease, the health professions, and, finally, the health system is new and indicative of an ongoing contemporary cultural movement among liberal democratic governments worldwide. These social dimensions of health and healthcare delivery serve as markers of a growing awareness, critique, examination, and redirection that is finally committed to the notion of embracing all of the nation's diversity (Byrd and Clayton, 2000, 2001a, 2002; Glazer, 1997; *The Healthcare Fairness Act of 1999*, 1999; Section of House Committee Report to Accompany H.R. 3064; Taylor et al., 1994). The World Health Organization has defined health as ". . . a complete state of physical, mental, and social well-being and not merely the absence of disease or infirmity" (Sutchfield and Keck, 1997, 3), and has proclaimed that "health [without qualification] is a human right" (Fluss, 1997, 377). These declarations, which are evidence of the fact that health is viewed as a universal human need—a "primary good," along with income, education, religious freedom, freedom of conscience, speech, press, and association, due process, the right to vote, and the right to hold office—are givens (Taylor et al., 1994, 4). Another corollary of this ongoing reassessment is that American health and healthcare are increasingly being viewed as immigrant, multicultural, racial, and ethnic minority stories with biomedical, medical historical, sociocultural and political, public health, health policy, and medical-social dimensions (Table 1).

This is why a brief overview of North American health and healthcare from racial, ethnic, and immigration perspectives is germane to this dis-

cussion (Byrd and Clayton, 2000, 2001a, 2002; Fluss, 1997; Garrett, 2000; Malone and Johnson, 1986; U.S. Commission on Civil Rights, 1999a, 1999b).

Native Americans, North America's original racial/ethnic group, are the indigenous people of the land now occupied by the United States. Scholarship concerning their fifteenth through twenty-first century interface with European explorers and invaders, the backdrop for America's racial and ethnic immigrant saga, is growing exponentially. It is becoming clear that health factors such as disease transmission, epidemics, and exposures of non-immune populations to new diseases had as much to do with early group interaction and eventual European dominance of New World, pre-Columbian (North, Central, and South American) people as to political and military activity (Burns and Ades, 1995; Byrd and Clayton, 2000, 2002; Diamond, 1999; Stannard, 1992; Watts, 1997).

We know that the 105 years between Columbus's landfall in the Caribbean and English colonization in 1607 had profound health effects in North America. Sixteenth-century Spanish colonies spreading from the Caribbean, South America, Mesoamerica (central and southern Mexico and adjacent areas of Central America), Mexico, and St. Augustine, Florida, bolstered by expeditions deep into North America itself, facilitated the spread of Old World diseases that greatly reduced American Indian populations. The resulting depopulation may have contributed to the myth of an "empty" American continent ripe for European settlement (Byrd and Clayton, 2000; Diamond, 1999; Watts, 1997). Not only does the Native American health experience serve as the opening chapter of the North American chronicle of racial and ethnic health, American Indian health and healthcare have been major factors shaping both their *demography* and their contact with Europeans. Prior to 1492, native people in the New World had few serious diseases compared with people of the Old World (Diamond, 1999; Pedraza and Rumbaut, 1996; Watts, 1997). Isolated from the Old World's domesticated animals\* and diseases such as smallpox, influenza, measles, typhus, malaria, leprosy, cholera, bubonic plague, gonorrhea, and chancroid—even New World exposure to virulent forms of tuberculosis or syphilis is questionable—95 percent of the 8 to 12 million Native Americans inhabiting the North American continent at that time succumbed to European conquests, politics, and diseases (Diamond, 1999; Pedraza and Rumbaut, 1996; Stannard, 1992; Watts, 1997). By

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\* Though it is not fully understood, the origins of the germs (bacteria, viruses, etc.) causing many human diseases can be traced to many animals domesticated in the Old World, such as pigs, cows, horses, sheep, and goats. SOURCES: Diamond J. *Guns, Germs, and Steel: The Fates of Human Societies*. Paperback Edition. New York: W.W. Norton and Company, Inc., 1999; Pedraza S, Rumbaut RG. *Origins and Destinies: Immigration, Race, and Ethnicity in America*. Belmont, California: Wadsworth Publishing Company, 1996.

**TABLE 1. Race, Ethnicity, and Immigration: North American Health and Health Care**

Selected Indigenous and Immigrant Groups: An Overview of Race, Ethnicity, and Immigration in Relationship to Health and Health Care in North America			
Indigenous and Immigrant Group	Time of Entry	Economic Conditions in North America	Governments and Actions
<b>Phase One: Pre-Columbian and North American Development: Prehistory-1600s</b>			
Native Americans– Indigenous Group	Prehistory-1600– 2002	Land-based, self-sufficient, local economies with some regional trade; Ranged from Pueblo agriculturalists of Southwest, hunting societies on the Plains, to mixed agricultural-hunting societies elsewhere; Autonomous bands and tribes of geographically isolated, discrete, hunter gatherer, and farming communities. Dysfunctional relationships with social and economic system result in persistent poverty and isolation.	
<b>Phase Two: Commercial Capitalism and the Slave Society: 1600–1865</b>			
English	1600s-1800s	Mercantilism; land taken from Native Americans; English entrepreneurs and commercial capitalism emerges.	
Africans	1600s-1800s	Enslaved as property; became major source of labor for plantation capitalism.	
Irish Catholics	1830s-1860s	Driven out of Ireland by oppression and famine; labor recruited for low-wage jobs in transport, construction.	
<b>Phase Three: Industrial Capitalism: 1865–1920</b>			
Chinese	1850s-1870s	Contract labor and low-wage work in mining, railroads, construction; menial service work for White settlers.	
Italians	1880s-1910s	Moved as peasants into industrial capitalism; overseas recruitment for low-wage industrial and construction jobs in the cities.	

Health and

Government Conditions and Actions	Some Health and Health Care Considerations
Autonomous tribal units based on chiefdoms, common land-ownership, and mutually supportive living conditions. Government participation in land take-overs, broken treaties, and traumatic relocations. Paternalistic, shifting, and conflicting relationship with government persists.	Benign New World health environment: virtually no exposure to infectious crowd diseases; Slower pace of city development; and high levels of population isolation compared with Old World. Traditional healers practicing archaic medicine with strong religious and magical overtones. In lieu of Indian Health Service, persistent poor health status and outcomes.
English state creates land companies; colonial governments define individualized property and protect property. Capitalism promoted by: Commercial agriculture and plantation oligarchy; Legal race-based slavery established.	From rustic and deficient health and health system beginnings, establish race- and class-based health system based on English models. Separate and unequal tiers of "health" and health system for blacks, the poor, Native Americans.
Colonial governments establish slave codes; U.S. Constitution legitimates slave trade; U.S. government substantially controlled by plantation oligarchy.	"Slave health subsystem" established, and "slave health deficit" perpetuated, medical abuse and exploitation for blacks (246 years). Racial inferiority myth backed up by medical/scientific community. Legal health system segregation and discrimination (100 years), with de facto segregation and discrimination to present.
U.S. government opens up western lands; Irish take urban political machines from British Americans.	Initially assigned to lower tiers of health system (public hospitals, dispensaries, charity care) as immigrants; Early poor health status and outcomes.
Local governments help recruit Chinese labor; later, anti-Chinese laws passed in California; 1882 Exclusion Act.	Health and health system discrimination and segregation reflect social, political, economic, and legal status.
Government backing for labor recruitment; U.S. treaties with Europe; intervention in European affairs (World War I); incoming numbers reduced by 1924 Immigration Act.	Initially assigned to lower tiers of health system (public hospitals, dispensaries, charity care) as immigrants; Early poor health status and outcomes.

TABLE 1. (Continued)

Selected Indigenous and Immigrant Groups: An Overview of Race, Ethnicity, and Immigration in Relationship to Health and Health Care in North America			
Indigenous and Immigrant Group	Time of Entry	Economic Conditions in North America	Governments and Actions
Eastern European Jews	1880s-1910s	Industrial capitalism utilized their skilled and unskilled labor; small entrepreneurs re-established themselves; much anti-Semitic discrimination.	
Japanese	1880s-1900s	Recruited as agricultural laborers for Hawaii; later migrated to West Coast as laborers; served in domestic work; created small businesses and farms.	
<b>Phase Four: Advanced Industrial (Multinational) Capitalism: 1920s–2002</b>			
Mexicans	1910s-2002	With Asian/European labor cut off, Mexicans recruited for farms and industry; low-wage jobs in new urban industries. Now biggest component of the largest racial/ethnic minority group (Hispanic).	
Puerto Ricans	1940s-2002	Early farm labor migration; U.S. corporations recruit labor; blue-collar work in service economy. Second component of the largest racial/ethnic minority group (Hispanic).	
Recent Asian and Caribbean Groups	1950s-2002	Many political and economic refugees; create economic niches, make use of expanding service economy.	

SOURCES: Byrd WM, Clayton LA. *An American Health Dilemma*. Volume 1. *A Medical History of African Americans and the Problem of Race: Beginnings to 1900*. New York: Routledge, 2000; Byrd WM, Clayton LA. *An American Health Dilemma*. Volume 2. *Race, Medicine, and Health Care in the United States: 1900-2000*. New York: Routledge, 2001; Burns R, Ades L. *The Way West: The Way the West Was Lost and Won, 1845-1893*. A six hour documentary series [videotape] for *The American Experience*, Boston: WGBH Educational Foundation, WGBH, Boston, 1995; Diamond J. *Guns, Germs, and Steel: The Fates of Human Societies*. New York: W.W. Norton and Company, 1997; Dowling HF. *City Hospitals: The Undercare of the Underprivileged*. Cambridge, Massachusetts: Harvard University Press, 1982; Feagin JR, Feagin CB. *Racial and Ethnic Relations*. Sixth Edition. Upper Saddle River, New Jersey: Prentice Hall, 1999; Feagin JR. *Racist America: Roots, Current Realities, and Future Reparations*. New York: Routledge, 2000; Frost, Richard H. The Pueblo Indian smallpox epidemic in New Mexico,

Government Conditions and Actions	Some Health and Health Care Considerations
Government backing for labor recruitment; U.S. treaties with Europe; incoming numbers reduced by 1924 Immigration Act.	Initially assigned to lower tiers of health system (public hospitals, dispensaries, charity care) as immigrants; Early poor health status and outcomes.
Government backing for labor recruiting; U.S. imperialism in Asia; conquest of Philippines and Hawaii; government laws exclude Asians.	Health and health system discrimination and segregation reflect social, political, economic, and legal status.
U.S. government provides labor recruitment programs and fosters U.S. agri-business in Mexico, stimulating out-migration; U.S. Border Patrol monitors immigration; new law regulates immigration.	Initial assignment to lower tiers of health system (public hospitals, dispensaries, charity care) as immigration continues. Hispanic uninsured rate now the highest of any racial or ethnic group and culturally and linguistically incompetent health system represents continuing problems.
Conquest of Puerto Rico in 1898; U.S. government-supported agribusiness takes over economy, creates surplus labor, stimulates migration to U.S.	Initial assignment to lower tiers of health system (public hospitals, dispensaries, charity care) as immigrants continues. Hispanic uninsured rate now the highest of any racial or ethnic group and culturally and linguistically incompetent health system represents continuing problems.
U.S. intervention in Asia from 1853 to 1990s; government action in South Korea, Vietnam, Taiwan, Philippines stimulates out-migration; Cubans and Haitians flee repression.	Initial assignment to lower tiers of health system (public hospitals, dispensaries, charity care) as immigrants continues. High uninsured rates and culturally and linguistically incompetent health system represent continuing problems.

1898-1899. *Bull Hist Med* 1990; 64:417-445; Garrett L. *Betrayal of Trust: The Collapse of Global Public Health*. New York: Hyperion, 2000; Office of Research on Women's Health. *Women of Color Health Data Book: Adolescents to Seniors*. Washington, DC: U.S. Department of Health and Human Services. NIH Publication No. 98-4247, 1998; Pedraza S. Rumbaut RG. *Origins and Destinies: Immigration, Race, and Ethnicity in America*. Belmont, California: Wadsworth Publishing Company, 1996; Trennert RA. *White Man's Medicine: Government Doctors and the Navajo, 1863-1955*. Albuquerque: University of New Mexico Press, 1998; U.S. Commission on Civil Rights. *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*. Vol. 1. *The Role of Governmental and private Health Care Programs and Initiatives*. Washington, DC: U.S. Commission on Civil Rights, 1999; U.S. Department of Health and Human Services. *Report of the Secretary's Task Force on Black and Minority Health*. Vol. 1. *Executive Summary*. Washington, DC: U.S. Government Printing Office, 1985.

1900, only about 250,000 Native Americans remained in the United States (Pedraza and Rumbaut, 1996). Though much of this toll was directly related to health-related causes such as smallpox epidemics, other causes included warfare with Europeans and Americans, mortality related to the Amerindian slave trade, and massive forced population relocations (Pedraza and Rumbaut, 1996; Stannard, 1992). Since the nineteenth century, Native American health and healthcare have been poor. Today the health of Native Americans is characterized as being isolated from the mainstream health system; administered by a government that is often culturally insensitive; inadequately funded and understaffed; paternalistic; disparate from health status and outcomes perspectives; and has been allowed to spread communicable diseases such as smallpox and tuberculosis (Frost, 1990; Garrett, 2000; Stuart, 1987; Trennert, 1998).

In contrast to relatively well-organized, Iberian-run health systems (Risse, 1987), early North American colonial health systems were rudimentary. The environment, poisoned by ongoing conflict with Native Americans, was dangerous. Moreover, as Leavitt and Numbers (1985, 3) noted, “Early settlers in America often suffered from malnutrition, which increased their vulnerability to infectious diseases. . . . The gravest threats to life and health were malaria and dysentery in summer and respiratory ailments, like influenza and pneumonia, in winter.” Thus, for the early English and Dutch settlers, these *endemic* (always present), and *epidemic* (appearing from time to time with great intensity) threats—most of which were infectious and transmitted from one person to another—brought basic human survival into question. By the eighteenth century, English commitment to a plantation economy and black chattel slavery had combined with Protestant and Puritan elements of the culture to implement legal racial slavery and a race- and class-based health system. Poorhouses and almshouses, based on English models, served as the first hospitals in the colonies. There was a dearth of scientifically trained physicians, and a separate and unequal *slave health subsystem* serviced African Americans. A *slave health deficit* whose origins can be traced back to the African continental and Atlantic slave trade was institutionalized (Blanton, 1930, 1931; Byrd and Clayton, 1992, 2000; Ewbank, 1987; Higginbotham, 1978; Leavitt and Numbers, 1985; Numbers, 1987; Trennert, 1998).

Territorial growth fueled by the elimination or displacement of Native Americans, as well as economic success spurred by commercial plantation agriculture and black chattel slavery, and the political freedom spawned by a successful Revolutionary War that liberated the colonies from England all served to foster the institutionalization (founding of medical schools, private hospitals, and a formally trained branch of the medical profession) and complexity of the health system. At that time, home care or self-care were the health delivery norms for all but poor or

marginal populations (Byrd and Clayton, 2000; Feagin, 2000; Vogel, 1980, 1985).

Late eighteenth and early nineteenth century Anglo-Protestant affluence and sophistication only added to the race- and class-based stratification of the health system. Adding to the squalor and crowding in America's rapidly growing eighteenth and nineteenth century cities and "dual" health system were waves of immigrants, many of whom arrived "half starved, half sick, and often barely alive" (Dowling, 1982, 9). By the Jacksonian and Antebellum periods, white immigrants (e.g., Germans, Scottish, Irish, Scandinavians) were assigned to the lower tiers of the mainstream system (public hospitals, dispensaries, and health charities) present in the East, the slave health subsystem burgeoned, and all Americans in frontier areas in the West, both slave and free, suffered deficient and primitive health conditions and services. The South, where most African Americans resided as slaves, was the most backward region with regard to public health policies and institutions. As a result, there were mid-nineteenth century increases in mortality affecting urban ethnic immigrants, black slaves, and free blacks (Breedon, 1989; Byrd and Clayton, 2000; Duffy, 1990; Leavitt and Numbers, 1985; Rosenberg, 1974, 1987, 1989; Savitt, 1978, 1985; Vogel, 1980, 1985). Between 10 and 15 percent of American doctors had medical degrees, while the rest were either apprentice-trained or pretenders (Barzun, 2000, 405; Garrett, 2000, 285; Trennert, 1998, 11). Native Americans in the throes of displacement or elimination had little contact with the health system until the latter half of the nineteenth century (Trennert, 1998).

The Civil War, in addition to being a turning point in the nation's political and economic affairs, was a watershed event in American health. It highlighted the weakness in U.S. public health, medical education, and health delivery systems. However, the Civil War convinced average European Americans of the importance of biomedicine and public health and paved the way for major medical educational and professional, sanitary, and health reforms—simultaneously spurring a national hospital movement (Byrd and Clayton, 2000; Duffy, 1990; Rosenberg, 1987, 1989). Black health plummeted due to Civil War collapse of the slave health subsystem. Deleterious effects were compounded by the preexisting slave health deficit, abandonment of African Americans by the mainstream health system, and continuation of racially discriminatory health policies and treatment. In lieu of emancipation, the war and its aftermath represented a health catastrophe for African Americans as their health status fluctuated wildly until 1910. This led influential biostatisticians such as Frederick Hoffmann, as well as many in the medical profession to confidently predict black extinction by year 2000 (Byrd and Clayton, 1992, 2000; Duffy, 1990; Jones, 1993; Morais, 1967; Tucker, 1994).



On one level, the late nineteenth century represented an era of reconciliation and progress for white European American ethnic groups—both the North and South—as the United States emerged as a world power. However, traditional patterns of racial and ethnic oppression and conflict between dominant White, Anglo-Saxon, Protestant groups, and non-European as well as more recent immigrant groups (e.g., Italians and Jews) continued (Feagin and Feagin, 1999). Improvements in biomedical education and science, medical practice, and a burgeoning hospital movement were evident. However, based on the evidence they do not explain the decline in infectious diseases and mortality and the general increase in life expectancy (which did not occur among blacks) (Byrd and Clayton, 2000, 2002; Duffy, 1990; Leavitt and Numbers, 1985). Instead, it is more likely that improvements in public health measures such as sanitation, water and milk supplies augmented by improvements in diet, housing, and personal hygiene are responsible for the decline in mortality (Leavitt and Numbers, 1985; Ewbank, 1987). Nevertheless, groups on the margins of, or sometimes excluded from, social progress or the health system such as African Americans, Native Americans, Asian Americans, Mexican Americans, other ethnic and religious minority groups, and large blocs of the poor, were not full beneficiaries of these positive results. Members of these groups, along with women, were segregated and isolated from the mainstream health system and systematically excluded from health professions training (Byrd and Clayton, 2000, 2002; Leavitt and Numbers, 1985; Trennert, 1998; Walsh, 1977).

After World War I, the Great Depression, and World War II it became clear to all the nation's racial and ethnic groups that medicine and medical care could make a difference in reducing infectious disease morbidity and mortality, increasing life spans, and improving health outcomes and quality-of-life in America (Byrd and Clayton, 1992, 2000, 2002; Fee, 1997a, 1997b; Leavitt and Numbers, 1985). As the efficacy of health interventions, therapies, and technologies increases, the equitable distribution of medical care and health services becomes even more important. As Byrd observed, "American medicine is now devastatingly effective, corrective, preventive, and selective. Doing without health care these days spells doom or defectiveness" (Byrd, 1986, 1026). For a plethora of reasons,\* race, class-, and ethnic-based health status, outcome, and services disparities

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\* Reasons for overall health improvement and convergence of health and healthcare for all Americans can be attributed to scientific (e.g., vaccinations, antibiotics), social (e.g., improved nutrition, housing, and sanitation), political (e.g., movement toward egalitarianism and the welfare state), economic, medical-social (e.g., acceptance of public health goals), and health policy (e.g., policies promoting a healthy population and good health) factors, all of which are detailed in the references.

between America's racial and ethnic minorities and the European American majority narrowed over the first three-fourths of the twentieth century. Though overall U.S. health status and outcomes continued to slowly improve, these history-based disparities have either stagnated or worsened during the past two decades for racial and ethnic minorities. *Understanding* the character, causation, mediators, and mechanisms of the racial and ethnic disparities in health and healthcare could eventually lead to recommendations and interventions to *eliminate* them (Byrd and Clayton, 2000, 2002; Clayton and Byrd, 2001; Collins, Hall, and Neuhaus, 1999; Garrett, 2000; Haynes, 1975; Malone and Johnson, 1986; Mayberry, Mili, and Ofili, 1986, 2000; U.S. Commission on Civil Rights, 1999a, 1999b; Williams, 1999).

### An Uneasy Mix of Diverse Peoples: The Dynamics of the United States' Racial and Ethnic Group Interaction

Other than Native Americans, all Americans are immigrants who arrived on the North American continent within the last 500 years (see Figure 1 for distribution of ancestry groups). Of the varying races and ethnicities, some entered English North America (later the United States), voluntarily, some were recruited, and others were brought in involuntarily. American immigration took place in waves during various socio-economic and political periods of our nation's history, with various groups dominating particular periods. Examining these immigrant waves from a racial-ethnic relations perspective (including group characteris-

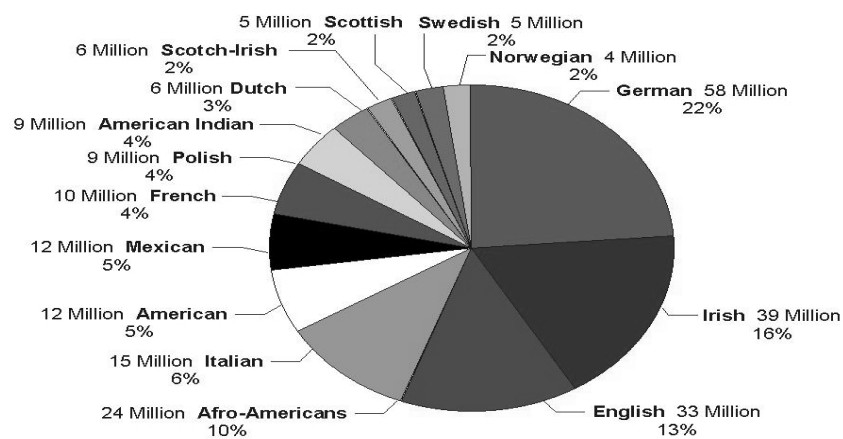


FIGURE 1 The top 15 ancestry groups, 1990 U.S. Census. SOURCE: U.S. Census Bureau, 1990 Census Report, CP-S-1-2, Detailed Ancestry Groups for States.

tics, group interactions, power relationships and experiences juxtaposed with a changing capitalistic economy and expanding political and governmental framework—Table 1) provides a backdrop that clarifies the immigrants' health status and outcomes and evolving relationships with and within the health system (Byrd and Clayton, 2000, 2001a, 2002; Diamond, 1999; Feagin, 2000; Feagin and Feagin, 1999; Garrett, 2000).

Shared culture and national origin are prime characteristics of both indigenous- and immigrant-Americans. Thus, all can be considered members of ethnic groups (Feagin and Feagin, 1999). Scientists who study race consider it a socially determined category based on shared physical characteristics (most often skin color and appearance) most commonly dividing the human family into three to five major "racial" groups. The dominant racial types as previously noted are Asian (sometimes referred to as Mongoloid or Yellow), White (sometimes referred to as Caucasoid or Indo-European), and Black (sometimes referred to as Negroid) with some authorities adding American Indian (sometimes referred to as Red) and Australian Aboriginal (sometimes referred to as Malay) types (Omi and Winant, 1994; Stringer and McKie, 1997; Thernstrom, Orlov, and Handlin 1980; Van den Berghe, 1967). Of the 2 to more than 60 arbitrary "racial" types that science has created over the centuries, the U.S. government has adopted the first 4, with Hispanic reserved as an ethnic category (Cavalli-Sforza, 2000; Cavalli-Sforza, Menozzi, and Piazza, 1994; Haynes and Smedley, 1999; National Center for Health Statistics, 2000). While virtually none of the authorities still believe in "pure" races, all concede that many groups overlap the various racial classification systems and that there are a few that cannot be classified at all. Further confusion is introduced when all attempts at definition are confounded by the belief that *race* is just one aspect of *ethnicity*.

The United States is still highly stratified on the basis of race, ethnicity and class, and growing income inequality over the past decades may be accentuating these trends (Feagin and Feagin, 1999; U.S. Census Bureau, 2001f; Wolff, 1995). Though they are analytically separable, race, socioeconomic status (SES), ethnicity, and class phenomena are closely interrelated in the United States. They are also health and healthcare variables. From the nation's seventeenth century beginnings, English Americans have had much greater power and resources than other groups, and such power and resource inequality has tended to persist from one generation to the next. Other factors facilitating white, European American groups in becoming members of the mainstream have been *identificational assimilation* and their progressive acceptance as "White Americans" between the mid-nineteenth century and World War II (Feagin and Feagin, 1999; Jacobson, 1998; Lipsitz, 1998; Steinberg, 1989). Historically, some groups are confined to lower-class positions because of lack of access to both

power and economic means that are built into the status system by formal and informal, structural, and to some extent, legal norms. The fact that individual class system mobility is also limited and that experiences differ markedly for certain groups is also based on understanding that there are two very different patterns of ethnic incorporation—*discrimination* versus *exclusion*.

Among those who suffered from discrimination were the Irish, Italians, Greeks, Jews, and Poles—the European immigrants, mostly from southern and eastern Europe, that came to America voluntarily in the mid-nineteenth to early twentieth centuries. Among those who suffered from social exclusion were Blacks, Native Americans, Mexican Americans, and Puerto Ricans—those whose history began as the product of involuntary conquest, annexation, and colonialism, as a result of which they were not allowed to become integrated into the major institutions of the society (Pedraza and Rumbaut, 1996, 16).

Few deny that African Americans, Native Americans, and Hispanics disproportionately occupy the lowest strata of the class system and have been traditionally restrained within these strata by political, ideological, legal and economic mechanisms. Traditionally, groups under Anglo-Protestant political or economic dominance, especially when compounded by racial worldview-caste considerations and *stereotyping*—Native Americans, Hispanics, African Americans, or Asians, or immigrants who arrived as indentured servants or laborers—have moved into and circulated within the lower rungs of the social hierarchy. However, in the ensuing racial and ethnic *acculturation* and *assimilation*, competition, and struggles that have evolved over time, individuals and groups, even of the less-favored races and ethnicities, have moved into positions of power (e.g., African-American and Italian Supreme Court justices; Mexican, African-American, Jewish, and Italian mayors). The various groups' distinctive health and healthcare profiles largely reflect these factors along with their demographics, sociocultural, and racial and ethnic experiences (Feagin, 2000; Feagin and Feagin, 1999; Harwood, 1981; Smedley, 1999; Takaki, 1993; Terry, 1992; Williams, 1999).

### **Black or African American [Black, not of Hispanic origin]**

Presently America's oldest, largest, non-indigenous racial group,\* the black population was projected by the U.S. Census Bureau to number

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\* Release of 2001 census data indicated Hispanics were tied with Blacks as America's largest racial/ethnic minority group. SOURCE: Canedy D. Troubling label for Hispanics: 'Girls most likely to drop out.' *New York Times*, Sunday, March 25, 2001, p. 1.

35,470,000 as of January 2, 2001, or 12.8 percent of the U.S. population (Bohannon and Curtin, 1995; U.S. Census Bureau, 2001b). Erroneously considered an homogenous population, the categories “Black” or “African American” include the descendants of the original seventeenth-through nineteenth-century slave population, as well as immigrants from Jamaica, Haiti, Trinidad, Barbados, and other Caribbean nations along with more recent immigrants from Ghana, Nigeria, Egypt, Ethiopia, Somalia, Sudan, the Cape Verde Islands, Liberia, and other African countries. Although viewing this group monolithically makes it easier to perform tasks related to health policy and health status indicators, it masks dramatic linguistic and cultural diversity issues, varied illness behavior, and preferences among these individuals and groups (Office of Research on Women’s Health, 1998; U.S. Commission on Civil Rights, 1999a).

Demographically, the black population remains younger (median age 30.4 years) than the general (median age 35.9 years) and white non-Hispanic population (median age 38.6 years), has less affluence and higher poverty levels (23.6% in poverty) than the general (9.8% in poverty) or white (7.7% in poverty) populations, suffers higher unemployment rates than the general or white populations, and exhibits lower educational levels (13% of blacks are college graduates) than the white (25% of whites are college graduates) population. Eighty-seven percent of African Americans live in cities and they reside in all 50 states. However, over half live in 13 Southern states—Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, South Carolina, Tennessee, Texas, and Virginia. Though subpopulations vary, people are usually assigned to the black or African-American category based on appearance—characteristics such as skin color, hair texture, and facial features. African Americans generally experience higher unemployment rates and employment in lower paying jobs, which helps explain their high rates of uninsuredness in a largely employment-based health system (Byrd and Clayton, 2000, 2002; Office of Research on Women’s Health, 1998; U.S. Census Bureau, 2001c, 2001d, 2001e).

*Mired in corrosive sociocultural, health and biomedical system legacies of 2000 years of being portrayed as being biologically and intellectually inferior; 246 years of chattel slavery, including a slave health deficit and a slave health subsystem; 100 years of legal segregation and discrimination and a “Negro medical ghetto;” and contemporary social, political, and economic isolation, oppression, exploitation, and a “dual” and unequal health system (Byrd and Clayton, 2000, 2002), “African Americans experience healthcare differently from [W]hites and other populations within the nation” (U.S. Commission on Civil Rights, 1999a, 23).* For a plethora of reasons, African Americans have experienced the worst health status, suffered the worst health outcomes, and been forced to utilize the worst health services of any racial or ethnic group.

Based on the latest available data as the new millennium began, African Americans are faced with persistent or worsening, wide and deep, race-based health disparities compared with either the white or the general population (Byrd and Clayton, 2000, 2001a, 2002; Clayton and Byrd, 2001; Collins, Hall, and Neuhaus, 1999; Mayberry, Mili, and Ofili, 2000; Williams, 1999).

### **American Indian or Alaskan [sic] Native**

Projected by the U.S. Census Bureau in 2001 to number 2,448,000, or 0.9 percent of the U.S. population, American Indians, Eskimos, and Aleuts\* are the smallest of the major racial and ethnic groups discussed in this report. However, their numbers are growing three times more rapidly than the white population. Comprising culturally diverse, complex, and distinctive groups of people speaking more than 300 languages, the American Indian or Alaskan Native population is made up of 535 federally recognized (plus 100 that are not officially recognized) tribes in seven nations (e.g., Navajo, Iroquois) on nearly 300 reservations in the lower 48 states, and approximately 500 government units in Alaska (Office of Research on Women's Health, 1998; U.S. Census Bureau, 2001b).

The commonality of their poor health experience, while obscuring their diversity, mirrors their shared sociocultural experience, which includes, but is not limited to:

- the rapid and forced change from a cooperative, clan-based society to a capitalistic and nuclear family-based system;
- the outlawing of language and spiritual practices [reminiscent of the black slavery experience];
- the death of generations of elders to infectious diseases or war; and
- the loss of the ability to use the land walked by their ancestors for thousands of years (Office of Research on Women's Health, 1998, 2).

For much of the twentieth century, the observations of the 1928 Meriam Report that the health of the Indian population was characterized by "a high birth rate and high death rate with excessively high infant mortality and a large proportion of deaths from tuberculosis" (Stuart, 1987, 1996), held true. Health-seeking behavior and responses to healthcare services such as being strongly autonomous, being non-linear thinkers (especially regarding time), using indirect communication and styles, and having a historical suspicion of authority reflects these experiences (Kingfisher, 1996).

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\* A Native American people inhabiting the Aleutian Islands and coastal areas of southwest Alaska.

Moreover, “Health care for the Amerindian population had been poorly provided by the Bureau of Indian Affairs since 1849” (Porter, 1999, 288). Their health and demographic profile—including poverty, lower education levels, and disease profiles often compounded by substance abuse—reflects the residue of this legacy. Due to treaty obligations, Native Americans largely receive their health services via the federal government, and “[T]he Indian Health Service (IHS)—since 1955 a part of the United States Public Health Service—provides healthcare through its clinic and hospitals to all American Indian/Alaska Natives who belong to federally recognized tribes and live on or near the reservations in its 12 service areas” (Office of Research on Women’s Health, 1998, 2). Though “[t]he health status of American Indians has improved dramatically during the twentieth century, particularly after the transfer of Indian health to the Public Health Service in 1955” (Stuart, 1987, 95), their diversity—compounded by their many small population groups scattered throughout the country—has made it difficult to provide consistent, quality, readily accessible healthcare. Their health status and outcomes are reflections of these circumstances (Burns and Ades, 1995; Office of Research on Women’s Health, 1998; Trennert, 1998; U.S. Commission on Civil Rights, 1999a).

#### **Asian American [Asian or Pacific Islander]**

Numbering less than one million until the Supreme Court ruled against immigration quotas in 1965, Asians and Pacific Islanders are the fastest growing minority group in the United States—representing 3 percent of the total population and around 13 percent of all people of color. Asian American immigrants to the United States have come from more than 20 countries. Having emigrated from countries such as China, Japan, India, the Philippines, Korea, Laos, Cambodia, Vietnam, and Thailand, Asians and Pacific Islanders represent more than 60 different ethnic groups and speak more than 100 different languages. Though only the largest subpopulations are detailed here—Filipino, Chinese, Japanese, Asian Indian, Korean, and Southeast Asian—that in no way lessens the importance of smaller groups such as the Laotians, Belauans, Micronesians from Nauru, Thai, Melanesians on Fiji, Cambodians, Tongans, or Hmong (Feagin and Feagin, 1999; Office of Research on Women’s Health, 1998). Under Title VIII of the 1975 Native American Programs Act, Pacific Islanders—who are not all immigrants to the United States as are many other Asians—along with American Indians, Alaska Natives (Eskimos and Aleutians), Native Hawaiians, and Samoans, are defined as “Native Americans.” Representing only 5 percent of the total Asian American and Pacific Islander (AAPI) category, they present bipolar health and social profiles of artificially aggregated groups, and their health outcomes are

akin to those of American Indians/Alaska natives rather than to other Asian subpopulations. Disaggregating their health status and outcomes from other Asian subpopulations whenever possible would seem to lend clarity to any health assessments or analyses of such arbitrarily combined groups (Feagin and Feagin, 1999; Office of Research on Women's Health, 1998; U.S. Commission on Civil Rights, 1999a).

U.S. Census Bureau projections of the AAPI population at 11,279,000, or 4.1 percent of the population, by November 1, 2000, reflect a population growth rate of 37 percent between 1990 and 1998, the highest in the nation. The AAPI population is young, with a median age of 32.1 years—3.8 years younger than the general population and 6.5 years younger than non-Hispanic whites. Fifty-six percent of Asian and Pacific Islanders live in the Western United States with the highest concentrations residing in Hawaii (63% of the total population), California (12%), Washington (6%), and New York and New Jersey (5% each). Asian and Pacific Islander Americans are more likely to reside in metropolitan areas (95% compared with 75% overall). In the late-1990s, 24 percent of the nation's foreign-born residents were AAPIs, with 6 of 10 being foreign-born. Only Mexico produced more foreign-born residents than the Philippines or China (including Hong Kong) (U.S. Census Bureau, 2001b; U.S. Commission on Civil Rights, 1999a).

Despite projections as a privileged and prosperous minority—now a part of their "*model minority*" image—many subgroups of Asian Americans are economically disadvantaged. While college graduation rates were the highest in the country for Asian and Pacific Islander Americans (42%) and the median income for Asian and Pacific Islander households as of 1998 was over \$46,000—the highest of all major racial and ethnic groups—some 14 percent of AAPIs have incomes below the poverty level, almost twice the rates of non-Hispanic whites (7.7%). Vietnamese Americans, for example, have an average family income that is about half that of AAPI populations as a whole. Moreover, AAPI families tend to be larger (3.15 persons compared with 2.23 persons in metropolitan white households), which translates into a lowered estimated income per member. There are more than 365,000 Pacific Islander Americans residing on more than 22 islands—including Polynesia (Hawaii, Samoa, and Tonga), Micronesia (Guam, Belau, and the Carolines, Marianas, Marshalls, and Gilberts), or Melanesia (e.g., Fiji). Their health profiles are distinct from other Asian groups. Half the Pacific Islander Americans live in Hawaii, 30 percent live in California, 4 percent in Washington, and 2 percent each in Texas and Utah. These islands represent autonomous governments with varied political relationships with the United States, and have varying levels of health and healthcare. The health system in Guam is relatively advanced, while the Commonwealth of the Northern Marianas offers a lesser level of care to its residents, and



the Republic of Belau and the Federated States of Micronesia have older hospitals and provide a generally poorer level of care. Though the health problems of the Native Hawaiians and other Pacific Islander groups today largely reflect their poor socioeconomic and educational status, whether in island or urban settings, barriers to health and healthcare such as linguistic isolation, cultural differences (e.g., obesity is acceptable in Polynesian culture and large body size is equated with power and respect), traditions, and health beliefs and practices remain problematic (Office of Research on Women's Health, 1998; U.S. Census Bureau, 2001c, 2001e, 2001g; U.S. Commission on Civil Rights, 1999a).

Educational attainment differs among Asian and Pacific Islander Americans, ranging from high school graduation rates of 31 percent among the Hmong, 64 percent for Tongans, 80 percent for Hawaiians, and 88 percent for Japanese. High AAPI college graduation rates vary from the very high rate for Asian Indians of 58 percent to Tongan, Cambodian, Laotian, and Hmong rates of 6 percent or less. As in other groups, educational levels are strongly correlated with health status and outcomes (Office of Research on Women's Health, 1998; U.S. Commission on Civil Rights, 1999a).

Based on the economic and educational progress some AAPI groups had made by the late-1960s, the "model minority" image replaced many of the negative stereotypes applied to Chinese and other Asian Americans. Some viewed this as an attempt, after several years of civil unrest and urban riots, to prove that the U.S. social system does work for minorities. "However, Asians often are pitted against other minority groups and are made scapegoats by low-income [W]hites and other minorities who indirectly blame Asians for their failure to succeed and claim that Asians take away their educational and job opportunities" (Office of Research on Women's Health, 1998, 18). Moreover, the "model minority" image tends to trivialize the health problems of Asians and suggests that they can take care of the problems themselves, while overlooking the diversity among Asian populations and the health and health system problems faced by the newest AAPI refugees (Office of Research on Women's Health, 1998; Steinberg, 1989; U.S. Commission on Civil Rights, 1999a).

### Hispanic

*Hispanic* has been a widely used term that was eventually designated by the government to identify persons of Mexican, Puerto Rican, Dominican, Cuban, and Central and South American ancestry and heritage. *Hispanic* is an English-language word derived from *Hispania*, the Roman name for Spain—emphasizing the Spanish heritage of these groups while ignoring the other (e.g., Native American, Mestizo, and African) geo-

graphical and cultural components. Although their origins are predominantly Native American (Indian), they also have significant infusions of blacks, whites, or Asians, which explains why Hispanics can be of any race. An alternative Spanish-language word and collective designation, *Latino*, recognizes the Latin American origins of these groups and is, therefore, more acceptable to many Spanish-speaking Americans (Feagin and Feagin, 1999, 291; Office of Research on Women's Health, 1998).

Projected by the U.S. Census Bureau to number at least 32,832,000 by November 1, 2000, Hispanics were reportedly tied with African Americans numerically as of March 2001 as constituting between 11.9 and 12.8 percent of the U.S. population (Canedy, 2001; U.S. Census Bureau, 2001b). The major subgroups are Mexican Americans (64%), Central and South Americans (14%), Puerto Ricans (10%), "other Hispanics" (7%), and Cuban Americans (4%).

More than one-third of Hispanic Americans are foreign-born, and approximately one-half the women giving birth to Hispanic infants were born outside the 50 states and Washington, D.C. Ninety percent of the nation's Hispanic population is urban and 70 percent reside in six of the most populous states (California, Texas, New York, Florida, New Jersey, and Illinois). The largest concentrations are in four cities (New York City, Los Angeles, Chicago, and San Antonio) and the South and West (three-fourths of all Hispanics) regions of the nation (Office of Research on Women's Health, 1998; U.S. Census Bureau, 2001b).

The diversity of the Hispanic population is remarkable. Comprising virtually all races, that group diversity includes 75% of all United States farm workers, which is important because Hispanic farm workers have a life expectancy of only 49 years. The Hispanic population also has infant mortality rates 25% higher than the United States average and higher cancer rates. Occupations and living conditions range from university professors and executives to people living in colonias, which are unincorporated areas lacking septic tanks, sewers, and running water. The median age of the Hispanic population is much younger (26.6 years) than the general (35.9 years) or white (37.0 years) population; educational levels are lower and they suffer higher poverty rates (22.8%) compared with the white non-Hispanic population (7.7%). Though subpopulations vary, Hispanics generally experience higher unemployment rates and are employed in lower-paying jobs, which helps explain their high rates of the lack of employer-based health insurance (Office of Research on Women's Health, 1998; U.S. Census Bureau, 2001b, 2001c, 2001e).

Hispanic subpopulations, especially Mexican Americans, appear to enjoy better health than would be predicted given their low socioeconomic status and their low utilization rates for healthcare services. Some groups, such as Mexican-American women, despite their greater poverty, have

lower rates of hypertension than Cuban, white, or African-American women. Among Hispanics, Puerto Rican and Cuban Americans use health facilities at rates comparable with whites while overall group utilization rates are lower. Moreover, prevalence rates for certain diseases like cancer and low birth weight infants favor new immigrant, less acculturated Hispanics. For poorly understood reasons, the risks for these health problems increase as these immigrants become more “American.” The unfortunate tendency to use such data to minimize Latino health problems must be acknowledged and ameliorated. There is so much variation in the health of Hispanic-American subgroups that looking at aggregated measures can obscure meaningful intragroup differences. This requires the collection of more focused and analyzed health data and statistics for these groups, along with more research to understand the patterns, forge health policy, and improve outcomes (Office of Research on Women’s Health, 1998; U.S. Commission on Civil Rights, 1999a).

Among the original occupants of the New World—from Cape Horn to Alaska and the Caribbean, to California, the Southwestern United States, and Texas—the ancestors of Latinos were dominated by Spaniards and Portuguese in the 1500s. After generations of intermingling between the dominant groups (Spaniards and Portuguese, Native Americans, black African slaves) and a complex series of political events and territorial wars, various Latino groups were either colonized (e.g., Cuba and Puerto Rico) or annexed (large parts of Mexico) by European minorities, which sometimes grew into majorities—while Latinos became second-class citizens in the process (Feagin and Feagin, 1999; Numbers, 1987; Takaki, 1993). Heavily recruited by the United States for agricultural and low-wage labor in the 20th century, these groups have acculturated and grown numerically while struggling against racism, prejudice and *stereotypes*, discrimination, poverty, being politically marginalized, and being looked upon as having a “foreign” language and culture. Their health experience reflects their social, economic, and political realities, which is a distinct theme of healthcare disparities in the United States (Canedy, 2001; Feagin and Feagin, 1999; Office of Research on Women’s Health, 1998; U.S. Commission on Civil Rights, 1999a).

### White Non-Hispanic Ethnic Groups

White non-Hispanic people, who number 196,929,000 (71.3 percent of the population), constitute the largest bloc of the U.S. population. These white ethnic groups are dominant players in American society, controlling the mainstream culturally, socially, economically, politically, and institutionally. This also applies to the U.S. health system: its professions, its politics, its policies, and its institutions (Byrd and Clayton, 2000, 2002;

Feagin, 2000; Feagin and Feagin, 1999; Starr, 1982; U.S. Census Bureau, 2001b). Often thought of in monolithic terms, brief descriptions of some of these European ethnic groups from ethnic and healthcare perspectives reveal that they are quite variegated. These “White American” ethnic groups are the major determinants at both the production phase and receiving ends of what constitutes “normal” health and healthcare in the United States. Although other specific white ethnic groups are not mentioned here—such as the French, Dutch, Scottish, Scotch-Irish, Swedish, Norwegian, or Slovak—this in no way lessens their importance in the health system or contribution to American society (Feagin and Feagin, 1999; Pedraza and Rumbaut, 1996; Starr, 1982; Stevens, 1971, 1999; U.S. Census Bureau, 2001a).

### English Americans and Anglo-Protestant Culture

Having led in the domination and settling of English North America, the Anglo-Protestant (sometimes referred to as White Anglo-Saxon Protestant [WASP]) transported the core “American” values of achievement, conscience, industry, antisensuality, and civic-mindedness to the new culture. However, at times they also brought a caste-like exclusivity, bigotry, and hierarchical views on matters of culture and race. As much a high status-power group as an ethnic group, until recently they dominated the presidency, cabinet, governmental, judicial, financial, educational, and corporate positions, established the nation’s institutional infrastructure and administered and managed its institutions. With 33 million claiming partial or total English ancestry, they rank numerically among the three largest white groups (Germans and Irish) and although currently being challenged culturally and politically, remain the most powerful group in America.

*Most significantly, “of America’s many groups . . . the English immigrants and their descendants require attention, for they possessed inordinate power to define American culture and make public policy” (Takaki, 1993, 7). They have been the determiners and the purveyors of the “overall American culture which serves as a reference point for immigrants and their children” (Feagin and Feagin, 1999, 76). In short, they set the tone for American political, business, and cultural life. The current U.S. health system is a by-product of these forces (Byrd and Clayton, 2000, 2001a; Domhoff, 1983; Feagin and Feagin, 1999; Jordan, 1968; Pedraza and Rumbaut, 1996; Schlesinger, 1998; Smedley, 1999).*

The presence of the English Americans and their culture is so pervasive that they are taken for granted and few references are made to their existence. Many allege they have lost much of their authority and power in the past five decades, especially after the 1960s when the Anglo-Protestant establishment was brought into question. Neverthe-

less, they are the leading edge of medical and health establishments and are a strong determinant of the “norms” for health and healthcare in America (Byrd and Clayton, 2000, 2002; Dowling, 1982; Starr, 1982; Stevens, 1971).

### **German Americans (1840s forward)**

At 58 million, German Americans are the largest American ancestry group. They have blended into the white majority so well that they are sometimes portrayed as a “model minority.” Their early health experience was shaped by the typical European immigrant health experience. The largest immigrant group of the mid-nineteenth century and unusually concentrated in urban areas of the Eastern seaboard, most early German immigrants were poor and dependent upon the public, dispensary, and charity care upon which other poor populations depended. Although squalor and overcrowding seemingly bred rampant disease rates, contributions by outstanding academic and practicing immigrant physicians eventually made a mark on American academic medicine (Lyons and Petrucelli, 1978; Pedraza and Rumbaut, 1996; Shryock, 1974; Viner, 1998).

For example, the heavy infant and childhood death toll suffered by German immigrant children living in New York tenements spurred immigrant physicians Abraham Jacobi and Maximilian Herzog to establish the German Dispensary and the Department for the Diseases of Children in the 1850s, the first of its type in America. From there they conducted research, studied, published scientific articles, and trained practitioners who influenced not only the New York medical community but also established the scientific basis of pediatric pathology, physiology, and therapeutic practice. Physician Emil Noeggerath made significant scientific contributions to pathology, obstetrics, and gynecology while headquartered at the German Dispensary. Such efforts not only led to medical school faculty appointments at the New York Medical College but “served to build a reputation for the Germans in the wider American profession, and to encourage the introduction of German science to American audiences” (Viner, 1998, 453). Moreover, institutions such as Philadelphia’s German Hospital (founded 1860-1861) and New York City’s German (now Lenox Hill) Hospital (founded 1869) appealed to ethnic and language-centered identity. These phenomena, along with a strong and influential nineteenth century transatlantic biomedical and scientific exchange with Germany and Austria, led to a strong German influence on the health system and facilitated German acculturation and blending into the mass of white American health, medicine, and healthcare just as they blended into larger white America (Lyons and Petrucelli, 1978; Pedraza and Rumbaut, 1996; Rosenberg, 1987; Shryock, 1974; Viner, 1998).

### Irish Americans

Separate branches of the same nationality, Irish Catholic and Scotch-Irish Americans total about 11 percent of the population. They represent the second (39 million) and twelfth (6 million) largest ancestral groups, respectively. The earlier Protestant Irish groups had settled disproportionately in the South and frontier areas, and acculturated and blended into white America by the nineteenth century while until recently, the much more numerous Catholic faction suffered significant amounts of racial stereotyping, discrimination, and religious bigotry. "Targets of nativist hatred toward them as outsiders, or foreigners, they sought to become insiders, or Americans, by claiming their membership as whites. A powerful way to transform their own identity from 'Irish' to 'American' was to attack blacks. Thus, blacks as the 'other' served to facilitate the assimilation of Irish foreigners" (Takaki, 1993, 151). Moreover, the Catholic group made significant contributions defining urban, ethnic politics, and forcing religious tolerance through their allegiance to the Roman Catholic church (Feagin and Feagin, 1999; O'Connor, 1995; Pedraza and Rumbaut, 1996; U.S. Census Bureau, 2001a).

Their early health experience was a stormy immigrant one. As Paul Starr observed, ". . . the Massachusetts General Hospital initially refused to admit Irish patients on the grounds that their presence would deter other people from entering the hospital" (Starr, 1982, 173). Such discrimination struck fear in ethnic and religious minority members already disadvantaged in the health system by their immigrant, cultural and SES circumstance. "Discrimination was a principal reason for the formation of separate religious and ethnic hospitals" (Starr, 1982, 173). As signs of ethnic progress, New York's Catholics founded St. Vincent's Hospital in 1849 and St. Francis Hospital in 1865. "By 1885, the Catholic community had opened 154 hospitals throughout the United States, more than had existed in the United States *in toto* in the late 1860s" (Rosenberg, 1987, 111). This not only assuaged Catholic religious concerns (e.g., being assured last rites), but also offered professional training and staff opportunities for Irish and other Catholic health professionals who would otherwise have been passed over. Recent indicators are that Irish Americans now rank at or above the national average for all whites on the educational, occupational distribution, and income levels (Feagin and Feagin, 1999; O'Connor, 1995; Pedraza and Rumbaut, 1996; Rosenberg, 1987; Starr, 1982; U.S. Census Bureau, 2001a).

### Italian Americans

Making up 6 percent of the U.S. population and the fifth largest ancestry group, Italian Americans have been less rapidly assimilated and

slower to yield their distinctive ethnic identity. Having endured poverty, difficult working conditions, anti-Catholic prejudice, and intense nativist attacks along with the poor health status and outcomes associated with those conditions, Italian Americans finally shrugged off the “inferior race” imagery and have made rapid progress up the political, social, and economic ladder, especially after World War II. Italian Americans are now one of the major groups in the American tapestry of blending and ethnic pluralism (Feagin and Feagin, 1999; Pedraza and Rumbaut, 1996; Rosenberg, 1974; U.S. Census Bureau, 2001a).

### **Jewish Americans**

Jews could be regarded as the most widely persecuted ethnic group in world history. They now constitute some 6 million persons or 2.5 percent of the population. Present in the Atlantic Coast colonies since at least 1654, Jewish Americans face and have endured the most severe and persistent levels of discrimination and anti-Semitism of all “White American” ethnic groups. Establishing unique niches in U.S. society, they have utilized educational and cultural means to become an economically prosperous group. Healthcare and the medical profession have been major vehicles for Jewish advancement, despite being early victims of hospital discrimination. “Jews feared they would have to eat non-kosher food and face ridicule for their appearance and rituals” (Starr, 1982, 173). Despite this and their hard-scrabble immigrant experience within the health system, the name change of “Jews Hospital” in New York City to Mt. Sinai was to signify that it served the community at large. Participation in the health system at the institutional and professional levels offered immigrant Jews another stepping stone into mainstream America. Through their struggles against nativist stereotyping and discrimination, they have also led the way in creating an environment of religious tolerance and diversity in America, while simultaneously spreading values of justice, tolerance, and fairness throughout the culture (Feagin and Feagin, 1999; Pedraza and Rumbaut, 1996; Rosenberg, 1974; Starr, 1982; Steinberg, 1989; Viner, 1998).

### **Polish Americans**

Polish Americans as an ancestral group make up approximately 4 percent of the U.S. population. Other than being of Eastern European origin and being subjected to a more intense nativist reaction in the early-twentieth century than some other “White American” ethnic groups, their racial and ethnic experience could be viewed as typical. Even the more privileged Northern European immigrant groups, including the French,

Dutch, Scottish, Swedish, and Norwegians sometimes experienced acculturation trauma and discrimination barriers to their entry into American society and the health system. In the 1960s, President John F. Kennedy appointed the first Polish American cabinet officer. “By the third generation, Polish Americans were entering universities in large numbers and joining the professional middle class” (Pedraza and Rumbaut, 1996, 204). Their health system experiences were similar to other immigrants modulated by what regions of the country they settled in, their religious affiliation, whether they were urban or rural, and if they migrated to the suburbs after World War II (Feagin and Feagin, 1999; Pedraza and Rumbaut, 1996; Starr, 1982; Steinberg, 1989; Stevens, 1999).

### **Racial and Ethnic Health and Healthcare Disparities and Their Documentation in the United States**

The black experience of poor health status, poor health outcomes, and limited access to the worst health services for the 366 years before 1985—well-known to African Americans, a small group of government officials, and a tiny cadre of academics—was not appreciated by the general public until relatively recently. Shock waves were generated throughout the health system by the release of then Secretary of Health and Human Services Margaret Heckler’s 1985-1986 report on minority health and its acknowledgment that “*there was a continuing disparity in the burden of death and illness experienced by blacks and other minority Americans as compared with our nation’s population as a whole [Heckler’s emphasis]*” (U.S. Department of Health and Human Services, 1985b). The response was characteristic of the high unawareness levels regarding disparate health and healthcare for the nation’s racial and ethnic minorities. The broadened focus on *all* of the nation’s racial and ethnic minority groups marked a new era in racial and ethnic health and healthcare in the United States. The *Report of the Secretary’s Task Force on Black and Minority Health* (also known as the Malone-Heckler report) noted the health disparity had existed “ever since accurate federal record keeping began” and that it “was the first time . . . a common effort [has been attempted] to carry out a comprehensive and coordinated study to investigate the longstanding disparity in the health status of blacks, Hispanics, Asian/Pacific Islanders, and Native Americans compared to the non-minority population” (U.S. Department of Health and Human Services, 1985b, ix, 2). Despite the Malone-Heckler Report findings that “Although tremendous strides have been made in improving the health and longevity of the American people, statistical trends show a persistent, distressing disparity in key health indicators among certain subgroups in the population” (U.S. Department of Health and Human Services, 1985b, 2), and “[t]hese disparities in health status



persist . . . 15 years later" (U.S. Commission on Civil Rights, 1999a, 16). *As well, major impediments to understanding and eliminating racial and ethnic health and healthcare disparities have been in areas related to inadequate data collection and analysis* (Byrd and Clayton, 2000, 2001b, 2002; Clayton and Byrd, 2001; Collins, Hall, and Neuhaus, 1999; U.S. Commission on Civil Rights, 1999a; U.S. Department of Health and Human Services, 1985a).

*Before 1985 requisite record keeping on black and minority health and healthcare was totally inadequate to the task of correcting the history-based disparities and sharing the beneficence of the health system and medical progress equitably across America's increasingly diverse racial and ethnic population.* Even though some health data on African Americans had been collected over time, it is only recently that specific efforts are underway to collect adequate health data for Native Americans, Hispanics, and Asian Pacific Island Americans. However, shortfalls in these areas remain (U.S. Commission on Civil Rights, 1999a; U.S. Department of Health and Human Services, 1985b). Characteristic of the difficulties inherent in racial and ethnic data collection that reflected the health status and outcomes of various population groups, "The first survey and tabulation of deaths by disease and race was taken by the U.S. Census Bureau in 1850" (Byrd and Clayton, 2000, 284). Moreover, before the implementation of a nationalized system for registering deaths in 1933, when all states registered as least 90 percent of their deaths and, thus, were qualified for inclusion in the Death Registration Area (DRA)\* system, it was difficult to describe mortality trends for any U.S. group before 1940 (Byrd and Clayton, 2002; U.S. Commission on Civil Rights, 1999a; U.S. Department of Health and Human Services, 1985b).

Some of the earliest records documenting racial and ethnic health disparities germane to the North American colonies and, later, the United States were embedded in slave trade data, race-based census data, *Annual Reports* from the Commissioner of Indian Affairs, insurance company data, and isolated instances of record keeping of racially comparative mortality rates and infant death rates. As well, records of epidemic diseases were kept by the mercantile slave traders, plantations, government agencies, insurance companies, cities and towns, and some states. A representative survey of available data sources from major historical periods are con-

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\* Death Registration Areas is a geographic area for which mortality data are published. SOURCE: Last JA, ed. *A Dictionary of Epidemiology*. Second Edition. New York: Oxford University Press, 1988, 35.

tained in Byrd and Clayton's database at the Harvard School of Public Health and their book, *An American Health Dilemma*.\*

Virtually all of the data suggest that from the United States' beginnings, even before the Revolutionary War, black, poor, Native American, and immigrant populations suffered the worst health status, outcomes, and healthcare. This reflected an evolving health system rigidly structured on the basis of race, ethnicity, class, gender, moralistic judgements, and indentured servitude-racial slavery. As the modern U.S. health system evolved during the twentieth century, it has made impressive medical and scientific progress. Despite changes in politics, health policy and administration; reforms in health professions education and research; restructuring of old along with the addition of new delivery systems; and major healthcare and health system financing changes, the U.S. healthcare system has had great difficulty shedding its racial-, ethnic-, class-, and gender-based tiering, hierarchies, and almost reflexively discriminatory medical-social culture (Byrd and Clayton, 2000, 2002; Farley, 1970; Farley and Allen, 1989; Garrett, 2000; Morais, 1967; Smith, 1999; Stuart, 1987; U.S. Commission on Civil Rights, 1999a).

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\* They include the African continental and Atlantic slave trade period (Curtin, 1969; Davidson, 1961; Kiple and King, 1981; Klein, 1978; Lewis, 1942; Ransford, 1983; Savitt, 1978; Sheridan, 1985), the North American colonial era (Blanton, 1930, 1931; Klein, 1978; Savitt, 1978, 1985; Sheridan, 1985), the Republican era (Boles, 1984; David et al., 1976; Ewbank, 1987; Fogel, 1989; Owens, 1976; Reuter, 1970; Steckel, 1979), the Jacksonian and Antebellum periods (Curry, 1981; Ewbank, 1987; Farley and Allen, 1989; Lewis, 1942; Savitt, 1978, 1985), the Civil War era (Barbeau and Henri, 1974; Bremner, 1980; Cobb, 1952; Mohr, 1986; Shryock, 1966), the Reconstruction era (Blassingame, 1973; Farley and Allen, 1989; Morais, 1967; White, 1970), the Gilded Age and Progressive eras (Du Bois, 1967; Manning, 1983; Rabinowitz, 1978; Stuart, 1987; Summerville, 1983), the Early 20th century from 1901-1929 (Du Bois, 1896, 1906; Ewbank, 1987; Farley, 1970; Farley and Allen, 1989; Stuart, 1987), the Great Depression and World War II eras from 1930-1945 (Ewbank, 1987; Farley and Allen, 1989; Hart, 1991; Lewis, 1942; Morais, 1967; Myrdal, 1944; Reuter, 1970; Stuart, 1987), the post-war and Civil Rights eras from 1945-1965 (Beardsley, 1987; Ewbank, 1987; Farley, 1970; Farley and Allen, 1989; Jaynes and Williams, 1989; Morais, 1967; Pettigrew, 1964; Rosenbaum, Layton, and Liu, 1991; Smith, 1999; Stuart, 1987; U.S. Bureau of the Census, 1975), the Civil Rights era in healthcare from 1965-1980 (American Cancer Society, 1988; Baquet et al., 1986; Clayton and Byrd, 1993a; Davis and Schoen, 1978; Davis et al., 1989; Haynes, 1975; Henschke et al., 1973; Leffall Jr., 1974, 1979; National Center for Health Statistics, 1991, 1992; René, 1987; Stuart, 1987; U.S. Department of Health and Human Services, 1985b, 1986), and the era of the Black Health Crisis of the 1980s and 1990s (American Cancer Society, 1997, 1998; Braithwaite and Taylor, 1992; Clayton and Byrd, 1993a, 2001; Collins, Hall, and Neuhaus, 1999; Jaynes and Williams, 1989; Livingston, 1994; National Center for Health Statistics, 1992a, 1992b, 1996, 1997, 1998a, 1998b, 2000; René, 1987; Singh and Yu, 1995; U.S. Department of Health and Human Services, 1985a, 1986, 1986a).

## CHANGING CONCEPTS OF RACE AND ETHNICITY

### On Racial Groups and Hierarchies

In contrast to *ethnicity*, race is a concept with roots stretching back to antiquity. The Feagins' (1999, 6) observation that, "This singling out of people within the human species in terms of a biologized 'race' hierarchy is a distinctively European and Euro-American idea," highlights the Western origins of today's pervasive racial *worldview*. The origins of the word "race" are disputed and may be derived from Arabic, Latin, Spanish, or German sources, and predate the sixteenth and seventeenth century beginnings of modern Western science. Initial English use of the word may have been in a 1508 poem by William Dunbar in which he referred to "bakbyttaris of sindry racis" (backbiters of sundry races) (Banton and Harwood, 1975, 13). The word "race" appeared in the formal English literature in 1580 according to *Webster's Dictionary* and other sources. The *Webster's Dictionary* definitions of race are so broad and variegated that they seem somewhat nebulous. *Webster's* first definition of race is "a breeding stock of animals," alluding to current biological definitions. It also defines race as "a family, tribe, people, or nation belonging to the same stock," and further describes race as "a class or kind of people unified by community of interests." Moreover, the destructive potential embodied in race—the Western cultural concept strongly grounded in human inequality with its bias producing capabilities that Jordan began documenting several decades ago (Jordan, 1968)—began to surface long before its sixteenth-century English language usage. Therefore, race serves as a biological term, a descriptive term for people sharing certain physical characteristics, and a culturally determined hierarchical human ranking system embodied in the Western *worldview* (Banton and Harwood, 1975; Byrd and Clayton, 2000; Smedley, 1999).

As recently as the early part of the twentieth century, laymen and some scientists used the word "race" to describe human groups that shared particular cultural characteristics such as religion or language (e.g., the "Jewish race" or the "French race"). Earlier, "[p]hysical anthropologists have called races the various sub-species of *Homo sapiens* characterized by certain phenotypical and genotypical traits (e.g., the 'Mongoloid race' or the 'Negroid race')" (Van den Berghe, 1967, 9). Some modern zoologists refer to subspecies or varieties as synonymous with a race—a partially isolated breeding population with some differences in gene frequencies from other related populations. Recent conceptualizations of race have reinforced movement away from the biological to the sociological sphere. Audrey Smedley noted "of fifty-eight introductory textbooks in physical anthropology published between 1932 and 1979 there has been a

progressive elimination of the term and concept of race from textbooks...in the United States . . . when either the term was no longer mentioned in the texts or the authors argued that races do not exist or are not ‘real’” (Smedley, 1999, 2). Such a paradigm shift has undermined the scientific standing of race as a purely biological or physical concept. Van den Berghe offers a precise and simple sociological definition of race referring “to a group that is *socially* defined but on the basis of *physical* criteria” (Van den Berghe, 1967, 9). Since there are virtually no biologically significant or inherent differences within the species *Homo sapiens*, understanding what happens to people after the social selection process takes place is paramount to understanding what’s important about race (Byrd and Clayton, 2000, 2001b, 2002; Smedley, 1999; Mayr, 1982; Van den Berghe, 1967).

Ancient founders of medicine and science’s precursors began a hierarchical, discriminatory, and bias-producing cycle as they started using race and ethnicity as means of classifying mankind. Driven since ancient times by folk beliefs, religious teachings, and social customs based on differences in physical appearances of various geographic populations, race became the subject of formal theoretical speculation and scientific investigation by the eighteenth century (Byrd and Clayton, 2000; Levi-Strauss, 1951; Smedley, 1999). *As an extension of Western culture’s intellectual preoccupation with human inequality, race became a focus of empiric and scientific inquiry for the next three centuries, codifying a color-coded, racial hierarchy of man—white, yellow, red, and black in descending order—in the process* (Banton, 1986; Byrd and Clayton, 2000; Smedley, 1999). By the middle third of the twentieth century, traditional biology- and anthropology-based ideas of race and “races of man” that had become dominant during the nineteenth-century rise of science began breaking down. This occurred as more objective anthropologic, genetic, paleontologic, archeologic, linguistic, biogeographic, and DNA and other molecular biologic studies proved: 1) the unity of the human species, 2) the common African origins of all racial groups, and 3) the biologic insignificance of the old parameters of racial classification such as skin and eye color, hair texture, physical features, and skull size and shape (Banton, 1986; Banton and Harwood, 1975; Cavalli-Sforza, Menozzi and Piazza, 1994; Cavalli-Sforza, 2000; Smedley, 1999). *Yielding to a deluge of scientific evidence, race has come to be more objectively considered a sociocultural concept wherein groups of people sharing certain physical characteristics are treated differently—often on the basis of stereotypical thinking, discriminatory institutions and social structures, a shared worldview and social myths* (Byrd and Clayton, 2000, 2001b; Diamond, 1999; Feagin, 2000; Feagin and Feagin, 1999; Smedley, 1999).

After briefly surveying the broad range of ideas about race, *racism*—the nefarious by-product that produces negative results and outcomes for the persecuted race—requires definition.

Racism is any set of beliefs that organic, genetically transmitted differences (whether real or imagined) between human groups are intrinsically associated with the presence or the absence of certain socially relevant abilities or characteristics, hence that such differences are a legitimate basis of invidious distinctions between groups socially defined as races (Van den Berghe, 1967, 11).

Race and racism are closely related and interdependent. As Van den Berghe points out:

The existence of races in a given society presupposes the presence of racism, for without racism physical characteristics are devoid of social significance. It is not the presence of objective physical differences between groups that creates races, but the social recognition of such differences as socially significant or relevant (Van den Berghe, 1967, 11).

Racism translates into *actions* that are both overt and covert.

It takes two, closely related forms: individual whites acting against individual blacks, and acts by the total white community against the black community. We call these *individual racism* and *institutional racism*. The first consists of overt acts by individuals, which cause death, injury or the violent destruction of property . . . the second type . . . originates in the operation of established and respected forces in the society, and thus receives far less public condemnation than the first type (Carmichael and Hamilton, 1967:4).

We must now turn our attention to understanding how racism—which usually has strong class overtones—works (the mechanisms) and creates its outcomes (through mediators) in health and the health system. This approach should also be useful in understanding the impact on health and healthcare of other bias-producing mechanisms such as ethnicity, culture, class, gender, disability, sexual preference, and age. We now know that:

1. The racial experience has been, and remains, the most intense in discriminatory levels and differential outcomes, especially with regard to health and healthcare;
2. As it is one of the oldest bias-producing concepts that simultaneously produced high interest levels, more is known about race and racism;
3. As critical theory, psychology, and the sociologic study of racism have revealed, it is an excellent surrogate and is often a fellow traveler with most other major types of bias, prejudice, and discrimination;
4. Race and racism embody virtually all of the moral, egalitarian,

medical ethical, and American creed issues that burden our society and health system as we enter the twenty-first century;

5. Understanding the basic human psychological mechanisms, regardless of who the perpetrators or victims may be, that produce racism, bias, stereotyping, discrimination, and group hatreds that might affect clinical decision-making is critical to crafting strategies and interventions for solving the problems; and

6. Finally, if the racial bias and discriminatory aspects of the U.S. health system are solved, America will have gone a long way toward achieving justice and equity in health and healthcare for all its citizens (Byrd and Clayton, 2000, 2002).

America's racial health problem should be at the leading edge of all our efforts to ameliorate racial and ethnic health disparities through cultural competence, multicultural medicine, anti-bias, and diversity training efforts. There are several archetypes we have found useful in understanding how race operates. These are genesis points of principles applicable to the health system and comprehending how some other types of bias operate (Byrd and Clayton, 2000; Smedley, 1999; Van den Berghe, 1967).

### **Racial Models as Tools for Analysis and Understanding**

Van den Berghe summarized some of the differences between the old-fashioned form of racism associated with slavery—*paternalistic racism* and the more modern variety, *competitive racism*. In the former type, blacks were viewed as immature, irresponsible, improvident, fun loving, child-adults—inferior, but lovable as long as they did not deviate from clearly defined roles. This paternalistic racism allowed for extreme intimacy because it maintained social distance. The prejudiced white superior loved and was committed to the dependent black who was loyal and loved the master in return. Resistance or rebellion by the slave triggered extreme brutality. With the abolition of slavery, poor and working class whites, who were the majority (and demanded control), no longer accepted the slaveowner's paternalistic image of blacks as good children or pets. To them, blacks were seen as clannish, uppity, insolent, aggressive, dishonest competitors for scarce resources. Therefore, *competitive racism* became the dominant racist mechanism of modern U.S. society (Van den Berghe, 1967).

Robert W. Terry's investigations on racism have evolved over the past three decades. His most recent efforts have crystallized on the concepts of *societal* and *individual* racism. Bias also operates at these levels. Incorporating many of his original theories, Terry also focuses on social and institutional mediators of racism defined through power relationships. These

mediators include: 1) *Power*, the unfair distribution or disproportionate capacity by the dominant white/Anglo group to make and enforce decisions; 2) differentially controlling *Resources* such as money, education, information, and political influence by the dominant racial group; 3) establishing societal *Standards* according to dominant white/Anglo definitions, automatically marginalizing other group norms; and 4) incorrectly defining *Problems* by the dominant white/Anglo group such that perceptions and solutions are distorted, inappropriate, manipulable, and dysfunctional. These four points are major contributors to what Feagin and others describe as “white privilege.” Terry’s work could also be viewed as the groundwork suggesting the application of some of these principles and concepts to public health as embodied in the work of Camara Phyllis Jones. Presenting a theory based on three levels of racism—*institutionalized racism*, *personally mediated racism*, and *internalized racism*—as explanatory and analytic tools for understanding race-associated differences in health outcomes, Jones posits a new paradigm that can be used for crafting interventions to mitigate the impacts of racism on health and health-care, and expand the national conversation on racism (Jones, 2000). In the health arena, all of these principles can be applied in both historical and contemporary configurations, and also lend themselves to understanding the European American dominance of the health system (Feagin, 2000; Feagin and Feagin, 1999; Feagin and Vera, 1995; Jones, 2000; Terry, 1992).

Psychiatrist Joel Kovel devised a psychological archetype of racism focusing on European Americans as the source of the race problem. His *dominative racism* was based on direct physical oppression and sexual obsession, while his more modern *aversive racism* is characterized by avoidance of the dominant group (whites) based on isolation of the subordinate group (blacks). Grounded in complex and infantile psychological mechanisms, it explains the white flight to the suburbs and the creation of inner-city black ghettos with all the attendant problems of segregation, isolation, and inequality. The most subtle, modern, and malignant form of racism is Kovel’s *metaracism*. It pervasively represents pure racism because it is systematic and independent of individual factors representing the last stage of racism that remains when racial passions have been washed away. *Metaracism* is “. . . the racism of technocracy, i.e., one without psychological mediation as such, in which racist oppression is carried out directly through economic and technocratic means” (Kovel, 1984, *xi*). It is the racism of differential taxation schemes wherein unequal, inner-city, public schools are produced; the racism wherein African Americans who have more kidney and heart disease than any other population subgroup receive fewer transplants and other highly desired invasive therapeutic procedures; discrimination and selection for education and jobs based on white culture-based “aptitude” and “achievement tests”; the racism of

police profiling wherein African Americans are automatically criminal suspects; the racism of “reverse discrimination” whereby white males are “protected” by Civil Rights laws that were designed to help blacks who were previously denied participation in American society; and the racism of computerized arrest record files for job screening in neighborhoods where most of the black adolescent males experience police encounters (whether convicted of crimes or not). Because it incorporates the most advanced forms of domination, mutates into multiple chameleon-like configurations (whatever forms are necessary to carry out its racist mission), and is the most detached from the older, hate-filled, odious forms of racism leading to discrimination and overt and covert violence, *metaracism* is the dominant mode of racism in postmodern, \* late capitalist, U.S. society. Applying and building upon what has been learned in these areas to other aspects of bias and discrimination in the health system represents the future of cultural competence, cross cultural training, diversity, and multicultural medicine (Byrd and Clayton, 2000, 2002; Feagin and Spikes, 1994; Kovel, 1984; Kozol, 1991; Lemann, 1999; Massey and Denton, 1993; Meyer, 2000).

### On Ethnic Groups

In contrast to *race* as a group designation, *ethnic group*—a group socially distinguished or set apart, by others or by itself, primarily on the basis of cultural or national-origin characteristics—is a much more recent concept and has been considered a more indefinite category (Feagin and Feagin, 1999; Thernstrom, Orlov, and Handlin, 1980). The preeminent paradigm in an attempt to subsume race since the end of World War II, deficiencies inherent in applying a model based on white ethnic history to non-white groups and its failures to explain or illuminate America’s lived racial realities have repeatedly undercut the concept’s utility (Feagin, 2000; Feagin and Feagin, 1999; Omi and Winant, 1994).

Aside from the difficulties in defining ethnicity, the term has been the focus of a long-standing academic controversy between scholars who choose to define the term narrowly and another group who want to use it broadly, subsuming previous racial, cultural, religious, national-origin, or linguistic categories (Feagin and Feagin, 1999; Sollers, 1989; Sowell, 1981; Steinberg, 1989, 1995; Van den Berghe, 1967). As Takaki noted “Race . . . has been a social construction that has historically set apart racial minorities from European immigrant groups. Contrary to the notions of

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\* Postmodern is a family resemblance term (often relating to art, architecture, or literature) that reacts against earlier modernist principles, as by reintroducing traditional or classical elements of style or by carrying modernist styles or practices to extremes.



scholars like Nathan Glazer and Thomas Sowell, race in America has not been the same as ethnicity" (1993, 10). Furthermore, many race relations authorities argue that such a strategy ignores the day-to-day realities of American bias, racism, and discrimination (Cose, 1993, 1997; Feagin, 2000; Feagin and Spikes, 1994; Feagin and Vera, 1995; Omi and Winant, 1994; Van Ausdale and Feagin, 2001; West, 1994); the country's racial history (Feagin, 2000); its systematic inequalities (Feagin, 2000; Feagin and Spikes, 1994; Feagin and Vera, 1995; Hacker, 1995; Steinberg, 1989, 1995); and the *ideological racism* encompassed in the worldview on race that is an integral part of Western and U.S. culture (Feagin, 2000; Feagin and Feagin, 1999; Feagin and Vera, 1995; Smedley, 1999). The stark differences in health status, services, and outcomes evidenced by African Americans, especially, and other racially identifiable non-white groups certainly seem to suggest the soundness of these principles. Whether the nation's racial and ethnic minorities are to be allowed adequate health status and outcome to fulfill their human capital and social potential—necessary prerequisites to be competitive in the twenty-first century—is the issue with which our system, ultimately, must grapple (Byrd and Clayton, 2000, 2002; Mayberry, Mili, and Ofili, 2000; U.S. Commission on Civil Rights, 1999a; Williams, 1999). Failure of our health system to successfully cope with increasing healthcare costs, increasing race- and ethnic-based health inequities and disparities, and increasing disability, cuts our nation's competitive edge, compromises overall quality-of-life, and poses a threat to the national good from a public health standpoint (Byrd and Clayton, 2000, 2002; Garrett, 2000; Haynes and Broder, 1996; Skocpol, 1997).

## ORIGINS AND EVOLUTION OF INEQUITIES AND BIAS IN WESTERN AND U.S. HEALTHCARE AND HEALTH SYSTEMS

### Introduction to a Historical Perspective on Inequities and Bias

Examining the origins, bases and evolution of health and healthcare inequities, inequalities, and biased thinking in Western *life sciences*, whether they are framed in racial, ethnic, class, gender, or cultural terms is a necessary foundation for understanding and eliminating racial and ethnic health disparities. For many readers, examining racial and ethnic bias and discrimination from the perspective of health professions, medical-sociology, and health systems requires a different mode of thinking—sociocultural, historical, *constructionist*, and *structural*, instead of *reductionist*, purely disease-oriented paradigms framed in public health, medical model, or quantitative terms. Such an exercise has certain drawbacks. For example, focusing on racial and ethnic biases, inequities, and inequalities may overlook the effects of other problems such as gender or class, which

are longstanding foci of bias, inequity, and inequality. In addition, only brief allusions to the broader historical or social contexts are possible; our examination will be limited to Western and, later, American medicine, health, and healthcare; and class dimensions will automatically creep in. With these caveats in mind, we will proceed.

### Ancient Origins

*The Classical period of Western scientific dominance beginning around 500 BC was pivotal, as the Greeks brought the gifts of objectivity, empiricism, and logic to the world and began separating the natural world from the religious one. However, along with their ethnocentrism and hierarchical cultural antecedents, their early efforts at taxonomy, which was a developmental stage of the scientific method, seemed to be preoccupied with human inequality (Byrd and Clayton, 2000; Drake, 1987, 1990; Finley, 1983; Goldberg, 1990). Greek philosophers—including Plato and Aristotle, often considered the fathers of modern science and medicine—began arbitrarily assigning slaves to lower categories within the human family, along with blacks and Asians (Harris, 1972, 13-28; Jordan, 1968, 11-12, 60; Wasserman, 1974, 13-20). For example, Plato's Great Chain of Being and Aristotle's modification, the Scala natura, which according to Lovejoy (1964) was "one of the half-dozen most potent and persistent pre-suppositions in Western thought," ranked everything:*

Peasants at the bottom, then servants to the gentry, then various grades of nobility and the monarch at top. Racism is embedded in the Chain of Being; the idea was used to rank the various races into "higher" and "lower." Of course, the white Europeans who devised it were at the top (Milner, 1990, 201).

These biased and inequitable tendencies were exacerbated by traditions of fee-for-service medical practice and the incorporation of the Hippocratic Oath, along with what many medical ethicists consider its self-serving medical ethical tradition and weak social covenant. As Veatch points out regarding the Hippocratic tradition, "It is consequentialistic; it is paternalistic; it is individualistic . . . [and] It permits physicians with bizarre and confused notions of benefit and harm to wreak havoc on unsuspecting patients" (1981, 147, 150). Further, "The Hippocratic tradition . . . does not have in its history even a token of a principle of justice or equality that could prick the conscience of the physician" (Veatch, 1981, 65). Its leanings toward individualistic contracts between independent agents; its vows to hide "trade secrets," even incompetence; and its pledges to channel the educational process to advantage each others' children have been downplayed as factors normalizing the "walling off" of the poor and dis-

advantaged from medical care and “normalizing” the medical profession as a socially distant upper-class activity (Byrd and Clayton, 2000; Goldberg, 1990; Veatch, 1981).

*By the third century BC in Alexandria, the overutilization of the poor, defenseless, and disenfranchised for medical experimentation and demonstration purposes was established as “Herophilos and Erasistratos...laid open men whilst alive—criminals received out of prison from the kings—and whilst these were still breathing, observed parts which beforehand nature had concealed”* (Majno, 1975, 354). Moreover, Galen—an academic physician-scientist and medical demigod who dominated Western medicine from AD 200 to AD 1700 (or 45 generations)—inserted his overtly racist and biased views into the formal medical corpus “documenting” black inferiority at physiologic, clinical, and intellectual levels (Davis, 1984; Devisse, 1979; Drake, 1987, 1990; Lewis, 1990). Bias, inequities, and inequalities were, thus, operationalized in the Greco-Roman world not only at the social but at ideological, so-called scientific, and health delivery levels as slaves, non-whites, the disadvantaged, and non-citizens received lesser, often very different, health services (Byrd and Clayton, 2000; Drake, 1987, 1990; Finley, 1983; Porter, 1999).

Prior to the Greek experience, the precursor civilizations of Western science and medicine were clustered around Mesopotamia and Egypt, starting around 4000 BC. Though these *archaic medical systems* were plagued with serious social, process, and structural biases and inequities based on slavery and class, there seemed to be little concern with race. Moreover, the Egyptian health system embraced some communitarian, public health, and egalitarian principals that were much ahead of their time (Byrd and Clayton, 2000; Lyons and Petrucelli, 1978; Porter, 1999; Thorwald, 1962).

### The Middle Ages

After the sixth-century collapse of the Roman Empire, Christian monks and Arab scholars recorded and perpetuated Western medical and health-care traditions throughout the Middle Ages. As clerical suzerainty over medicine and health from AD 500 to AD 1130 waned, Arab Moslem culture became dominant between the eighth and twelfth centuries. Fueled by the wars of the reconquest on the Iberian peninsula between the white Christians and African Moors, increases in anti-black prejudices and biases and the exclusive relegation to slave status for people of color in Moslem and Christian societies resulted. Racial, class, and ethnic bias contained in the preserved Platonic-Aristotelian, Hippocratic, Galenic medical corpus combined with the inequities contained in patriarchal slave-based Moslem societies to promote a growing deprecatory view and treatment of blacks in both Moslem and European cultures and to undergird the receipt of less

and lower quality healthcare for slaves and nonwhite people (Byrd and Clayton, 2000; Finley, 1983; Lewis, 1990; Sanders, 1978).

### The Renaissance

The Galenic-Greek-Arabic medical corpus and traditions remained dominant in the West during the Renaissance. Some influential physician-scientists such as Paracelsus hypothesized that blacks were inferior to whites (Stannard, 1992, 209). Royal, clerical, and aristocratic patronage for health-related enterprises such as medical schools and hospitals influenced the medical profession's acceptance as a prestigious pedagogy and profession in European Medieval universities, but the mantle of elitism distanced the profession socially from the populations they served. Moreover, the health system itself remained inequitable and strongly structured along class lines (Bullough, 1966; Sirasi, 1990; Wear, 1992). As the Mediterranean and Atlantic slave trades during the fourteenth and sixteenth centuries ended a drought of European and African contact, iconographic and documentary evidence suggests rising levels of bias, prejudice, and discrimination against blacks in Europe (Devisse, 1979; Devisse and Mollat, 1979; Pieterse, 1992). More destructive were the residual biases, practices, and hatreds generated by the Moslem-African versus Christian-European wars in Spain, a nascent Atlantic slave trade, and the travelers' tales (which at the time had a veneer of science) depicting African and other nonwhite people as inferior to Europeans. These developments set the standards for the inequitable and unequal hierarchical health arrangements, political ideology, and later scientific justifications for the slave trade and overseas conquests and domination during the Age of Discovery (Byrd and Clayton, 2000; Davidson, 1961, 1984; Jordan, 1968; Klein, 1978; Lewin, 1988; Sanders, 1978; Stannard, 1992).

### The Age of Science and Enlightenment

Inequities already established in health and healthcare in Western Europe and America continued and increased during the Age of Science and Enlightenment—the period between 1600 and 1800. Huge gaps existed in access to and the quality of healthcare delivered to the peasant masses and European aristocracy, and many aspects of these systems were exported worldwide to the colonies (Ackerknecht, 1982; Lyons and Petrucelli, 1978; Numbers, 1987; Rosen, 1993; Wear, 1992). French physician Francois Bernier wrote the first scientific article on racial classification in the Paris *Journal des Scavans* in 1684, and Carl Linnaeus, a Swedish physician-scientist and the "Father of Biological Classification," published *Systema Naturae*, a seminal work establishing binomial nomenclature as the standard in biological clas-

sification, which appeared in several editions after 1735. Both used skin color as major classification criteria and both marginalized blacks, the former as a different species (Davis, 1966, 454; Marshall and Williams, 1982, 242-243) and the latter adding degrading psychological and behavioral characteristics (Byrd and Clayton, 2000, 94-95, 214; Jordan, 1968, 218-222; Marshall and Williams, 1982, 245). Other dominant physicians and natural scientists of the era such as George-Louis Leclerc Buffon, Johann Fredreich Blumenbach, Petrus Camper, and Georges Cuvier all added to the bias-producing myth of white male superiority and non-white inferiority in their teachings, scientific discourse, and published works. The growing influence of science manifested in that much of this hierarchical material was utilized to justify social inequities and inequalities such as slavery, colonization and exploitation, and social segregation and stratification (Boorstin, 1989; Byrd and Clayton, 2000; Gossett, 1965; Gould, 1981; Haller, 1971; Haller and Haller, 1977; Jordon, 1968).

Enterprises contributing substantially to biases, inequities, and inequalities in health and healthcare during the period from 1600 to 1800 were the Atlantic slave trade and the worldwide establishment of European colonies (Byrd and Clayton, 2000; Kiple and King, 1981; Savitt, 1978; Sheridan, 1985). The Atlantic slave trade and New World slavery were not only dominant world events, they were also deficit-producing situations healthwise for the expropriated Africans and the Native Americans forced into slavery. Both situations produced new epidemiologic exposures, crowd diseases, marginal nutrition, poor sanitation, disciplinary brutality, and high mortality rates. More important may have been the deleterious effects these events had on the health system *subculture* (Byrd and Clayton, 2000; Kiple and King, 1981; Savitt, 1978; Sheridan, 1985; Stannard, 1992; Watts, 1997). In the North American English colonies, the aforementioned slave health deficit was perpetuated, a slave health subsystem was institutionalized, and black slaves joined the poor and disenfranchised by being overutilized for surgical, medical demonstration, and dissection purposes. Meanwhile, the health system and the delivery of health services were founded and structured on the basis of race, class, and puritan-oriented moral judgments—inherently biased and inequitable ideological, structural, and process arrangements. In English North America, oversight of the health and healthcare enterprise was under the stewardship of a tiny cadre of elite, often European-trained, physicians and boards of elite and wealthy Christian philanthropists (Blakely and Harrington, 1997; Byrd and Clayton, 1991, 1992, 2000; Dowling, 1982; Kiple and King, 1981; Rosenberg, 1987; Savitt, 1978; Schultz, 1992; Sheridan, 1985).

### **The Colonial, Republican, Jacksonian, and Antebellum Periods**

In the rapidly evolving medical and scientific communities during the American Colonial, Republican, Jacksonian, and Antebellum periods between 1619 and 1861, *scientific racism* burgeoned. As Reed pointed out, before the twentieth century “Scientific racism was not ‘pseudoscience’ but an integral part of the intellectual world-view that nurtured the rise of modern biology and anthropology” (1989, 1358). During the early nineteenth century the scientific study of race not only became more hierarchical with blacks, other non-whites, and women being relegated to the lower echelons of humanity, it continued to be dominated by European males. Influential studies by prominent academic European physicians such as Charles White (*Account of the Regular Gradation in Man*, 1799), James Cowles Prichard (*Researches into the Physical History of Man*, 1813-1847), Charles Hamilton Smith (*The Natural History of the Human Species*, 1848), and Robert Knox (*The Races of Men*, 1850 and 1862) (Banton, 1986; Byrd and Clayton, 2000) supplemented those by the three most dominant natural scientists of the nineteenth century, Georges Cuvier, Charles Darwin, and Sir Charles Lyell, all of whom held blacks in low esteem (Gould, 1981, 35-36). However, between the 1830s and the Civil War, the “American school” of anthropology emerged, which was the first seriously considered American scientific movement. Building upon the work of Louis Agassiz, a physician and chief biologist at Harvard, and Samuel George Morton (*Crania Americana*, 1839, *Crania Aegyptiaca*, 1844), a prominent University of Pennsylvania academic physician, the first extensive body of quantitative data in support of “polygenism”—the theory that human races were separate biological species and descendants of different Adams—took the scientific lead in the reification of race and its relationship to racial hierarchies and biological determinism. Americans dominated the field until they were supplanted by Darwin’s theory of evolution after 1859 (Byrd and Clayton, 2000, 2001b; Gould, 1981; Haller, 1971; Reed, 1989; Stanton, 1960).

### **The Civil War**

With the exception of the material circumstances of Southerners and their slaves, whose health status and outcomes were adversely affected by major shortages in providers and medical resources, there were no discernable changes in the hierarchical and layered delivery of healthcare for non-military populations on the basis of race, gender, moral judgments, and class during the Civil War. Black Union Army soldiers received inferior healthcare at all levels, from the Medical Bureau in Washington, to the field hospitals and combat units, individual professional

providers, to the field soldiers on the battlefields. In lieu of the generalized improvements in medicine, public health, and health services as a result of the Civil War, higher African-American mortality rates and poorer health outcomes reflected another set of realities—black social and economic collapse; health segregation, discrimination, and exploitation at all levels throughout the Civil War, Reconstruction, Gilded Age, and Progressive eras; collapse of the slave health subsystem; and refusal by the mainstream health system to incorporate Freedmen (Barbeau and Henri, 1974; Byrd and Clayton, 2000; Cobb, 1952; Cornish, 1966; Duffy, 1990; Rabinowitz, 1978). Meanwhile all African Americans, whether slave, free, or contraband, suffered health crises related to the war and abetted by collapse of the slave health subsystem. Disappearance of the bedrock of traditional slave providers and slavery's institutional justifications for the delivery of some healthcare, along with continued anomic and discriminatory wartime acts and policies toward the few trained black physicians, exacerbated an already critical situation (Byrd and Clayton, 2000; Cobb, 1952a, 1952b, 1981; Duffy, 1990; Mohr, 1986; Morais, 1967; Shryock, 1966). Black Civil War soldiers were utilized as subjects of the United States Sanitary Commission Anthropometric Study—the largest “scientific” comparison of the races ever undertaken—an enterprise undertaken to “document” black inferiority and white superiority for the next half-century (Byrd and Clayton, 2000; Haller, 1971).

### **The Reconstruction, Gilded Age, and “Progressive” Eras**

The Reconstruction period threatened the disappearance of the entire black population due to social conditions exacerbated by health or health-related causes. Epidemics, homelessness, breakdowns in housing and sanitation, and abandonment of the Freedmen by the mainstream health system were all factors. Emergency measures and Freedmen's Bureau legislation led to a “First Reconstruction in black health,” which led to the opening of African-American-accessible hospitals, clinics, and medical schools. This reversed some of the results of bias and inequities in the health system and may have saved the black population from extinction (Byrd and Clayton, 2000; Morais, 1967). Throughout the nineteenth century, physicians, politicians, and other opinion leaders utilized biased analyses of the Ninth, Tenth, and Eleventh censuses of 1870, 1880, and 1890, corroborated by insurance company data produced by companies such as Prudential—to confidently predict such an outcome (Byrd and Clayton, 2000, 411; Numbers, 1978, 16-19; Tucker, 1994, 33). Perhaps the most important countervailing force was the establishment of entrepreneurial precedents that established separate, albeit limited in some respects, black health, health delivery, and health professions training

traditions and institutions (Byrd and Clayton, 1992, 2000; Cobb, 1981; Morais, 1967). The nadir of black health during and immediately after the end of Reconstruction in 1877 was related to social chaos and dislocation affecting the Freedmen, barriers to black entry into the mainstream health system, the termination of most of the Freedmen's Bureau health activities by 1872, the lack of health facilities and personnel willing to serve African Americans, all of which were exacerbated by rampant scientific racism sweeping over the society and the health system. The growth of a "Negro medical ghetto"—a group of black health professionals and institutions serving the black community—and the acceptance of separate but unequal health, healthcare, and tiers of the health system based on race and class as the norm characterized the Gilded Age and Progressive eras of the U.S. health system. Persistent bias and inequities in the health system were also caused by the split of the medical profession into white (the American Medical Association) and black (the National Medical Association) factions, the former becoming a monolithic supporter of social conservatism and the status quo while the latter crusaded for health justice and equity and established the tradition of promoting egalitarian approaches to health and healthcare (Byrd and Clayton, 1992, 2000, 2002; Cobb, 1981; Duffy, 1990; Morais, 1967; Tucker, 1994).

### The Early 20th Century

Early nineteenth-century scientific racist movements such as anthropometry, phrenology, and craniometry were displaced by movements such as social Darwinism, eugenics, and psychometric testing later in the century. Both the medical and scientific establishments provided elaborate classifications for and predicted the imminent extinction of inferior "races" such as blacks, criminals, Jews, the Irish, the poor, and the insane. Much of the research and deprecation, especially with the rise of IQ testing, was directed at newly arrived white (e.g., Irish, Eastern European Jews) and non-white (e.g., Chinese, Mexicans, and Japanese) immigrant groups. Good breeding and sterilization of the "unfit" were posited as solutions to all social and many medical problems. Thus, medical and scientific developments continued to provide an underpinning for ongoing biases, inequities, and inequalities in health and healthcare as they related to race, ethnicity, gender, class, social status, and moral criteria (Byrd and Clayton, 2000, 2002; Chase, 1980; Haller, 1963; Kevles, 1985; McClintock, 1995; Reilly, 1991; Tucker, 1994; Weisbord, 1975).

As the United States emerged as a world power in the early twentieth century, the U.S. health system remained locked in patterns of bias, inequity, and inequality. Seemingly unable to shed its racial, class, gender, and moralistic shibboleths, the Progressive era worsened many racial,



class, and ethnic biases, prejudices, and inequities in the health system, often shifting issues such as poverty, insanity, imbecility, and congenital malformations, in attempts to divorce them from areas of social concern, into the domain of healthcare under the aegis of so-called scientific dispensation. So-called scientific data such as family trees and IQ tests were used to justify sterilization, incarceration, and immigration restriction. Biometric testing, which had classified most of the U.S. World War I soldiers as mentally limited or deficient, reached its zenith during the 1920s and was later adapted for educational selection and tracking. Between the late-nineteenth and the first quarter of the twentieth century, educational reform swept through the health professions training and research infrastructure. Medical schools and medical research laboratories became the darlings of the elite foundation and corporate benefactors, with black institutions relegated to a caste status remaining on the margins (Allen, 1995; Brown, 1979; Byrd and Clayton, 2000, 2002; Chase, 1980; Epps, 1989; Guthrie, 1998; Hunt, 1993; Jonas, 1989; Lemann, 1999; Summerville, 1983).

The health system at all levels remained racially segregated and highly discriminatory along race, class, ethnic, and gender lines. This reflected a continuum of nationally adopted health traditions and policies extant since the Colonial era, and a burgeoning, deficient, public, largely tax-supported subsystem for the poor, immigrants, or incapacitated was erected. Reform of the growing medical education and research system conformed to previous race-, gender-, and class-biases and inequities (Byrd and Clayton, 2000, 2002; Dowling, 1982; Flexner, 1910; Hunt, 1993), and the medical profession became more elite, homogenous, and distant from the general public they served. The cultural fabric of the society changed with an unquestioning acceptance of biologically, statistically, and psychologically determined principles of scientific racism, while growing eugenics and social Darwinism movements shaped and influenced the health system with regard to immigrants, blacks, the impoverished, and the mentally challenged. At the same time, an increasingly dominant private health system for the well-to-do and middle class blossomed with new medical advance and technology (Byrd and Clayton, 2000, 2002; Chase, 1980; Haller, 1963; Kevles, 1985; Reilly, 1991; Tucker, 1994).

As a result of these occurrences, white health improved dramatically. In contrast, the health of African Americans improved very little, remaining the worst of any racial or ethnic group as they continued to receive little or deficient healthcare, especially in rural areas. As well, immigrant health was poor as they were either excluded or marginalized by the mainstream health system, being confined in many instances to the system's deficient public or charity-supported lower tiers. At the same time, Eugenics and social Darwinism movements flourished, shaping and influencing the health system with regard to the care and disposition of immi-

grants, blacks, the impoverished or the mentally challenged while the Negro medical ghetto continued to grow in size and complexity (Cobb, 1947, 1948, 1981; Gamble, 1995). Scientific exploitation of blacks and the poor continued (Byrd and Clayton, 2000, 2001; Chase, 1980; Kenney, 1941; Townsend, 1911) and underrepresented African-American physicians came of age with their own agenda (Byrd and Clayton, 1992, 2000, 2002; Bullough and Bullough, 1972; Chase, 1980; Cobb, 1947, 1948, 1981; Dowling, 1982; Farley, 1970; Farley and Allen, 1989; Leavitt and Numbers, 1985; Rosenberg, 1987; Starr, 1982).

### **The Great Depression and World War II**

The Great Depression disrupted and almost destroyed a health system with contours one could recognize today. By World War II, this forced more government involvement in healthcare and some restructuring of the system, especially as related to healthcare financing. Nevertheless, patterns of bias and inequities in health and healthcare continued as black and white health inequities and gaps continued at the policy, systems, professional, health status, outcomes, and services levels. White health progress slowed, the medical profession remained segregated by race with the white profession becoming a power center and a leader in the fight against progressive health reform (other opponents included insurance companies, a conservative series of Congresses, some members of the pharmaceutical industry, and white health professions organizations). The black profession continued to be victims of discrimination while the Negro medical ghetto continued, and repeated efforts to reform the health system along unitary, egalitarian and more communitarian lines failed (Beardsley, 1987; Byrd and Clayton, 1992, 2002; Campion, 1984; Cray, 1970; Hirshfield, 1970; Morais, 1967; Starr, 1982; Stevens, 1971, 1999).

### **Groundwork for Civil Rights in Healthcare**

From a bias and equity perspective the two decades after World War II (1945-1965) laid the groundwork for Civil Rights Movements in both the healthcare system and society at large. Nevertheless, the same health and healthcare patterns of bias and inequities detailed above continued until 1964, when the courts outlawed government-sponsored hospital segregation and in 1965, when Congress passed the Medicare and Medicaid legislation (Title 18/19). This took place despite vigorous opposition from the AMA and the healthcare and medical establishments. A successful civil rights struggle often led by black physicians, especially W. Montague Cobb, and organizations such as the NAACP culminated in a national civil rights campaign for justice and equity in health and healthcare, a

series of desegregation lawsuits won against segregated medical schools and hospitals, and a series of Imhotep Hospital Integration conferences that took place between 1957 and 1964, which ultimately led to desegregated hospitals (Beardsley, 1987; Byrd and Clayton, 1992, 2000, 2002; Cobb, 1981; Cray, 1970; Morais, 1967; Smith, 1999).

Simultaneously, due to pressures to further scientific advance and climates of national urgency generated by World War II and the Cold War, unethical experimentation on blacks, incarcerated populations, military populations, infirm elderly, and other disadvantaged groups increased in volume and intensity. The silences surrounding the atomic bomb experiments on U.S. soldiers, widespread institutional research abuse, government radiation and nuclear experiments on individuals, and the Tuskegee experiment would not break until later (Beecher, 1966; Byrd and Clayton, 2002; Hornblum, 1998; Jones, 1993; Washington, 1994a, 1994b; Welsome, 1999).

### **A Civil Rights Era in Healthcare**

Between 1965 and 1980 some of the most momentous progress in healthcare history for African Americans and other disadvantaged groups occurred. For blacks, the period between 1965-1975 represented a "Second Reconstruction in health and healthcare" as: there were dramatic improvements in black health status and outcomes; access, and quality of care improved dramatically as hospitals desegregated, affirmative action began increasing minority representation and access to health professions, and a community health center (CHC)/neighborhood health center (NHC) movement burgeoned (Byrd and Clayton, 1992, 2000, 2002; Davis and Schoen, 1978; Sardell, 1988). These events occurred despite lax enforcement of the Civil Rights laws applicable to health and healthcare (Smith, 1999; U.S. Commission on Civil Rights, 1999a, 1999b; Wing and Rose, 1980). Nevertheless, mainstream resistance to reform of the system occurred, as many white doctors refused to participate in Medicaid/Medicare programs; dual track health and public policy, public health, and health system strategic planning relative to blacks and the disadvantaged poor remained in place; covert racial segregation was often maintained and institutional racism went unaddressed; blacks, ethnic minorities, and the poor were still largely confined to the public healthcare sector (e.g., public hospitals, NHCs, CHCs, teaching hospital clinics, and health departments); mainstream medicine and its establishment continued to fight against progressive health reform and policies; and increasing inequities for black doctors continued to be incorporated into professional training—principally as underrepresentation—and intensified in the peer review processes (Byrd and Clayton, 1992, 2000, 2002; Campion, 1984; Cobb, 1981; Ehrenreich and Ehrenreich, 1970; Morais, 1967; Sidel and Sidel, 1984; Smith, 1999).

### **A Retrenchment Era in Healthcare**

After the legislative defeat of the AMA and the mainstream system in 1965 with the passage of Medicare and Medicaid and a short period of being held at bay, mainstream resistance to reform of the system continued unabated. Retrenchment after 1975 consisted of unaddressed health system structural segregation, discrimination, and institutional racism; continued ethnic, class, gender, cultural segregation and discrimination in health and the health system; stagnation or deterioration of health status and outcomes for blacks and the poor; steep cuts in public funding for healthcare; and complicity in non-enforcement of civil rights laws and regulations (Byrd and Clayton, 1992, 2000, 2001b, 2002; Campion, 1984; Cobb, 1981; Morais, 1967; Smith, 1999).

There was continuing evidence of bias and inequities in American medicine, health, and healthcare during the Reagan-Bush era from 1980-1992. In fact, new areas cropped up and several established areas intensified and included increasing race- and class-based inequities and gaps in health status and outcomes; drastic cuts in public healthcare sector funding such as Medicare, Medicaid, and tax-supported institutional funding cuts; retrenchment on Civil Rights laws; maintenance of structural inequities and segregation of the health system; and continued under-representation of blacks and other disadvantaged minorities in the health system and health professions (Andrulis and Carrier, 1999; Byrd and Clayton, 2001, 2001b, 2002; Clayton and Byrd, 2001; Smith, 1999). Black doctors suffered increasing professional inequities centered around the managed care peer review process as: black doctors continued to be reviewed without benefit of representation in the peer review process; and as providers for poorer and sicker patients, which is the typical black/minority provider profile, black doctors received systematically harsher treatment. There was also an increased prevalence of patient and practice profiling, economic credentialing became widespread, and practice norms and profiles continued to be determined by the white, less ill, majority (Andrulis and Carrier, 1999; Byrd and Clayton, 2002; O'Bannion, 1995). Other systemic bias and inequity problems surfaced as 1) the Malone-Heckler report (U.S. Department of Health and Human Services, 1985b) reminded the nation of continuing racial and ethnic health disparities despite the Second Reconstruction in healthcare; 2) increasing uninsured rates disproportionately affected minorities, children, and the working poor; 3) a "Mainstream health crisis" (runaway cost inflation, 14% of GDP consumed by health, huge health budget, growing numbers of uninsured) emerged; and 4) the little acknowledged and constitutionally different "African-American and disadvantaged patient health crisis" (segregated health/health policy/health system, structure-based race/class inequities

and inequalities, origins almost four centuries old, health insurance crisis) formed what was in reality a “dual health crisis in black and white” (Byrd and Clayton, 2000, 2002; Clayton and Byrd, 1993b, 2001; U.S. Department of Health and Human Services, 1985a; Woolhandler and Himmelstein, 1992, 1998). Nevertheless, after revelations surrounding the Tuskegee experiment, documentation of scores of thousands of unethical sterilizations and surgical abuse, widespread experimental abuse of prison and military populations, and instances of experimental exploitation and abuse of frail elderly populations and disabled children, some improvements occurred in these areas regarding blacks, the disadvantaged, and other vulnerable groups (Byrd and Clayton, 2002; Chase, 1980; Hornblum, 1998; Jones, 1993; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; Reilly, 1991; Washington, 1994a, 1994b; Welsome, 1999).

### **Failed Reform and Corporate Takeover**

The 1993-1994 period was dominated by the failed Clinton health reform (Johnson and Broder, 1996; Skocpol, 1997). Between 1995 and 2001, what some view as a corporate takeover of medicine, health, and health care by an insurance company-dominated managed care infrastructure has occurred. However, bias, inequity, and inequality in health and health care are still problems as “patchy destabilization” of the health system is occurring with increasing regularity; de-funding, contraction, and neglect of the public healthcare sector continues; managed care organizations selectively lock out black and poor patients and the providers that care for them; inequitable managed care peer review continues for black and disadvantaged minority doctors; biased clinical decision-making, a tradition more than 380 years old in America, continues; and increasing race-, ethnic-, and class-based inequities, inequalities, and disparities continue (Andrulis and Carrier, 1999; Byrd and Clayton, 2002; Clayton and Byrd, 2001; Collins, Hall, and Neuhaus, 1999; Garrett, 2000; Gray, 1991; Knox, 1999; Mayberry, Mili, and Ofili, 2000; Navarro, 1993; Schulman et al., 1999; Starr, 1982).

### **A Health System Shedding Some Negative Aspects of Its Past?**

The Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Health Disparities represents an important early step at solving a major set of problems in the United States’ health system. The roots of American racial and ethnic health and healthcare disparities are more than 2,000 years old. The adverse health experience of Native Americans and African Americans are the oldest, with the former being

five centuries old and the latter nearly four centuries old. Both groups' health experiences parallel their citizenship and social status in many respects. For African Americans there have been two periods of health reform to address black health inequities and disparities. The First Reconstruction in Black Health occurred between 1865 and 1872 and the Second Reconstruction in Black Health occurred between 1965 and 1975. Both were underfunded and stopped too soon to have permanent positive effects on Black health. For other ethnic minorities, especially non-Europeans, disparate health is a persistent norm. As we enter the new millennium these racial and ethnic disparities in health care remain to plague the system (Byrd and Clayton, 2000, 2002; Collins, Hall, and Neuhaus, 1999; Mayberry, 2000; U.S. Department of Health and Human Services, 1985a; Williams, 1999).

Many actions must be taken if amelioration of the nation's history-, health system-, and medical-social culture-based racial and ethnic health and health care disparities is to occur. Specific recommendations are in other realms of this report, but changes will have to occur in these general areas:

- (1) Ideological and philosophical levels;
- (2) Educational levels—diversity, cultural competence, anti-bias;
- (3) Health policy level;
- (4) Structure and processes levels of health system;
- (5) Functional component levels of the health system;
- (6) Race, class, and ethnically relevant research levels;
- (7) Specific interventions levels required; and
- (8) Community advocacy, adoption, and involvement levels (Byrd and Clayton, 2001a, 2002).

This study represents the nation's potential to ameliorate a set of problems that are over 394 years old for the Native American community,\* over 382 years old for the African-American community, is a growing problem in various Hispanic communities, and is becoming more of a problem in various Asian/Pacific Islander communities (Byrd and Clayton, 2000, 2002; Garrett, 2000; Malone and Johnson, 1986; Mayberry, Mili, and Ofili, 2000; Sullivan, 2000; U.S. Commission on Civil Rights, 1999a, 1999b; Williams, 1999). As Laurie Garrett observed:

American . . . health leaders . . . struggle with questions of race, genetics, ethnicity, and economic class, unable to define the relative impacts those

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\* This applies to the Native American health experience in the North American English colonies. If Christopher Columbus's landfall is taken as the starting point, 105 years are added making a grand total of 499 years.

had on individual and population health. And that debate, coupled with social exclusions from the health system . . . form a critical, lasting, and shameful theme of U.S . . . health (Garrett, 2000, 306).

The issues have again been placed on the agenda, and the health system, public health, the political process, and American public are at another crossroads. The future health of America's health system, and indeed its population, may hinge on attaining a satisfactory resolution of its racial, class, and ethnic disparities—one of the major sets of twenty-first-century health system problems that lingers from the nation's health past, in an antigovernment age with an impending majority minority population. This background information has been provided to lend some of the historical, sociocultural, and medical-social facts and contexts necessary to understand and eliminate the health system flaws and biases related to our complex racial and ethnic health experience (Bonnyman, 2000; Byrd and Clayton, 2000, 2002; Garrett, 2000; Johnson and Broder, 1996; Skocpol, 1997).

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## GLOSSARY

**ACCULTURATION** The modification of the culture of a group or an individual, a process encompassing infancy onward, as a result of contact with a different culture. This cultural assimilation, which can take two

to three generations, moves toward the dominant Anglo-Protestant culture.

**AMERICAN INDIAN OR ALASKAN [sic] NATIVE\*** A person having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliations or community recognition.

**ANGLO-PROTESTANT** A more accurate term for those often referred to as White Anglo-Saxon Protestant Americans.

**ANGLO-SAXON** a term that originally referred to Germanic tribes, the Angles and the Saxons, that came to the area now called England in the fifth and sixth centuries A.D.; it was later applied to the inhabitants of England and to those English who came to North America.

**ARCHAIC MEDICAL SYSTEM** Though possessing religion and magic as distinct features, archaic medical systems were distinguished by empiricism, systemization, practical organization, recording its experiences and cases for future utilization, and incorporating some public health measures into its corpus of knowledge and practice.

**ASIAN OR PACIFIC ISLANDER** A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa.

**ASSIMILATION** An incoming group's adoption of the cultural traits and identity of the host group or integration into the primary networks and secondary organizations of the host group.

**BIAS** 1. A preference or an inclination, especially one that inhibits impartial judgement; 2. An unfair act or policy stemming from prejudice.

**BLACK** A person having origins in any of the black racial groups of Africa.

**CLASS** A social stratum whose members share certain economic, social, or cultural characteristics.

**CONSTRUCTIONIST** Refers to the social formed dimensions of an inquiry. Such an inquiry includes elements such as the history, social dimensions, and culture shaping a subject.

**CULTURE** The accumulated store of shared values, ideas (attitudes, beliefs, values, and norms), understandings, symbols, material products, and practices of a group of people. Culture has both *material* and *non-material* aspects.

**DEMOGRAPHY** The study of the characteristics of human populations, such as size, growth, density, distribution, and vital statistics.

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\* This population is currently referred to as "Alaska Native."

**DISCRIMINATION** Actions carried out by members of dominant groups, or their representatives, that have a differential and harmful impact on members of subordinate racial or ethnic groups.

**DOMINANT GROUP** A racial or ethnic group with the greatest power and resources in a society (also called a majority group).

**ETHNIC AMERICAN** Historically, groups that have been designated with a hyphenated name: "African Americans," "Asian-Americans," "Native-Americans," "Hispanic-Americans." The hyphenation implies that a second person would not recognize these individuals as Americans unless designated as such.

**ETHNIC GROUP** A group socially distinguished or set apart, by others or by itself, primarily on the basis of cultural or national-origin characteristics.

**ETHNICITY** Ethnicity is a concept referring to a shared culture and way of life, especially as reflected in language, folkways, religious and other institutional forms, material culture such as clothing and food, and cultural products such as music, literature, and art. The collection of people who share an ethnicity is often called an ethnic group.

**EUROPEAN AMERICAN** Denotes individuals usually called "white" which need no designation (such as ethnic or hyphenated Americans) because they are recognized and presumed to be Americans.

**HEALTH** A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. [WHO definition]

**HEALTHCARE** Those services provided to individuals or communities by agents of the health services or professions, for the purpose of promoting, maintaining, monitoring, or restoring health. Health care is broader than, and not limited to medical care, which implies therapeutic action by or under the supervision of a physician.

**HISPANIC** A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race.

**IDENTIFICATIONAL ASSIMILATION** A term involving giving up one's ethnic identity for that of the dominant Anglo-Protestant culture, or an incoming group's development of a sense of identity linked to that of a host group.

**IDEOLOGICAL RACISM** An ideology that considers a group's unchangeable physical characteristics to be linked in a direct, causal way to psychological or intellectual characteristics and that, on this basis, distinguishes between superior and inferior racial groups.

**INSTITUTIONALIZED RACISM** Differential access to the goods, services, and opportunities of society by race. Institutionalized racism is normative, sometimes legalized, and often manifests as inherited disadvantage. It is structural, having been codified in our institutions of

custom, practice, and law, so there need not be an identifiable perpetrator. It is often evident as inaction in the face of need.

**INTERNALIZED RACISM** Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth. It is characterized by their not believing in others who look like them, and not believing in themselves. It involves accepting limitations to one's own full humanity, including one's spectrum of dreams, one's right to self-determination, and one's range of allowable self-determination, and one's range of allowable self-expression. It manifests as an embracing of "whiteness" (use of hair straighteners and bleaching creams, stratification by skin tone within communities of color, and "the white man's ice is colder" syndrome); self devaluation (racial slurs as nicknames, rejection of ancestral culture, and fratricide); and resignation, helplessness, and hopelessness (dropping out of school, failing to vote, and engaging in risky health practices).

**LIFE SCIENCES** An inclusive term designating all branches of science (i.e., biology, medicine, anthropology, epidemiology, or sociology) that deal with living organisms and life processes.

**MAINSTREAM** A term that is often used to describe the "general market," usually refers to a broad population that is primarily White and middle class.

**MEDICINE** The science and art dealing with the prevention, cure, or alleviation of disease...the Western Greek model sites of activity are: the bedside, library, hospital, community, and the laboratory.

**MINORITY** A group that is singled out because of physical or cultural characteristics whose members become objects of discrimination; it typically has less power and resources than the dominant group (also called a subordinate group).

**MODEL MINORITY STEREOTYPE** The non-Asian stereotype that views certain Asian American groups as uniquely exemplary in socioeconomic and moral characteristics compared to other people of color.

**PERSONALLY MEDIATED RACISM** Prejudice and discrimination, where prejudice means differential assumptions about abilities, motives, and intentions of others according to their race, and discrimination means differential actions toward others according to their race.

**PREJUDICE** An antipathy, felt or expressed, based upon a faulty generalization and directed toward a group as a whole or toward individual members of a group.

**RACE** 1. As many physical anthropologists abandon racial taxonomies altogether, race can be more objectively considered a sociocultural concept wherein groups of people sharing certain physical characteristics are treated differently based on stereotypical thinking, discriminatory

institutions and social structures, a shared worldview, and social myths; 2. A term developed in the 1700s by European analysts to refer to what is also called a racial group (see racial group).

**RACIAL GROUP** A social group that persons inside or outside the group have decided is important to single out as inferior or superior, typically on the basis of real or alleged physical characteristics subjectively selected.

**REDUCTIONISM** The belief, very prevalently used in science, that the whole of reality consists of a minimal number of entities or substances. The major methodological reductive triumph of recent years is the demonstration that the classical unit of heredity, the gene, is a macromolecule—deoxyribonucleic acid, or DNA.

**SCIENTIFIC RACISM** The creation and employment of a body of legitimately scientific, or patently pseudoscientific, data as rationales for the preservation of poverty, inequality of opportunity for upward mobility, and related regressive social arrangement. Usually creating a myth of two distinct races of mankind—one consisting of a small, healthy, wealthy, educable elite, while the second race is a far larger population of poor or nonwealthy, vulnerable, and allegedly uneducable by virtue of hereditarily inferior brains—scientific racism has often also institutionalized and lent scientific respectability to racist dogma and practices that were all far, far older than science itself.

**SLAVE HEALTH DEFICIT** The dramatic and deliterious Black/White differentials in health status and outcome presumed to be the consequence of slavery and subordinate racial status.

**SLAVE HEALTH SUBSYSTEM** The inconstant, inferior, alternate health system made up of traditional healers, root doctors, granny midwives and nurses, overseers, and planters' wives, sometimes backed up by formally trained physicians, provided African Americans during slavery. Some plantation infirmaries and hospitals and slave dispensaries and hospitals served as institutional sites.

**STEREOTYPE** A rigid, oversimplified, often exaggerated belief or image that is applied to both an entire category of people of a racial or ethnic outgroup and to each individual within it, usually negative, that is false or that greatly distorts the real characteristics of the outgroup.

**SUBCULTURE** A subculture pertains only to those standards that are operative when a person is acting in a particular social capacity or group. For example, occupations and ethnic groups develop their own subcultures—standards for what exists, what goals are to be valued, how one should behave—which are relevant when one is acting either on the job or as a member of the ethnic group but which are largely

irrelevant outside those contexts. The medical profession and health system are excellent examples of subcultures (see culture).

**SUBORDINATE GROUP** A group that is singled out because of physical or cultural characteristics for differential and unequal treatment and whose members become objects of discrimination; it typically has less power and fewer resources than the dominant group.

**WHITE** A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.

**WORLDVIEW** A culturally structured, systematic way of looking at, perceiving, and interpreting various world realities. The Western racial worldview holds that racial groups are by nature unequal and can be ranked along a gradient of superiority—inferiority.

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# The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives

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At a recent meeting held to examine health disparities for American Indians and Alaska Natives, Dr. Nathan Stinson, the deputy assistant secretary for Minority Health, recalled how proud he was of himself when as a resident he was able to see eight patients in a day. But when he joined the federal Indian Health Service (IHS), he found it daunting that he could only see, in one day, 75 of 100 Navajo patients. Dr. Stinson lamented:

*I didn't allow people to have more than one problem . . . and when I walked away, I didn't feel I'd done a very good job; I didn't give the best care I could, I didn't speak the language, I didn't have the best facilities, and I turned away people (Albuquerque Journal, 2001).*

## The History of Health Disparities Among American Indians/Alaska Natives

Health disparity has long haunted the lives of American Indians and Alaska Natives, beginning with the European contact and continuing over the next four centuries as tribe after tribe was either completely decimated or severely depopulated by waves of communicable diseases and by warfare. Although the types and severity of these health disparities have changed over time, some diseases continued to have an impact on the surviving tribes after they were removed and resettled on federal reservations.

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Today there are slightly over two million self-identified American Indians and Alaska Natives in the United States. While a majority live in the western states, only 38 percent continue to reside on federal trust lands; the rest now reside predominantly in off-reservation or urban communities. Substantial numbers among the latter are descendants of families that were first relocated to the cities by the federal government in the 1950s with promises of a better life and greater economic opportunities. While most American Indians and Alaska Natives who moved to the cities traded one form of poverty for another, most agree that poor economic conditions on many reservations keep them in the cities.

Evidence-based documentation on the extent or types of health disparities for all 500+ tribes and villages nationwide remains elusive, as is information on the quality of healthcare provided to this population. General information, however, is available about some factors that contribute to health disparities for American Indians and Alaska Natives, and this information includes a number of geographic, cultural, education, and financial barriers to adequate healthcare. Some information, for example, indicates that a majority of American Indians/Alaska Natives have fewer years of education and are three times more likely to live in poverty and be uninsured than the U.S. general population (The Henry J. Kaiser Family Foundation, 1997).

The lack of health coverage was also underscored by researchers examining medical care expenditures. They found that only one in three American Indians/Alaska Natives interviewed had private health insurance, compared with 80 percent of whites, 52 percent of African Americans, and 50 percent of Hispanics (Braden and Beauregard, 1993). Many of those uninsured reported that they depended solely on IHS for their healthcare.

Unlike other minority populations in the United States, the federal government has historically had a central role in healthcare delivery for American Indians/Alaska Natives. Currently, IHS reports a service population of approximately 1.51 million (IHS, 1998, 1999a). The users of IHS services comprise a population that is young, with a median age of 24.2 compared with 32.9 years for the U.S., all races. Despite the young population, the mortality picture for American Indian/Alaska Natives often indicates diseases experienced by an older population. For instance, the two leading causes of death for American Indian/Alaska Native women are diseases of the heart and cancer; the two leading causes of death for men are diseases of the heart and accidents (IHS, 1998, 1999a).

Health disparities for American Indians/Alaska Natives are also reflected in an array of other mortality and morbidity statistics. For example, the most recent data (1994-1996) indicate the following causes of age-adjusted death rates for American Indians/Alaska Natives that are *greater*

than for the U.S., all races: 1) alcoholism—627 percent; 2) tuberculosis—533 percent; 3) diabetes mellitus—249 percent; 4) accidents—204 percent; 5) suicide—72 percent; 6) pneumonia and influenza—71 percent; and 7) homicide—63 percent (IHS, 1998, 1999b:6). While cancer incidences are lower among American Indians/Alaska Natives, five-year survival rates are significantly lower, in part because of stage at diagnosis and problems with access to follow-up care.

In 2000, Dr. Michael Trujillo, the director of the IHS, attributed health disparities for American Indians/Alaska Natives to a number of underlying causes, including social and cultural disruption of tribal societies, poor education, longstanding poverty, lack of political presence, limited access to health services, and a widening gap in healthcare spending (Trujillo, 2000). The spending gap for healthcare is especially telling when the IHS per capita spending for healthcare is compared with other federal programs. The IHS<sup>2</sup> annual per capita healthcare spending at \$1,430 is less than one-half that for the general U.S. population (\$3,766). This IHS per capita spending is also substantially lower than that for Medicare (\$3,369); Bureau of Prisons (\$3,489); and Veterans' Administration (\$5,458) (FCNL, 2000). Moreover, when the per capita figures are adjusted for rates of inflation, the per capita spending for Indian health in real dollars is lower than it was in 1977 (FCNL, 2000).

The role of the federal government in the healthcare of American Indians and Alaska Natives is rooted in history, in federal statutes, and in various treaties negotiated with tribes prior to 1871 (AILTP, 1988). Treaties between the U.S. government and the tribes, for example, often included modest provisions for a hospital, a physician, medical supplies, and furnished housing for the physician. Other than allocation of funds to fulfill specific treaty obligations with select tribes, Congress did not appropriate funds for a health program for all American Indians and Alaska Natives until 1832. It was then that monies were allocated for a smallpox vaccination program for tribes deemed friendly to the United States and/or for individuals who, if they contracted smallpox, would pose a health threat to non-Indians in or near various military outposts (Stern and Stern, 1945). Other similar one-time congressional appropriations for specific health problems dot the history of Indian/federal relationship, but concern over poor health conditions was not a major issue for staff employed in the Office of Indian Affairs in the U.S. Department of War, an agency preoccupied with other priorities.

In 1849, the Office of Indian Affairs was transferred from the War Department to the newly established Department of Interior, where peri-

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<sup>2</sup>The Level-of-Need Funding for IHS is estimated at \$15 billion. The fiscal year 2000 funding level for IHS was approximately \$2.4 billion (FCNL, 2000:2).

odic reports by the staff mentioned unhealthy conditions on many reservations, but these problems were not addressed, due to lack of authorization and funding. The harsh living conditions on Indian Reservations, however, continued to exacerbate the declining health status of the population, fueled directly and indirectly by inadequate nutrition, unsanitary conditions, substandard housing, and lack of healthcare. When these devastating health conditions could no longer be ignored, the Secretary of Interior commissioned a study to determine the status of tribes across the country. *The Meriam Report*, published in 1928, documented the extreme poverty and hardships faced by tribes and issued a number of recommendations (Meriam, 1928). Unfortunately, the efforts initiated to correct some of these problems were abruptly halted at the onset of WWII and were never aggressively resumed.

The health conditions on most reservations therefore remained deplorable and periodically rekindled concerns of advocates who lobbied for federal action (Trennert, 1998). In 1954, Congress reacted by transferring the health responsibility from the Bureau of Indian Affairs (BIA) in the Department of Interior to the U.S. Public Health Service (PHS), an agency within what was then called the Department of Health, Education, and Welfare.<sup>3</sup> The transfer resulted in additional resources for IHS and provided an opportunity for many subsequent IHS providers to enlist in the PHS Commission Corp with all its military privileges and rank.

For American Indians and Alaska Natives, the War on Poverty in the 1960s served as the key staging ground for their quest for self-determination and self-governance. With direct funding from the Office of Economic Opportunity (OEO), some tribes were able to initiate community-controlled health and education programs, although most were on a small scale. The success helped mobilize tribal communities across the country to advocate for more local control and for a more active role in the federal programs serving their communities. The mobilization helped build a political voice in the Indian health arena, including fostering a number of national organizations that focused primarily on health, such as the National Indian Health Board. The chair of this national organization, Sally Smith, an Alaska Native, recently reminded members of the Senate Indian Affairs Committee that:

*For American Indian and Alaska Native people, the federal responsibility to provide health services represents a "pre-paid" entitlement, paid for by the cession of over 400 million acres of land to the United States. In many of the treaties which were negotiated between Tribes and the U.S. government, specific provisions for basic healthcare, such as the services of a physician and the construction and maintenance of hospitals and schools were included (FCNL, 2000).*

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<sup>3</sup> Now known as Department of Health and Human Services (DHHS).

In contrast to the conviction shared by many tribal leaders, the federal government has maintained that federal support for health services for American Indians/Alaska Natives is not an entitlement but is voluntary (or discretionary). The government argues that health service is not mandated under the federal government's trust responsibility to the tribes and that funds appropriated for Indian health are public monies and not treaty or tribal money (OTA, 1986). The federal government, however, also acknowledges that the courts have relied on trust responsibility to construe treaties or statutes in favor of tribes and that the Supreme Court has ruled that special programs for American Indians and Alaska Natives are not racial in nature, but are based on a unique political relationship between Indian tribes and the federal government (OTA, 1986).

Although the health services are not considered racially based, there are strict eligibility requirements for those who access the Indian Health Service. The general definition of who is eligible includes a number of criteria, not least of which is the requirement that the individual be of Indian descent, be regarded as a tribal member by his or her tribe, has some legal evidence of tribal enrollment or a Certificate of Indian Blood, resides on or near his or her federal reservation, and/or meets other local requirements (OTA, 1986). Generally, those who meet these eligibility requirements are not subjected to an economic means test in order to receive service, although most American Indians/Alaska Natives served by the federal IHS or tribal health programs are three times more likely to live in poverty than other Americans (The Henry J. Kaiser Family Foundation, 1997).

Because federal funding for Indian healthcare has historically been discretionary, improvement in healthcare resources for American Indians/Alaska Natives has continued to be piecemeal and void of consistent longrange planning. Even when Congress passed the *Snyder Act* in 1921 (the first legislation to recognize a need to provide some ongoing federal healthcare resource), the language remained broad and vague—for the “relief of distress and conservation of health and for the employment of physicians” (OTA, 1986). The Act did not encourage long-term planning, nor did it provide resources based on need, but it did establish an annual discretionary appropriation. The appropriation, which has fluctuated annually since the 1920s, has also produced a rationed healthcare system that continues today.

In an attempt to understand the piecemeal approach, one former BIA employee posited that the vague federal commitments were most likely influenced by the prevailing attitude of the 19th century that American Indians and Alaska Natives would eventually vanish or disappear into the American mainstream as they became “civilized” and assimilated. Either outcome promised to help relieve the federal government of its trust

responsibility and/or its involvement in the "Indian" business (McNickle, 1973).

The circumstances of dire health and poverty faced by most tribal communities, however, overshadowed any large-scale motivation for assimilation. Infectious diseases and poor sanitation continued to plague the communities, although a number of these diseases and health conditions such as tuberculosis and trachoma were targets of special governmental interventions at various times. The special interventions, however, left other dismal health conditions unchecked (Trennert, 1998). For example, the maternal mortality rate for American Indians/Alaska Natives hovered near 82.6/100,000 live births between 1955 and 1982, a rate that was nearly three times that for other women in the United States. This rate declined significantly by 1991, but still remained higher than the U.S. all races rate (The Henry J. Kaiser Family Foundation, 1997:5).

Few would question the fact that mortality and morbidity statistics declined after the transfer of the IHS to the US Public Health Service. This has been credited to aggressive public health programs that promoted immunizations and improved sanitation, as well as to other developments such as the introduction and use of antibiotics and the increased health resources and manpower brought about by improved funding (Rhoades et al., 1987). An 82 percent decrease in infant and maternal mortality by the 1980s has been used to underscore these two improvements (Rhoades et al., 1987). Other observers of Indian health status, however, attributed the improvements to a national trend (Kunitz, 1983; Kunitz, 1996).

Following the *Snyder Act*, the next major legislative milestone aimed at addressing health disparities for American Indians and Alaska Natives was vested in the passage of the *Indian Health Improvement Act* in 1976 (reauthorized and amended since its passage). The intent of the statute was clear on two points:

- a) Federal health services to maintain and improve the health of Indians are consonant with and required by the federal government's historical and unique legal relationship with, and resulting responsibility to, the American Indian people, and
- b) A major national goal of the United States is to provide the quantity and quality of health services which would permit the health status of Indians to be raised to the highest possible level and to encourage the maximum participation of Indians in the planning and management of those services (Bergman et al., 1999:591).

This legislative action provided much needed funding by: 1) improving health services; 2) improving the health infrastructure; 3) providing

scholarships to train more American Indian/Alaska Native healthcare providers; 4) allowing for Medicare and Medicaid reimbursements to IHS or to tribal health programs; and 5) formally recognizing the healthcare needs of tribal members living in off-reservation or urban areas (OTA, 1986).

The *Act* also called for maximum participation of Indians in the planning and management of healthcare services, reinforcing an earlier statute: the *Indian Self-Determination and Education and Assistance Act* of 1975. The *Indian Self-Determination Act* and its subsequent amendments have allowed tribes to take over all or partial management of Indian programs operated by the federal government under two alternatives—contracting or compacting. Under the former, tribes can negotiate to take over and manage existing programs without making substantial programmatic changes. Compacting, however, gives tribes more flexibility in re-prioritizing or changing the program to meet what they perceive to be the most urgent healthcare needs in their communities.

### Changes in the Healthcare Arena

The passage and the results of these two pieces of legislation have substantially decreased the role of IHS as more and more tribes assumed the management and delivery of direct healthcare. At the present time, the tribes manage 13 hospitals, 158 outpatient health centers, 158 village clinics in Alaska, 76 health stations, and five school health programs (<http://info.ihs.gov>). According to the National Indian Health Board, the redistribution of healthcare management has been primarily in compacting. The Board reported in 1999 the following percentages under the three types of healthcare management: 45% compact, 30% under contract, and 25% IHS. In addition, the Board predicted that these percentages in the next six years would further decrease the role of IHS, and they predicted the following breakdown by percentage: 56% compact, 38% contract, and 6% IHS (NIHB Reporter, 1999).

Currently, IHS continues to operate approximately 36 hospitals, 63 health centers, 44 health stations, and five school health programs nationwide (<http://info.ihs.gov>). With the exception of three large hospitals (the Alaska Native Medical Center<sup>4</sup> in Anchorage, Alaska; the Gallup Indian Medical Center in Gallup, New Mexico; and the Phoenix Indian Medical Center in Phoenix, Arizona), other hospitals throughout the country have

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<sup>4</sup> The Alaska Native Tribal Health Consortium assumed management of the Alaska Native Medical Center in 1999. The 150-bed hospital serves as the key hospital for the statewide network of 15 rural native health facilities serving over 200 tribes.

less than 50 beds and most do not provide surgical or obstetric services. Other services offered by IHS, albeit on a decreasing scale include public nursing, a public health sanitation program, environmental health, dental and optometry services, etc.

Although the passage of the *Indian Healthcare Improvement Act* permitted some federal support for urban-based Indian health programs, most of these clinics were previously created as not-for-profit storefront urban clinics. The clinics survived on donated medical equipment, supplies, and volunteers until eventually some became more firmly established and managed to secure funding from a variety of sources (Grossman et al., 1994). One funding resource was made possible by the passage of the *Indian Healthcare Improvement Act*. Today, approximately 36 urban Indian health programs in over 40 locations nationwide are now partially supported by IHS (IHS, 1998, 1999a). The types of healthcare services provided by the urban clinics differ from location to location. Some offer only referral services, while others operate comprehensive outpatient clinics that may include dental care, mental health services, substance abuse treatment programs, etc. (Namias, 2000; OTA, 1986). The current users of these urban clinics continue to be families or individuals who are on public assistance or who are either unemployed or are employed in low wage jobs that do not include health benefits.

Currently, as increasing numbers of American Indian/Alaska Native health programs come under the management of tribes or native organizations, there is some fear that the decentralization of IHS will eventually benefit only those tribal communities or organizations able to garner additional resources needed to augment the dwindling federal health dollars. One Indian physician noted "that unless there is continuing congressional and political support, the realization of self-determination by tribes may make it easy for the federal government to terminate its federal responsibility" (Bergman et al., 1999:601).

Whether they live in urban or rural communities, healthcare services for American Indians and Alaska Natives eligible for Medicare or Medicaid are another new problem for IHS and for other health programs intended to serve Indians. In a number of places, IHS, tribal, and urban programs find themselves in competition with Managed Care Organizations (MCOs) for American Indian/Alaska Native beneficiaries. While space does not permit lengthy discussion about the challenges MCOs pose for Indian health programs, it is worth noting that the growing competition may force changes in the future, such as capitated fees or other payment arrangements (The Henry J. Kaiser Family Foundation, 1997:13).



### Healthcare Dollars

Over the decades, the existing healthcare system, whether managed by IHS, tribes, or urban programs, has had to broaden its base of financial support in order to respond to the needs of the growing population of American Indians and Alaska Natives. Financing and paying for patient care by private or non-IHS or non-tribal facilities or providers is partially possible with funds allocated under Contract Health Service (CHS).<sup>5</sup> Despite periodic increased funding, however, CHS dollars are generally depleted by IHS and tribal providers before the end of the fiscal year (The Henry J. Kaiser Family Foundation, 1997). Although they provide service to American Indians/Alaska Natives, most urban programs do not receive CHS funding.

All three types of providers (IHS, tribal, and urban), however, are able to tap Medicaid and Medicare. In 2000, Congress enacted a bill allowing these entities to bill directly for services provided to Medicaid and Medicare beneficiaries after a few demonstration sites documented that it improved cost recovery and lessened the bureaucracy. In the 1990s, IHS, tribal, and urban-based programs also won the right to be included with other Federally Qualified Health Centers, a designation that enabled them to bill Medicare and Medicaid for actual and not fixed fees (The Henry J. Kaiser Family Foundation, 1997).

Access to Medicaid remains a problem for tribal members at many other places, including the cities. As part of her testimony before the Senate Select Committee, Barbara Namias, the president of the National Council of Urban Indian Health, recently recounted the barriers in accessing Medicaid faced by people who live in the city. Some of these barriers include applicants' inability to understand the Medicaid application process, lack of required documents such as a driver's license (especially if the person does not own a vehicle), and/or being denied Medicaid because the applicant is unable to verify a current address (Namias, 2000:19). She noted that many of these applicants remain highly mobile, frequently in search of affordable housing. Namias also informed the Committee that securing Medicaid coverage in urban communities does not guarantee access to medical service, as many providers refuse to accept Medicaid patients.

The underutilization of Medicaid by American Indians and Alaska Natives has been documented elsewhere. For example, although not all states collect or report Medicaid participants by race, statistics from a 1995 report by the Health Care Financing Administration (HCFA) found that

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<sup>5</sup>In Fiscal Year 1997, \$133.4 million was allocated for CHS, with 18% of that earmarked for tribes who contract or compact their healthcare (Schneider and Martinez, 1997:3).

American Indians/Alaska Natives were least likely of all racial groups to access Medicaid—only 65% of eligible Indians have Medicaid coverage compared with 82% for African Americans, 83% for Asians and Pacific Islanders, and 91% for Hispanics (HCFA, 1995).

The participation of American Indians/Alaska Natives in Medicare also has its share of problems. The National Indian Council on Aging (NICOA) reported that out of 112,588 American Indians/Alaska Native Medicare beneficiaries in a study they conducted by linking and matching IHS identifiers with Medicare recipients, 85% were racially misclassified (NICOA, nd:4).

### **The Tribal/Consumer Perspective**

Although cautious and concerned about both the possible impacts of MCOs and the threats to self-governance, most tribal health leaders, American Indian/Alaska Native health professionals, and the leadership of the urban and village-based health programs are not pessimistic. A study reported by the National Indian Health Board in 1999 found that a majority of the 210 tribes and health organizations they surveyed support local control of health services and self-determination. In addition, many articulated a number of health improvements they had been able to accomplish under self-governance, including the fact they were able to respond to local needs and to find various resources to expand their health services to meet those needs (NIHB Reporter, 1999). Others interpreted this model of health delivery as essential to improving quality of health services, in that they are able to re-focus on disease prevention and/or provide culturally relevant options, such as the inclusion of traditional tribal healing resources.

Those surveyed also expressed a need for more research on the effects of tribal health management on Indian health, while others wanted more political action to ensure future protection of tribal sovereignty (NIHB Reporter, 1999). Dwindling funding resources or insufficient funding were also common problems shared by many of those who participated in the NIHB survey. Some of the consequences of insufficient funding included problems such as the inability of the programs to offer competitive salaries and benefits to health professionals (The Henry J. Kaiser Family Foundation, 1997; NIHB Reporter, 1999).

The increased local control also appears to satisfy many consumers of these health services, although there are few published reports about consumer satisfaction with Indian healthcare other than those available from focus groups or other anecdotal sources. One preliminary study conducted in the early 1970s found that people with more schooling tended to express greater satisfaction with the healthcare they received at IHS

facilities than those with less schooling. The latter often experienced more dissatisfaction, some of it due to language differences, high provider turnover, and cultural insensitivity. Some consumers attributed cultural insensitivity to the lack of adequate ongoing or systematic orientation for the ever-changing cadre of providers (Kekahbah and Wood, 1972).

In a recent focus group conducted in Albuquerque, New Mexico, American Indian consumers echoed some of the same issues raised by consumers in the 1970s, but a number of these participants also voiced a greater appreciation for the cultural understanding and non-discriminatory healthcare provided them by IHS or tribal health programs. There was even a strong vote of confidence for IHS providers when one participant remarked: "I'm happy with IHS. I've got Medicaid for my children. I'm happy with the doctors that my children see there. The only one that gives me a hard time is that receptionist" (Grady and Edgar, 2001). The Albuquerque group directed much of its dissatisfaction and concern over cultural insensitivity and discriminatory behavior at healthcare providers from the private sector rather than at IHS or tribal providers. When discussing the lack of understanding of traditional tribal healing by providers outside IHS and/or tribal health programs, one participant added that she would like these providers to also "understand how traditional medicine can lead to healing [for] the [Indian] patient" (Grady and Edgar, 2001).

While most IHS providers understand and/or are aware of the traditional tribal healing practices, most providers in the private sector are less likely to know about these practices or their value for Indian patients facing serious health problems. IHS facilities and its leadership in many communities have always allowed patients and their families either time or a place (in the clinical setting) to consult with tribal healers or practitioners. The services provided by most of these tribal healers or practitioners are seen as complementing modern medicine and provides a source of spiritual help for many patients.

The role of traditional tribal healers is more widely accepted and utilized now, especially as tribal health programs attempt to address health problems such as diabetes and other conditions that cannot easily be remedied by modern medicine (Joe, 1994). The role of traditional tribal healing is especially important in health promotion because the concept of health for most tribes is wellness centered, enforced by social rules of behavior and taboos intended to help prevent illness or misfortune. Use of traditional tribal healing and its practitioners, however, was not always accepted by non-Indian healthcare providers. In fact, some healing practices were outlawed by the federal government in the late-nineteenth century at the urging of missionaries who deemed such practices as

barbaric and un-Christian. It was not until the mid-1930s that ceremonies such as the Sun Dance could be conducted without fear of reprisal.

One other notable difference between consumers surveyed in the 1970s and those who participated in the recent Albuquerque focus group is the difficulties with healthcare financing. The delays and frustrations experienced by consumers were frequently mentioned by participants in the Albuquerque focus group, especially the delays due to limited Contract Health Service (CHS) resources and/or the reluctance of Medicaid to assume fiscal responsibility for Indian patients (Grady and Edgar, 2001: 176). Consumers who have either private insurance or Medicare seemed to have fewer difficulties in accessing healthcare in New Mexico.

### **The Interviews**

In the present study, we sought to qualitatively assess current thinking from a cross-section of tribal health leaders, consumers, healthcare providers, and urban healthcare administrators on such topics as health disparities, quality of healthcare, healthcare financing, local management of healthcare, and issues of discrimination. To accomplish this, we conducted approximately 22 telephone interviews (including one telephone conference call with 7 providers) over approximately 2½ months, between late June and early September 2001.

Initially, a list of approximately 25 potential interviewees was developed in consultation with a number of sources. Each potential interviewee was contacted by telephone, by email, or by letter. The invitation included a cover letter with a brief description of the study as well as a list of proposed questions, which were also developed in consultation with several healthcare providers. The 22 participants represented IHS (12), tribal and urban health programs (8), and tribal leaders (2). The following sections contain the questions and the responses obtained from the interviews.

#### **Do Tribal Communities Receive or Not Receive Quality Healthcare?**

The responses to the first part of the question were mixed. Some participants indicated that tribal members were receiving quality care but qualified their responses by saying that while this was true in their own facilities, they did not think patients received quality care when referred to providers in the private sector (non-tribal or non-IHS facilities). Although they were not asked to discuss how quality care was determined, some of the interviewees referenced certain criteria they used to make this judgement. For example:

*[Retired CEO for Regional Health Organization]: I would say yes, but services are not always accessible. Some of our villages are comprised [sic] of islands with no road connections, and healthcare providers have to fly in to give care (EL 10/4/01).*

*[Provider]: I have two part answers for this question. The first part is yes, I believe overall that tribal members in our area are receiving quality care given our limited resources. The second part is I do not believe tribal members are getting good preventive services, and the limited CHS (Contract Health Service) dollars prevents many from getting needed care (JY 6/22/01).*

*[Tribal leader/consumer]: It seems persons with chronic health problems like diabetes probably get quality care. Those with acute or emergency problems are often taken to non-IHS facilities, and they are less likely to get quality care (JR 6/24/01).*

*[Provider]: Our ability to provide quality or preventive care is hampered by not having legislative authority. For example, CMS [Center for Medicaid and Medicare Services, formerly HCFA] is able to negotiate or set rates for medical services they purchase for the poor or the elderly (JY 6/22/01).*

As noted above, providers generally reported that their tribally managed, community controlled, or IHS health facilities provided quality care, despite limited funding. Others identified ways they try to maintain quality care, such as retaining providers who provide quality care. In one tribal community, for example, a tribal leader reported that her tribe was able to retain providers by supplementing their salaries with income from the tribe's gaming operation. Others point to various facility accreditations (e.g., JCAHO) as their evidence of providing quality care. Only one respondent indicated that her local program conducted on-going consumer satisfaction surveys to gauge the community's satisfaction with the health-care services provided. She reported that so far consumer satisfaction has remained high, although she did not elaborate on types of questions asked and/or how frequently the surveys were conducted.

There were a number of significant responses about barriers to the delivery of quality healthcare. Funding limitations and under-funding that has forced rationing of healthcare were the most frequently mentioned barriers. It should be noted, however, that while fiscal handicaps are well known to the providers and program administrators, consumers appear to have difficulty understanding why some people are denied services or why some patients experience lengthy delays before they get approval to be seen by specialists or to receive diagnostic services. For example, one mother who participated in the focus group held in Albuquerque, New Mexico, remarked:

*Right now I'm having a lot of trouble with Medicaid and the Indian Hospital fighting with each other [over] who's going to pay. They [Indian Hospital] don't*

*want to pay because they think Medicaid should pay. Medicaid don't want to pay because they think PHS [IHS] should pay. Like I said, in the meantime my little girl has to wait until they make up their mind, and this takes months and months (Grady and Edgar, 2001:185).*

This mother added that she has no choice but to wait, because she has no other alternative. Both consumers and providers express frustration over their rationing of medical care. One IHS health program administrator noted: "We are rationing healthcare, and depending on what medical services are needed, some individuals might not be able to receive the type of care needed directly in our facilities" (JY 8/31/01).

Another provider stated that unlike other large federal health programs, healthcare rationing is necessary because the federal Indian health appropriation is not based on need. He said that other major federal health providers of entitlement programs have more budget flexibility and purchasing power. IHS, he notes, does not have similar legislative authority or other provisions that would give the agency the purchasing power to negotiate a reasonable price for pharmacy products and to establish set rates with the private sector for medical services purchased for Indian patients.

It is not surprising that concerns about limited resources and the rationing of healthcare loom large. A number of the respondents spoke to the fact that the IHS funding level is only at 60 percent, a continuing situation that has forced the agency to limit or dispense with a number of valuable public health programs in order to sustain primary medical care services. The 60 percent funding level has also been affected by the increasing number of contracts or compacts that IHS has had to fund. According to some providers, this diminishing role of IHS has had a negative impact on staff morale and increased the uncertainty about future employment among the remaining cadre of IHS providers and its other federal employees.

Most providers also could not talk about rationing healthcare without referencing the severely underfunded Contract Health Service. While some reported that they are able to "stretch" their CHS allocation by utilizing the Catastrophic Health Emergency Funds (CHEF),<sup>6</sup> this option does not prevent most of them from exhausting both resources before the end of each fiscal year. The situation is more urgent, according to providers and program administrators from Oklahoma, where CHS is the sole source for 11 of the 35 tribes that do not have clinics and therefore must rely on CHS dollars to pay for primary and emergency healthcare.

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<sup>6</sup>In Fiscal Year 1997, Congress authorized \$12 million for CHEF to supplement CHS.

Elsewhere, the CHS dollars are reserved primarily for life-threatening emergencies that might involve automobile accidents or other major accidents or situations that may result in permanent disability or loss of a limb. Decisions as to who will receive CHS coverage are handled in a number of ways, depending on the location. Sometimes the decision is made administratively, but in other places, a committee of providers might meet weekly to make these decisions. One IHS health administrator who has responsibility for the CHS program in one IHS area in the Southwest commented that "one or two major automobile accidents can wipe out a CHS budget in one month," and added: "CHS is expensive, and rationing care does not save the agency dollars" (JY 6/22/01).

Along similar lines, IHS providers in Oklahoma noted that, "Once CHEF is depleted, the local facility often has to decide if it can absorb a medical bill for \$300,000" (9/4/01). In some cases, a critical diagnostic procedure such as an MRI is denied when CHS dollars are low, and the procedure may be delayed for as long as six months.

According to one of the interviewees, the cost-cutting efforts have also resulted in the purchase of cheaper treatment alternatives. He notes: "Some Indian patients with cancer do not get aggressive treatment because it may be too expensive, but have to settle for less aggressive treatments that may be less likely to be successful" (NC 6/12/01).

Besides CHEF, tribes who have other resources also report other ways they try to supplement their CHS dollars. Tribes with gaming or other business enterprises, for example, encourage their employees to take advantage of a tribal benefit package that includes health insurance. One physician who works with some of these tribes, however, reports that the need for CHS often exceeds these and other financial supplements.

Some tribally managed health programs also report that they are forced to "stretch" their CHS dollars by limiting eligibility to individuals who are members of their immediate tribe. Non-tribal members in these communities have to seek other resources, including care from an urban-based Indian health program. While the influx of reservation patients to urban programs has yet to be overwhelming, one urban Indian health program administrator stated: ". . . they [reservation patients] come without insurance, without Medicaid, or any other resources. We try to help them get enrolled in Medicaid, but it can be costly for our programs too" (RF 8/28/01).

Access to CHS even during times of emergencies is not without problems for the patients. For example, Indian patients who utilize a non-tribal or a non-IHS facility during a medical emergency have only 48 hours to notify their respective IHS facility and/or appropriate tribal health administrator to be considered for coverage under the CHS program. Those who fail to notify the appropriate facility are told they are personally re-

sponsible for any medical bills associated with the emergency care. Moreover, it is not unusual for many of these non-IHS or non-tribal facilities to also deny services to Indian patients unless they receive prior authorization. Staff at one tribal program reported:

*A tribal member was referred from one of our tribal clinics to a non-Indian facility for diagnostic testing. He was kept waiting for hours when the referral facility demanded visible, not verbal, verification of coverage. When the referral facility finally got a copy of the written authorization, instead of examining the patient, the patient was told to schedule an appointment for another time (HN 9/3/01).*

Rationing healthcare and the restriction of CHS resources also affects non-tribal members, including those married into the tribe. For example, as one provider notes, if an Alaska Native woman is married to a member of a tribe in Southwest, the woman is eligible to receive basic health services at the local tribal or IHS facility. However, should she need care aside from pregnancy-related care provided by a non-tribal or non-IHS provider, “she has to seek CHS coverage from her respective health facility in Alaska, a situation that requires her to travel back to her home community to be considered for CHS coverage” (NC 6/12/01).

In addition to rationing care, other factors also hamper the delivery of quality healthcare in many communities. A number of the interviewees reported that increasing numbers of tribal and IHS health programs have difficulty attracting and keeping good providers. One tribal leader indicated that her community would like to hire an American Indian physician, but that they have not been able to recruit one. “There are too few of them,” she adds (JY 6/24/01).

In other areas of the country, access to health facilities remains a key problem. One provider remarked: “Sixty percent of the Indian people in our geographic area live [far] away from Indian Health Service and tribal health program sites. . . . Transportation is a barrier and if people cannot access our services, we cannot count them as a part of our user population. . . . Our funding is based on user population” (KA 9/7/01).

### **Has Compacting/Contracting Improved Quality of Care?**

While some of the problems delineated in the previous section remain endemic, some interviewees saw quality healthcare improvement as tribes have assumed local control of health programs by contracting or compacting. For example, one IHS provider noted:

*My sense is that on balance, contracting and compacting has improved health-care services. In Alaska, where healthcare has been compacted for the last 4-5*



*years, there are improvements in clinical care. If you walk into the Alaska Native Medical Center today, you get treated today, whereas under the old system, sometimes it was a couple of weeks before you could get an appointment (NC 6/12/01).*

A director of one of the tribal health programs also reported positive trends under compacting. She noted that they have been able to build two new clinics and to increase the range of services offered by the tribal communities. Other tribal health program administrators also report that recent policy changes that allowed for indirect costs have strengthened their local health program infrastructures.

Another tribal health provider who agrees that quality of care has improved added that compacting has also helped improve continuity of care. This individual thought that tribally managed health facilities are more responsive to local needs. These non-federal facilities, he added, are also free to keep or let go of employees who are not delivering quality care. Another provider cautioned that not all tribally managed programs have been progressive. He thought that how well a tribe managed its health programs was dependent on the stability of its political or other infrastructure such as its board of directors. He lamented that in some communities, after each new election, the health program focus may suddenly take a new direction, a direction that may not necessarily result in positive outcomes.

Another note of caution was voiced by one tribal leader whose community was studying whether it will contract with IHS. She remarked:

*I am a [tribal] council member and don't know how I will vote [on contracting] until I have more information. We have recently contracted and took over some of the BIA functions, and it's working fine. But it is one thing to run out money to buy salt for the road and another thing to ration healthcare because there is no money (JR 6/12/01).*

This council member concluded by saying that until she gets further assurances, she is still skeptical about the federal push to encourage tribes to take over management of the federal program. She said she feared that self-determination could be the beginning of termination<sup>7</sup> or the end of federal obligations.

Most interviewees agreed that the quality of healthcare is improving under local control, but most also noted that financial shortfalls plague all of these programs, forcing them to ration care. Most also agree that the quality of care received or not received by tribal members is influenced by

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<sup>7</sup>Termination of the federal government's trusteeship.

racial discrimination or the lack of cultural sensitivity, especially by providers or employees in the private sector. The next section highlights some of these observations made by interviewees during the telephone interviews.

### **Does Discrimination Affect Quality of Care for Tribal Members?**

The responses to this question were varied, and the examples offered tended to be anecdotal. For example, one tribal leader said it was her experience that when she and other tribal leaders lobby for increasing healthcare dollars for Indian health, some legislators fear that if they support these efforts, their other constituents will think that Indians are getting something for nothing or that Indians will have a special advantage over other Americans.

An urban health program director said that discrimination was a major problem in his state but is not being addressed, even by state leaders. He reported that there have been efforts by tribal leaders and others to have the state legislature examine discriminatory practices such as police profiling, but to no avail.

Other observations offered by the interviewees tended to reflect experiences or examples that have happened at the local level:

*[Tribal leader]: Discrimination is a problem on two levels—one is that a lot of our people don't have private insurance, except Medicare and Medicaid. Sometimes there are different attitudes by university or private hospital staff towards these individuals because they have limited English-speaking skills or are timid. When clerical staff at these facilities do not get our people to answer fast, they can get nasty, rude, or become patronizing (MB 8/20/01).*

*[IHS Health Administrator]: There are some biases, stigmatization, and stereotyping that goes on, especially in the private sector. There is always an assumption made [by non-Indian providers] that any illness presented by an Indian patient is alcohol-related or other forms of substance abuse. Sometimes the stereotyping is further complicated by the fact that some Indian patients lack sophistication in dealing with majority culture (JY 6/12/01).*

*[Tribal leader/consumer]: Private hospitals tend to place Indian patients in charity rooms or cubicles in hospitals, rarely in a room with a window, with a private bath or nice surroundings. I have accused the hospital of placing our tribal members in these 'Indian beds,' but they denied it. I know because my husband was hospitalized a number of times at this hospital, and he was always placed in one of these 'Indian beds' (JR 6/24/01).*

*[Tribal health staff]: Providers in the private sector sarcastically refer to our tribal health insurance program as 'casino insurance' and will frequently deny service to those on Medicaid or Medicare because they do not have 'casino*

*insurance' .... Whether an Indian patient gets health service in the private sector is often dependent on stereotypical views held by these providers (HN 9/3/01).*

One of the staff members on the conference call went on to indicate that the ability to pay or the possession of a bonafide authorization does not always translate into quality care for Indian patients. Another tribal health program staff member elaborated:

*Even [our] tribal members with insurance do not receive quality care in the private sector because of cultural insensitivity and racism. If you look like an Indian, some facilities will not make you feel welcomed (HN 9/3/01).*

A majority of those interviewed indicated or provided examples perhaps indicating that Indian patients are more likely to experience discrimination by providers or employees working in non-IHS or non-tribal health facilities. Comments by a number of the interviewees, however, did not distinguish between outright racial discrimination and situations where providers might refuse to treat all patients with Medicaid or Medicare insurance. One tribal leader, for example, defined a situation as discriminatory when a fellow tribal member referred for knee surgery was refused by a specialist because the tribal member was on Medicaid.

Other examples were more specific and linked to racial discrimination. For example, one provider in Oklahoma reported that compared to non-Indian clients, Indian clients placed in a nearby psychiatric facility under Emergency Detention Order either did not receive immediate evaluation or were not immediately transferred to an appropriate treatment facility. He reports that Indian clients are kept much longer in the locked facility before they are evaluated or are referred to other treatment facilities.

Other examples also give glimpses of discriminatory action, at least from the view of the Indian patients. One longtime urban health program administrator reported that a considerable number of Indian patients they refer out to the private sector for specialty care or x-rays may not receive the service because the patients either do not feel welcomed or are treated with disrespect. He concluded that some patients are "told directly they cannot be served, while others are kept waiting for so long that they get uncomfortable and just leave" (RF 8/28/01).

Another IHS provider cited the results of a study that indicated a form of discrimination in providing treatment. The study examined the kinds of breast cancer treatments received by Indian women in one region of the Southwest. The study team found that compared with non-Indian women, Indian women are more likely to undergo a radical mastectomy rather

than breast conserving therapy, even for early stage cancer. As a clinician himself, he speculated that the surgeons might opt for mastectomy because of a stereotypical view of Indians—that Indian women, who often live miles away from the treatment facilities, may be lost to follow-up because they likely will not return for the series of radiation or chemotherapy treatments. The interviewee continued:

*I don't think it's malicious or negative stereotyping, except in the sense that the surgeons don't quite trust the Indian patient to be as compulsive about follow-up as their non-Indian patients. They [surgeons] may be doing a disservice to a number of Indian patients who would be perfectly good at finding their way for follow-up (NC 6/12/01).*

Lack of cultural sensitivity or stereotyping has also been presented as another form of discrimination or as contributing factors to discrimination. One provider, for example, notes such insensitivity has led to labeling Indian patients as “difficult,” especially when an Indian patient may want to withhold making an important health decision until they’ve consulted with family or kin. In contrast, noted the interviewee, “decision-making about the treatment process by healthcare providers tended to be unilateral rather than bilateral.” He also noted that most non-Indian patients tend to have more knowledge about their health problems than expected and may, in many instances, already have decided on an expected course of treatment.

A few of the respondents also mentioned that some Indian patients also want extra time to consult or to seek the services of their traditional tribal healers before consenting to a major treatment plan. The services of a traditional tribal healer, for example, may be sought by the patient and the patient’s family to help ensure a successful outcome of the treatment being proposed by physicians or specialists. Such requests are familiar and frequently honored by providers in IHS or tribal or urban based health programs, but are not familiar to providers in the private sector. Providers and administrators of the urban programs, however, find it difficult to provide patients in the cities with access to traditional tribal healers due to distance and differing intertribal needs for this service.

Some of those interviewed also described ways they have attempted to address discrimination. One IHS director of a consortium of tribal health programs in the eastern United States reported that they constantly try to educate agencies or entities that deny services to Indian patients to teach them that as citizens of their respective states, Indians are eligible for state, county, or local health resources. He admitted, however, that the educational efforts are difficult because his organization has to work with

14 different eastern states and across four different federal regions (MT 8/31/01).

Other tribal health program administrators said they attempt to lessen the blow of discriminatory practices by having Community Health Representatives (paraprofessionals) escort patients to non-tribal or non-IHS facilities. The escorts are asked to help with translation or to serve as patient advocates. In another region of the country, communities were able to vote in a tribal member to the local non-Indian hospital board, and once on the hospital board, the representative (despite strong objection by fellow board members) was able to convince the hospital to hire tribal persons to help coordinate care for Indian patients referred to that hospital.

### **What Is Being Done to Address Health Disparity?**

The bottom line about health services for American Indians/Alaska Natives, according to one provider, is that most of the health programs do not have adequate funding or resources to reduce health disparities. One noted exception mentioned by a number of individuals interviewed has been the recent special congressional five-year diabetes prevention initiative that has funded a number of communities to initiate diabetes prevention programs.

IHS providers also recount a few longstanding efforts to address health disparities, such as their ongoing aggressive immunization programs, efforts to improve sanitation and water supply for tribal communities, improvement in standards of care for clinical patients through chart audits, and increased screening for a number of preventable mortalities, such as diabetes, cancer, heart disease, etc.

Tribally managed programs that are able to tap into other resources also mentioned a number of programs that they have initiated, such as wellness programs, adolescent treatment programs, substance abuse treatment, integration of traditional tribal healing practices, and disease prevention programs.

In general, most agreed that closing the gap on health disparities for this population would require a national and federal recommitment, especially in the form of increased federal funding that would allow patients to have access to specialty care. There was also consensus that there should be renewed interest and resources for disease prevention, development of culturally relevant interventions (such as inclusion of traditional tribal health resources), more resources to conduct meaningful health research, and diversifying avenues that will allow more American Indians/Alaska Natives to enter health professions.

### Summary

Unlike other racial or ethnic minority groups, the federal government (through IHS) is responsible for delivery of health services to federally recognized American Indians and Alaska Natives through IHS, tribal, and urban-based Indian programs. For several decades, the goal of the federal government has been to raise the health of this population to the highest level in order to lessen the gap of health disparities. The road taken by tribes and the IHS to accomplish this goal continues to be fraught with difficulties and detours.

The difficulties in closing the gap of health disparities continues to be underscored by a number of indicators, including mortality statistics for specific diseases that significantly exceed those in the majority culture. Numerous factors have been identified as contributing to these disparities, including, but not limited to, poverty, access to healthcare, years of neglect, diminishing resources for disease prevention, longstanding social and cultural disruptions, and a widening gap in healthcare spending that forces rationing of healthcare. The gap in healthcare spending is especially significant when the annual per capita spending for Indian health is less than half that per capita for the nation—\$1,430 compared to \$3,766, respectively.

The inadequate funding of CHS and CHEF contributes to the most severe form of healthcare rationing. This funding gap results in delaying treatment or diagnosis, compelling patients to accept cheaper and less effective treatment interventions, to go without treatment, and/or to be denied services. Moreover, some patients are unable to receive timely care due to jurisdictional and bureaucratic disputes over which agency is the first party payer.

Racial discrimination and stereotyping of Indian patients, especially by providers in the private sector, is commonplace. Its consequences have left patients without care, with inadequate care, or in some instances, with inappropriate care, such as radical mastectomy for early stage cancers.

Lack of adequate funding ripples into all aspects of the healthcare delivery systems, which has affected the ability of the Indian health programs to recruit and hire staff, to commit to long-range health planning, to target resources for prevention and research, and to ensure culturally appropriate healthcare. Tribal and urban-based Indian health programs have developed strategies to off-set the ever growing financial hardships, but they, along with IHS, are now facing other new challenges, such as managed care.

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# Patient-Provider Communication: The Effect of Race and Ethnicity on Process and Outcomes of Healthcare

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## ABSTRACT

*Compelling evidence documents racial, ethnic, and social disparities in healthcare in the United States. While many studies have focused on technical aspects of healthcare—including the receipt of certain tests, procedures, and therapies—a smaller number of studies have focused on differences in interpersonal aspects of healthcare that may contribute to disparities across a wide range of conditions. Our goal in writing this paper is to further our understanding of ethnic disparities in health outcomes through an investigation of the interpersonal processes related to the provision of healthcare. We have found that an array of social factors in addition to race—including gender, age, literacy, social class, health status, and the normative expectations that guide the therapeutic relationship—are not only relevant, but central to an understanding and appreciation of the role of ethnicity in the interpersonal dynamics of healthcare. Consequently, our review places issues of race and its consequence for patient-provider communication within this broadened context.*

*Recent empirical studies of communication reveal interesting and unexpected results. Actual use of patient-centered communication skills identified in audiotape analysis differs by patient and physician race and ethnicity. However, patient reports of the communication experience are inconsistent with the empirical record, suggesting that both provider beliefs and attitudes towards patients as well as patient expectations and judgments of physicians are in operation.*

*We provide the following considerations for future research. First, more in-depth exploration of social cognitions and stereotyping behavior by patients, phy-*

sicians, and other healthcare providers is needed. The reciprocal nature of the patient-physician relationship is a critical factor that should be highlighted in future work. Studies of race-concordant, patient-provider relationships will provide opportunities to increase our understanding of the constructs of cultural competence. Inasmuch as physician ethnicity is confounded with age and gender (minority physicians are more likely to be female and younger than white physicians), future research will require disentanglement of the complex interactions among patient and physician age, gender, and ethnicity, and their impact on patient-physician communication. Finally, future research should include healthcare providers who are not physicians and ethnic minority groups other than African Americans.

The challenge in transforming the practice of medicine to more effectively meet the needs of ethnically diverse patients will include the generation of racial and ethnic-neutral social norms regarding patient expectations and judgments of physician conduct, as well as the establishment of medical practice norms that value communication skills, interpersonal sensitivity, and cultural competence. Increasing diversity in the physician workforce will help contribute to a societal norm that does not inherently define "doctor" in gender or race-linked terms, but this will not be sufficient to transform medical practice. Until we have more evidence as to the impact of institutional resources in improving cultural competency we must rely on physician training in interpersonal skills that emphasize those aspects of communication identified with documented benefits on patient health (e.g., patient-centeredness) coupled with patient activation and empowerment strategies as promising vehicles to improve quality of care and outcomes and reduce ethnic disparities in interpersonal aspects of healthcare.

## INTRODUCTION AND SCOPE OF TOPIC

A compelling amount of evidence documents racial, ethnic, and social disparities in healthcare in United States (Ayanian et al., 1993; Blendon et al., 1989; Carlisle, Leake, and Shapiro, 1997; Conigliaro et al., 2000; Escarce et al., 1993; Lee et al., 1997; Makuc, Breen, and Freid, 1999; Wenneker and Epstein, 1989; Whittle et al., 1993). While many studies have focused on technical aspects of healthcare, such as the receipt of certain tests, procedures, and therapies, a smaller number of studies have focused on differences in interpersonal aspects of healthcare. Recent work has pointed to the role of physician bias in understanding ethnic and racial disparities in healthcare (Schulman et al., 1999; van Ryn and Burke, 2000; Weisse et al., 2001). Additionally, patient views about healthcare, including satisfaction, have emerged as important outcomes that differ by race, ethnicity, social class, language, and literacy level (Blendon et al., 1995; Gross et al., 1998; Carrasquillo et al., 1999; Murray-Garcia et al., 2000;

Sun et al., 2000; Baker et al., 1996). Moreover, ethnic minority patients, patients with poor health status, older patients, and patients with less than high school education rate their visits with physicians as less participatory (Kaplan et al., 1995; Cooper-Patrick et al., 1999). Specifically, recent work has shown that African Americans and other ethnic minority patients, in the common race-discordant relationship with their physicians, report less involvement in medical decisions, less partnership with physicians, and lower levels of satisfaction with care (Cooper-Patrick et al., 1999; Saha et al., 1999). Continued disparities in healthcare across a wide range of conditions suggest that fundamental components of healthcare delivery, like patient-provider communication, should be further investigated.

Ethnic groups currently defined as minorities are expected to comprise 40% of the U.S. population by 2035 and 47% by 2050 (U.S. Bureau of the Census, 1996). Addressing the healthcare needs of an increasingly diverse population has become a very important public health goal (Agency for Healthcare Policy and Research, 1999; U.S. Department of Health and Human Services [DHHS] Office for Civil Rights, 1998; U.S. DHHS, 1999; U.S. DHHS Office of the Secretary, 1999). Healthcare providers, systems, and policy-makers will need to rise to the challenge of providing care that takes the cultural and linguistic needs of the U.S. population into account.

Arthur Kleinman's seminal article (Kleinman, Eisenberg, and Good, 1978) articulated the importance of culture in healthcare. Culture, defined as "the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group" (Cross et al., 1989), is relevant to everyone's healthcare. However, the importance of race/ethnicity as a critical cultural indicator is perhaps especially salient for ethnic minority patients in the United States, who are almost always in race-discordant relationships with physicians.

Cultural competence may be defined as the ability of individuals to establish effective interpersonal and working relationships that supersede cultural differences. At the patient-provider level, it may be defined as a process in which the healthcare provider continuously strives to work effectively within the cultural context of a client, who may be an individual, a family, or community (Campinha-Bacote, 1999). There are three broad strategic approaches through which multicultural communication can be enhanced: 1) the provision of direct service designed to meet disparate language needs (interpreters and linguistic competency in health education materials); 2) the incorporation of cultural homophily in the provision of care (use of staff who share cultural background, inclusion of

family, inclusion of traditional healers or folk remedies, use of community health workers); and 3) institutional accommodation (clinic location, hours of operation, physical environment, increasing ability of professionals to interact effectively within the culture of the patient population) (Brach and Fraser, 2000). Each of these strategies is likely to have an impact on the role of patient-provider communication in understanding and eliminating racial and ethnic disparities in healthcare.

Our goal in writing this paper is to further our understanding of ethnic disparities in health outcomes through an investigation of the interpersonal processes related to the provision of healthcare. We have found that an array of social factors in addition to race—including gender, age, literacy, social class, and the normative expectations that guide the therapeutic relationship—are not only relevant, but central to an understanding and appreciation of the role of ethnicity in the interpersonal dynamics of healthcare. Consequently, our review has placed issues of race and its consequence for patient-provider communication within this broadened context (Figure 1).

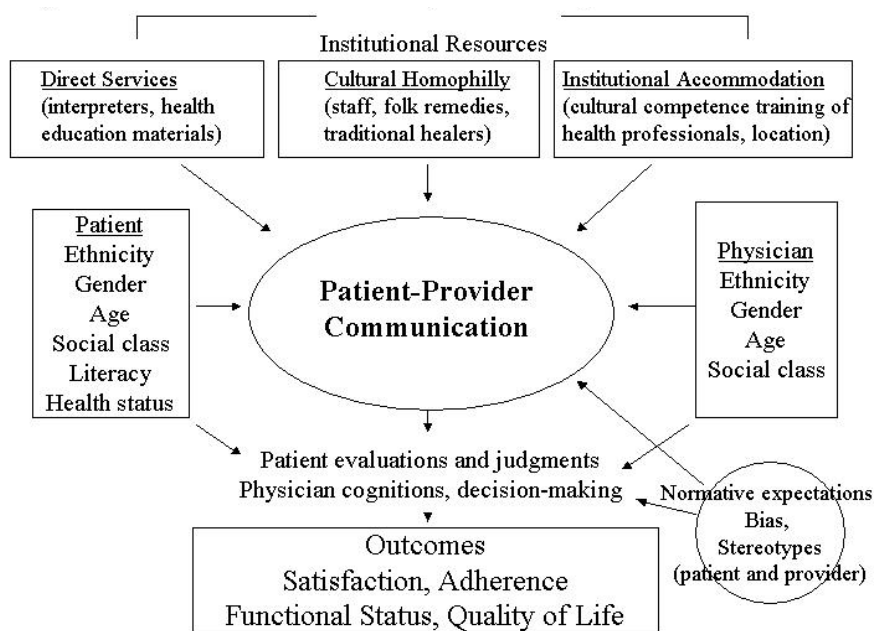


FIGURE 1. The effect of race and ethnicity on patient-physician communication.

### **Physician Role Obligations and Medicine's Unwritten Social Contract**

It has been argued that the basis of trust between patients and their physicians lies in the physician's dedication to "universalism," that is, the responsibility to treat all patients alike without regard to particular attributes or ascribed traits (Parsons, 1951). It is reasoned that if patient care is not universalistic, suspicion and caution will prevail over trust and confidence in the patient-physician relationship. Fear that physicians might act upon ageist, class, or racist stereotypes could undermine the fabric of the social contract upon which the therapeutic relationship rests. In light of the significance of potential violations of physician universalism, investigation of the association between patient attributes and aspects of care should be a research priority. However, this has not been the case. There have been relatively few methodologically sound studies designed specifically to investigate the role of sociologic factors in medical visits (Greene, Adelman, Charon, and Hoffman, 1986; Gerbert, 1984; Roter, Hall, and Katz, 1988; Roter and Hall, 1992).

### **The Nature and Consequence of Broad Normative Expectations, Bias, and Racial Stereotyping by Providers and Patients**

There are three mechanisms by which one might hypothesize physician behavior would relate to patient characteristics (Roter and Hall, 1992). First, there may be an unintended association between the care process and patient attributes that is produced by mutual ignorance of social or cultural norms. The marked differences that often exist between physicians and their patients (for example, patients who are poor, uneducated, and belong to an ethnic or racial minority group) may lead to very basic communication difficulties. For instance, citing sociolinguistic theorists, Waitzkin (1985) has generalized to the medical context the finding that middle-class subjects tend to be verbally explicit, while working-class subjects tend to communicate more implicitly through nonverbal signals. If not attuned to these nonverbal signals, physicians could easily miss or misinterpret patient requests for information or reassurance.

A second explanation for an association between patients' socio-demographic characteristics and the medical care process is that physicians may be consciously and quite appropriately addressing the varying responses to illness demanded by socially patterned expectations for care. These needs reflect the diverse attitudes, beliefs, and expectations of the groups to which the patients belong (Fox and Storms, 1981). For instance, in his classic study of ethnicity and pain, Zborowski (1952) found that patients' interpretation of pain and expectations regarding pain control varied widely across ethnic groups and that members of these groups

communicated these expectations to their physicians. In these instances, effective tailoring of pain management maximized medical care.

Finally, it is possible that physicians, like others in our society, are negatively affected by stereotypes. Physicians have generally scored about the same as non-physicians in surveys reflecting attitudes toward the elderly or the poor (Marshal, 1981; Price, Desmond, Synder, and Kimmel, 1988). Further, the range in physicians' political and ideological beliefs indicates a broad spectrum of response to patient groups (Waitzkin, 1985). Physicians appear to share the same negative stereotypes about physically unattractive people as do others in our society (Nordholm, 1980). Numerous studies indicate that patient race and ethnicity influence physicians' beliefs about and expectations of patients (Lewis, Croft-Jeffreys, and David, 1990; van Ryn and Burke, 2000; Porter and Beuf, 1994; Schulman et al., 1999). One recent study used survey data from patients and physicians during post-coronary angiogram encounters to examine the effect of patient race and socioeconomic status (SES) on physician perceptions of and attitudes towards patients (van Ryn and Burke, 2000). This study showed that even after adjustment for patient age, race, frailty/sickness, depression, mastery, social assertiveness, and physician characteristics, physicians tended to perceive African Americans and members of low and middle SES groups more negatively on a number of dimensions than they did whites and upper SES patients. For example, African-American patients were perceived as being less intelligent, more likely to engage in high-risk behavior, and less likely to adhere to medical advice. These ethnic minority patients received lower ratings of affiliation by physicians. Patients in the lowest SES group were also perceived as having more negative personality attributes (lack of self-control, irrationality), less abilities, more negative behavioral tendencies, and fewer role demands (van Ryn and Burke, 2000). Patient SES appeared to have an even broader effect on physician perceptions than patient race. These perceptions could not be completely explained by epidemiologic evidence about the patients' racial or SES group or from patients' reports of their actual behaviors and tendencies. Physicians' negative attitudes or the assumptions they make about a patient's personality, motivation, or level of understanding clearly have implications for the care they give.

### **Correlates of Communication**

Individuals coming together in medical dialogue bring with them all of their personal characteristics, including their personalities, social attitudes and values, race, ethnicity, gender, sexual orientation, age, education, and physical and mental health. This applies to the physician as well as to the patient, though research on physician characteristics is less com-

mon, owing to typically small physician samples in communication studies (Roter and Hall, 1992). Furthermore, the endpoints we might wish to measure, such as satisfaction or clinical outcomes, have many determinants. When interpreting non-experimental comparisons such as that comprising most of the literature on physician-patient communication, it is important not to make assumptions about the causal relations among variables. Even when potentially confounding variables (such as socio-demographic variables or health status) are statistically controlled, strong inferences of causality are often not justified. Causation may lie in variables unrelated to those under study, and even when one has measured the right variables, complex paths of causation can exist. In the medical interaction for example, mutual (reciprocal) influence is possible. Although a given behavior may be produced by a quality of the person engaging in it, it may also be caused by how that person responds to the other person, or how that person is treated by the other. Therefore, while we tend to think of physicians as the active agents and patients as responding to them, influence does not always flow from the physician to the patient (Roter and Hall, 1992). Physicians are influenced by patients, too. For example, one recent study shows that the effect of patients' race or ethnicity on physicians' beliefs about patients can be moderated by patient behavior. Krupat and colleagues (1999) conducted a study in which physicians observed randomly assigned videotapes of women seeking care for breast cancer. The videotapes varied patients' sociodemographic characteristics, general health status, and assertiveness. The study showed that assertive behavior among black and low SES patients, but not in white or upper SES patients, resulted in a greater likelihood that physicians would order full tumor staging.

In the sections that follow we present research relating physician-patient communication to some of the antecedent and outcome variables that are relevant for understanding and eliminating racial and ethnic disparities in healthcare.

### **The Role of Physician Sociodemographic Characteristics on the Medical Dialogue**

*Physician race and ethnicity.* Few studies have explored the impact of physician race and ethnicity on medical communication. Most of these studies have used patient ratings of the quality of the patient-physician relationship and the physician's communication style, rather than actual measures of communication, such as audiotape, videotape, or direct observation. A study of 1,816 adults and 64 primary care physicians in a large managed care organization in the Washington, DC, metropolitan area examined how race and gender of physicians and patients were asso-

ciated with patient ratings of physicians' participatory decision-making (PDM) style. The physician sample was 56% white, 25% African American, 15% Asian American, and 3% Hispanic. This study showed that there were no differences between ethnic minority and white physicians with respect to patient ratings of PDM style, even when adjustments were made for patients' age, gender, education, health status, and length of the patient-physician relationship (Cooper-Patrick et al., 1999). This finding is in contrast to the Medical Outcomes Study, in which nonwhite physicians were rated as less participatory than white physicians. In this study, the ethnic mix of the nonwhite physician group was not reported. It is therefore unclear which cultural or ethnic factors contributed to the lower participatory ratings by patients and whether the lower participatory ratings can be attributed to one specific ethnic or racial group of physicians (Kaplan et al., 1996). More research has been conducted to understand the role of physician gender in communication with patients. Methods used in these studies may provide a framework for how the role of physician ethnicity and communication style in understanding racial and ethnic disparities in healthcare might be further elucidated.

*Physician gender.* A large amount of research conducted in non-clinical settings has found gender differences in communication style (Brody and Hall, 2000; Dindia and Allen, 1992; Eagly and Johnson, 1990; Hall, 1984). Indeed, the magnitude of gender differences in nonverbal expression rivals or exceeds the gender differences found for a wide range of other psychological variables (Hall, 1998). As compared with women, men have been shown to engage in less smiling and laughing, less interpersonal gazing, greater interpersonal distances and less direct body orientation, less nodding, less hand gesturing, and fewer back-channel responses (interjections such as "mm-hmm" which serve to facilitate a partner's speech), and to have more restless lower bodies, more expansive arm movements, and weaker nonverbal communication skills (in terms of judging the meanings of cues and expressing emotions accurately through nonverbal cues). Men have also been found to use less verbal empathy, to be less democratic as leaders, and to engage in less personal self-disclosure than women. Also relevant is research suggesting that women experience many emotions more frequently and more intensely than men do, and refer more to emotions in their language.

Observational studies of physician-patient communication typically have many fewer physicians than patients and a typical male-female physician ratio of 2:1. This, plus the relative recency of interest in the role of gender on the process of care, has resulted in only two dozen or so studies that have systematically compared the communication styles of male versus female physicians using audio or video recording or neutral third-party observers (Roter and Hall, 1998; Roter and Hall, 2001).



One study found that although male and female physicians did not differ in how much biomedical information they conveyed, the male physicians' talk included less psychosocial discussion. Male physicians also asked fewer questions of all sorts, engaged in less partnership-building behaviors (enlisting the patient's active participation and reducing physician dominance), produced less positively toned talk and less talk with emotional content, used less positive nonverbal behavior (e.g., smiling and nodding), and had overall shorter visits than female physicians. Consistent with these direct observational effects, male physicians report liking their patients less than female physicians report (Hall et al., 1993) and hold less patient-centered values than female physicians (where a patient-centered response is the belief that the patient's expectations, feelings, and life circumstances are critical elements in the treatment process) (Krupat et al., 2000).

Based on a recent meta-analysis of the literature, the effect sizes for these gender differences are often small. However, they could have an important impact when generalized over many medical visits and many patients (Roter, Hall, and Aoki, 2001, manuscript under review). To the extent that male physicians' behavior and attitudes are less patient-centered than those of female physicians, there may be implications for overall quality of care and health outcomes. Considering that the gender differences among physicians closely mirror those found in the general population, it is likely that female physicians will have fewer barriers to overcome when learning to apply the biopsychosocial model in medical practice to reduce ethnic disparities in patient-physician communication.

*Physician social class (parental socioeconomic status).* Medicine is practiced largely by members of the middle class and reflects middle-class ethics in terms of hard work, delayed gratification, economic independence, and autonomy (Mechanic, 1974). Medicine is also a vehicle for social mobility, but only for those who have demonstrated mastery of middle-class values through academic performance (Kurtz and Chalfant, 1991).

One effect of social class origin on the way physicians relate to patients is in terms of class-based communication styles. Several studies have demonstrated sociolinguistic differences among members of varying social classes. Reviewed by Waitzkin and Waterman (1974), the evidence suggests that there are indeed social class differences in linguistic skills. Most prominent is a tendency for middle-class subjects to be verbally explicit, while working-class subjects tend to communicate more implicitly through nonverbal signals. While most consideration of the consequences of these linguistic differences has been in terms of patients' communication, it is also possible that social-class background relates to differences in physicians' communication. These differences might act to

enhance communication between physicians of lower social class origin with patients of similar social class backgrounds, or to impede the ability of physicians from poorer backgrounds to communicate with patients of higher social classes (Waitzkin and Waterman, 1974).

While not well studied, this issue has been explored. Physicians' social class background, as measured by their fathers' occupations and the physician's style of communication, was studied in audiotapes of 34 doctors in 336 medical visits (Waitzkin, 1985). When compared with doctors from upper- or upper middle-class backgrounds, physicians from working-class backgrounds tended to spend more time informing their patients, giving more explanations, and providing responses that were at the same technical level as the questions asked. The study concluded that "Orientation to verbal behavior may be a class-linked phenomenon that affects doctors as well as patients. Thus, doctors from working-class backgrounds may differ in their verbal behavior from doctors who come from a higher class position" (Waitzkin, 1985, p. 92).

Another example of the evidence of how social background affects physicians' styles of practice is found in Hollingshead and Redlich's (1958) classic study of psychiatrists in New Haven, Connecticut. The social background of the 30 psychiatrists in the study was strongly associated with how they related to patients, as well as their therapeutic orientation. Therapeutic orientation was found to fall within two distinct approaches to the treatment of patients. The first approach is analytic and psychological in orientation, with an emphasis on patient insight and as little physician directiveness as possible. These psychiatrists were almost passive in relation to management of their patients and almost never performed physical or neurologic examinations. The second approach is much more active and biomedical in nature. These psychiatrists were very directive in their therapy, often combining suggestions and advice with medical procedures, drugs, and neurologic and physical tests.

There were marked differences in the social and cultural backgrounds of the psychiatrists in these two treatment approach groups. As a group, the analytic psychiatrists had moved upward much farther in the class structure than the directive group. Almost three-quarters of the analytic group, compared with 42 percent of the directive group, moved upward one or more classes from the positions occupied by their fathers (Hollingshead and Redlich, 1958). The investigators also found that the number of generations the psychiatrist's family had been in the United States was linked to his or her theoretical orientation. Only 8 percent of the analytically oriented group were from "old American stock," whereas 44 percent of the directive group were from that background. In contrast, 58 percent of the analytic group were first- and second-generation Americans, compared with 38 percent of the directive group.

Hollingshead and Redlich speculate that the analytic psychiatrists “like all phenomenal upward mobile persons, those who have achieved their present class positions largely through their own efforts and abilities have passed through a social, possibly also psychological, transformation” (Hollingshead and Redlich, 1958, p. 165), which accounts for their practice style. While not specifically studied, it is interesting to speculate that the psychiatrist orientations described by Hollingshead and Redlich may also apply to primary care physicians and their tendency to relate to patients in a more or less directive manner.

Relevant to the point are the findings from a large survey of physicians (Haug and Lavin, 1983), which found that those who rose to the middle class reported greater attitudinal acceptance and behavioral accommodation to consumerist-type patient challenges than those who originally came from upper- and upper-middle-class backgrounds. This may reflect a more directive and “take charge” orientation of physicians from higher social class origins than those who are upwardly mobile. Haug and Lavin (1983) note that these findings are contrary to the theory that the upwardly mobile are more conforming to traditional norms. It is difficult to predict, based upon available evidence, what role physician social class might play in understanding racial and ethnic disparities in patient-physician communication.

### **The Role and Impact of Patient Sociodemographics on Medical Communication**

In this section we will explore the extent to which the literature presents evidence of how patient characteristics, such as race and ethnicity, gender, social class, literacy, health status, and age cohort affect patient-provider communication.

*Patient race and ethnicity.* Ethnic origin and cultural background contribute not only to the definition of what symptoms are noteworthy, but are also responsible for how symptoms will be presented to the physician. Studies have found that physicians deliver less information, less supportive talk, and less proficient clinical performance to black and Hispanic patients and patients of lower economic class than they do to more advantaged patients, even in the same care settings (Bartlett et al., 1984; Epstein, Taylor, and Sewage, 1985; Hooper, Comstock, Goodwin, and Goodwin, 1982; Ross, Mirowsky, and Duff, 1982; Waitzkin, 1985; Wasserman, Inui, Barriatua, Carter, and Lippincott, 1984). Various interpretations are possible. One is that physicians perform more poorly with such patients because they devalue them and their needs. Another is that the poor performance stems from stereotypes about the expectations, capacities, and desires of such patients. Still another is that due to cultural

norms or lack of confidence, such patients do not request or demand a high level of performance from their physicians (which would, of course, confirm whatever stereotypes the physicians may already have). All of these possibilities could be relevant, for example, to the finding that Asian-American patients in Hawaii report a lower degree of participation in their medical visits than mainland Americans do (Young and Klinge, 1996). An additional example is provided by preliminary data from our ongoing study of primary care physicians and patients in the Baltimore-Washington, DC, metropolitan area showing that African-American patients experience shorter, more physician verbally dominated, and less patient-centered visits than white patients (Cooper-Patrick et al., 2000).

Other studies of the role of patient ethnicity in the medical dialogue have been conducted in Eurocentric groups. These studies provide a basis upon which studies may be designed and analyzed for patients belonging to traditionally underserved ethnic minority groups. One classic study of health and ethnicity (Zola, 1963) found that among patients seeking medical care from several different outpatient clinics, those of Italian rather than Irish or Anglo-Saxon descent were much more likely to be labeled as having “psychiatric problems” by their physicians, despite the fact that there was no objective evidence that these problems were more frequent among this particular group. For instance, when the doctors could not identify any specific disease to explain the patient’s symptoms—which happened equally often in each of the ethnic groups—Italians almost always had their symptoms attributed to psychological problems; this almost never happened in the case of the Anglo Saxons and Irish.

Differences were evident, however, in how the Italians presented their chief complaints. Italians reported more pain, more symptoms overall and in more bodily locations, and more consequent dysfunction, including interference with their social and personal relations. From these findings, the investigator (Zola, 1963) speculates that the Italians and Irish have ways of communicating illness that reflect different ways of handling problems within the culture itself. The Italians tend toward drama and exaggeration as a means of dissipating and coping with anxiety, whereas the Irish have a tradition in which control and denial are foremost (Barzini, 1965). This became evident in the very different ways these patients presented their symptoms to their doctors. Similar findings were reported by Zborowski (1952) in describing ethnic variations in response to pain. Anglo-Saxon patients viewed pain in an “objective” and rather unemotional way, the Irish often denied pain, and Italian and Jewish patients were highly emotional and exaggerated in their pain expression. Moreover, the Italian patients sought immediate relief from pain and were satisfied as soon as the pain ceased, but the Jewish patients were more

concerned about the significance of their pain for future health and resisted pain medication for fear that it would mask a significant symptom. It is also important to note that appropriate treatment was tied to the way in which patients presented their pain. For example, painkillers would be effective for the Italian patients, but not for the Jewish patients until reassurance about future health was also provided. Only a physician sensitive to these distinctions could appropriately recognize these needs.

A follow-up study, using the same clinics as in the Zborowski study some 20 years later (Koopman, Eisenthal, and Stoeckle, 1984) found similar differences in pain reporting between Anglos and Italians. However, the effects of culture were most evident with patients over 60 years of age. Sex was also found to be important in this study; pain was most likely to be reported by older female Italians and least likely to be reported by older male Anglos. For younger patients, now second and third generation in this country, the process of acculturation had diminished the ethnic effects.

Given the correlation between social class and ethnicity in our society, it is not surprising that doctors' treatment of patients in different ethnic groups tends to parallel that for different social classes. Whites have been shown to receive care that is of higher technical and interpersonal quality than blacks or Hispanics receive, as well as to receive more positive talk and more information, even within the same medical practices (Hall, Roter, and Katz, 1988; Tuckett et al., 1985). One study found that blacks received fewer recommendations for open-heart surgery, although they had equal clinical need; of all patients who received such a recommendation, blacks had surgery less often (Maynard, Fisher, Passamani, and Pullum, 1986).

Another one of the few communication studies to address directly the issue of ethnicity found that physicians demonstrated better questioning and facilitating skills and more empathy skills when with Anglo-American as compared to Spanish-American patients (Hooper et al., 1982). The investigators suggest that poorer performance is particularly evident in communication skills requiring listening.

We believe that negative stereotypes of disadvantaged social groups affect the way doctors interact with these patients. We also believe this is unintentional and that doctors are only dimly aware of differences in their behavior, if at all. Like most people, doctors probably attribute any differences they do notice in their own behaviors to the character, aptitude, or needs of the other (in this case, the lower-class or ethnic minority patient). When one's own behavior can be construed as negative, one is particularly inclined to blame it on the other person. Attributing one's own behavior to causes outside of oneself would greatly decrease the likelihood

that doctors recognize a connection between their own attitudes and behavior (Roter and Hall, 1992).

*Patient gender.* Among patients with chronic disease, females are more likely to prefer an active role in medical decision-making than males (Arora and McHorney, 2000). Indeed, this preference appears to be borne out in practice, as male patients report that they experience less opportunity for decision-making in their encounters with their physicians than female patients report (Kaplan et al., 1995). In that study, patient participation in decision-making was particularly low when male patients interacted with male physicians, a finding consistent with the finding that in male patient-male physician interactions the contribution of the patient relative to the physician is the least of all gender combinations (Hall et al., 1994b).

Waitzkin (1985) found that female patients were given more information than male patients, and that the information was given in a more comprehensible manner. The same data set also revealed that the greater amount of information directed toward women was largely in response to women's tendency to ask more questions in general and to ask more questions following the doctor's explanation (Wallen, Waitzkin, and Stoeckle, 1979). Similar conclusions were reached in an English study by Pendleton and Bochner (1980), who found that female patients were given more information than males and that this information was in response to the women's more frequent questions. These findings are consistent with those relating to patient activation described above.

Investigators have also found that female patients receive more positive talk and more attempts to include them in discussion than males. In one study, physicians were more likely to express "tension release" (mainly laughter) with female patients and to ask them more for their feelings (Stewart, 1983).

*Patient age.* Patient age is associated with both the frequency of medical contacts and the communication dynamic of these visits. Older patients are plagued by multiple and complicated medical problems and are often required to make difficult decisions regarding the management of debilitating conditions. Moreover, it is the elderly who are most often required to confront fundamental choices at the end of life. While faced with these challenges, the elderly may be at a special disadvantage in fully understanding the complex choices they are asked to make. The elderly typically demonstrate lower levels of literacy and have had less exposure to formal education than younger birth-cohorts (Gazmararian et al., 1999).

Particularly relevant to these decision-making demands is the fact that older patients appear to experience medical visits during which they are more passive and less actively engaged in the treatment decision-making

process. The Medical Outcomes Study (MOS) (Kaplan et al., 1995), based on surveys of over 8,000 patients sampled from the practices of 344 physicians, found that patients aged 75 and over reported significantly less participatory visits with their doctors than all but the youngest age cohorts of patients (those younger than 30 years). Interestingly, the most participatory visits were evident in the scores of only slightly younger patient groups including those aged 65 to 74, and the middle-aged group ranging from 45 to 64 years. In addition to age, ethnic minority status, poor health status and lower educational achievement were associated with lower reports of participatory visits. Thus, older ethnic minority patients may be at fourfold risk for low levels of participatory engagement with their doctors. All of the above factors may act alone or in concert to diminish the likelihood that full patient-physician partnerships will develop.

Older patient visits are also distinguished from those of younger adults by the presence of a visit companion; estimates of the percentages of all visits that include a companion range between 20% and 57% (Prohaska and Glasser, 1996). There are only a few empirical studies of the effect of companions on the dynamics of exchanges in discussions, but their presence appears to change communication patterns. Greene et al. (1987) found that when a companion was present, older patients raised fewer topics, were less responsive to topics they did raise, and were less assertive and expressive. Moreover, patients were sometimes excluded completely from the conversation when a companion was present. Additional communication difficulties have been identified, including a tendency for a family member to take on the information-giving role in the visit, sometimes contradicting the patient or disclosing information the patient had not wanted revealed (Hasselkus, 1994). It appears that the content, tone, and nature of the medical discussion may be shaped by the roles adopted by the patient companion, and these may range from advocate and supporter to antagonist (Adelman, Greene, and Charon, 1987; Greene, Adelman, Friedman, and Charon, 1994).

We know little about moderating effects such as the visit companion's ethnicity and culture, age cohort, and the nature of familial relationships on communication dynamics. An intriguing question is the effect on communication when "baby boomers" serve as companions in the medical visits of their aging parents, compared with spouses or contemporaries acting as visit companions. We might speculate that these adult children bring an assertiveness to their medical encounters that can dominate the visit and perhaps contribute to a verbal withdrawal by the patient from the medical dialogue (as described by Greene et al., 1987, above). Alternatively, the presence of a consumerist companion may spur assertive behavior on the part of some patients. These dynamics are made all the more complicated when consideration is given to the impact of changing

social norms for communication across racial groups, particularly for African-American birth cohorts (Satcher, 1973).

*Patient social class.* The effect of social class on patients' presentation of themselves and their problems also has relevance for the medical treatment patients receive. Doctors talk more with patients who are higher in social class. This has been found in Florida, Massachusetts, California, England, and Scotland (Roter and Hall, 1992). How does such treatment affect the patient and what accounts for such findings? Does the higher social class patient have more to say? Or does this patient not have more to say, but instead, has the assertiveness to say it? Does the doctor give more opportunity for such a patient to talk by nonverbal indications of interest and by asking more inviting questions?

Doctors give more information to the higher-class patients, even though, when asked later, patients of different classes do not differ in how much information they say they want. In their English videotape study of 79 general consultations, Pendleton and Bochner (1980) found that patients' social class was a significant predictor of how many explanations were volunteered by doctors. Physicians spontaneously offered more explanations to patients of higher-class backgrounds during visits than to other patients. The investigators suggest that physician explanations are less likely to be volunteered to patients of lower-class backgrounds because they are perceived as less interested in information and more diffident in question-asking.

In an earlier Scottish study, Bain (1976) found that patients of lower-class backgrounds were less verbally active overall during medical visits than others. This was especially evident in areas such as patient presentation of their symptoms, question-asking, and social talk. Physicians were much more likely to give higher-class patients information regarding problem resolution and to engage in social talk with them than with lower-class patients. In further analysis of these data, Bain (1977) found that communication regarding drugs was significantly less successful with patients of lower-socioeconomic backgrounds as their recall of diagnosis, drugs prescribed, and advice given regarding how often drugs should be taken and the duration of treatment was less than other patients. Bain's later U.S. study (1979) involving 22 physicians and a total of 556 patients, confirmed similar differences in the overall content of communications for patients from different socioeconomic groups. Patients with higher socioeconomic class backgrounds engaged in nearly 60% more talk with the physician during the visit than patients of lower socioeconomic groups.

Work by Cartwright and others appears to support the contention that patients of lower-class backgrounds appear diffident in asking questions, not because they do not wish to know about medical matters, but rather because the social distance between themselves and their physi-



cians discourages verbal assertiveness (Cartwright, 1967). Waitzkin (1985) attributes the paucity of direct question-asking by working-class patients to their sociolinguistic culture, which tends to be less verbal than that of the middle class. Because of the tendency away from direct (verbal) communication, working-class patients may be communicating their desire for information in ways physicians are likely to miss. Doctors, like other members of the middle class, expect communication to be verbal and explicit; if patients have questions, physicians expect that they will be asked. Consequently, non-solicited information is not offered and reticence is taken as an indication of disinterest.

Waitzkin's (1985) large study in the United States found that better educated patients and patients of higher socioeconomic backgrounds received more physician time, more total explanations, and more explanations in comprehensible language than other patients. Ironically, physicians not only gave more information to higher-class patients, they also appeared to go out of their way to offer these explanations in clear, non-technical language. Multivariate analysis of these data further demonstrated that patients' level of education was more important than social class in general in explaining information transmittal. Thus, Waitzkin concludes that the educational aspect of social class determination is a particularly strong factor in doctor-patient communication.

In a similar vein, Stewart (1983) reports that better-educated patients were much more likely to receive a justification for their treatment regimens from their physicians than less-educated patients. In this study, however, more information came at the price of communication, which offered emotional support. The better-educated patients in this study received less "solidarity" from their physicians than did those patients without some university level training.

The opposite finding in regard to emotional support has been reported in several communication studies of pediatric visits wherein better-educated parents of patients received more emotional support than less-educated parents. The classic study by Korsch and associates (Korsch, Gozzi, and Francis, 1968) of pediatric encounters in an emergency walk-in clinic found that better-educated parents of patients were more likely to express their fears and hopes to the doctor and that they had a better chance of having these responded to or dealt with than less-educated parents. Similarly, the pediatric study by Wasserman and associates (Wasserman, Inui, Barriatua, Carter, and Lippincott, 1983) found that better-educated mothers received more reassurance, encouragement, and empathy during pediatric visits than less-educated mothers. Finally, in the most extensive observational study of pediatric practice, Ross and Duff (1982) observed indicators of performance quality, both technical and interpersonal, in over 400 pediatric visits and reported that poorly educated par-

ents received worse care on all accounts from their physicians. Also noted in this study was that low-income families did not have as consistently negative experiences as did the children of the poorly educated. These authors concluded, as did Waitzkin (1985), that education has more significance for health experience than other socioeconomic indicators.

In sum, we can say that physicians engage in more talk overall, and especially more informative talk, with patients of higher as compared to lower social classes. Moreover, the evidence suggests that education may play a key role in the differential communication to patients of varying socioeconomic groups. The communication advantage for the better educated is especially evident in socioemotional support expressed during pediatric encounters.

It has long been known that poorer and less educated patients have trouble finding healthcare and get less of it. Now it appears that the problems of these groups are not entirely structural. They suffer poorer treatment even after they gain access to the healthcare system. The poor also have worse health, and although this has usually been assumed to stem from lifestyle factors such as stress or poor nutrition or from difficulties in getting care, the possibility must also be raised that disadvantaged patients may be sicker partly because of the way in which they and their doctors communicate.

*Patient health status.* The state of a patient's physical and mental health is related to both patient and physician communication (Bertakis, Callahan, Helms, Rahman, and Robbins, 1993; Hall et al., 1996). When the patient is more distressed, either physically or mentally, both the patient and the physician engage in less social conversation and make more emotionally concerned statements, engage in more psychosocial discussion, and ask more biomedical questions. Sicker patients also provide more biomedical information. The research also suggests that physicians may respond ambivalently to sicker patients; physicians report less satisfaction after visits with sicker patients, and they report liking sicker patients less than more healthy patients (Hall et al., 1993, 1996). This apparent ambivalence, in conjunction with numerous findings showing that people with worse health status are less satisfied with their care (as reviewed by Hall, Feldstein, Fretwell, Rowe, and Epstein, 1990), raises the question of whether physicians produce dissatisfaction in their sicker patients by displaying negative behaviors toward them. Hall, Milburn, Roter, and Daltroy (1998) used structural equation modeling to test this hypothesis and also to test whether the dissatisfaction stems directly from the sicker patient's negative outlook. In general, the direct path was supported over the physician-mediation path, with one exception: physicians' curtailing of social conversation with sicker patients accounted for some of these patients' dissatisfaction. This is unfortunate, for in curtailing this "ex-

pendable" category of interaction in the service of devoting time to more pressing medical issues, physicians may unknowingly undermine their relationships with the very patients to whom the quality of the relationship may matter most. To the extent that ethnic minority patients have poorer access to healthcare, present for care at later stages of disease, and have poorer health status, the impact of their health status may further exacerbate the communication problems they are already experiencing due to cultural or social class differences from their physicians (Hall and Roter, 2002).

*Patient literacy.* Access to healthcare is traditionally assumed to occur once the patient walks through the examining room door. Yet, providing access to care is more than simply achieving patient presence; it also involves enabling patient engagement in the process of care. While not as obvious as cost and transportation barriers, low literacy skill is a significant obstacle to full access to effective medical care (Miles and Davis, 1995; Baker, Parker, and Clark, 1998). Even after adjusting for confounding sociodemographic variables such as ethnicity, gender, and age, Baker and his colleagues (1998) found that patients with low literacy skills have poorer health, higher rates of hospitalizations, and incur higher healthcare costs than those patients with adequate literacy.

The problem of poor literacy and its significance to patient care is made more meaningful when put within the health context. The Test of Functional Health Literacy Assessment "TOFHLA," developed by Parker and colleagues, is based on specific measures that reflect a patient's ability to perform health-related tasks that require reading and computational skills. These tasks include taking medication, keeping appointments, appropriately preparing for tests and procedures, and giving adequate informed consent (Parker et al., 1995). Using the TOFHLA measure, Baker and colleagues have demonstrated that fully one-third of patients admitted to their inner-city hospital were functionally illiterate, while another 13 percent demonstrated marginally functional health literacy (Baker et al., 1998). These findings are consistent with prior research reporting inadequate or marginal functional health literacy to be 35 percent among English-speaking patients and 62 percent among Spanish-speaking patients seeking care at public inner-city hospitals. The prevalence of low literacy among elderly patients (more than 60 years of age) was greater than 80 percent for both English- and Spanish-speaking patients (Williams et al., 1995).

With so high a prevalence of low literacy skills among the general population, physicians are likely to encounter patients with limited literacy skills. Nevertheless, physicians are unlikely to recognize patients with poor literacy skills or appreciate the negative consequences of low literacy on patient outcomes (Weiss and Coyne, 1997). Common miscon-

ceptions surrounding illiteracy may hamper such recognition. In their comprehensive overview of challenges in teaching patients with low literacy skills, Doak et al. broke several widespread myths associated with illiteracy: 1) that people with low literacy skills are intellectually impaired and slow learners; 2) that most adults with low literacy skills are poor, immigrants, and minorities; 3) that total years of schooling is a good measure of literacy levels; and 4) that people will tell you if they cannot read or they will get help when they need it (Doak et al., 1996).

In fact, most people with low literacy skills have an average IQ and function reasonably well by compensating in other ways for lack of reading skills (Doak et al., 1996; Jackson et al., 1991). The circumstances underlying low literacy are varied. Limited educational opportunity accounts for many of the poor literacy skills evident among the elderly and new immigrants, while undetected or inadequately addressed learning disabilities may account for a large proportion of the younger population who have poor literacy skills despite exposure to formal education (Kirsch et al., 1993). While low literacy is more frequent among persons of lower socioeconomic status, the poorly educated, the elderly, American-born ethnic minorities, immigrants, and the disabled, it is not limited to these groups. According to the U.S. Department of Education's National Adult Literacy Survey (NALS), in absolute terms, the majority of the low-literate population are white native-born Americans (Kirsch et al., 1993). Furthermore, more than 20 percent of adults tested in the NALS and 18 percent of patients in the study by Baker et al. who had demonstrated the lowest levels of literacy had earned a high school diploma. As noted by Baker et al., years of schooling reflect education completed, not skills attained, and is a rather insensitive measure of literacy (Baker et al., 1998). Indeed, adults typically read 3-5 grade levels lower than years of formal education completed (Jackson et al., 1991; Doak and Doak, 1980).

Commonly held expectations about reading ability and social approbation that often follow discovery of literacy limitations may serve to inhibit disclosure, silence patients, and further discourage efforts to seek information or request assistance. Parikh and colleagues report that one in three patients characterized by the TOFHLA as having low functional health literacy did not acknowledge difficulty reading or understanding what they read. Among those patients who admitted having trouble reading, 40% acknowledged feeling shame, and more than half of these patients had never told their spouses or children about their difficulties reading (Parikh et al., 1996).

Poor literacy may be a marker for an array of communication and information processing problems that go far beyond reading ability. Communication difficulties faced by patients may be due in part to differences in vocabulary, but may also be attributed to differences in the structure and complexity

of speech used by literate and low-literate populations (Roter, Rudd, and Comings, 1998). Some insight into the explanatory mechanisms linking literacy to health outcomes is provided by LeVine and colleagues in several studies conducted in developing countries (LeVine et al., 1994). These investigators have found a relationship between literacy skills level and comprehension of oral communication. The authors suggest that literacy builds a cognitive process that facilitates comprehension of formal spoken language, such as that commonly included in health messages. Even further, Dexter et al. have demonstrated that poor literacy skills are linked to an individual's ability to give adequate health-related descriptions (Dexter et al., 1998). This research suggests that low literacy not only presents obvious barriers to effective patient education, but may also complicate the process of history taking and establishment of the primary complaint.

Patients in the United States have also noted difficulties understanding physicians' oral communication. An analysis of focus groups and individual interviews with low-literate patients revealed serious and widespread communication difficulties with their health providers (Baker et al., 1996). Patients complained that they felt they were neither listened to nor adequately informed about their medical problems and treatments in ways they could understand. Despite this frustration, few patients asked questions or otherwise revealed their difficulties to their providers. Indeed, few patients disclosed their poor literacy to providers at all. Though some patients concealed this information out of embarrassment, others simply did not think this was something the physician would be interested in knowing.

While better-designed, learner-centered materials are undoubtedly helpful to patients, there is little offered in the literature to help physicians better communicate with their low-literate patients. Consequently, it is not surprising that when patients with poor literacy skills are recognized, few physicians feel competent to adequately respond to their needs (Miles and Davis, 1995; Weiss and Coyne, 1997).

### **The Consequence of Race Concordance on Patient Reports of Physician Participatory Decision-Making (PDM) Style and Other Aspects of Communication**

In our telephone survey study of 1,816 adult managed care enrollees attending primary care practices in a large urban area, we examined the association between race or ethnic concordance and discordance on patient ratings of physicians' PDM style (Cooper-Patrick et al., 1999). The patient sample was 43% white, 45% African American, and 12% other race/ethnic groups (5% Asian, 5% Hispanic, and 2% Native American). To study the potential influence of race concordance or discordance be-

tween physicians and patients on PDM, we stratified patients according to the race/ethnicity of their physicians. We then measured the relationship between PDM style and patient race within each physician race group, adjusting for patient age, gender, education, marital status, health status, and length of the relationship. African-American patients had significantly *less* participatory visits with white physicians than white patients ([beta] = -4.3, SE = 1.7,  $p < 0.02$ , adjusted). Asian and Hispanic patients had less participatory visits with African-American physicians than African-American patients; however, these results were based on very small sample sizes. There were no significant racial differences in PDM scores among patients seeing Asian or Hispanic doctors. However, there were only two Hispanic physicians in the study sample; therefore, reliable conclusions regarding the participatory decision-making style of Hispanic physicians could not be drawn.

To explore the overall significance of racial and ethnic concordance in the physician-patient relationship, we conducted an analysis to assess the relationship between race/ethnic concordance between physicians and patients and PDM style. Patients in race-concordant relationships with their physicians rated their physicians as significantly more participatory than patients in race discordant relationships ([beta] = 2.6, SE = 1.1,  $p < 0.02$ , adjusted) (Cooper-Patrick et al., 1999).

In another study of the impact of racial concordance on patient ratings of care by physicians, researchers used data from a nationwide telephone survey of 2,201 white, black, and Hispanic adults who reported having a regular physician (Saha et al., 1999). In this study, black respondents with black physicians were more likely than those with non-black physicians to rate their physicians as excellent overall, at treating them with respect, explaining problems, listening, and being accessible to them. Hispanic patients with Hispanic physicians were more likely than those with non-Hispanic physicians to be very satisfied with their healthcare overall, but not significantly more likely to rate their physicians as excellent. The Hispanic respondents were primarily of Mexican and Puerto Rican descent, and the majority of them were born in the United States.

Studies have shown that ethnic minority physicians, particularly blacks and Hispanics, are more likely to provide healthcare to ethnic minority, underserved, medically indigent, and sicker populations than are their white counterparts (Moy and Bartman, 1995; Komaromy et al., 1996; Xu et al., 1997). Furthermore, ethnic minority patients are more likely than white patients to report having an ethnic minority physician as their regular doctor (Gray and Stoddard, 1997). Nevertheless, minority patients are far more likely to receive their care from white and Asian physicians than from physicians who are African American or Hispanic since the number of physicians from these ethnic groups is so small.

Another study by Saha and colleagues, using The Commonwealth Fund 1994 National Comparative Survey of Minority Healthcare, showed that black and Hispanic respondents who had the ability to choose their physician were more likely to choose a racially or ethnically concordant physician (Saha et al., 2000). About 42% of the Hispanic respondents who chose a Hispanic physician did so because of language. Other reasons for ethnic minority patient preference for and higher ratings of care in race-concordant relationships with physicians are unclear, but potential explanations include more cultural sensitivity to the needs of these patients by race-concordant physicians and more shared cultural values, beliefs, and experiences in society between ethnic minority patients and physicians (Cooper-Patrick et al., 1999; Nickens, 1995).

#### **Evidence of Race-Concordance Consequences for the Communication Process**

In an ongoing cross-sectional study using post-visit surveys and audiotape analysis, we have examined the relationship between race concordance and actual patient and physician communication behaviors (252 adult patients—142 white, 110 African-American; 31 primary care physicians—13 white, 18 African-American). Our preliminary analysis shows significant differences in communication dynamics along several dimensions. Both African-American and white patients appear to have shorter visits (by about 2.0 minutes) when in race-discordant relationships with physicians. In addition to length of the visit, the strongest communication element that discriminated between race-concordant and discordant dyads was positive patient affect.

When the same survey questions used in earlier research were used to determine patient ratings of PDM, the ratings were significantly associated with audiotape measures of patient-centered interviewing ( $p < 0.01$ , Cooper, Roter, Ford, Steinwachs, Powe, published abstract, 2000). Patients in race-concordant dyads rated their physicians as more participatory than patients in race-discordant dyads (consistent with previous work, Cooper-Patrick et al., 1999). Since African-American patients are more likely to be in race-discordant relationships with physicians than white patients, they are more likely to have shorter visits, less positive affect, and less perceived participatory decision-making.

#### **The Relationship Between Communication Style and Patient Satisfaction and Health Outcomes**

The physician-patient relationship and its expression through the medical dialogue has been described or alluded to in the history of medi-

cine since the time of the Greeks (Emanuel, 1961) and in the modern medical and social sciences literature for the past 50 years (Engel, 1977; Freidson, 1970; Parsons, 1951; Szasz and Hollender, 1956). George Engel's articulation of the biopsychosocial model of medical interviewing in the 1970s (Engel, 1977, 1988), later translated into a patient-centered clinical method by McWhinney (1988, 1989), has given substance to the prominence of a general reference to "patient-centeredness" in medical communication curricula and research (Lipkin, Putnam, and Lazare, 1995; Mead and Bower, 2000).

Patient-centered communication skills are not unlike the many other technical skills that comprise the basis of medical practice and for which proficiency is expected. Patient-centered care is defined as healthcare that is closely congruent with and responsive to patients' values, needs, and preferences (Delbanco, 1992; Gerteis, Edgman-Levitan, Daley, Delbanco, 1993). The corresponding communication behaviors include data-gathering skills (i.e., use of open-ended questions, particularly in the psychosocial domain), relationship skills (i.e., use of empathy, reassurance, support, and emotional responsiveness), partnering skills (i.e., paraphrasing, asking for patient opinion, negotiation and joint problem solving) and counseling skills (i.e., informativeness) (Lazare, Putnam, and Lipkin, 1995; Roter, 2000a).

Visits that include more patient questions and physician information giving, a higher proportion of psychosocial and emotional statements relative to biomedical statements, and less verbal dominance by physicians are considered more patient-centered. Strong evidence links these communication behaviors to valued patient outcomes, including improvements in markers of disease control such as hemoglobin A1c and blood pressure, enhanced reports of physical and emotional health status, functioning, and pain control (Barsky et al., 1980; Greenfield et al., 1988; Kaplan et al., 1989; Giron et al., 1998; Stewart, 1995). Specifically, visits in which the physician uses a participatory decision-making style have been associated with higher levels of patient satisfaction (Kaplan et al., 1995). Additionally, a meta-analysis concluded that three dimensions of communication (informativeness, interpersonal sensitivity, and partnership building) were consistently associated with patient satisfaction, compliance, and recall of information (Roter, Hall, and Katz, 1988).

### **Implications for Physician Training and Patient Activation to Improve Patient-Physician Communication Within Culturally Diverse Populations**

Researchers have commented on the fact that physicians perform thousands of medical interviews during their career with virtually no for-



mal training in communication skills (Epstein, Campbell, Cohen-Cole, McWhinney, and Smilkstein, 1993). For a long time, the assumption was that physicians naturally have adequate communication skill or that this skill inevitably develops through frequent experience. Now, medical educators agree that training is necessary, that a solid foundation of behavioral science research exists to support training programs, and that training improves the communication of physicians. Communication skills training during medical school has been shown to have effects lasting as long as five years (Maguire, Fairburn, and Fletcher, 1986).

Despite variations in the length and format of training programs, all or most of these programs focus on the principles of relationship-centered medicine (e.g., Bensing and Sluijs, 1985; Cohen-Cole, 1991; Novack, Dube, and Goldstein, 1992; Putnam, Stiles, Jacob, and James, 1988; Roter et al., 1995). The study of Novack et al. (1992) found improvements in sensitivity to psychosocial aspects of the patient's illness, the ability to relate to patients, the ability to elicit information from patients, and the ability to communicate empathy. The training program of Roter et al. (1995) emphasized physicians' ability to recognize and handle psychosocial problems. After only eight hours of training, physicians did better with their actual patients (who were audiotaped several weeks post-training) in terms of emotion handling, recognizing psychological problems, and taking a problem-solving approach—with no increase in the overall length of the medical visit.

Smith et al. (2000) have developed a standardized training program for primary care residents that has produced very encouraging results in terms of residents' knowledge, attitudes, self-confidence, skills in interviewing patients and dealing with relationships, skills in managing and communicating with somatizing patients, and skills in educating patients. Elements in Smith's training program include setting the stage (welcoming the patient, using the patient's name, introducing self, removing barriers to communication, putting the patient at ease), agenda setting (indicating time available, indicating own needs, obtaining list of all issues the patient wants to discuss, summarizing and finalizing the agenda), non-focused interviewing (appropriate use of open- and closed-ended questions, observing the patient's cues), and focused interviewing (symptom discovery, learning personal context of symptoms, addressing emotions).

In contrast to the existence of many programs aimed at physicians and many published evaluations of such programs, relatively little research has tried to intervene with patients to improve the communication process. Classic is Roter's (1977) waiting-room intervention to increase patients' question-asking. More striking still are the experimental studies showing that a brief waiting-room intervention to increase patients' participation in the medical visit can have significant effects on health out-

comes. In these studies, a research assistant reviewed the medical record with the patient, helped the patient identify decisions to be made, rehearsed negotiation skills, encouraged the patient to ask questions, reviewed obstacles such as embarrassment and intimidation, and after the visit gave the patient a copy of the medical record for that visit. In a sample of patients with diabetes, such an intervention reduced blood sugar, reduced patients' reports of functional limitations (mobility, role functions, physical activities), and improved patients' perceptions of their overall health (Greenfield, Kaplan, Ware, Yano, and Frank, 1988). Mechanisms accounting for these effects are not entirely understood because the intervention contained a number of different elements, but are likely related both to information exchange and to feelings of empowerment. In that diabetes study, experimental patients elicited more information from physicians, talked more, and were more assertive. Encouraging results have occurred in similarly designed studies using different patient populations, such as patients with ulcer disease (Kaplan, Greenfield, and Ware, 1989). Recently, an even simpler intervention, consisting of a mailed booklet designed to instruct patients in seeking, verifying, and providing information during the medical visit and to give them the opportunity to write down their concerns and questions, had significant effects on patients' information seeking and success in obtaining information. There was also a significant effect on how much information they gave to their physicians, and on self-reported adherence two weeks later (Cegala, McClure, Marinelli, and Post, 2000).

Studies show that ethnic minority, low literate, and low SES patients experience lower levels of patient-centered communication and greater verbal passivity with physicians than whites and patients with higher levels of education. While health education programs often target disenfranchised populations, those groups are hard to reach and the least able to take advantage of innovations in educational and communication technology.

### **Directions for Future Research**

Future research to better understand the contribution of patient-provider communication to racial and ethnic disparities in care should be multifaceted, using combinations of clinical data, patient and provider surveys, audiotape and/or videotape analysis, and qualitative methods. Additionally, intervention studies that develop and test methods for improving patient-provider communication in encounters with ethnic minority patients, as well as studies that evaluate the impact of such interventions on processes and outcomes of care, are needed. Because most of the existing research focuses on African Americans, more studies includ-

ing other ethnic minority groups, such as Hispanics and Asian Americans, are needed. Moreover, there is a paucity of research on the impact of using institutional resources (direct services, cultural homophily, and institutional accommodations) to increase cultural competency. Issues identified in existing research that are of potential interest for future research include: 1) the degree to which physicians' cultural competence is explained by use of patient-centered communication; 2) the degree to which other attitudes and skills are necessary in order to achieve cultural competence in patient-physician communication; and 3) identifying which patient and provider attitudes and behaviors, in addition to patient-centeredness, explain higher patient ratings of partnership and satisfaction in race-concordant patient-physician relationships. For example, preliminary results from our study of race-concordance and communication show that race-concordance, while associated with better ratings of interpersonal care from physicians, particularly for African Americans, is not directly associated with patient-centeredness as measured by audiotape analysis, implying that other attitudes and perceptions on the part of patients and physicians are in operation.

In a recent review of the literature on the provider contribution to racial and ethnic disparities in healthcare, van Ryn (2002) discusses several studies that support a central hypothesis: that provider beliefs about patients and provider behavior during patient encounters are independently influenced by patient race/ethnicity. van Ryn goes on to suggest that a deeper understanding of automatic and social cognition processes involved in the patient-provider relationship will allow the development of better evidence-based interventions that target patient-provider communication to address racial and ethnic disparities in care. Our review of the literature supports the hypothesis put forth by van Ryn and extends it to include the importance of reciprocity in the patient-physician relationship and the impact of patient expectations and judgments of physicians, placing all of these factors within the context of other patient and physician sociodemographic factors such as age, gender and social class.

In summary, we provide the following considerations for future research. First, more in-depth exploration of social cognitions and stereotyping behavior by patients and physicians is needed. Furthermore, the reciprocal nature of the patient-physician relationship is a critical factor that should be highlighted in future work. Studies of race-concordant patient-provider relationships may provide opportunities to increase our understanding of the constructs of cultural competence. Finally, inasmuch as physician ethnicity is confounded with age and gender (minority physicians are more likely to be female and younger than white physicians), future research will require disentanglement of the complex interactions

among patient and physician age, gender, and ethnicity and their impact on patient-physician communication.

### **The Role of Cross-Cultural Training for Healthcare Professionals**

Researchers and medical educators have developed models for cross-cultural training of healthcare professionals (Sue, Zane, and Young, 1994; Gardenschwartz and Rowe, 1998; Carrillo, Green, and Betancourt, 1999; Loudon et al., 1999) that typically include the following objectives: 1) increase learners' awareness or mindfulness of the impact of culture and cultural differences on their own and others' behaviors during the process of communication between themselves and dissimilar others; 2) increase learners' knowledge of critical concepts useful in intercultural adjustment, including knowledge that others find essential for success in their own culture; 3) challenge learners' emotional states engendered by intercultural interactions and facilitate their progression through developmental stages of intercultural sensitivity (i.e., denial, defense, minimization, acceptance, adaptation, and integration); and 4) develop culture-general (ability to manage stress, tolerate ambiguity, establish realistic expectations, acquire "antennae" for cultural differences in interpersonal interactions, develop empathy with emotions expressed by dissimilar others) and culture-specific skills (those that are unique to a given people or context) (Bennett, 1986; Brislin and Yoshida, 1994). These objectives have face validity; however, there is scant evidence that relates any of these objectives of cultural competence training to having an impact upon patient outcomes.

An alternative description of the cultural competence process incorporates many dimensions of patient-centeredness. Campinha-Bacote (1999) describes cultural awareness, cultural knowledge, cultural skills, cultural encounters, and cultural desire as constructs of cultural competence. Cultural awareness is the deliberate, cognitive process in which healthcare providers become appreciative and sensitive to the values, beliefs, lifestyles, practices, and problem-solving strategies of clients' cultures. The cultural awareness process involves examination of one's own prejudices and biases toward other cultures and in-depth exploration of one's own cultural background.

Cultural knowledge is the process of seeking and obtaining a sound educational foundation concerning the worldviews of various cultures. The goal of cultural knowledge is to understand clients' worldviews, or the way individuals or groups of people view the universe to form values about their lives and the world around them. Additionally, the process of cultural knowledge involves the process of obtaining knowledge regarding specific physical, biological, and physiologic variations among ethnic groups.

Cultural skill is the ability to collect relevant cultural data regarding clients' health histories and presenting problems, as well as accurately performing a culturally specific physical assessment. The literature offers several assessment tools that healthcare providers can use when conducting cultural assessments (Berlin and Fowkes, 1983; Kleinman, Eisenberg, and Good, 1978; Buchwald et al., 1994). These tools essentially serve as reminders for physicians to use patient-centered communication skills when they are caring for patients from diverse cultural backgrounds.

Cultural encounter is the process that encourages healthcare providers to engage directly in cross-cultural interactions with clients from culturally diverse backgrounds. The larger the number of cultural encounters a healthcare provider has with individuals from specific ethnic groups, the more likely he/she will gain an appreciation for intra-ethnic variations and the less likely he/she will be to engage in stereotyping behavior that might develop as a result of academic knowledge without direct experience. Cultural desire is the motivation and genuine desire of health providers to engage in the process of cultural competence. This is based on true caring (empathy), curiosity or interest, and respect regarding clients whose cultures differ from one's own. We believe cultural skills and cultural desire include most of the dimensions of patient-centeredness that have been shown to have positive and significant effects on patient outcomes.

### Conclusions

To the extent that cultural skills and cultural desire are synonymous with patient centeredness, more broadly defined communication skills programs that prepare healthcare providers to deliver high quality interpersonal and technical healthcare to an ethnically diverse population are promising as a strategy to reduce ethnic disparities in healthcare, particularly when these programs are consistent with patient empowerment strategies. Patient empowerment strategies increase patients' ability to: 1) fully participate in the medical interview, 2) negotiate treatment plans by engaging in joint problem-solving and collaborative treatment decision-making with physicians, and 3) gain confidence and competence in illness self-management, including adherence to treatment and management recommendations (Roter, 2000b). Because strong evidence links these communication strategies to improved patient outcomes, intervention studies that target ethnic minority patients and incorporate communication skills training for physicians and empowerment strategies for patients should be conducted. These studies should include rigorous measurement of healthcare processes and outcomes.

The centrality of patient voice is all the more critical in recognition of the cultural diversity that often characterizes vulnerable populations and

distinguishes them from the majority culture. Ethnic minorities, the elderly, the poor, and the non-functionally literate are victims of disparities in health and the receipt of health services (Agency for Healthcare Policy and Research, 1999). This disparity appears to be growing and its elimination constitutes a priority area for the future direction of both provider and patient education efforts.

The progressive transformations of the patient-provider relationship will depend on its embracing a broad empowerment agenda (Roter et al., 2001). This will challenge the profession on many levels and test our commitment to serve patients' needs, and to empower patients themselves to define those needs. The broadening definition of quality in medical care of the past decade has called for systematic efforts to incorporate the patient's perspective in defining their own medical goals and actively participating in management and treatment considerations, and to include patients in the judgment of their own functioning and well-being (Moloney and Paul, 1993).

The challenge of transforming the practice of medicine to more effectively meet the needs of ethnically diverse patients will include the generation of racial and ethnic-neutral social norms regarding patient expectations and judgments of physician conduct, as well as the establishment of medical practice norms that value communication skills, interpersonal sensitivity, and cultural competence. Increasing diversity in the physician workforce will help contribute to a societal norm that does not inherently define "doctor" in gender or race-linked terms, but this will not be sufficient to transform medical practice. Until we have more evidence of the impact of institutional resources on improving cultural competency, physician training in interpersonal skill, emphasizing those aspects of communication identified with documented benefits on patient health (e.g., patient-centeredness), coupled with patient activation and empowerment strategies, are promising as the vehicle by which the ethnic minority patient's voice and perspective will be enhanced. Interventions incorporating these strategies will likely improve quality of care and outcomes for all patients, but those at highest risk—the poor, elderly, chronically ill, low literate, and ethnic minority patients, may stand to benefit the most from these efforts.

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# The Culture of Medicine and Racial, Ethnic, and Class Disparities in Healthcare

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## INTRODUCTION

Racial disparities in medical treatments and in health status have been documented in numerous studies over the past two decades. In a recent editorial in the *New England Journal of Medicine*, Epstein and Ayanian (2001) noted that “there is little evidence that racial disparities in medical care or in measures of health have substantially diminished.” Gary King (1996), in an insightful theoretical analysis of this research, argues that explanations of racial differences in medical care and of participation rates in medical research are grounded in institutional racism and in the professional ideologies of medicine and healthcare systems that lead to power imbalances between minorities and medicine’s elite professionals. King identifies three phases of research in this field, all of which have relevance to our project: (1) initial “exploratory research,” which documented differences between blacks and whites in medical care, utilizing quantitative data; (2) “contemporary” research, which focuses on coronary artery disease and other specific diseases, using rigorous methods to investigate causes of disparities in treatment; and (3) most recently, “an incisive period in which researchers attempt to combine theory, methods and policy considerations.” King argues that to understand documented differences, one must come to understand covert as well as overt racism and the multifaceted dimensions of institutional racism in medical and health institutions. His work and that of numerous other researchers who have documented disparities in health and treatment for ethnic and linguistic minorities, in addition to examining black-white differences, raise ques-

tions about how we might best understand the mechanisms—attitudinal, structural, institutional, and ideological—that produce disparities in medical care and in health status.

Our initial study questions for the Institute of Medicine (IOM) Group on Racial and Ethnic Disparities focused on the culture of medicine. How do the culture of medicine, the training of medical students and residents, and the organization and delivery of healthcare affect patient treatment in such a way as to produce obvious and documented disparities in therapeutic action? Whether it is treatment for cardiac disease, asthma, kidney disorders, or mental illnesses, some Americans receive less than optimal or even standard best medical therapies. Two decades of research have documented that whether bounded by ethnic or racial identities, immigrant status, English language fluency, educational attainment, poverty, low socioeconomic status (SES), or urban/ rural residence, minorities and the poor receive less care and poorer quality care than their middle-class and educated compatriots. The committee invited our group to address the question, “how could well-meaning people (healthcare providers) provide inequitable care to minority and non-minority patients?”

This question and the Committee’s initial larger query about the culture of medicine and its contribution to patterning disparities in medical care and treatment have proved daunting to address. Empirical studies on medical training and racism appear scant in our literature searches. Our own research (B. Good, 1994; M. Good, 1995; Good and Good, 2000) on the socialization of medical students and on the culture of medicine, while suggestive, has not directly addressed disparities in care granted patients. However, in our studies over several decades, we found that “the medical gaze” soon becomes the dominant knowledge frame through medical school, that time and efficiency are highly prized, and that students and their attendings are most caring of patients who are willing to become part of the medical story they wish to tell and the therapeutic activities they hope to pursue. Nevertheless, we identified no clear relationship between medical hierarchy, the culture of training, or professional ideologies that would readily explain patterned disparities in care by race, SES, and ethnicity (such as the study group’s suggestion of a modeled preference for private rather than public patients although clearly such preferences may exist at many institutions). We contend that such relationships are multidimensional and subtle, and that to identify the production of disparities in care requires considerable additional critical observation of our institutions of training and care. For example, differences in value of public and private patients may be conveyed not only in direct but in indirect and subtle process. In our own academic community, such distinctions may be demonstrated through a common but not hegemonic hierarchy of value. For example, many physicians regard

practicing at a community clinic as less prestigious than practicing at an academic medical center, where private as well as public patients receive care. The diversity of medical professional communities also allows for “the saint” or hero physician, who is devoted to the care of the underprivileged or the poor. Professional careers are made in community-oriented medical service and in teaching “cultural competence” to one’s medical students and residents. Nevertheless, both the charismatic hero physicians who are leaders in social medicine (see Farmer, 1999), and the less publicly known academic and community physicians, who are to be commended for their commitment to improving the quality of care provided to the underserved or to ethnic minorities, work within a biomedical knowledge frame. Although tempered with a social medicine perspective and interpretative sensibility, these physicians also employ the medical gaze in their daily clinical work and practice. Thus, we do not wish to underestimate the power of the medical gaze and the biomedical sciences that inform it to shape patterns of care and thus differences in care as well. In such a hierarchy of valued knowledge, psychological and social data are often regarded as inadmissible evidence by students who are learning to hone their case reports and presentations to focus on the essence of “what medicine cares about” (M. Good, 1995). The social data may produce patterns of care not otherwise critically examined, even for more practiced and socially concerned clinicians.

This simple picture of “valued knowledge,” while the dominant model and underlying ideology in early medical training, hardly captures the complexities of contemporary medical education. In contrast to a singular biomedical model of training, which gives scant attention and value to the social aspects of medicine, many American medical schools over the past quarter-century have increasingly incorporated curriculum materials on diverse patient cultures. In addition, students have often been encouraged to engage in activities oriented to caring for underserved, poor and minority patients. Our observations of and engagement with medical education since 1976 have exposed us to social medicine-sensitive curricula even as we have contributed to it (Good and Good, 1980, 1981). Examples include the University of California at Davis, which in the late 1970’s and early 1980’s developed cultural courses that addressed “the health needs, beliefs, and practices” of California’s various ethnic populations and immigrants (Asian, Mexican, Mexican American, Chicano, Vietnamese immigrants, and other refugees from Indochina—with a notable lesser emphasis on African Americans). Harvard Medical School’s commitment has flourished in the past two decades, increasing curricula in medical anthropology and social medicine, although the school has had a long tradition through the informal curriculum of encouraging students to participate in international as well as local community programs pro-

viding healthcare for the poor or marginally served ethnic groups. A third program, and among the most impressive, was begun when the University of New Mexico established its medical school in 1968. The highly committed, state-sanctioned, and legislated programs of the University of New Mexico School of Medicine teach students about the state's diverse populations and the healthcare needs of rural as well as urban ethnic communities. The school mandates practice training in underserved areas to provide care to the American Indian (Hopi, Navajo, Zuni, and others) and Hispanic rural populations. Many schools have produced formal and informal curricula, which on paper appear to be promoting cultural competence. Rarely, however, does medical training focus on the culture of medicine itself; rarely do students have the time or the formal sanction to critically analyze the profession and institutions of care to examine how treatment choices, quality of care and research practices are shaped; or how medical culture may produce processes that evolve into institutional racism or aversive racism in clinical practice (King, 1996; Whaley, 1998). Theories about how professional elites and the imbalance of power produce institutional racism, such as King's, call for empirical documentation.

Why do racial and ethnic disparities continue to exist despite the two decades of documented research, of educational efforts to teach medical and health professionals "cultural competence" and social medicine, of programmatic efforts to attend to health needs of underserved communities, and most recently of NIH/NCMHD and previous governmental efforts to redress the inequities in medical care and health status? Are educational and research programs ineffective in changing clinician behavior and institutional and professional culture? Does the culture of medicine—as exemplified in the medical gaze and its underlying ideologies and political economy of what constitutes legitimate medical knowledge, bioscience, and appropriate medical decision-making—too readily exclude patients whom clinicians assess as likely to pose "problems" and compromise the efficacy and efficiency prized by the medical world? Do professionals' concerns about patient compliance and community and patient trust at times serve as justifications for their employing different approaches to treating minority patients, and thereby and perhaps naively, to their providing a lesser quality of care? Or are disparities in care ingrained in the social and economic inequalities that are rife in our larger society, feeding inequalities of treatment in America's healthcare system? Clearly, differences in insurance coverage influence the kinds and quality of care patients receive. Do patients contribute to these disparities in care, and if so, how? We contend that multidimensional processes are at the root of different types of ethnic and racial disparities in health status and medical treatment. These processes are structural, economic, environmen-

tal, political and attitudinal. Individual behavior as well as institutional culture and practices are implicated.

In the remainder of this essay, selected findings from studies documenting disparities are presented. In addition, exploratory qualitative data from recent interviews with physicians-in-training and with faculty attendings are introduced to suggest possible directions for a critical analysis of the culture of medicine and the political economy upon which it is based and from which it is produced. A cultural analysis of bias in mental healthcare is presented as one model suggestive for future research in other domains of medicine. In this case, differences in diagnosis and treatment by race and gender in psychiatry are examined, demonstrating how cultural and social analyses contribute to an explanation of racial and ethnic disparities in care and treatment. The conclusion draws on these materials and the wider literature documenting disparities in healthcare, with the aim that future research findings and interpretations may contribute to formulating policies that will redress disparities in the quality of care.

#### **The Culture of Medicine: Insights from Physicians in Academic Teaching Hospitals**

Clearly, the financing of healthcare coverage, type of health insurance, or accessibility to government programs, as well as lack of coverage, are relevant to understanding what happens within healthcare institutions and in the intimate exchanges that we characterize as clinical interactions, and how these interactions result in decisions that produce racial and ethnic disparities in treatment. The Harvard Medical Practice Study analyzed over 32,000 records from New York State hospitals located in metropolitan/urban town/suburban/rural areas. The project found that patients who had no health insurance and who lived in poor urban areas were more likely regardless of race or ethnicity to experience an adverse event (Weiler et al., 1993). Where one receives healthcare, including how one enters a healthcare institution, via an Emergency Room or via a controlled appointment process, influences the type and scope of care provided. It may also influence how healthcare providers, from nurses and physicians to medical students and technologists, interpret who their patients are, what life experiences they carry with them, and what problems they may cause for those who will be delivering care. These processes, whether stereotyping, prototyping or profiling, clearly have consequences for treatment choices and medical decisions. Disparities in care and differences in therapeutic actions, regardless of provider race in certain cases (Chen et al., 2001), rest in part on these larger social processes within our complex medical institutions. The following discussion examines findings from

our pilot interviews and seeks to raise what we believe are some reasons disparities persist.

Our past research on medical education and the socialization of medical students was carried out at Harvard Medical School in 1986-1991, and addressed how medical students and physicians-in-training learn to see, present and write up patient cases (B. Good, 1994; M. Good, 1995; Good and Good, 2000). Students come to embody the medical gaze as they learn to see what is relevant data and to speak the language of medicine. Early in training, they enter the molecular worlds of disease and therapeutic interventions and the world of medical practice and medical culture. They also learn socially acceptable behaviors—when to speak, how to listen, and what is relevant to the clinical task. Students struggle to learn “what medicine cares about.” Students are also socialized to attend to social and economic issues in healthcare; some embrace the “social medicine” perspective even as they come to speak and be in the molecular medical world. Those who do so incorporate into their studies projects in international health, urban health, and volunteer work providing basic healthcare for poor or immigrant or minority populations. These social medicine projects become less central in students’ education as they move into clinical clerkships and become responsible for the clinical care of patients and for decisions of therapeutic consequence. Other research on medical education from the classic work of Robert K. Merton’s *Student Physician* (1957) to Howard Becker et al. *Boys in White* (1961) to more contemporary projects such as Fred Hafferty’s *Into the Valley: Death and the Socialization of Medical Students* (1991) document similar experiences, suggesting historical depth and continuity in the culture of medical education. This continuity of medical educational culture persists despite a sea change in the gender, and to a lesser extent, the racial and ethnic profile of medical students. In addition, extraordinary developments in medical technology, biomedical science and the political economy and financing of medicine and delivery of healthcare appear to be subsumed into this culture and way of learning medicine.

Scholars interested in narrative analysis such as that provided by Katherine Hunter (1991), as well as many physicians interested in medical narratives, have all explored ways physicians present and speak about patients. Narrative forms of the culture of medicine are ingrained; they have historical depth and substance and make for continuity of professionalism despite changes in practice environments. They are reinforced by the modeling that occurs through the hierarchy of medicine, through interactions between students and interns, interns and residents, and residents and attendings. What is important in medicine is learned through daily interactions with peers and with the hierarchy, and students are rewarded as they come to behave as competent, reliable, and responsible



clinicians who have learned appropriate professional behavior. How does this professional socialization affect physician behavior so as to have an impact on the treatments offered to patients of different social groups?

First, the culture of medicine emphasizes the dismantling of patient life narratives and the reconstitution of patient concerns and experiences of illness and associated social context into medically meaningful narratives that allow physicians to determine a diagnosis and formulate plans for therapeutic actions and procedures. In our research, patient life issues were often regarded by students and attendings, as “inadmissible evidence”; senior clinicians modeled for juniors how to streamline medical narratives and to edit out data irrelevant to the clinical decision or task currently at hand. Patients are not ignored, however. As students and residents mature as clinicians they learn to create clinical narratives for patients; these clinical narratives are biomedical stories through which physicians explain to patients about their disease diagnoses and processes, therapeutic options, and treatment courses and goals. Good doctors engage patients in these clinical stories, teaching and guiding and helping patients own what is happening. Some clinicians describe this very simply as empowering patients, while others reflect little but work hard at fitting patients into the medical world of treatment, helping patients understand and accept what may be difficult treatments for frightening and life threatening diseases. These narratives smooth the working of what one of our junior colleagues calls “the medical machine” (personal communication, Herskovits, 2001).

### Disruptions in the Medical Machine

Recent interviews with attending physicians, residents, and medical students in the Boston area suggest several ways the medical gaze may lead to disparities in healthcare. Interviews were carried out with physicians who were both men and women and were from Euro-American, Asian and African-American backgrounds. A second year medicine resident at a major teaching hospital who had recently completed a Ph. D. in medical anthropology made the following observations as we explored what might lie behind the reasons for disparities in healthcare for minorities, immigrants, and lower class patients. She had been thinking about these issues, in large measure due to publication of recent research on health disparities and to the publicity of NIH minority research activities:

*“People who don’t fit into the medical machine” are ones who may not get offered the latest therapeutic interventions. Here at [x hospital] is a medical machine—we are all cogs in it, not just the docs, but the patients too. And the more we fit into our role, the smoother the machine runs. In internship—it is relearning to listen to patients without listening to them. It is painful, because it is the*

*opposite of anthropology. You learn to do a better job by not listening to your patients. We become different types of subjects, disciplined (after Foucault), to fit into the machine. Or Fordist. The machine model breaks down when patients don't get referred into high tech medical therapies, the most cutting edge of medicine. When physicians experience difficulties in interacting with patients, it befuddles the doctor, and derails them. In ER shifts, there is the discipline of time, and when a patient derails you, it is glaringly obvious. In the ER, you have an immediate problem—what do I do with this person—the faster you make a decision the better you are as an ED doctor; it is a different yardstick to figure out what is troubling them.*

Patients derail physicians when they present with what an attending described as “socially complex problems.” The notions of the medical machine, of derailment and befuddlement, are relevant to explaining why disparities exist. The comments of a cardiac specialist, who has practiced in community clinics as well as in a major teaching hospital, highlight similar issues. He remarked: “One needs to attend to the more mundane aspects of doctoring.” In today’s practice environment, “we need cooperative patients because of the tightness of time.”

Another attending noted how language problems and family issues can disrupt practice flow and influence choice of therapeutic options. Her work with patients at a community mental health clinic became most difficult when she found that many of her patients of color had social situations that were “so dismal that it far outweighed the clinical problems” she was expected to address. She remarked that her work over the four years at this clinic led her to re-evaluate

*why I became a clinician... when patients would ask for disability papers when I thought they should have a job and structure; when I had to turn in many patients for abusing their children. I felt I was in an adversarial role that I did not want to be—court papers, reports, and people needed social interventions and no one was offering it. In the past, clinicians had the luxury of time to teach and do paper work, now they are scheduling brief therapeutic sessions instead of 50 minute sessions to allow time for insurance paperwork.*

A fourth year medical student had experienced similar pressures of time that the attending and resident discussed. He explained:

*a measure of success (as a student) is extracting a history of illness and developing a treatment regimen that allows you to discharge the patient with some improvement. Things that interfere with the above make physicians uncomfortable. If you have a minority patient who allows you to do the history and treatment plan (in a timely fashion) then the interaction is not problematic for the most part. I am of course speaking for myself.*

When we discussed if he detected any bias in the curriculum or in modeled behavior by attendings or residents that might have an impact on how minority patients were treated he reflected:

*One modeled message currently about hospital care is rapid assessment, efficiency, and treatment. One thing about minority, indigent, low-income patients, is that their social situations are complex in negative terms and not fixable by any intervention that can happen in the hospital. As a result, one becomes almost discouraged to begin to explore these things. With some people you work with a translator and even when not, there is a reluctance rather than an inclination to get a good social history and explore the social roots of the illness.*

When I asked whether he observed any differences by racial or ethnic groups in terms of their trust in the medical system he remarked that he had not interacted with that many African Americans but his impression was that

*Absolutely. African-American patients do not come into the hospital expecting to be treated well. White lower class patients, for example at the MGH, expect to be and they have been treated well. Asians—so many different kinds. New immigrants versus academics.*

This very thoughtful student and I discussed how readily one distinguished different groups of Asians, some difficult to care for because of language barriers and social situations, others more similar in educational status and class to the medical community and easy to communicate with but that it was easy to slip into grouping African-American patients into one category.

A resident also noted the stereotype of African-American patients as being “dreadfully sick and their social life is so disorganized that they are ‘non-compliant’ and living in a state of chaos, with a disorganized household, or that they are socially isolated. And incredibly sick and incredibly difficult to manage.” In these cases “it is really hard to make progress and take care of patients,” if for example diabetes is out of control and vague symptoms are difficult to manage. The resident concluded, however, that she did not have experiences that fit the stereotype she had just elaborated; her experiences were more varied. When asked if she had stereotypes for Asian patients, she noted that she did not have any, although she thought of East African patients (Somalians) as different from African Americans and Asians. This resident reported that she and her colleagues have a profile for young Hispanic women with total body pain—“they hurt everywhere” and “you simply cannot interview them. You take it on their terms or abdicate helping them. Some people work with them, I use the notion of *nervios* with patients, and it speaks to the political and do-

mestic violence in their lives, if I think it makes sense; a sense of culture bound category. Everybody calls them crazy including Hispanic doctors.” In this case, the resident’s advanced degrees in medical anthropology have added to her ability to bridge cultural gaps between this population of patients and the medical world.

Race and ethnicity continue to define responses of clinicians. Assumptions are often made that may have inadvertent influence on how treatment interventions are offered to patients and how disease etiology is explored. One mode of profiling racial groups is through case formulations—the way certain diseases are discussed in relationship to certain minorities. Examples include African-American patients who are associated with hypertension and diabetes; Asian patients with hepatitis; poor Hispanics, Puerto Ricans, and Mexicans or Central Americans with diabetes and obesity; or working-class Irish with alcoholism. Case examples may follow an epidemiological pattern—diseases more prevalent in certain groups will be described in terms of patient demographics associated with those groups. Thus, though in a subtle way, race, ethnicity and class become part of the world of the medical gaze and the standard patient formulation. Does this lead to explicit racism or bias in what is offered to patients in terms of medical interventions? An African-American attending psychiatrist noted that in his consultations on psychotropic medications he often finds that primary care physicians prescribe less current drugs for their black patients. When he asks them why, they are baffled and unaware. Current antipsychotics and psychoactive drugs are not only an improvement over older medications in treating mental disorders, but also are better tolerated than older drugs.

### The Bias of Efficacy

All physicians we spoke with expressed concern about how effective their interventions will be when patients may be “train wrecks”—the student’s term for victims of complex social problems—the term used by residents and attendings. The following example recounted by a resident suggests how complex responses by clinicians may be and how clinicians may take actions to offset the perceived bias:

*Last night I had an elderly African-American woman [in the ER], ‘the classic invisible cardiac patient who does not get referred to cath.’ I was trying to make a strong case that she needed to get cathed, to see if blockages [were the cause of] her intermittent episodes of shortness of breath. Her story was fuzzy in the way it came out. We push people to answer questions in a format we phrase for them. We guide and teach them how to answer the questions. If we try to coach them and they don’t respond to it or submit, it throws us off. Her job was to put her words into mine.*

The attempt was successful. The resident commented on a second patient, with whom she was having less success. She had grown familiar with her through the patient's many visits to the ER.

*I was thinking about how to help these patients and figure out what was wrong with them. I had another African-American lady, a huge part of her problem is chaos in her life, with teenagers living in her house who use drugs. She does not have keys to her own apartment, the kids stole the keys, she has to be let in. I got the social workers to impose their external presence to intimidate the kids, and get them out of the house. She [the patient] comes less often into the ER. I also gave her a tranquilizer. I feel bad about dosing a social problem. If chaos is in their life, patients such as this woman don't get referred to high tech care, to cath, because they have a "difficult social situation." There is a danger of quickly moving to that interpretation and physicians are biased in looking at the patient and saying 'oh, difficult social situation' and sure black physicians do this, too. Some people do this and some don't—it needs to be documented.*

### **Political Correctness, the Medical Machine, and the Meaning of Bias**

In the clinical contexts we discussed, political correctness appears to be the normative order in public discussion. Medical students with whom we spoke note they never hear overtly negative racist comments in the hospital or among classmates. This sensitivity is new to the late twentieth century generation of medical students and faculty in our study area. However, when race is not a category of response, certain groups of patients are fair game for jokes and occasional expressions of dismay and amazement about discrepancies in expectations, behavior, and their treatment of physicians. Patients from the former Soviet Bloc—Russians and others—are in particular maddening for physicians. Because "race" is not part of the package, physicians feel freer to comment on what they regard as strange behavior inappropriate in our society's wider medical culture. Examples that are perceived as disrespectful behavior toward physicians and the healthcare system include not showing up for appointments and not notifying the clinics, calling in the middle of the night for minor problems, choosing to go on vacation instead of keeping surgical schedules, and demanding particular treatments when paying, without regard for physician recommendations and expertise. "No-shows" are calculated into the time schedules for many community clinics and ambulatory care units; surgical units and surgeons are aware they may have problems with such patients as well. These problems are also encountered with other new immigrants, many of whom do not speak English. The community clinics with large immigrant non-English-speaking populations appear to be scheduled differently than are units at the teaching hospitals.

The gap between the culture of medicine and the social and cultural resources, contexts and frames of reference of certain social groups clearly is related to how healthcare is delivered and how therapeutic options are offered and chosen by clinicians. The boundaries are fluid. They are sometimes associated with race, sometimes with class, sometimes with immigrant status, sometimes with disease state and age (the “train wrecks”—the old heroin addict for whom little can be done that is effective and efficient.)

Anne Fadiman’s *The Spirit Catches You and You Fall Down* (1997) is an account of misunderstandings and mistakes by the medical system, by well-meaning physicians, and by the state in the care of a young Hmong girl suffering from epilepsy. The story Fadiman tells is not only dense but it has some facile answers to “the problem”: get translators, increase understanding, listen to patients and their families. However, as we review the larger picture of disparities in healthcare, the issues are more resistant to analysis, and rest not only in relationships between physicians and patients but also in larger organizational practices, cultures, and the financing of healthcare systems.

The labor force in American medical institutions today, at least in the Northeast and in California, is remarkable for its ethnic diversity. In the metropolitan area where the authors work, the hospitals’ staffs include many new immigrants, some of whom speak English as a second language and with limited fluency. The impression of our interviewees as well as of the authors is that the majority of the medical teams in the local teaching hospitals, including the nurses and doctors, are of European background and considered “white.” However, the medical staff is a minority of the hospital labor force. The majority of the hospital labor force are of mixed race and ethnicity and reflective of community surrounds. Interestingly, a major shift has also occurred in the race and ethnic composition of attendings and residents in these hospitals, a sea change that has occurred in the past decade. When interviewees identified the residents with whom they worked by race and ethnicity, the picture was of great diversity. And even greater diversity is evident in the local medical schools. For example, one fourth-year medical student in recent rotations worked with several Jamaican residents, with African Americans from New York and Alabama, with Asian Indians, Chinese Americans, Chinese, Korean Americans, Hispanics, and Mexican Americans. Reflecting on his response to this question, he noted that he may have had more “minority” residents than not in his rotations. As a white male, he found himself in the minority. A woman resident in medicine noted that her colleagues were African American and Hispanic as well as Asian American and South Asian Indians. Whites included many Jewish physicians, and nearly half of the residents with whom she worked were women.

This change in resident color, gender and ethnicity is the future face of medicine in the United States. However, color, race, and gender do not make medical culture. The profession of medicine is powerful in the reproduction of culture and practice, expectations and “gazes,” and in defining what is important and significant in medicine. The financial and organizational shifts are also important, and recent changes in the financing and organization of medical care have had great impact. Universalism in patient care becomes more difficult to achieve when pressures of time and money shape clinical interactions and treatment choices. Thus, attitudes of clinicians are but a limited part of the culture of medicine and the reasons for discrepancies in care. Institutional practices that favor the privately insured patient over the publicly insured patient, that favor patients with greater social and personal resources—education, money, and social position—and respond more readily to patient demands are likely to neglect or give less attention to patients who are poorer and who may be less socially and psychologically integrated.

This diversion of ethnicity and race in the healthcare labor force and in the medical profession suggests that regardless of what caused disparities in the past, ongoing disparities in care cannot simply be explained by racial differences between providers and patients. A recent *NEJM* article by Chen et al. (2001) documented that racial difference in cardiac catheterization after an MI was not related to physician race; the study was carried out with a population of white and black physicians and patients. The importance of a change in the ethnic and racial diversity of American physicians may be measured in part by closer examination of disparities in care and by addressing these issues in government-sponsored NIH research. The training of healthcare professionals is also of high priority in reducing disparities in care. The following section addresses ways that health professionals have been trained thus far and the limits of current approaches.

### **Addressing Healthcare Disparities Through the Training of Healthcare Professionals**

The literature on health disparities among ethnic minority populations includes discussion of sources of inequality based on institutional, clinician-centered, and patient-centered factors. A substantial literature on cultural sensitivity and cultural competence—particularly in relation to clinician training—has thus evolved. In the recent past, the vast majority of the scientific publications on cultural competence have been in the nursing literature. Most of these publications focus on compelling reasons to train “culturally competent” clinicians, including the pronounced ethnic and racial disparities in healthcare access and outcomes, the bur-

geoning ethnic minority population within the United States, and the well-documented underrepresentation of ethnic minority practitioners in healthcare professions (Nickens, 1992; Stoddard et al., 2000; Gonzalez et al., 2000). Curricula or principles supporting the development of cultural sensitivity or cultural competence in healthcare professionals are outlined in these articles. Notwithstanding the indisputable face validity to developing such curricula and principles, there has been an unfortunate relative dearth of studies that systematically investigate either (1) effective strategies for training clinicians or (2) how such training improves patient and clinician satisfaction and healthcare access and outcomes (Brach and Fraser, 2000). This literature on cultural competence is no doubt invaluable in mobilizing interest in promoting cultural sensitivity through moral rhetoric (e.g., Richardson, 1999), but also underscores the shortage of evidence-based data in addressing and resolving healthcare disparities.

The developing interest in cultural competence in clinician training is both a pragmatic response to the increasing proportion of ethnic minority individuals in the United States population and the failure of a strictly biomedical model in achieving uniform outcomes in this diverse population and a moral response to the inequities of healthcare among ethnically diverse populations. Although legitimated by epidemiologic studies of disparities in healthcare access and outcomes, the specific features of cultural competence have drawn substantially from the tradition of cultural relativism (initially promoted by social anthropologists, e.g., Franz Boas, Margaret Mead, and Ruth Benedict) and have been developed and applied within the more recent anthropologic subdiscipline of medical anthropology. The seminal work, *Patients and Healers in the Context of Culture* (Kleinman, 1980), introduced and popularized the concept of “explanatory models” of illness. The frequent divergence of explanatory models between clinician and patient and the clinician’s failure to appreciate and negotiate this were arguably a primary source of non-adherence to treatment recommendations as well as clinician and patient dissatisfaction with the clinical encounter (Good and Good, 1980, 1981). Subsequent concepts developed within the field of medical anthropology, such as “semantic networks of illness meanings” (B. Good, 1977), “idioms of distress” (Nichter, 1981), the distinctions between disease and illness (Kleinman, 1988a), and the social course of illness (Ware and Kleinman, 1992) provided the theoretical underpinnings of an informed approach to cultural diversity in the clinical encounter, allowing both culturally sensitive and strategic healthcare delivery to ethnically diverse populations. Eventually, the impact of this theoretical body of knowledge was manifested in clinical materials; for example, in an appendix outlining a means of formulating relevant cultural details to enhance understanding of psychiatric illness presentation among diverse



populations in the *DSM-IV* (American Psychiatric Association, 1994), used by most practicing psychiatrists.

Several tensions are identified by educators in addressing cultural sensitivity in clinician training. For instance, Good (1994) has described being encouraged to edit out so-called extraneous details (often the very details that illuminate relevant sociocultural background that may have an impact on communication and adherence in the clinical encounter) in the preparation of oral presentations. In this case, the growing pressures to be efficient in the evaluation, triage, and disposition of patients reduce a patient to his or her physiologic condition and encourage exclusion of social context in negotiating clinical care. Despite this prevailing tendency in traditional medical education, data from a recent study on physician communication patterns (Roter et al., 1997) support that patient satisfaction is significantly higher in clinical encounters during which the physician practices a “psychosocial” communication pattern (i.e., in which physician talk is almost evenly divided between psychosocial and biomedical issues). This study also found that the frequency of this communication style was relatively low (< 10 percent), possibly because physicians felt that such an approach is more time-consuming; however, the study documented that psychosocially oriented clinical interactions did not, in fact, significantly increase the length of the patient visit. Failure to attend to social context may not only have adverse consequences in case formulation and treatment decision-making, but may also contribute to the disenfranchisement of ethnic minority populations relative to their healthcare. That is, exclusion of psychosocial context may contribute to diminished opportunities for collaboration in the clinical encounter, especially between ethnically dissimilar clinicians and patients. For example, a recent study demonstrated that ethnic minority individuals report less positive perceptions of their physicians than whites (Doescher et al., 2000) and another found that race-concordance in the physician-patient encounter was associated with higher participatory decision-making (Cooper-Patrick et al., 1999).

Another dilemma in training clinicians identified by two psychiatrists teaching psychiatry residents about cultural competence in a Boston teaching hospital is in negotiating the tension that occurs when clinicians are exposed to the diversity of cultural traditions while resisting the tendency to stereotype or racially profile patients. Whereas it is useful to teach clinicians about the diversity of and patterns in culturally-based help-seeking practices and traditional remedies—particularly with immigrant populations with whom they will have contact—it is important to maintain a perspective that fits this information into heterogeneous personal and social contexts. A failure to do so risks clinical reductionism that resembles prejudice, and more importantly, misses the opportunity to grasp the com-

plexity of cultural, social, and personal variables that come to bear on the health problem at issue. These two psychiatrists agreed that case studies provide an excellent avenue for residents to explore “the multiple layers” and “complexity of clinical decision-making.”

Another paramount concern identified in the education of clinicians on cultural sensitivity and competence is in helping clinicians-in-training to move beyond a mastery of the catalogue of diverse healthcare-related practices to an examination of their own preconceived notions and feelings in clinical encounters with patients from ethnically diverse backgrounds. A recent paper on nursing education (Tullmann, 1992) illustrated the distinction between a certain competence with respect to ethnically diverse patient practices and the unfortunate and persistent racism still manifest in various clinical interactions. The paper’s author concludes that a frank examination of racism needs to accompany exposure to cultural diversity. Similarly, the two above-mentioned psychiatrists have observed that because of a concern among residents “about being politically correct” in their seminar and specifically, because “no one wants to be on record with peers or with you about certain [racially sensitive] things,” creating a safe environment in which to explore and discuss countertransferential feelings generated in racially and ethnically diverse clinical encounters remains “a training challenge.” They report that “although we are not living in an era in which there is complete closure to this subject [of cultural sensitivity],” they have noted an increasing sophistication among residents with respect to awareness of cultural diversity, in part due to greater exposure to experiences working in other countries. However, increasing opportunities for exposure to other cultures can also preclude people from looking at their own deeply held attitudes about the Other. These psychiatrists thus frame their seminar as “not about knowing what to say or even what to think” but rather, as a process of deepening the process of self-examination vis-à-vis one’s attitudes toward diverse peoples. Without such self-examination, Laszloffy and Hardy (2000) point out that, within the context of therapy, “it is possible for acts of racism to occur ‘innocently,’ routinely, and with little detection or accountability.” Finally, based on a case study of a medical school course addressing race issues in medicine, Fischbach and Hunt (1999) suggest the need for “proactive” and ongoing programs to address racial and cultural sensitivity in medical education. The concern about creating space to tackle the problem of racism in clinical encounters is consistent with a recent policy statement issued by The American Public Health Association (2001) calling for government funding to research the impact of racism on racial and ethnically based healthcare disparities in the United States.

Increasing time constraints on clinicians arguably place pressure on

them to seek “shortcuts” in managing complex clinical problems. In a recent review of biases in clinical judgment, Lopez (1989) writes that clinician error may occur in the absence of clinician prejudice as a result of selective information processing. That is, the time-pressed clinician uses available information and past experience about patient characteristics such as race and social class to arrive at a clinical hypothesis. Unfortunately, this practice may lead to systematic over- or under-diagnosis of certain illnesses among certain populations. Lopez argues that this conceptual framework for understanding clinician bias suggests specific strategies for training clinicians that contrast with more traditional emphasis on examining and changing prejudicial attitudes. Specifically, he suggests that education will need to focus on how clinicians process information to avoid such errors.

Notwithstanding strong impressions based on anecdotal and epidemiologic data, limited research has investigated whether there are systematic deficits in the education of clinicians with respect to cultural competence. Two studies have assessed the prevalence of formal instruction on cultural sensitivity and cultural competence in medical schools and found that such courses are present in only a minority of institutions. Lum and Korenman (1994) surveyed American medical schools in 1991-92 and identified only 13 schools offering cultural sensitivity training; similarly, Loudon and colleagues (1999) identified 13 programs with such training in North America, less than half of which were compulsory. A study assessing the prevalence of cross-cultural content within psychiatry residency training programs showed a much higher prevalence of cultural content integrated into training materials, with 92 percent of programs surveyed reporting inclusion of such content (Baker et al., 1997). The health professional education literature contains relatively few studies on whether inclusion of cultural sensitivity or cultural competence material enhances skills of trainees. Robins and colleagues (2001) developed two standardized patient cases and assessment instruments to explore how medical students responded to cultural data in a clinical encounter. Their study demonstrated differences in cultural sensitivity based on the ethnic background of the student; based on their results, the authors advocate curricular intervention, but did not use their intervention to test outcome in acquisition of cultural competence skills. One study was able to document an increase in language skills and cultural knowledge among medical student participants in a didactic and experientially based program (including an educational trip to learn firsthand about health practices in Mexico) as compared with controls. Another study found higher levels of cultural competence (as measured by knowledge of, tolerance of, and comfort with diverse populations) among preclinical medical student participants in a “global multiculturalism track” as compared with non-partici-

pants (Baker et al., 1997). Two outcome studies on cultural competency training in nursing school showed somewhat contradictory results. One study examining the impact of specific instruction on culturally appropriate care to nursing students found that students who received the instruction actually felt less prepared to provide culturally sensitive care (Alpers and Zoucha, 1996) and another showed that both recipients and non-recipients of a cultural sensitivity intervention improved self-reported cultural competency skills (Napholz, 1999). Further research will be necessary to determine whether increased cultural sensitivity can be achieved among healthcare professionals with various curricular programs and if so, which types of programs are most effective.

In the following case analysis, the use of cultural analysis to explain clinician bias is discussed. Examples of research, such as the work on mental health services, may suggest ways to pursue analyses of reasons for disparities in medical treatment in the non-psychiatric domains of medicine.

#### **A Case Analysis of Disparities in Mental Health Services: Evidence for the Role of Clinician "Bias" and the Culture of Mental Health Institutions**

Just as we were completing this review of the role of health professionals and the culture of institutions in reproducing health disparities, Surgeon General David Satcher announced the release of his office's report on disparities in mental healthcare in America. Entitled *Mental Health: Culture, Race, and Ethnicity. A Supplement to Mental Health: A Report of the Surgeon General* (Surgeon General, 2001), the report sets out to assess evidence for disparities in mental healthcare and the burden of mental illness for racial and ethnic minorities in America. After providing a wide-ranging review of current data, the report provides the stark conclusion that "ethnic minorities collectively experience a greater disability burden from mental illness than do whites. The higher level of burden stems from minorities receiving less care and poorer quality of care, rather than from their illnesses being more severe or more prevalent in the community." The report argues that minorities have less access to mental health services and are less likely to receive needed services, that minorities in treatment often receive a poorer quality of mental healthcare, and that minorities are underrepresented in mental health research. It argues that while all Americans face fragmented and inadequate levels of mental health services, as well as societal stigma toward mental healthcare, racial and ethnic minorities experience a particular constellation of barriers that deters them from reaching services, including mistrust and fear of treatment, racism and discrimination, and cultural and language barriers. The report argues that mental health disparities are grounded in historical and

present day struggles with racism and discrimination, and that minorities are overrepresented among vulnerable, high-need subgroups such as persons who are homeless, incarcerated, or institutionalized. But its strongest conclusions focus on disparities in access to and use of services and the quality of care that members of minority groups may expect to receive.

In a section of the Executive Summary entitled “Main Message,” the report sets out one of its primary claims: “The main message of this supplement is that ‘culture counts.’” Culture, it argues, is the “common heritage or set of beliefs, norms, and values” of members of a group. Language and culture are particularly significant for mental healthcare. Since mental disorders affect thoughts, moods, and integrative aspects of behavior, the report notes, the diagnosis and treatment of such disorders greatly depend on verbal communication and trust between patient and clinician. At the same time, the report notes explicitly that mental health professionals also constitute a culture, and makes the provocative claim that “the culture of the clinician and the larger healthcare system govern the societal response to a patient with mental illness.” Given the stark indictment of the mental health system, this claim would suggest that racism and discrimination may well be a part of “the culture of the clinician and the larger healthcare system,” responsible for a significant proportion of the disparities identified, even though broader social experiences of violence, poverty, and discrimination increase minorities’ vulnerability to mental illness.

What is meant by suggesting that racism and discrimination are a part of the culture of the mental health profession and the healthcare system, given that community mental health professionals are often among the leading advocates for the poor and for minority persons suffering mental illnesses? We focus here on two very specific debates—the overdiagnosis of schizophrenia among African Americans, and the elevated rates of involuntary commitment of African Americans. We hope that these may provide a model for thinking more generally about how the “culture” of clinicians and health institutions may contribute to reproducing disparities in health services and outcomes. In particular, review of these issues will make clear the importance of close attention to the particularities of the medical conditions and health services being examined.

### **African Americans and the “Over-Diagnosis” of Schizophrenia**

In 1981, Adebimpe, an African-American psychiatrist, reviewed studies of psychiatric treatment of black patients and reported that “a modest body of circumstantial evidence” suggested that members of minority subcultures are at particularly high risk for error in psychiatric diagnosis and assessment. Although it is not easy to carry out empirical studies, evidence continues to mount that specific patterns of misdiagnosis may

put members of minority communities at special risk for poor medical care. In particular, research dating back to the 1960s provides strong evidence that African Americans in mental health settings are diagnosed with schizophrenia at much greater rates than white Americans and that whites are diagnosed with affective disorders at much higher rates than African Americans, with data suggesting a similar—though less severe—pattern among Hispanics. A review of health services literature by Snowden and Cheung (1990) found that black Americans in in-patient psychiatric services are diagnosed with schizophrenia at almost twice the rate of white Americans, and that Hispanics are diagnosed with schizophrenia at one and a half times the rate of non-Hispanic whites. Most researchers believe these statistics reflect over-diagnosis of schizophrenia and under-diagnosis of affective disorders, rather than differences in prevalence or care-seeking (for reviews of this literature, see Neighbors et al., 1989; Good, 1992b; Good, 1997). Since a diagnosis of schizophrenia carries powerful implications for treatment with anti-psychotic medications, assignment to mental health services designed for the chronically mental ill and social stigmatization, and since failure to diagnose bipolar disorder may lead to the failure to use effective medications, these findings are particularly troubling.

Researchers over the past decade have continued to investigate this phenomenon. The most recent data continue to show great discrepancies in the diagnoses of black and white patients. For example, Strakowski et al. (1993) found that 79 percent of African Americans in a public-sector hospital were diagnosed with schizophrenia, compared with 43 percent of whites. In another study, Strakowski et al. (1995) found that 28 percent of African Americans in a university hospital emergency room were given such a diagnosis, compared with 20 percent of whites. Furthermore, treatment patterns seem to reflect these judgments concerning the severity of illness. Strakowski et al. (1995) found that black patients seen in an emergency room were significantly more likely to be hospitalized, and Segal, Bola, and Watson (1996) found that African-American patients seen in an emergency room received 50 percent higher doses of antipsychotic medications than patients of other ethnic groups, while their doctors devoted less time to assessing them and scored significantly lower on an Art of Care Scale. Although these studies do not prove that black patients are misdiagnosed, they are consistent with a conviction among many researchers that African Americans are at serious risk for receiving a misdiagnosis of schizophrenia, for being provided inappropriate and inappropriately high levels of antipsychotic medications, and for receiving poorer care than white patients in the same settings.

Research has pursued several lines of explanation for this apparent phenomenon.

### **Culture and the Expression of Mental Illness**

One leading hypothesis about the source of the high level of apparent misdiagnosis in minority and immigrant populations is that it may result from cultural differences in the experience and expression of symptoms between such patients and “typical” majority patients. Since the current diagnostic manual is based explicitly on symptom criteria, the experience of culturally distinctive symptoms, such as “nervios” and “ataques” among Mexican-American patients, hearing voices of the dead among bereaved Indians, and hallucinations not associated with psychosis among Puerto Ricans or African Americans, may lead clinicians to misunderstand patients whose culture is different from majority culture norms. This can result in mistaken diagnoses. Current diagnostic categories are derived largely from research among majority populations, particularly those found in hospitals or specialty psychiatric clinics, and thus tend to lend support for the impression that such expressions of illness are universal (Mezzich et al., 1996). Cross-cultural research seriously challenges the validity and universality of some diagnostic criteria and diagnostic categories derived from such research, indicating a series of hypotheses that have important implications for medical care for immigrant populations or minority communities (Kleinman, 1988b). Thus, one hypothesis, consistent with the message that “culture counts” in the Surgeon General’s report, is that cultural differences between majority norms and normative ways of experiencing and communicating symptoms among minority persons, including African Americans, may lead to mistaken diagnoses. Although there is now a large literature on cultural shaping of psychiatric symptoms, few studies have systematically examined explicitly whether these differences lead to increased levels of misdiagnosis for cultural or ethnic minority patients, such as difficulties in assessing and diagnosing African-American patients who suffer psychoses, depression or anxiety disorders.

### **“Clinician Bias,” “Aversive Racism,” and Misdiagnosis**

A second set of hypotheses suggests that systematic patterns of misdiagnosis may result from clinician bias, and that the social and cultural context of diagnosis and diagnostic judgments should be submitted to sustained research. Using experimental techniques to investigate how both clinician and patient variables influence assessment, psychological investigations were begun in the 1960s that focused on patterns of “overpathologizing bias” which occurs when clinicians treat women, the elderly, members of racial and ethnic minority groups, the poor, and the mentally retarded. Lopez argues that research on social class shows the most consis-

tent findings of bias, and that “bias is also consistently revealed in diagnostic judgments of Black and White patients” (1989:191). He finds little evidence to date for bias toward Hispanic patients. Lopez concludes from his review that “systematic errors in judgment based on patient variables may pertain to all clinicians and not just to those clinicians with prejudicial attitudes,” and that “investigators should give careful consideration to the symptoms or disorders used as their clinical stimuli” (1989:194).

Support for these conclusions comes from an interesting study, conducted by Loring and Powell (1988). Loring and Powell mailed questionnaires to psychiatrists, stratified by gender and race, asking them to participate in a study of the reliability of DSM-III by making diagnoses of two case vignettes. Two hundred ninety psychiatrists responded. The case narratives, written in the style of the DSM-III Casebook, included clear-cut diagnostic criteria to support diagnoses of undifferentiated schizophrenic disorder (an Axis I diagnosis) and dependent personality disorder (an Axis II diagnosis). Descriptors identifying the gender and race of the case, or excluding such characteristics, were randomized, allowing the researchers to analyze how diagnosis is influenced by race and gender of both psychiatrist and patient. Findings are suggestive. First, “correct” diagnoses were given for only 38 percent and 45 percent of the two cases, respectively. Correct diagnoses were most often given when no identifying characteristics of the client were provided. Second, a highly complex pattern of interaction between race and gender of psychiatrist and race and gender of the case emerged. For example, white female psychiatrists diagnosed the first case as brief reactive psychosis 50 percent of the time when the client was identified as a white female, and paranoid schizophrenic disorder 53 percent of the time when the client was identified as a black male. No single interpretation of the overall response pattern can be given. However, black patients were given significantly more severe diagnoses, and black psychiatrists shared in this pattern of rating. However, one clear pattern emerged. Black male clients were diagnosed with paranoid schizophrenic disorder in 43 percent of the first cases (compared with 6 percent, 10 percent and 12 percent for white males, white females and black females, respectively), and with paranoid personality disorder in 50 percent of the second cases (compared with 26 percent for the total sample). As the authors conclude, “clinicians appear to ascribe violence, suspiciousness, and dangerousness to black clients even though the case studies are the same as the case studies for the white clients” (p. 18).

Whaley (1998) provides an insightful, complementary perspective on sources of racism in mental health services. Providing a comprehensive view of social-cognitive models of racism, Whaley elaborates a theory of “aversive racism,” which may be relevant. Drawing on the work of Gaertner and Dovidio (1986), he ascribes aversive racism to “low prejudice” white



subjects who hold negative stereotypes of black people. He argues that “whites who identify with a liberal political agenda (e.g., endorse public policies that promote racial equality and combat racism, view themselves as nonprejudiced and nondiscriminatory, and sympathize with blacks’ history of victimization) but who harbor negative perceptions of black people” will experience “prejudice-related conflict” rather than hostility or hate, expressing “discomfort, disgust, uneasiness, or fear” indirectly or in situations that do not threaten their liberal self-image (Whaley, 1998:49). He cites evidence that liberal whites are as likely as conservative whites to discriminate against blacks in situations that do not implicate racial prejudice as the basis for their actions, then goes on to examine how such “aversive racism” might function in mental health settings.

Whaley focuses particular attention on research that identifies “bias in mental health professionals’ judgments associated with the racial stereotype of blacks as violent” (1998:51). He reviews evidence that African Americans are likely to be sent to local correctional facilities, while white patients with similar levels of psychopathology and violent behavior are more likely to be referred to a mental health hospital. He interprets the Loring and Powell (1988) study cited above as evidence that black patients are more likely to be given a more severe diagnosis “because they are stereotyped as more dangerous.” And he links this specifically to the literature on over-diagnosis of schizophrenia for black patients. However, since violence is not among the diagnostic criteria for schizophrenia, he is forced to make an indirect argument, saying that “The racial stereotype of violence may set off a chain reaction in the mental health evaluation and treatment process for black persons seeking help” (1998:52). He cites evidence that a diagnosis of psychotic disorder “is associated with fewer sessions with a primary therapist, greater likelihood of being treated with medication, less likelihood of being in outpatient treatment, and a lower chance of being in treatment with a professional therapist (Flaskerud and Hu, 1992),” arguing that “severe diagnoses and restrictive interventions,” both forms of “therapeutic social control,” are linked to the view that mentally ill persons are dangerous. “Thus, the stereotype of violence is the common denominator in perceptions of black individuals and the diagnosis of schizophrenic disorders,” accounting for both the over-diagnosis of schizophrenia for African-Americans and a “chain reaction in the mental health evaluation and treatment process for black persons seeking care” (Whaley, 1998:52).

### **Race, Perceptions of Violence, Involuntary Commitment, and Diagnosis of Schizophrenia**

Lower socioeconomic classes and minority persons, and in particular African Americans, are over-represented in public mental health in-

stitutions. However, perhaps even more troubling is a consistent finding that African Americans are over-represented among those who are committed involuntarily. After an extensive review, Lindsey and Paul (1989:172) conclude that after individuals "have reached the public system for admission, Blacks have been and continue to be even more over-represented in comparison with Whites among those who are involuntarily committed. Such over-representation appears across all periods of data collection and all areas of the country, without regional differences (e.g., North vs. South)." Recent accounts by patients and patient advocates provide reminders that involuntary commitment is still often associated with abusive treatment and abrogation of human rights (Nordhoff and Bates, 1989), and those experiences of coercion influence inclination to participate in treatment (Lidz et al., 1995). (There is a large literature on elevated rates of schizophrenia among Afro-Caribbeans in Britain, as well as higher rates of involuntary confinement. See Coid et al., 2000 for a recent example.)

Involuntary commitment is linked in part to assessment of severity of a person's illness and to diagnosis, suggesting an added reason for concern about misdiagnosis and its over-representation in minority communities. However, involuntary commitment is also linked to assessment of "dangerousness," formally defined as the likelihood that an individual will use violence against self or others. The study of actual rates of violence among persons identified as suffering mental illness has recently been the focus of research and sharp debate. Analysis of data from the NIMH Epidemiological Catchment Area studies found that the claim that the mentally ill are no more likely to be violent than those who are not ill is untrue (Swanson et al., 1990; Link, Andrews, and Cullen, 1992; Monahan, 1992). However, research also indicates that "excess risk for violence among mental patients is modest compared to the effects of other factors," in particular when compared with the effects of alcohol and drug abuse, and "only patients with current psychotic symptoms have elevated rates of violent behavior and it may be that inappropriate reactions by others to psychotic symptoms are involved in producing the violent/illegal behavior" (Link, Andrews, and Cullen, 1992:290). The sources and types of risk of violence among persons suffering mental illness and those who engage in substance abuse, as well as the implications for mental health services and involuntary commitment, are significant issues in ongoing research (Link and Stueve, 1995; Junginger, 1996).

Although Lindsey and Paul (1989:179) conclude that "empirical data to date provide no direct assistance in narrowing the range of explanations proposed for the over-representation of Blacks" among those who are involuntarily committed, the data are consistent with Whaley's theory of aversive racism discussed above. Both epidemiologic and ethnographic

research are needed to understand how this explanation fits with other social and institutional factors, and to extend the analysis to other minority groups. Detailed ethnographic and clinical research will be required to identify how assessment and commitment processes function in particular settings and with particular populations—for example, rural Indians jailed for drinking, African Americans apprehended by the police, or persons assessed in psychiatric emergency rooms of general hospitals or state institutions. Findings from such research would have important implications for improving mental health services in community settings, correctional institutions, and psychiatric institutions, and for eliminating racial and ethnic bias in assessment and treatment.

For the purposes of this review, the linking of perceptions of violence, psychiatric diagnosis, and involuntary confinement may provide a model for understanding how clinical judgments and treatment decisions that have discriminatory impact, resulting in disparities in health services, may be made by persons who are not overtly racist and by persons who are strong advocates for minority communities and patients. The linkages in this case are highly specific, rather than a result of generalized attitudes or tendencies to discriminate. Indeed, because good care requires assessment of levels of dangerousness to self and others, the role of stereotyping those who are to be considered “violent” may well “slip under the radar” of efforts to provide training to support “cultural sensitivity” or culturally competent care. To be useful, this model needs to be verified in research and extended to other types of ethnic stereotyping. For example, research suggests that Asians may receive inadequate levels of psychotropic medications precisely because they are viewed as relatively free of emotional and mental health problems. And rather than hypothesizing attitudes such as “aversive racism,” research should be directed at measuring them.

### **Cautions: Health Systems Issues and the Complexities of Mental Health Phenomena**

It is important to temper the hopes that a single line of reasoning, such as that outlined above, is adequate to fully explain disparities in mental health services. We have not yet mentioned disparities in access to health insurance, or the tendency for persons who belong to ethnic and racial minorities to be over-represented among those who are poor and homeless and to grow up in settings where violence is a part of the routine social environment. No mention has been made as to how managed care, or “managed behavioral health services,” is affecting the relationships formed between patients and clinicians. Yet we know that health insurance is closely linked to access to mental healthcare. McAlpine and Mechanic (2000) recently demonstrated that for a sample of persons with severe men-

tal illness, who are disproportionately African American, unmarried, male, less educated, and low income, almost three-fifths received no specialty mental healthcare in a 12-month period, one in five were uninsured, and only 37 percent were insured by Medicare or Medicaid. Because “persons covered by these public programs are over six times more likely to have access to specialty care than the uninsured,” any explanations that ignore formal mechanisms for access to care are likely to be extremely partial. Furthermore, privatization of mental health services has led to disbanding of clinics devoted to the care of high risk children, youth and families. Therefore, psychiatrists have far fewer visits to develop relationships with patients that allow them to move beyond initial stereotypes—on the part of both the clinician and the patient—and to develop truly therapeutic and understanding relationships than is true under other forms of mental health services. Thus, great care should be taken in developing explanations that focus on decision-making processes of individual clinicians.

Finally, in the specific case discussed here—the apparent “over-diagnosis of schizophrenia” among African Americans—the robustness of the phenomenon remains in question. Because there is no gold standard or biological marker for diagnosing schizophrenia, one line of research attempting to determine reasons for higher rates of schizophrenia among hospitalized African Americans has compared diagnoses using standardized diagnostic interviews with recorded hospital or emergency room diagnoses. The best such study, carried out by Neighbors et al. (1999), found that use of a standardized diagnostic interview reduced the percentage of black patients diagnosed with schizophrenia in a Michigan hospital from 58 percent to 39 percent. However, the study found that white patients diagnosed with schizophrenia were reduced from 49 percent to 31 percent, and that levels of “misdiagnosis” (assuming the research diagnoses were correct) for white patients were somewhat higher for whites than for blacks. Misdiagnosis in this study was shown to be as high for whites as blacks, and even the most carefully designed study continued to find higher rates of schizophrenia among hospitalized African Americans than among hospitalized white Americans. Thus, although mental healthcare provides an important model for how to approach the issues to be addressed in this review, it remains a particularly difficult domain to make claims with great certainty.

### Concluding Questions

The multidimensionality of reasons for disparities in healthcare and medical treatment for racial and ethnic minorities, along with the lack of data focused explicitly on the role of the culture of professionals and health institutions in producing these disparities makes it difficult to fully

respond to the charge given to these authors by the IOM Committee. "Culture counts," as Satcher's report notes. Until recently, when cultural analyses were proposed, the focus was largely on patient culture. Burdens of difference were on patient communities, and medicine and health professionals were expected to learn to be culturally competent in attending to the diverse populations that make up American society. When we are challenged to examine the culture of medicine and of our healthcare institutions, we are also challenged to bring a critical perspective that has largely been ignored by most research to date or that has circumscribed cultural inquiry to the differences between patients' and physicians' "beliefs." Disparities in medical treatment are not simply matters of differences in "beliefs." Clearly, political and economic factors that shape our medical commons and our larger society are implicated in the production of these disparities. Physicians interviewed as well as research reviewed indicate that societal racism and persistent inequalities may be responsible for many of the differences, now so widely documented. In a recent study sponsored by the Robert Wood Johnson Foundation, Hargraves et al. (August 2001) found that minority physicians who were more likely to be in solo practice were also less likely to obtain referrals to specialists and had greater difficulty admitting patients to the hospital. Given that minority physicians care for a greater proportion of minority patients, differences in high-technology care may be related to environmental practice factors. As Hargrave et al. (2001) note, "Minority physicians' inability to arrange important medical services for their patients may be positively associated with problems minority patients have with access to care." Minority physicians in this study included Hispanic and African-American physicians. (See also Gray and Stoddard, 1997 and Komaromy et al., 1996.) Minority physicians also feel there is discrimination in peer review, hospital promotions, Medicaid and Medicare reimbursement, malpractice suits and private insurance oversight (Byrd et al., 1994). Bias appears in the awarding of managed care contracts as well, with disparities between white and minority, in particular Asian, physicians documented in a national survey (Mackenzie et al., 1999). These complexities of bias and practice environment clearly indicate that differences are found not simply in cultural diversity or in practice "beliefs."

In sum, we recommend the following approaches to further understanding of reasons for disparities.

1. Attend to a critical analysis of the culture of medicine in its broadest meaning and in different practice and training environments and geographical regions. The dimensions of time, efficiency and efficacy and the medical gaze may be useful starting points, but analyses should examine

behavioral modeling and hierarchical relationships that may influence patterns of care and choice of treatments as well.

2. Examine the political economy of cultural practices in medicine, from the arrangement of healthcare delivery systems to the financing of biomedical innovations and practices, to the justification for choice of treatment and care.

3. Examine the practice arrangements of minority physicians by ethnicity, age, and region (urban/rural and state).

4. Explore how the sea change in the ethnicity and race of medical students, physicians, nurses, and healthcare staff affects provision of care to ethnic and racial minorities, new immigrants, and the poor.

5. Identify interventions and programs that have been successful in medical and nursing education and have influenced the way care is provided to ethnic and racial minority patients.

6. Assess the success of programs directed to redress imbalances in care such as minority outreach programs and clinics; what are positive lessons, negative if unintended consequences and avoidable difficulties?

These are elementary suggestions, and the questions with which we began this chapter are but partially addressed. Unfortunately, we have not been able to conclude with a clear set of findings. Clearly, more work focused explicitly on these questions is required, and such research will have to include depthful, qualitative work—observations; in-depth confidential interviews with health practitioners, including those in training; and similar in-depth interviews with patients from diverse minority groups about their experiences in healthcare. In terms of policy responses to eliminate racial and ethnic health disparities, these will not only have to come from innovative research and programs in the medical commons and the healthcare arena, but as David Williams suggests, from larger societal changes (Williams and Rucker, 2000). And such responses will have to use new and innovative understandings of culture, ethnicity and racism to develop multidimensional results.

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## The Civil Rights Dimension of Racial and Ethnic Disparities in Health Status

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It is hard to talk about race. Discussions about race in general and racial discrimination in particular are potentially unnerving, which explains in large measure why such conversations are so few and far between. In the health care context, discussions about race and racial discrimination are particularly rare.

But this is slowly beginning to change, and two primary forces have triggered the change. First, the Initiative to Eliminate Racial and Ethnic Disparities in Health has focused considerable attention on improving the health status of people of color in the United States. The disparities initiative was launched in 1998 by former President Clinton and Secretary of Health and Human Services Donna Shalala. Under this bipartisan initiative, President Clinton and Secretary Shalala committed the nation to the ambitious yet attainable goal of eliminating racial and ethnic disparities in six areas of health status while continuing the progress that has been made in improving the overall health of people in America. The six focus areas of this initiative are: (1) infant mortality; (2) cancer screening and management; (3) cardiovascular disease; (4) diabetes; (5) HIV infection/AIDS, and (6) immunizations. This Initiative enjoys the support of current HHS Secretary Tommy Thompson.

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The second factor that has triggered a discussion about the role of discrimination in health care is the dramatic increase in immigrant populations in urban and rural settings across the United States. These major demographic shifts have forced health care providers, government officials, and communities to address the unique challenges confronting immigrants. The growing dialogue surrounding the need for a culturally competent health profession reflects the recognition of the changing face of America.

The disparities initiative and the rapid expansion of immigrant populations across America have focused the attention of health professionals, politicians, and policy makers on the critical question of why it is that communities of color and immigrant communities are lagging behind the rest of America in so many critical measures of health status.

Racial disparities in many areas of health status are well-documented, disturbing, and preventable.<sup>2</sup> In order to eliminate health disparities, it is important first to understand the root causes. Until recently, the role of discrimination was largely ignored. Instead, disparities have been defined in other terms: economic—poor people are more likely to have difficulty accessing quality health care; geographic—those who live on the wrong side of the tracks and near the toxic waste dump are more likely to encounter health problems; and sometimes genetic—certain races or ethnicities may have a genetic predisposition to certain illnesses. Finally, disparities frequently have also been defined in terms of education or behavioral issues—if we could simply teach better habits.

All of these explanations are undoubtedly true depending on the context, with some factors perhaps playing a larger role than others. However, another factor is rarely discussed—discrimination. This paper addresses the role that discrimination plays in explaining health disparities, and outlines a host of civil rights interventions that can be put into place to address these disparities. This paper is divided into four parts.

Part one addresses what specifically is meant by “discrimination” in the legal sense. Discrimination is an often misunderstood concept, and this section seeks to demystify and destigmatize discrimination by explaining what it means legally in the health care context. This section

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<sup>2</sup> Dr. Jack Geiger has performed perhaps the most comprehensive study to date tracking down the literature on racial and ethnic disparities in health care. Geiger, HJ. 2001. Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and Consideration of Causes, *Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care*. Examples of studies documenting disparities include: Bach PB et al. 1999. Racial Differences in the Treatment of Early Stage Lung Cancer. *New England Journal of Medicine*, 341:1198-205; Ayanian, JZ et al. 1999. The Effect of Patients' Preferences on Racial Differences in Access to Renal Transplantation. *New England Journal of Medicine*, 341:1661-69.

introduces Title VI of the Civil Rights Act of 1964, one of the principal tools used in addressing discrimination in the health care context.

Parts two and three explore whether discrimination is actually alive and well in the health care setting. Part two outlines research regarding the potential role of discrimination in explaining health disparities. This section is not intended as an exhaustive review of the literature, but it does outline noteworthy studies that have triggered further discussion about the role of discrimination in explaining disparities.

Part three discusses actual discrimination cases in the health care context. There are some respected experts who believe that discrimination is not a significant problem in health care.<sup>3</sup> Regrettably, the evidence belies these assertions, and there is a substantial body of cases involving discrimination in a variety of health care settings, and this section discusses these cases. A generation ago, discrimination in health care was quite similar to discrimination in other settings. That is, hospitals, nursing homes, and other health care facilities, like schools, were segregated and needed to be integrated. Thus, early discrimination cases in the health care context focused on issues such as equal access to medical facilities.

Today's civil rights challenges in health care generally are more subtle, but no less compelling. The six categories of cases discussed in section three are (1) intentional discrimination cases; (2) access to health care for people with limited English skills; (3) medical redlining in a variety of settings, including managed care and home health care; (4) other managed care issues, including physician participation; (5) discrimination in access to treatment; and (6) other unique challenges confronting immigrant population in addition to language access.

Parts two and three lay out the case that discrimination is a root cause of health disparities, and underscore that a comprehensive strategy to eliminate disparities must incorporate a strong civil rights component. Part four contains a series of recommendations for eliminating disparities that focus on the civil rights dimension of the disparities challenge. These recommendations include (1) promoting the collection of data related to race, ethnicity and primary language by federal, state and local governments and health care facilities; (2) enhancing the federal infrastructure for enforcing civil rights laws in the health care context; (3) expanding the capacity of private organizations to enforce civil rights laws in the health settings; (4) implementing a comprehensive language access agenda; (5) amending federal law to re-establish that private parties can enforce all provisions of the Title VI regulations; and (6) reviewing federal law and

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<sup>3</sup> See, for example, Havighurst, C. and O'Neill, J. September 6, 2001. Invited Presentation at panel discussion, "Race, the Medical Marketplace, and Health Care Disparities," *National Academies of Sciences*.

removing barriers to participation for legal immigrants in critical programs, such as Medicaid and the State Children's Health Insurance Program (SCHIP).

Effective data collection is a lynchpin of any comprehensive strategy to eliminate health disparities. In order to fully appreciate the value of collecting data on race, ethnicity and language of preference in health care, it is useful to draw upon civil rights experiences in non-health care settings. Part four explains how advocates and government officials have used federal laws pertaining to data collection in the home mortgage and the policing context to address the issues of mortgage lending discrimination and racial profiling, respectively. Policymakers concerned about data collection in health care can learn a number of valuable lessons from these experiences.

Implementing all of the recommendations outlined in part four will assist in reducing, but will not eliminate racial and ethnic disparities in health. Indeed, eliminating racial and ethnic disparities in health will require a comprehensive strategy that reflects a keen understanding of the multi-faceted nature of the challenge. The principal aim of this paper is to give policymakers, providers, advocates and other stakeholders a better understanding of the civil rights dimension of the challenge, as well as a set of suggestions on how to address these civil rights concerns.

### PART ONE: DEFINING DISCRIMINATION

Discrimination can be a scary term, as it frequently conjures up images of nefarious actors engaging in conscious acts of bigotry designed to deny people of color an important benefit or opportunity. While isolated incidents of such discrimination regrettably exist, discrimination in today's health care marketplace is much more subtle, but no less serious in its effect. Understanding what discrimination means under federal civil rights laws is critical to understanding precisely how civil rights laws can be used to combat racial and ethnic disparities in health.

Title VI of the Civil Rights Act of 1964 (Title VI) and its accompanying regulations are the primary tools used to attack discrimination in health care. Title VI prohibits discrimination based on race, color, or national origin, in any program or activity that receives federal financial assistance.<sup>4</sup> Virtually every health care provider receives some form of federal

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<sup>4</sup> Title VI provides that "[n]o person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance" 42 U.S.C. § 2000d.

financial assistance, so it is not difficult as a practical matter to fall within the ambit of Title VI.

The language of Title VI itself addresses intentional discrimination. However, the regulations issued pursuant to Title VI make clear that Title VI itself reaches far beyond intentional discrimination. The regulations prohibit health care providers from using “criteria or methods of administration which have the effect of subjecting individuals to discrimination on the basis of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program [with] respect [to] individuals of a particular race, color or national origin.”<sup>5</sup> Thus, there are two types of discrimination under Title VI: (1) intentional discrimination; and (2) policies or practices that may be neutral on their face but have the *effect* of discriminating on the basis of race, color, or national origin (the “disparate impact” theory or “effects” test).

Title VI applies to a range of discrimination concerns, including access to health services, redlining, and physician staff privileges and participation in managed care. Until earlier this year, private litigants were permitted to sue to enforce Title VI regulations prohibiting acts with discriminatory effects. However, the United States Supreme Court in *Alexander v. Sandoval* ruled that there is no private right of action under the Title VI regulations (121 S.Ct. 1511 [2001]). The case itself involved a class of non-English speaking residents of Alabama, who alleged that the state’s policy of offering the driver’s license exam only in English amounted to national origin discrimination under the aforementioned “effects” provision of the Title VI regulation. The Court of Appeals for the Eleventh Circuit agreed, but the Supreme Court ruled that private parties lacked the authority to file a lawsuit to enforce the effects provision of the Title VI regulation.

*Sandoval* represents a significant setback for civil rights advocates, who had pursued a steady diet of civil rights cases in health care using the disparate impact theory under the Title VI regulation. Private plaintiffs must now establish that the conduct in question amounts to intentional discrimination under Title VI. It is important to note, however, that *Sandoval* only applies to private parties, and has no effect on the federal government’s ability to pursue civil rights cases using the effects test under the Title VI regulation. The authority of agencies such as the Office for Civil Rights (OCR) at the Department of Health and Human Services (HHS) remains unchanged.

There are two ways to invoke the protections of Title VI: an aggrieved person can (1) file a written complaint with OCR and/or (2) file a lawsuit

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<sup>5</sup> 45 C.F.R. 80.3(b)(2).

under Title VI.<sup>6</sup> It is not necessary to first file an administrative complaint in order to file a lawsuit. OCR is the federal agency responsible for enforcing Title VI in the health and human service context, and has been doing so for over 35 years. OCR will investigate that complaint by, among other means, reviewing the pertinent practices and policies of the hospital or provider that is the subject of the complaint, the circumstances under which the possible noncompliance occurred, and other factors relevant to a determination as to whether the hospital or other recipient has failed to comply with Title VI.<sup>7</sup> OCR may also, on its own, review the practices of a recipient of federal funds to determine whether they are complying with Title VI. A complaint is not necessary.<sup>8</sup>

If OCR finds noncompliance, it will first seek voluntary compliance by the recipient. OCR's ultimate sanction is to terminate federal funding, either in an administrative proceeding or by referring the case to the Department of Justice for litigation. The advantages of filing an OCR complaint are that: (1) it does not require a lawyer; (2) a finding of discrimination by a federal agency can be very powerful; (3) the involvement of OCR frequently results in a resolution of the case, sparing the expense and uncertainty of protracted litigation; and (4) OCR can investigate both allegations of intentional discrimination under Title VI and disparate impact under the Title VI regulations, whereas private litigants can only sue under an intentional discrimination theory.

Title VI is not the only civil rights tool that is employed to address discrimination in health care. For instance, the Hill-Burton Act proscribes discrimination in health care settings, and provides a statutory hook to attack racial discrimination in health care. However, relatively few health care providers fall within the jurisdiction of the Hill-Burton Act, whereas virtually every actor in the health care system receives federal financial assistance, and is therefore covered by Title VI. Title VII of the Civil Rights Act of 1964, and 42 U.S.C. 1981 are anti-discrimination provisions that can be used by employees or other providers who feel that they have been victims of discrimination.<sup>9</sup> For instance, physicians of color who have been

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<sup>6</sup> 45 C.F.R. 80.7(b).

<sup>7</sup> 45 C.F.R. 80.7(c).

<sup>8</sup> 45 C.F.R. 80.7(a).

<sup>9</sup> Title VII provides, in part, that it is unlawful for an employer to "fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to his compensation, terms, conditions or privileges of employment, because of such individual's race, color, religion, sex, or national origin" 42 U.S.C. 2000e-2(a)(1). Like Title VI, Title VII prohibits intentional discrimination as well as disparate impact discrimination. Section 1981 prohibits racial discrimination in the making and enforcement of contracts, and applies to public and private contracting.



terminated from managed care networks have sought redress under Title VII and/or section 1981.

These statutes provide legal framework for addressing the role of discrimination in health care.

## **PART TWO: IS DISCRIMINATION ONE OF THE ROOT CAUSES OF DISPARITIES: WHAT DOES THE RESEARCH SAY?**

### **Research Regarding the Potential Role of Bias in Physician Decision-Making**

There is a growing body of research addressing whether discrimination is one of the root causes of racial and ethnic disparities in health. The 1999 Schulman study generated the most attention.<sup>10</sup> In this study, researchers addressed whether the patient's race or gender affected the physician's decision to recommend cardiac catheterization. The study involved simulated patients (white males, white females, African-American males, African-American females) who had identical backgrounds in all respects except race and gender, identical risk factors and symptoms. The researchers controlled for other factors, and concluded that the patient's race and gender indeed affected the physician's decision to recommend cardiac catheterization. Specifically, the study found that African Americans and women with chest pain had relative odds of referral for cardiac catheterization that were 60 percent of the odds for whites and men. African-American women faced the greatest disparity, as they had relative odds that were 40 percent of those for white men.

The real implication of the study was actually quite simple: doctors are human. Like lawyers, businesspeople, and other professionals, doctors are fallible and may discriminate, consciously or subconsciously. In other civil rights contexts, it has been shown that racial bias can infect the corporate boardrooms, the schoolrooms, and the police precinct rooms. This study simply concluded that racial bias can affect who gets to the operating room.

Yet, the Schulman study provoked a firestorm of criticism, as if it were the only study to document the potential role of discrimination in explaining racial and ethnic disparities. In a "Sounding Board" article in the *New England Journal of Medicine* a few months later, three physicians described the results of the Schulman study as "overstated," although they also noted that their purpose in writing was "not to deny the occurrence of

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<sup>10</sup> Schulman K. et al. 1999. The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization. *New England Journal of Medicine*, 340:618-626.

racial or sex bias."<sup>11</sup> These commentators and others questioned the underlying methodology, and suggested that the results are not as stark as the study suggested.

Most recently, a study by a team of researchers led by Dr. Jersey Chen concluded that minority and non-minority physicians alike were more likely to recommend a white patient for cardiac catheterization than a minority patient.<sup>12</sup> The Schulman study did not control for the race of the physician. The Chen study prompted one commentator to opine at a panel discussion sponsored by the Institute of Medicine that the Schulman study has been "largely discredited."<sup>13</sup>

Such statements seeking to dismiss the Schulman study miss the mark, and ignore the wide body of research, both before and after the Schulman study, suggesting that race continues to matter in health care, and racial bias may contribute to racial and ethnic disparities in health status.<sup>14</sup> Such statements also ignore serious methodological flaws in the Chen study that a number of experts have noted.<sup>15</sup> Most notably, the African-American physicians in the Chen study tended to be internists, not cardiologists, when compared with the white physicians. There are so few African-American cardiologists that it would likely be difficult, if not impossible, to devise a study that addresses the question presented in the Chen study using a sufficient sample of both African-American and white cardiologists.

The reality is that discrimination may be hard to quantify, but is difficult to deny. As Drs. Arnold Epstein of the Harvard School of Public Health and John Ayanian of the Harvard Medical School pointed out in response to the Chen study,

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<sup>11</sup> Schwartz, L. et al. 1999. Misunderstandings About the Effects of Race and Sex on Physicians' Referrals for Cardiac Catheterization, *New England Journal of Medicine*, 341:279-282.

<sup>12</sup> Chen, J. et al. 2001. Racial Differences in the Use of Cardiac Catheterization After Acute Myocardial Infarction, *New England Journal of Medicine*, 344:1443-1449.

<sup>13</sup> Symposium of September 6, 2001, at the National Academies of Sciences on The Role of Discrimination in Explaining Racial and Ethnic Disparities in Health Status, testimony of June O'Neill.

<sup>14</sup> See e.g., Gornick, M.E. 2000. *Vulnerable Populations and Medicare Services*. New York: Century Foundation. van Ryn, M. Burke, J. 2000. The Effect of Patient Race and Socioeconomic Status on Physicians' Perceptions of Patients, *Social Science Medicine*, 50:813-828; U.S. Civil Rights Commission. 1999. Smith, D.B. 1999. *Health Care Divided: Race and Healing a Nation* (University of Michigan Press). *The Health Care Challenge: Acknowledging the Disparity, Confronting Discrimination, and Ensuring Equality*. Washington, DC: U.S. Civil Rights Commission. Mayberry, R.M. 1997. *Racial and Ethnic Differences in Access to Medical Diagnosis and Treatment*. Atlanta, GA: Morehouse School of Medicine.

<sup>15</sup> See e.g., 2001. Report of Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care.

*“Racial bias is difficult to detect in surveys of physicians or medical records. Physicians may have various biases, but they often do not perceive them, and would not report them as such. Thus, it is no surprise that previous studies have not directly documented bias. Instead, racial bias has always remained a possible explanation for residual racial differences in treatment, after other explanatory factors have been accounted for.”<sup>16</sup>*

Dr. Neil Calman, a professor of family medicine at Albert Einstein School of Medicine and President and co-founder of the Institute for Urban Family Health, has written and spoken extensively about his own efforts to come to grips with his own racial bias.<sup>17</sup> A white physician practicing in the Bronx with a predominantly minority patient mix, Dr. Calman has written about how this experience has forced him to confront his own racial stereotypes that have stood in the way of quality treatment of his patients. Based on his experience, he has concluded that “the shadow of racial prejudice looms over us all.” According to Dr. Calman, until and unless physicians develop the capacity to confront their own stereotypes, it will be difficult to prevent conscious or subconscious bias from interfering with the physician-patient relationship.

Dr. Calman’s thesis is consistent with those put forward by Dr. Vanessa Gamble, former vice president of the Association of American Medical Colleges, and a frequent contributor on issues of race and medicine. In a 1997 article, Dr. Gamble wrote about race and medicine, and discussed a newspaper story reporting on an African-American woman who went to the emergency room of a county hospital in Los Angeles for treatment of a suspected broken arm.<sup>18</sup>

According to the article, interns, who were white, asked her to position her arm “like she would having a beer on a Saturday night.” The patient responded: “Do you think I’m a person on welfare?” “Well aren’t you?” was the response. The patient was actually an administrator at the University of Southern California Medical School.<sup>19</sup> Dr. Gamble used this experience to discuss the role of discrimination in health care, and examine the forces at work that would enable a physician to basically look at a person and conclude they are on welfare.

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<sup>16</sup> Epstein, A., Ayanian, J. 2001. Racial Disparities in Medical Care. *New England Journal of Medicine*, 344:1471-73.

<sup>17</sup> Calman, N. 2000. Out of the Shadow, A White Inner City Doctor Wrestles With Racial Prejudice, *Health Affairs*, 19:170-74.

<sup>18</sup> Gamble, V. 1997. Under the Shadow of Tuskegee: African Americans and Health Care, *American Journal of Public Health*, 87:1773-78.

<sup>19</sup> Moustafa, K. April 1, 1995. U.S. Remains Worlds From Top Notch Health Care. *The Fresno Bee*.

The Calman and Gamble articles are also consistent with a more recent study led by Dr. Michelle van Ryn examining whether physicians' perceptions of patients are affected by the patient's race or socioeconomic status.<sup>20</sup> Researchers concluded that physicians tended to perceive African Americans and members of low and middle SES groups more negatively on a number of measures than they did whites and upper SES patients. As a result of this study, it is difficult to dismiss the aforementioned encounter in Los Angeles as an unrepresentative anecdote.

It is also interesting to examine the van Ryn research in the context of studies on race concordance in the physician-patient relationship. A recent study of white and African-American patients by a research team led by Dr. Lisa Cooper-Patrick found that patients seeing physicians of their own race rated their physicians' decision-making styles as more participatory.<sup>21</sup> Another study found that African American and Latino patients were more likely to rate care as excellent and very good from physicians of the concordant race.<sup>22</sup>

These studies on race concordance and the physician-patient relationship do not stand for the proposition that racial bias on the part of physicians is the reason why African-American and Latino patients tend to prefer to be treated by African-American and Latino physicians, respectively. However, these studies are frequently cited in discussions on cultural competency, and suggest that Dr. Calman and Dr. Gamble are correct in stating that it is important for physicians to develop an enhanced capacity to step into the shoes of their patients. These studies, and Dr. Calman's insights, reinforce the conclusion of the Schulman study, as well as other studies, that it is important to focus on the potential role of racial bias as a possible factor explaining racial and ethnic disparities.

More recently, Dr. Kevin Schulman was the co-author of another study similar in nature to his aforementioned 1999 study that provoked such widespread debate. In this study, the research team again used simulated patients in an effort to understand the effect of race and gender on provider decision-making, except that medical students, as opposed to physicians, were the providers in question.<sup>23</sup> Once again, the researchers concluded that the race and gender of the patient had a significant effect

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<sup>20</sup> van Ryn, M. et al. 2000. The Effect of Patient Race and Socioeconomic Status on Physicians' Perceptions of Patients, *Social Science and Medicine*, 50 (2000):813-828.

<sup>21</sup> Cooper-Patrick L. et al. 1999. Race, Gender, and Partnership in the Patient-Physician Relationship, *JAMA*, 282:583-589.

<sup>22</sup> Saha, S. et al. Patient-Physician Racial Concordance and the Perceived Quality and Use of Health Care. *Archives of Internal Medicine*, 159:997-1004.

<sup>23</sup> Rathore, S., Schulman, K. et al. May 2000. The Effects of Patient Sex and Race on Medical Student's Ratings of Quality of Life, *American Journal of Medicine*, 108:561-566.

on the medical student's assessment. In other words, race matters for both medical students and physicians alike, according to the two Schulman studies. Some medical students appear to be entering medical school with certain stereotypical notions of people of other races, and these erroneous notions can have an ill effect on their ability to treat people of different races effectively and fairly.

The discussion thus far has focused on physician perceptions and physician behavior in providing patient care. In the debate about the potential role of racial bias in physician decision-making, what is frequently overlooked is the perceptions of the patients themselves. As mentioned earlier, Drs. Epstein and Ayanian, in responding to the recent Chen article, noted that many physicians may not perceive bias. It is important to understand the starkly contrary perceptions of many patients of color.

In a 1999 survey by The Henry J. Kaiser Family Foundation, African Americans were more than twice as likely as whites to state that discrimination in health care is a major problem, almost three times as likely to believe that African Americans receive lower quality health care than whites, and fourteen times as likely to report that they were treated unfairly because of race when seeking medical care in the recent past.<sup>24</sup> According to the Public Health Special Report of Seattle and King County, nearly one-third of African-American respondents living in central and southeast Seattle reported experiencing racial discrimination when seeking health care, compared to 13% of all respondents.<sup>25</sup>

Surveys of perceptions undeniably have certain limitations; yet, they are critically important because perceptions so frequently drive behavior, and perceptions are often a function of historical, negative experiences with the health care system. The aforementioned data suggest that there is a strong perception within communities of color that discrimination, whether conscious or subconscious, indeed plays an important role in explaining racial and ethnic disparities in health.

Overall, while there are some who believe that the research does not support the conclusion that discrimination plays an important role in explaining racial and ethnic disparities, the weight of the evidence from the research is to the contrary. It would be imprudent to fixate on the use of odds ratios in one study and ignore the strong body of research suggesting that physicians are indeed human, and are susceptible to conscious

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<sup>24</sup> The Henry J. Kaiser Family Foundation. 1999. *Race, Ethnicity, and Medical Care: A Survey of Public Perceptions and Experiences*.

<sup>25</sup> Seattle and King County Public Health Department. 2001. *Racial and Ethnic Disparities in Health Care Settings, Public Health Special Report*.

and subconscious racial bias. It would be equally imprudent to ignore the apparently strongly held beliefs of communities of color that discrimination is indeed alive and well in health care.

### **The Need for Broader Research on the Potential Role of Discrimination in Explaining Racial and Ethnic Disparities in Health**

The Schulman studies and others have triggered a much-needed dialogue about the potential role of discrimination as one factor explaining the persistence of racial and ethnic disparities in health status. However, it is vitally important not to limit the scope of the research regarding the potential role of discrimination as a factor in racial and ethnic disparities to physician and provider behavior. As noted earlier, there are two types of discrimination under Title VI: intentional discrimination and disparate impact discrimination. Intentional discrimination addresses whether an individual acted intentionally or with a discriminatory purpose. Disparate impact discrimination does not require proof of discriminatory intent, and cases alleging disparate impact frequently address systemic policies or practices that have a disproportionate adverse impact on the basis of race, color or national origin.

The overwhelming percentage of actual discrimination cases in health care involves disparate impact. The current research focus on potential discrimination in physician behavior is important, and should continue, but it is not enough. In addition, it is important for researchers to examine the remainder of the health care system, broadly defined, to determine whether there are policies and practices in place that have the effect of discriminating against communities of color. For instance, as discussed in Part three, it is important to examine whether there are policies or practices in place in the process of applying for Medicaid and SCHIP that have the effect of discriminating against communities of color. Another potential area of research may focus on how health care providers market themselves in their communities. Are there marketing practices in place that have the effect of discriminating on the basis of race, color or national origin? Do referral rules and policies regarding privileges have the effect of discriminating on the basis of race, color or national origin? There are a wide range of systems issues that should be but are not currently, the subject of a sustained research agenda.

Overall, it is important to continue to support a robust, broadly defined research agenda that focuses on the potential role of discrimination at a number of points in the health care system, and is not limited to the area of physician behavior.

### **PART THREE: IS DISCRIMINATION ONE OF THE ROOT CAUSES OF DISPARITIES: WHAT DOES THE TITLE VI ENFORCEMENT HISTORY SUGGEST?**

#### **Introduction**

There are at least two ways to determine whether discrimination plays a role in explaining racial and ethnic disparities. The first method, discussed in the preceding section, is to look at the research. The second way is to look at actual cases, and this section discusses discrimination cases in the health care setting, and flags emerging civil rights issues in health care. It is not intended as an exhaustive history of discrimination in health care. David Barton Smith has written an exhaustive chronicle of discrimination in health care, from 1920 to the present. In *Health Care Divided, Race and Healing a Nation*, Smith documents the role of race in shaping our system of medical care, and concludes that discrimination indeed is a force that explains in part the persistence of racial and ethnic disparities.<sup>26</sup>

This section focuses on the current and recent landscape of Title VI cases, and demonstrates that discrimination regrettably is not a thing of the past. As noted earlier, Title VI and the Title VI regulations are quite broad in their reach. Anyone who receives federal financial assistance of any kind is subject to these anti-discrimination provisions. The regulations prohibit not only intentional discrimination but also “facially neutral” policies or practices that have the effect of discriminating on the basis of race, color, or national origin.

Given its broad reach, Title VI has been used in many contexts. For instance, Title VI has been used to challenge the closure of a health care facility in a minority community, the relocation of a health care facility away from a minority community, or the denial of admitting privileges to a physician. This section focuses on six areas that are of particular relevance to the disparities debate: (1) intentional discrimination cases; (2) managed care; (3) medical redlining; (4) access to treatment; (5) access to health care for people with limited English skills; and (6) barriers (in addition to language) for immigrant populations. The bulk of the cases discussed herein emanate from OCR.

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<sup>26</sup> For additional documentation of discrimination in health care, see Watson, S. 1990. Reinventing Title VI: Defending Health Care Discrimination—It Shouldn't Be So Easy, *Fordham Law Review*, 58:939-978.

### **Types of Discrimination** **Intentional Discrimination**

A generation ago, discrimination in health care, like discrimination elsewhere, was quite overt. Hospitals, nursing homes, and other health facilities were segregated, and the challenge was to integrate them. Today, discrimination generally is more subtle, but no less serious. Yet, from time to time, Title VI has been used recently to attack discrimination that one would think was a thing of the past. A sample of recent cases settled by OCR provides sobering evidence that intentional discrimination, while no longer as prevalent as a generation ago, still rears its ugly head.<sup>27</sup> In recent years, OCR has been involved in the following cases:

- OCR reached a settlement with a national pharmacy chain that had a franchise that repeatedly refused to fill the prescription of an African-American Medicaid recipient. As part of the settlement, the chain apologized to the victim, posted notices of the company's non-discrimination policy in stores nationwide, and posted the same notice in an advertising circular that was distributed nationwide to 25 million people.
- OCR settled a case involving a hospital in New York City that had de facto segregated maternity wards; the segregation appeared to be based on source of payment, although source of payment was a proxy for race.
- OCR reached a settlement with a hospital located near the U.S.-Mexico border in McAllen, Texas, that ordered its security personnel to dress up in uniforms that closely resembled the U.S. Border Patrol. This policy had the effect of deterring Latinos in the area from using the facility.
- OCR reached a settlement with a national home health agency that had a franchise that refused to provide assistance to an African-American family after the family moved from one part of town into a predominantly minority low-income housing development in a different part of town. The investigation revealed that the agency served a predominantly non-minority elderly housing complex that was located a very short distance from the predominantly minority housing development that it refused to serve.
- OCR reached an agreement with a hospital in South Carolina that had a policy of prohibiting women with limited English skills from receiving an epidural during labor and delivery.

These cases are not meant to illustrate that there is widespread pattern of intentional discrimination in health care. Rather, these cases are

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<sup>27</sup> Additional information about the cases discussed herein can be obtained by contacting the Office for Civil Rights.



set forth as a reminder that while the civil rights landscape in health care is indeed evolving, pockets of straightforward discrimination persist. These cases also illustrate the wide-ranging contexts in which forces of discrimination can inhibit or prevent communities of color from accessing critical services. As noted earlier, focusing exclusively on whether racial bias affects the physician-patient relationship is important, but it is equally important to look at whether discrimination is at work in other entry points within the health care system.

### Limited English Proficiency

Under Title VI and its implementing regulations, health providers who receive federal financial assistance have a legal obligation to ensure that people with limited English skills can meaningfully access health care. Language access cases under Title VI typically proceed under a disparate impact theory pursuant to the Title VI regulations. The failure to provide effective language assistance services amounts to national origin discrimination. There is no need to prove intentional discrimination.

In August 2000, OCR published policy guidance in the *Federal Register* outlining the responsibilities of health and human service providers under Title VI to ensure that people with limited English skills can meaningfully access health and human services.<sup>28</sup> It also provides a roadmap to assist providers in meeting their obligations. Although Title VI has been on the books since 1964, the publication of the guidance reflected the first time that OCR had formally published guidance in the *Federal Register* outlining the requirements of providers under Title VI to serve people with limited English skills, OCR's process for investigating such complaints and initiating compliance reviews, and the steps that providers can take to ensure compliance.

The failure of health providers to ensure meaningful access for people with limited English skills is one of the most prevalent civil rights problems in health care. Language access cases are easily OCR's most frequently encountered type of Title VI case, and have been the subject of a steady diet of private litigation. Language access cases are also the most frequent subjects of OCR Title VI compliance reviews and technical assistance. According to many immigrant advocates, the large number of OCR complaints actually understates the extent of the problem, because many victims are immigrants who are reluctant to come forward.

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<sup>28</sup> HHS (Office for Civil Rights). 2000. Title VI Prohibition Against National Origin Discrimination As It Affects Persons With Limited English Proficiency: Policy Guidance. *Federal Register* 65(169):52763-774.

The language access challenge arises in virtually every health care setting. OCR has investigated and resolved language access complaints in hospital settings, managed care settings, fee for service settings, and human service settings. The most frequently encountered problems are providers who (1) require the patients to provide their own interpreter service, through family members or friends; (2) fail to provide interpreter service, or provide untrained personnel; and (3) subject people with limited English skills to lengthy delays as a result of the lack of readily available interpreter services.

The failure to ensure meaningful access for people with limited English skills can have serious, even life or death, consequences. A brief sampling of cases illustrates this point in vivid detail:

- OCR settled a case with a hospital in the mid-Atlantic region whose absence of an effective language assistance policy almost had fatal consequences for a pregnant woman with limited English skills who came to the hospital with severe bleeding.
- A Laotian woman in California who was diagnosed with tuberculosis was jailed for months because local law enforcement and public health authorities, as a result of communication gaps resulting from the failure to make use of a Laotian interpreter, mistakenly concluded that she would refuse to follow her treatment regimen unless she was jailed.
- A young boy in Los Angeles interpreted a consent form for his father that pertained to his ailing mother. The son thought the form meant that a nurse would make daily visits to care for his mother, and the father signed the form. Instead, the mother was sent to a nursing home.

Until recently, language access cases were perhaps the most frequent cases brought by private plaintiffs. However, as noted earlier, the Supreme Court in *Sandoval* recently made it much more difficult for private litigants to bring language access cases under Title VI. As a result of *Sandoval*, private litigants can no longer attack defective language access policies using the disparate impact theory under the Title VI regulation. Instead, private litigants will have to prove that the failure to provide effective language assistance services amounts to intentional discrimination under Title VI itself.<sup>29</sup>

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<sup>29</sup> Private plaintiffs may still be able to meet the higher intent standard in language access cases. By virtue of the OCR guidance issued last year, and subsequent outreach efforts, health providers have been put on notice of their obligation under Title VI to ensure meaningful access for people with limited English skills. As a result, a private plaintiff can argue that the failure to comply with a civil rights obligation that has been clearly communicated amounts to intentional discrimination under Title VI. In addition, a number of states, such as California, have laws and/or regulations requiring the provision of language assistance services. Private plaintiffs can continue to avail themselves of these provisions.

Given the difficulty that private plaintiffs may encounter as a result of *Sandoval*, OCR's role in promoting language access has become even more important.

The need for health care providers to ensure meaningful access is growing, as the population becomes more diverse, and immigrant communities migrate to both urban and rural settings. According to recent census data, the nation gained more immigrants in the 1990s than in any previous decade. One in five people in America do not speak English at home, and more than 10.5 million said they speak little or no English, up from 6.5 million in 1990. Over 3 million, or approximately one-third of the people who speak little or no English, reside in California.<sup>30</sup>

Overall, OCR's enforcement experience, and the recent census data outlined above, demonstrates that language access challenges abound in health care, and the stakes are quite high, and getting higher. For immigrant populations, the lack of effective language assistance services is one of the most important factors impeding access to health care. Addressing the language access challenge would go a long way in reducing racial and ethnic disparities among many immigrant populations across America.

### Redlining

Redlining is most frequently associated with housing and mortgage lending, and historically related in those settings to the practice of literally drawing a red line around certain poor, predominantly minority sections of cities and refusing to provide a mortgage or sell homeowner's insurance. If a person could not get a mortgage or homeowner's insurance, it was impossible to own a home. The Department of Justice, and many private civil rights organizations, have successfully pursued a host of redlining cases in the mortgage lending and insurance setting.

In the health care setting, there is insufficient evidence to determine the extent of the redlining problem. Unlike the housing context, the problem has not been studied in any detail in health care. Anecdotal evidence shows that redlining has taken a number of forms.

In recent years, OCR has handled cases involving allegations of redlining in the home health industry. The cases involved claims that home health agencies refused to provide service to people who resided in certain areas of town. OCR reached settlements in separate cases involving two national home health agency chains. As noted earlier, in one case involving a national home health chain, the investigation revealed that the home health agency, while refusing to serve an African-American cli-

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<sup>30</sup> Cohn, D., Cohen, S. August 6, 2001. Census Sees Vast Change in Language, Employment, *Washington Post*, p.A-1, 5.

ent who lived in a predominantly minority public housing development, regularly served a resident of a predominantly non-minority elderly housing development located a short distance away.

Redlining is a concern in the pharmacy setting. A study that surveyed 347 pharmacies in New York City found that in nonwhite neighborhoods, only 25 percent of the pharmacies had sufficient supplies of pain medication, while 72 percent of white neighborhoods had adequate supplies. Experts disagree on the root cause of this disparity. Some cited potential racial bias, while others opined that low demand in minority neighborhoods, or fear of robbery, were the explanations.<sup>31</sup>

The National Medical Association (NMA) has raised concerns about redlining in managed care. Specifically, the concern is that managed care organizations are bypassing predominantly minority zip codes in their marketing. To date, the concerns are anecdotal. However, under managed care, there are market pressures to ensure that the patient pool of a managed care organization is as healthy as possible. As a result, concerns have been raised that a managed care organization may conclude that a minority community is poorer, sicker, and therefore not an economically viable area in which to conduct business.

### Managed Care

The advent of managed care has raised a variety of civil rights challenges, in terms of both patient care and physician participation. The aforementioned allegations of redlining in managed care are closely related to concerns expressed by a large number of physicians of color that they are terminated from managed care networks, or prevented from joining these networks, because of race. For instance, a 1994 survey of African American physicians found that 92% believed that managed care organizations terminated the contracts of African-American physicians more often than those of white physicians.<sup>32</sup> At the 2001 annual conference of the National Medical Association, an entire afternoon was devoted to discussion of discrimination against physicians of color. The most frequent topic of discussion was discrimination in managed care.

The concerns of the NMA and physicians of color may stem at least in part from a number of studies showing that African-American and Latino physicians are more likely to care for African-American and Latino pa-

<sup>31</sup> Grady, D. April 6, 2000. Little Access to Pain Drugs in Some Areas, *New York Times*.

<sup>32</sup> Lavizzo-Mourey, R. et al. 1996. The Perceptions of African-American Physicians Concerning Their Treatment By Managed Care Organizations, *Journal of the National Medical Association*, 86:191-199.

tients, respectively, and are more likely to care for poor patients.<sup>33</sup> As a result, the practice patterns of many physicians of color may be on a collision course with the market pressures that managed care organizations face to engage in economic credentialing, which relates to the use of economic criteria, unrelated to quality of care or professional competence, in making contracting decisions.<sup>34</sup>

A recent federal lawsuit illustrates the concerns of physicians of color. Eight primary care physicians of color were part of a network of physicians who had contracts with Humana and its local affiliate in Florida. In their federal complaint, the physicians allege, among other things, that their contracts were not renewed because of their race, and that all 17 white physicians on the Humana panel remained with the managed care organization. Rather than file a claim under Title VI, the plaintiffs relied on 42 United States Code, Section 1981, a civil rights statute that prohibits racial discrimination in contracting and contains broader damages provisions than Title VI. Humana contends that race had nothing to do with the decision not to renew the contracts, and that the terminations were for business reasons, which is acceptable under Florida law. In all likelihood, this case will boil down to one question: Were Humana's and its local affiliate's actions motivated by race, or by legitimate business considerations.<sup>35</sup>

This case reflects an emerging civil rights issue in managed care: Does a qualified physician with a sizeable minority patient population have an actionable civil rights claim under Title VI if a managed care organization terminates him or her from a provider network, or refuses to permit him or her to join the provider network? It is impossible to address this question without gathering additional information. Termination cases are frequently complicated by the fact that there are often provisions in the managed care contracts permitting the managed care organization to terminate the contract "without cause." Such provision means that even if a physician is delivering quality care to his or her patients, the managed care organization can still terminate the contract. The managed care organization cannot, however, terminate the contract for a discriminatory reason. As a result, the analysis will frequently return to whether a decision was motivated by business reasons, or discrimination.

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<sup>33</sup> Kington, R. et al. 2001. Increasing Racial and Ethnic Diversity Among Physicians: An Intervention to Address Health Disparities? *The Right Thing To Do, The Smart Thing to Do, Enhancing Diversity in Health Professions*, pp. 57-90 (Institute of Medicine).

<sup>34</sup> Dallan, C. 2000. Understanding Judicial Review of Hospitals' Physician Credentialing and Peer Review Decisions, *Temple Law Review*, 73:597.

<sup>35</sup> Jackson, C. January 8, 2001. Florida Doctors Charge Racial Discrimination By Humana After Being Dropped From Panel, *American Medical News*.

“Business reasons” in this context often does *not* mean that the physician delivered substandard care. Instead, it often means that the physician spent too much money caring for a patient, so that it becomes economically unfeasible for the managed care organization to maintain this relationship. As noted above, this places many physicians of color in a difficult conundrum, because they tend to care for a larger percentage of patients of color who are frequently poorer and sicker. It is not difficult to understand why so many physicians of color are concerned about discrimination in managed care. Such discrimination, if present, affects not simply physicians of color, but the disproportionately minority patient population that they serve.

Proving discrimination is a different matter. Given the prevailing dynamic, it will not be surprising for allegations of discrimination in managed care to emerge as one of the primary areas of civil rights litigation in the health care setting.<sup>36</sup>

Other civil rights in managed care include language access. OCR continues to investigate a steady diet of cases involving managed care organizations. In addition, OCR has performed testing in an effort to measure the extent to which provider networks can meet the needs of people with limited English proficiency. Working in a community with a sizeable Spanish and Vietnamese population, testers contacted providers to determine whether and how they would ensure access to a Spanish- or Vietnamese-speaking patient. A substantial percentage of providers indicated that they would not provide such language assistance.

In resolving managed care cases, especially involving Medicaid managed care, it is important to work not only with the managed care organizations themselves, but also with the state agencies that oversee managed care programs. As recipients of federal financial assistance, both the state and the managed care organizations are responsible for Title VI compliance. Consequently, OCR has worked both with states and with managed care organizations themselves to ensure that individuals with limited English skills enrolled in Medicaid managed care can meaningfully access the programs. The emergence of Medicaid managed care, with its high percentage of enrollees who do not speak English, heightens the importance of aggressive enforcement of Title VI in the managed care setting.

### Access to Medical Treatment

A number of recent reports have raised questions about the ability of people of color to access certain types of critical health care. For instance,

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<sup>36</sup> For further discussion of civil rights issues in managed care, see Rosenbaum, S. et al. 1999. U.S. Civil Rights Policy and Access to Health Care by Minority Americans: Implications for a Changing Health Care System, *Race, Diversity and Health Care, Improving Access in a Diverse Society* (The Henry J. Kaiser Family Foundation).

a lengthy report in *Newsday* in 1999 documented racial disparities in a wide range of health areas in Queens, Nassau County, and Suffolk County, New York.<sup>37</sup> For instance, according to the report,

- Even though they die of coronary heart disease at lower rates than African Americans, whites had 138 cardiac bypass procedures per 100,000 residents, as opposed to 31 per 100,000 among African Americans.
- One cardiac surgeon from a nationally recognized facility, who drew patients from a broad geographic area, performed 267 bypass operations during the year in question; one of the patients was African-American, two were on Medicaid, and three had no insurance;
- Another well-respected cardiologist performed 284 inpatient angioplasties during a given year; there were no Medicaid patients; one African American, and two without insurance.
- Whites received hip replacements at a rate twice as high as African Americans, knee replacements at a rate 23 percent higher, and gall bladder operations at a rate 53 percent higher.

It is extremely difficult to understand the root causes of these disparities. However, it is impossible to rule out race discrimination. As a result, in 1999, OCR, led by Michael Carter in New York, initiated a series of investigations designed to determine the root causes of disparities in a number of discrete areas. The initial OCR investigation focused on a number of facilities in the New York City area, in part because there was a significant amount of data available from New York State. Using the services of outside experts, OCR began the difficult process of ascertaining the root cause of the apparent disparities. These analyses seek to address a host of questions, including:

- Why is it that of the scores of cardiac catheterizations that a given provider performed over a certain period, only a handful were performed on people of color?
- Why is it that a particular facility with a sizeable minority population within its service area has extremely low utilization rates among this population?

There are no easy answers to these questions, but this is the first time that these questions are being addressed through the civil rights prism of Title VI. It may turn out that discrimination is not a factor in explaining these facts. Again, it is important to reiterate that there are two types of discrimination, intentional discrimination and disparate impact, and these

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<sup>37</sup> Fessenden, Ford. November 29-December 6, 1998. The Health Divide, *Newsday*.

investigations have focused on both theories. That is, is intentional discrimination somehow at work? Alternatively, and perhaps more likely, is there perhaps something in the hospital's marketing plan, referral patterns, or rules governing admitting privileges that has the effect of discouraging communities of color from using the facility?

A recent study on the experience of minority physicians in obtaining referrals for specialists and hospital admissions concluded that African-American physicians were more likely to report problems obtaining hospital admissions, and Hispanic physicians were more likely to report problems obtaining referrals to specialists.<sup>38</sup> The authors were unable to pinpoint the precise cause of the problems, although they noted that discrimination was a potential explanation that could not be ignored.

These inquiries are not capable of rapid resolution, but they are critically important to the disparities debate. In addition, it is virtually impossible for private litigants to undertake this ambitious task because it is extremely costly, is often more difficult for private litigants to obtain critical information, and the likelihood of recouping the costs of pursuing such an inquiry is speculative. As a result, OCR and the Department of Justice must take the lead in pursuing these questions.

Regardless of whether discrimination is the explanation for these apparent disparities, there is cause for concern, and time is of the essence. As a result, OCR, in addition to conducting the investigation under Title VI, has embarked upon an ambitious program of outreach and technical assistance designed to bring stakeholders together to discuss the disparities challenge, and identify and implement solutions. For instance, OCR developed a civil rights self-assessment tool designed to assist providers in asking a series of important questions that will allow them to assess current policies and practices, and make the necessary modifications to ensure that the provider is serving communities of color effectively. Overall, investigation, prevention, outreach, and enforcement are all equal parts of the overall OCR strategy.

### **Discrimination Concerns Unique to Immigrant Populations**

The immigration explosion of the 1990s has forced communities across America, urban, suburban, and rural, to identify solutions to meet the unique needs of immigrant populations. The language barrier is perhaps the most frequently encountered challenge that adversely affects the ability of immigrants to access health care. It is by no means the only challenge.

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<sup>38</sup> Hargraves, J.L. et al. August 9, 2001. Minority Physicians' Experiences Obtaining Referrals to Specialists and Hospital Admissions, *Med Gen Med*.



In addition, fear plays an important role in explaining the reluctance of immigrant populations to seek health care. Many citizens and legal immigrants are very reluctant to seek medical treatment, or apply for public benefits, such as Medicaid or State Children's Health Insurance Program (SCHIP) benefits, to which they are entitled. They are fearful for at least two reasons: (1) legal immigrants fear that accessing public benefits or uncompensated care will jeopardize their pending application for citizenship; and (2) there is a fear that accessing such services or benefits may force them to disclose information about the immigration status of a household member who is undocumented.

In reality, these fears are sometimes unfounded, and are based on a misunderstanding of federal policies. For instance, a legal immigrant can access Medicaid and SCHIP benefits without jeopardizing his or her application for citizenship in any way. Immigration officials do not take this into account in processing the application. In these cases, the solution is aggressive public education to ensure that immigrant populations have an accurate understanding of their rights.

Some fears are triggered by policies or practices by governments and health care providers that are neutral on their face, but have the effect of deterring many immigrants from seeking critical benefits to which they are entitled. These are the policies and practices that must be changed in order to maximize participation in critical health care programs.

OCR and private advocacy organizations spend considerable time and energy identifying and eliminating unnecessary barriers to participation in critical health programs for immigrant populations. For instance, OCR initiated an investigation of the state of Georgia upon learning that Georgia's application for Medicaid benefits required all applicants to certify under penalty of perjury that all members of the household were legal residents of the United States. The only relevant immigration question for Medicaid purposes was the immigration status of the applicant himself or herself. The effect of including such a question was to deter eligible applicants from applying, because they were fearful that family members who were not documented would be reported to the Immigration and Naturalization Service.

This practice not only deterred eligible applicants from applying; it also violated the Title VI regulations because it constituted a policy or practice that had a disproportionate adverse impact on the basis of national origin. As a result, OCR reached a settlement with Georgia, and the application form has been redesigned.

OCR then reviewed the application forms for benefits of all states, and found that many states asked a number of irrelevant questions that had the effect of deterring eligible immigrants and citizens from seeking critical benefits. OCR led an HHS effort in conjunction with the Depart-

ment of Agriculture that resulted in the dissemination of policy guidance to states outlining how states could fine-tune their application forms to maximize participation in critical benefits programs, and avoid potential liability under Title VI.<sup>39</sup> Maximizing participation of eligible immigrants in programs such as Medicaid and SCHIP is a critical measure that will assist in reducing disparities and enhancing health status among immigrant populations.

The Social Security Administration's "Enumeration at Birth" program is another example of a laudable initiative that deterred immigrants from accessing critical benefits as a result of one irrelevant question in the application process. This important program is designed to obtain social security numbers for babies at birth. Obtaining social security numbers at birth enables the baby to become eligible immediately for benefits, such as Medicaid. An implementation problem occurred when the application form required the parents to provide their social security numbers in order for the baby to receive a social security number. However, many of the immigrant parents of children born in the United States do not have Social Security numbers. Even though the baby was clearly eligible to receive a social security number, and access benefits, this irrelevant question had the effect of deterring parents from applying for a social security card. This in turn prevented or delayed the citizen child from accessing critical health benefits that are necessary to a healthy start. Upon learning of the problem in 2000, the Social Security Administration prompted issued guidance that corrected the matter, and eliminated this barrier to access for citizen children of immigrant parents.

Identifying barriers that prevent or inhibit immigrants from seeking health care is critical to reducing health disparities among this growing population. Upon close analysis, a number of the barriers for immigrants have a civil rights dimension, so that civil rights laws can be employed to eliminate them, and promote access to critical health benefits.

#### **PART FOUR: USING CIVIL RIGHTS STRATEGIES TO ASSIST IN ELIMINATING RACIAL AND ETHNIC DISPARITIES**

The research and the Title VI enforcement experience demonstrate that eliminating racial and ethnic disparities in health is both a civil rights and a public health challenge. As shown above, a number of barriers confronting communities of color have a clear civil rights dimension.

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<sup>39</sup> Department of Health and Human Services and Department of Agriculture. September 21, 2000. Policy Guidance Regarding Inquiries Into Citizenship, Immigration Status and Social Security Numbers in State Applications for Medicaid, SCHIP, Temporary Assistance for Needy Families and Food Stamp Benefits (on file with OCR).

Whether discrimination plays a role in explaining other barriers is less certain, and requires additional inquiry. This section outlines specific recommendations for eliminating racial and ethnic disparities in health that focus on the civil rights dimension of the disparities challenge.

### **1. Mandate the Collection of Data on Race, Ethnicity, and Language of Preference**

It is impossible to address racial and ethnic disparities in health status without adequate data. Data provide knowledge, and knowledge provides power to construct effective interventions. Yet, there are currently widespread data gaps that prevent stakeholders from obtaining the necessary information that permits the development of a comprehensive plan to eliminate health disparities in a particular area.

The need for adequate data collection on race, ethnicity, and language of preference is first and foremost a quality of care issue. For instance, health plans seeking to improve care for minority populations are often hindered because they do not collect data on the race and ethnicity of their members. As a result, it is impossible to study disparities in care, and measure the success of efforts to eliminate disparities in a particular area.

Data collection is also useful as a civil rights compliance tool. In other civil rights settings, data on race and ethnicity is routinely collected. For instance, the Department of Education collects data on race and ethnicity in the public school setting. The Equal Employment Opportunity Commission (EEOC) collects data on race, gender, and ethnicity of employers with greater than 15 employees. These data are useful to both employers and employees alike. In some cases, data show a pattern or practice of discrimination. On the other hand, the vast majority of employment discrimination claims filed with the EEOC result in a finding in favor of the employer, and the statistical evidence can be very helpful in providing the big picture that places an individual case in a useful context.

Regrettably, data collection is not required in the health care setting. The Department of Health and Human Services has the authority under the Title VI regulation to require providers and states to collect data on race, ethnicity and language of preference.<sup>40</sup> However, HHS does not have the legal obligation under the regulations to require the collection of data on race, ethnicity and language of preference.<sup>41</sup>

Thus, the decision to require the collection of data on race, ethnicity and language of preference rests within the discretion of HHS, and HHS

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<sup>40</sup> U.S. Department of Health and Human Services Title VI Regulation, 45 CFR 80.6.

<sup>41</sup> *Madison Hughes v. Shalala*, 80 F.3d 1121 (6<sup>th</sup> Cir. 1996).

has exercised this discretion in a piecemeal fashion. For instance, OCR has required data collection as part of a resolution of a particular discrimination case. In addition, the OCR Title VI policy guidance on language access notes the importance of collecting data on language of preference. The recent SCHIP regulation, published June 25, 2001, in the *Federal Register*, requires states to collect data on race and ethnicity. The original version of the SCHIP regulation also required collection of data on language of preference. The final regulation omitted this critical requirement, which is quite regrettable.

Nonetheless, the collection of data on race and ethnicity will enable state officials to measure more effectively their level of success in enrolling children of color in SCHIP. Many states are already collecting data on race, ethnicity *and* language of preference. Consequently, there is useful data available in a number of states.

It is important to note that collecting data on race, ethnicity and language of preference does not violate federal law. A number of providers have raised concerns that it is illegal under federal law to collect data on race and ethnicity. To the contrary, as noted earlier, Title VI regulations explicitly empower HHS to require the collection of such data. HHS has taken a number of steps to educate providers on this issue. For instance, in January 2001, OCR and the Surgeon General sent letters to over 30 prominent health care organizations underscoring the importance of data collection, and providing assurances of its legality under federal law. HHS has also funded numerous projects on data collection.

Overall, the current data collection system is patchwork at best. The issue of whether the federal government can require providers to collect racial and ethnic data is *not* a question of statutory or regulatory authority. HHS has the authority to require data collection. Mandating data collection boils down to a question of political will.

It is useful to look at the evolution of data collection efforts in other civil rights settings in order to fully appreciate the efficacy of data collection.

#### **Data Collection in Mortgage Lending— The Home Mortgage Disclosure Act**

The historical debate surrounding the role of discrimination in mortgage lending is quite similar to the current debate in health care. Communities of color had difficulty obtaining a mortgage, and many groups were concerned about redlining. To put it slightly differently, widespread concerns existed about whether there were racial disparities in the rate of denial of applications, and whether these disparities, if any, were a function of discrimination, or some other non-discriminatory factor.

In 1968, Congress had passed the Fair Housing Act, which contained an explicit anti-redlining provision. However, problems of discrimination in housing persisted, and Congress in 1975 passed the Home Mortgage Disclosure Act (HMDA).<sup>42</sup> HMDA illustrates how federal regulations mandating data collection can serve as a powerful tool for social and policy change to improve the lives of marginalized and disenfranchised minority populations.

The stated purposes of HMDA are:

- (i) To help determine whether financial institutions are serving the housing needs of their communities;
- (ii) To assist public officials in distributing public sector investments so as to attract private investment to areas where it is needed; and
- (iii) To assist in identifying possible discriminatory lending patterns and enforcing anti-discrimination statutes.

HMDA is a pure data collection statute. There is no private right of action under HMDA, meaning that the enforcement of HMDA is entirely dependent upon federal regulators. HMDA data are insufficient to state a civil rights claim under the Fair Housing Act or any other federal provision. However, HMDA data frequently give a broad snapshot of trends that allows investigators to determine whether additional investigation is warranted.

A number of federal agencies are involved in the data collection effort, including the Federal Reserve, the Federal Deposit Insurance Corporation, the National Credit Union Administration, the Comptroller of the Currency, and the Office of Thrift Supervision. Collectively, these agencies comprise an interagency entity called the Federal Financial Institutions Examination Council (FFIEC). Financial institutions must comply with HMDA, and the term “financial institution” is broadly defined to include banks, savings associations, credit union and mortgage lending institutions, as well as their subsidiaries. They are required to report a variety of information on their mortgage lending practices to the FFIEC, including but not limited to information relating to the race and ethnicity of applicants for mortgages.

From 1975 to 1989, HMDA was in place but had little effect on lending practices. According to one expert, it had little effect because the data were collected but were not widely publicized or collected in a publicly accessible format.<sup>43</sup> In 1989, HMDA was amended to make the data pub-

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<sup>42</sup> 12 United States Code 2801.

<sup>43</sup> Interview with Kenneth Zimmerman, executive director, New Jersey Institute for Social Justice, Newark, New Jersey.

lic for the first time. Once the data were publicly disseminated, community-based organizations and other advocacy groups were empowered because they could use the HMDA data to compare data on area lenders and put pressure to bear on lenders that appeared to have problematic data.

It was not until the Sunshine Amendment of 1989 that an industry of social scientists emerged who spent considerable effort breaking down HMDA and other data to pinpoint the potential role of various explanatory factors, including but not limited to discrimination. As a result of these analyses, investigators were able to answer for the first time the critical question: did discrimination infect the process, or were the disparities a function of other, non-discriminatory factors? In a number of cases, discrimination was pinpointed as a root cause, and the Department of Justice settled a number of mortgage lending cases during the 1990s, including:

- *United States v. Albank*: The bank agreed to provide \$55 million in loans at below market rates to settle a suit alleging that the bank refused to take mortgage loan applications from significant minority populations.
- *United States v. Decatur Federal Savings and Loan*: The bank agreed to pay \$1 million to compensate 48 victims of discrimination after extensive review of bank records revealed that the bank applied stricter underwriting standards to African-American applicants than it did to white applicants.

### The Lessons of HMDA

There are a host of lessons that can be gleaned from the HMDA experience. First, HMDA has given meaning to the adage that “knowledge is power” because it has assisted in answering critical questions about the role of discrimination. Knowledge can also be powerful in the health care context.

Second, HMDA illustrates that it is not simply important to collect data; rather, it is important to collect the right data. In the health context, stakeholders can and must develop consensus on standard data collections methods, as well as the types of data that should be collected. Otherwise, it becomes difficult to compare and analyze data. Perhaps data collection will differ between geographic areas. However, it is important to develop a commonly accepted language of data collection.

Third, it is also important to reevaluate the data being collected on a periodic basis. In the HMDA context, for instance, there currently is no data being collected by race and ethnicity on the interest rate that is being charged. With the emergence of predatory lending as a formidable civil rights challenge, the absence of these data is problematic. Similarly, in the

health care settings, it is important to reexamine data collection protocols regularly and adjust to meet emerging concerns.

Finally, and perhaps most importantly, it is not simply important to collect data. It is also important to report data, and ensure that data are accessible to the public at large. The 1989 Sunshine Amendment marked a critical turning point under HMDA. Similarly, allowing public access to data will enable policymakers and the public at large to have a better handle on critical questions and potential trends. In so doing, it is important to be mindful of considerations of medical records privacy, as well as the recently enacted federal medical records privacy regulation. However, it is possible to obtain basic necessary information without running afoul of the privacy regulation.

### **Racial Profiling: The Importance of Data Collection**

Racial profiling by law enforcement is one of the most frequently discussed civil rights issues. Once again, the debate mirrors the racial disparities discussion. Critics contend that police officers target African Americans and Latinos on account of their race, and stop them improperly and illegally. Police officials counter that a person's race is not the basis for a traffic stop. Rather, a police officer takes a host of factors into account. Racial profiling was the subject of debate during the past presidential election race, with both candidates decrying the practice.

There is considerable disagreement about how to go about answering the question of whether police officers are engaging in racial profiling. The Special Litigation Section of the Civil Rights Division of the Department of Justice has the authority to investigate racial profiling cases. It has concluded that an effective means of resolving this issue is to collect data on traffic stops. As a result, a number of recent consent decrees in police misconduct cases have included provisions mandating the collection of racial and ethnic data on traffic stops. Agencies that have agreed to collect data include the Pittsburgh Police Department and the New Jersey State Police.<sup>44</sup>

Data collection is not limited to consent decrees. According to a February 2000 fact sheet issued by the Bureau of Justice Statistics of the United States Department of Justice, a total of 37 police agencies collect racial demographic information on traffic-related arrests with close to a dozen states mandating such efforts. This number is growing. Congress is debating a bill that would mandate the collection of data on race and ethnicity in traffic stops. If passed, this bill, among other things, would

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<sup>44</sup> To review these consent decrees, see [www.usdoj.gov/crt/split](http://www.usdoj.gov/crt/split).

require the development of a uniform system for collecting the data, so that the appropriate data are collected.

Critics are concerned that the data will somehow be misused. The federal legislation addresses this concern with its provision for the development of a uniform data collection system. Opponents of data collection continue to express concerns about potential misuse of data, and a belief that collecting the data will not answer the question.

Regarding data collection, two things appear clear in both the racial profiling and the health care context. First, simply collecting the data will not answer the question of whether discrimination is at work. The data will have to be analyzed and, as shown in the HMDA setting, such inquiry can shed light on critical questions. Second, failing or refusing to collect data guarantees that the critical questions about the root causes of disparities will never be answered definitively. As one high-ranking official of the San Diego County Sheriff's Department stated, after the Department agreed to collect racial and ethnic data on traffic stops, "[the community] deserve[s] an answer on what's really going on here."<sup>45</sup> The public also deserves an answer on what is really going in the disparities context, and the collection of racial and ethnic data holds a key to answering so many critical questions.

### **Conclusions Regarding Data Collection**

Effective data collection is the lynchpin of any comprehensive strategy to eliminate racial and ethnic disparities in health. Collecting data on race, ethnicity, and language of preference is a quality of care as well as a civil rights issue. Health providers should not wait for HHS to mandate the collection of data relating to race, ethnicity and language of preference. Fortunately, many health care providers have already begun to collect these data, and many states also require the collection of data. But these patchwork efforts are not nearly sufficient. HHS must exert leadership and mandate the collection of data, and assist in the development of uniform data collection systems. The expertise certainly exists within HHS to perform this critical task.

### **2. Strengthen the Federal, State, and Private Health Care-Related Civil Rights Infrastructure**

Discrimination in health care is the forgotten frontier of civil rights. It is seldom discussed. There are relatively few private advocacy organizations

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<sup>45</sup> February 26, 1999. San Diego To Study Racial Profiling—Officers Will Collect Race Data on Every Traffic Stop. [www.apbnews.com/cjprofessionals/behindthebadge/1999/02/26/sandiego0226\\_01.html](http://www.apbnews.com/cjprofessionals/behindthebadge/1999/02/26/sandiego0226_01.html).



involved in a steady diet of health care related civil rights advocacy. The National Health Law Program is perhaps the most effective national advocacy organization that focuses on the intersection of health care and civil rights. Due to resource constraints, other private civil rights organizations have been forced to scale back their health care practices in recent years.

The Department of Justice's Civil Rights Division has 10 different sections that address critical areas such as education, employment, housing, disability rights, and the like. There is no section whose exclusive or even primary mission is to address the intersection of health care and civil rights. There are sections that address health-related civil rights issues, and these sections make an important contribution. However, given the importance of health care, and the history of discrimination in health care, it would be useful if health care were on equal footing with education, housing, employment, and other critical building blocks of self sufficiency.

The Office for Civil Rights at HHS is the lead federal agency combating discrimination in the health care setting. The first budget of HHS OCR (fiscal year 1980) was \$22 million, which supported approximately 550 employees. The budget remained stagnant for the ensuing two decades, and the budget for fiscal year 2000 was also \$22 million, which supported only 215 employees. As a result, it has been difficult for OCR to carry out its critically important mission in a fully effective manner. Nonetheless, OCR has established a body of cases that document continuing instances of discriminatory activity, in violation of Title VI.

A 1999 report from the U.S. Civil Rights Commission was quite critical of some of OCR's work in the Title VI context, and cited the chronic underfunding. Among other things, the Report recommended a substantial boost in funding for OCR. The budget for fiscal year 2001 increased substantially to \$28 million. However, this substantial increase is only a fraction of OCR's true need. OCR's staff has decreased over 50 percent during the past 20 years, even though its enforcement responsibilities have increased dramatically with the passage of new civil rights laws, such as the Americans with Disabilities Act. As a result of *Sandoval*, OCR's role in enforcing Title VI has become even more important, because it is more difficult for private plaintiffs to bring many Title VI claims.

In order to address the disparities challenge effectively, OCR must have substantial increases in its budget. The substantial hike in 2001 was important, but should be viewed as just a start. HHS as a whole is spending hundreds of millions of dollars addressing racial and ethnic disparities. OCR should have a much greater share of these dollars. Among other things, increased resources would enable OCR to develop the institutional capacity to perform the sophisticated analyses necessary to answer difficult questions discussed earlier, such as why so few people of color are accessing certain medical procedures in a particular facility.

State governments must also expand their health care-related civil rights enforcement infrastructure. California, for instance, has more people with limited English skills than any other state. Yet, the state office responsible for ensuring that counties comply with their civil rights obligations in the language access context has only a handful of people. It is simply impossible to carry out effective enforcement and compliance monitoring with a skeleton crew.

The foundation community has been supportive of private advocacy organizations that are involved in a wide-ranging set of initiatives designed to address racial and ethnic disparities in health. The California Endowment, for instance, has made a major investment in the area of language access. However, additional foundations must step to the plate and expand the capacity of private organizations to address these disparities. In some circumstances, such as combating discrimination in managed care, this may mean supporting litigation activities, which a number of foundations have been reluctant to do.

Strengthening the governmental and private civil rights infrastructure will go a long way toward ensuring that the civil rights concerns are addressed.

### **3. Develop a Comprehensive Language Access Agenda**

Ensuring language access for people with limited English skills is arguably the most important measure that could be taken to reduce disparities among the rapidly expanding immigrant populations. Ensuring language access is also a quality of care issue. The solutions are not difficult to envision. In fact, many providers across the country, large and small, urban and rural, have put into place model programs that are both cost-effective and are improving the quality of life for people with limited English skills.

Yet, the solutions are all too elusive in too many parts of the country, and the demand for these services is increasing. Under the leadership of Secretary Donna Shalala, HHS focused substantial time and energy on language access issues. The OCR Title VI policy guidance was issued in August 2000, on the heels of an Executive Order in which former President Clinton directed leaders across the federal government to address language access challenges. Following the policy guidance, HHS developed an agency-wide Strategic Plan on language access, designed to ensure that HHS has the capacity in its own programs to ensure meaningful access to people with limited English skills. In short, HHS has attempted to set the tone on language access, and these efforts are continuing.

A number of additional steps can be taken on the language access front. Potential steps include the following:

**A. More Foundations Must Get Involved**

Foundations must continue to provide support to language access efforts. For instance, there are many best practices across America, but surprisingly little sharing of information. Foundations can promote sharing of best practices, as can HHS. Foundations must also continue to support efforts to implement innovations. The United Hospital Fund, for instance, has been instrumental in bringing together providers and community-based organizations to develop a promising system of medical interpretation that uses wireless remote technology and would enable providers to meet a wide range of need. More foundations need to make a substantial commitment to language access.

**B. Educate and Train Providers on Their Obligation to Provide Language Assistance Services**

A massive training and education campaign must be undertaken to ensure that providers understand their obligations to ensure meaningful access to people with limited English skills, and also appreciate that it is possible to implement solutions that work and are not prohibitively expensive. OCR spends as much time on language access issues, including training and outreach, as any issue in its portfolio of responsibilities. Despite these efforts, and despite the recent publication of the OCR guidance, all too many providers are unaware of their responsibilities under Title VI to ensure meaningful access to people with limited English skills.

Foundations and HHS should support the establishment of technical assistance centers that would assist providers in developing language assistance programs, educate communities on their rights under Title VI, and conduct research on a number of critical issues in the language access context, such as whether the provision of effective language assistance services is actually cost-effective. Providers frequently express a desire for technical assistance in developing effective programs. However, some providers are reluctant to reach out to OCR for assistance, because they fear that OCR will conduct a review and find them in violation of Title VI. They are sometimes fearful of reaching out to community-based organizations or advocacy groups, because they perceive that these groups may sue them. Technical assistance centers would be the neutral entity with expertise to assist providers in a non-threatening manner, disseminate best practices, and perform research.

**C. Address the Critical Financing Challenge**

Any plan to enhance language access must address the financing challenge. For providers, the financing challenge is *the* critical issue in language access. Many providers contend that they are willing to comply

with Title VI, but simply cannot afford the cost of an interpreter. For instance, following the issuance of the OCR policy guidance on language access, the American Medical Association expressed concerns to then Secretary Shalala and, subsequently, to Secretary Thompson that the costs of compliance for physicians would be prohibitive.

Cost concerns are certainly understandable. It is important to learn from the numerous providers and states that have developed comprehensive programs that have not placed the exclusive burden of compliance upon physicians. For instance, Washington State has developed an impressive program of cost reimbursement for language assistance that makes substantial use of Medicaid matching funds. As a result, if a physician is seeing a Medicaid patient with limited English skills, he or she simply makes arrangements with the state agency that will provide a qualified interpreter at no charge to the physician or patient. The state also provides translation of critical documents and forms, such as consent forms, into over 60 languages.

Washington's experience illustrates that it is possible to meet the financing challenge. However, meeting the challenge requires leadership, ingenuity and financial commitment from the state. It can be done, but Washington regrettably is an exception rather than the rule. The lesson from the Washington experience is that the financing challenge requires leadership from state government leaders. In the Medicaid and SCHIP context, HHS already provides matching funds for the costs of language assistance services, and there is no upper limit on the amount of matching funds that HHS will provide. States must step forward and commit to tapping into these matching funds by declaring that language assistance services are essential services, just as a physician is essential. More states need to follow Washington State's lead.

#### **D. Encourage Innovation**

There are a number of promising practices in language assistance, and the federal government and private foundations must expand their support for innovation. The Office of Minority Health and the Agency for Health Research and Quality (AHRQ) within HHS, along with a number of private foundations, have funded a number of innovative programs. However, other federal agencies, as well as additional foundations, can and should support these efforts.

#### **E. Develop a Research Agenda on Language Access**

A robust research agenda exists in language access, and should be supported by HHS and private foundations. Questions that merit further research include:

- Is the provision of adequate language assistance services cost-effective for providers?

- Are certain types of language assistance more effective in ensuring meaningful communication?
- Does fluency in English affect access to critical services, such as immunizations?
- What do the most effective language assistance programs have in common?

Overall, language access is the low hanging fruit of racial disparities in that many promising interventions have been identified, and are capable of implementation. Yet, the low hanging fruit is still on the tree, and additional leadership and visibility must be given to this issue.

#### **4. Identify and Eliminate Other Barriers for Immigrants**

Language access is critical for immigrant communities. However, all stakeholders must be vigilant in continuing to identify and eliminate additional barriers that inhibit many legal immigrants from accessing critical health care. OCR has led a nationwide initiative to examine application forms for public benefits to ensure that they do not make irrelevant inquiries that have the effect of chilling participation in programs such as Medicaid and SCHIP. Considerable work lies ahead on this issue, and other barriers frequently emerge. Community-based organizations are critical to this effort, as their collective fingers are closest to the pulse of immigrants, and they enjoy the trust of immigrants. As a result, it is important to support their efforts, and important for government to partner with community-based organizations on outreach and education campaigns.

#### **5. Preventing Discrimination Through Education of Providers and Patients**

In addressing the root causes of disparities, Dr. Jack Geiger noted recently that racial bias and lack of cultural competence on the part of health care workers “may be the most directly remediable problem, if they are honestly recognized and if programs are designed to address them.”<sup>46</sup> Many providers and schools have begun to implement programs of study on cultural competence. The Office of Minority Health at HHS issued Standards on Cultural and Linguistic Competence in 2000.<sup>47</sup> There is sub-

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<sup>46</sup> Geiger, J. June 12, 2001. Racial Stereotyping and Medicine: The Need for Cultural Competence, *Canadian Medical Association Journal*, 164(12):1699-1700.

<sup>47</sup> Department of Health and Human Services. 2000. Office of Minority Health National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care. Federal Register 65(247).

stantial financial support from governments and foundations for these overall efforts to promote cultural competence. There are proposals to make such efforts a requirement for the accreditation of health professional schools. But the work is just beginning, and it is necessary to expand these efforts, and to develop tools that will enable policymakers and providers to measure the effectiveness of these training programs. This training must include discussion of civil rights obligations of health care providers.

It is important not only to educate health care providers, but also to educate and empower patients themselves, and assist them in navigating the often-treacherous terrain of health care. Harlem Hospital in New York, for instance, has implemented a patient navigator program designed to provide advocates for patients who can assist them in asking the appropriate questions, and making the necessary inquiries as they access the health care system. Many immigrants are reluctant to question authority figures, such as physicians, and patient navigator programs are helpful in ensuring that the necessary questions are asked. Community-based organizations can play a critical role in educating and empowering patients. It would be useful to implement and study the effectiveness of a number of patient empowerment programs that affirmatively reach out to vulnerable populations and educate them about a wide panoply of issues in health care, including but not limited to civil rights.

## 6. Fix *Sandoval*

Congress should act to restore the status quo that existed prior to *Sandoval* by passing legislation to reestablish that there is a private right of action for disparate impact discrimination under the Title VI regulation. The failure to restore the private right of action will mean that private advocacy organization will have to fight many health care discrimination battles with one hand tied behind their backs. The failure to restore the private right of action will also place more pressure on an already overburdened OCR to pursue disparate impact cases.

*Sandoval* is not limited in its impact to language access cases. Private plaintiffs interested in pursuing disparities complaints in other contexts, such as access to treatment in hospitals, will find it more difficult, if not impossible, to make use of Title VI. For instance, if the evidence demonstrates that a hospital policy, such as a referral practice or admission policy, is having a disparate impact on the ability of minorities to use the facility, a private plaintiff would be prohibited under *Sandoval* from suing the hospital under Title VI.

Proving disparate impact discrimination under Title VI is hard enough, given the difficulty of unpacking the complex maze of interactions in the

health system. *Sandoval* provides an additional disincentive for an already small cadre of lawyers who address civil rights issues in health care.

### **7. Develop the Capacity and Infrastructure to Address Critical Civil Rights Questions in Managed Care**

Some of the most complex civil rights issues occur in the managed care context. Racial disparities may be a function of a potential collision of market forces and practice patterns of minority physicians, who tend to have patient pools that are disproportionately minority, poor, and potentially less healthy. Given this potential collision, it is not difficult to understand why over 90 percent of African-American doctors believe that managed care organizations discriminate against them in contracting. The critical question is whether the perceptions of discrimination are the reality, or whether managed care organizations are engaging in legitimate business practices.

Regrettably, there is very little research that has addressed this critical question.<sup>48</sup> There are few lawsuits that have addressed this issue; however, as a result of continuing concerns raised by the National Medical Association and its membership, this may change. Grantmakers both within and outside government should support efforts to study this issue in greater depth, and attempt to determine whether the perceptions of many physicians of color are accurate or not. The lack of a sufficient private infrastructure of organizations that address discrimination in health care is hindering the effort to answer these critical questions. OCR's activities in managed care have focused primarily on language access issues. Issues of redlining in managed care and potential discrimination in selection and de-selection of physicians for provider networks, have received less attention, not because they are less important. Supporting a research agenda in this area, and supporting the efforts of private organizations to study the critical questions of potential discrimination in managed care, either in a litigation or non-litigation context, is critical to addressing the broader concerns once and for all.

### **8. Perform a Civil Rights Self-Assessment**

It is exceedingly difficult, time-consuming, and costly to perform the sophisticated regression and other analyses that will enable investigators

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<sup>48</sup> For a further discussion of civil rights issues in managed care, see Rosenbaum, S. 2001. *Racial and Ethnic Disparities in Health Care: Issues in the Design, Structure and Administration of Federal Health Care Financing Programs Supported Through Direct Public Funding*, Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care.

and researchers to pinpoint with precision the precise causes of a particular disparity. Many providers are not waiting for the completion of this analysis, and initiated a series of activities, such as cultural competence training and review of language access programs. As part of its outreach and technical assistance, OCR, led by Michael Carter, regional manager in New York, developed a civil rights self-assessment tool. This instrument is aimed at enabling providers to ask a series of important questions that will enable the provider to assess current policies and practices, modify policies and practices that may have a discriminatory effect, and institute innovative measures to ensure that communities of color can have meaningful access to the facility. The self-assessment tool is a prevention tool designed to encourage voluntary compliance efforts. Providers should consider using this tool or some other instrument that will enable it to perform a critical civil rights self-assessment.

### CONCLUSION

Eliminating racial and ethnic disparities in health status is a moral imperative for which there is no single magic bullet. As policymakers, politicians, and the health care profession grapple with how to eliminate disparities, it is time to acknowledge certain realities about disparities. It is indeed deadly to be poor in America, and communities of color are disproportionately poor. Yet, the disparities story does not end with economics, and any story that does is simply incomplete. Similarly, a disparities story that ignores the potential role of race and racial discrimination is also incomplete.

This paper has documented specific settings where forces of discrimination are at work in the health care system, and has identified other areas where there is insufficient information to make a definitive judgment about the role of discrimination. It is critically important to understand the civil rights dimension of the disparities challenge, and acknowledge the unpleasant reality that race often matters in health care. It is equally important to implement solutions, many of which are described above, to address areas where discrimination is clearly at work, and to support the necessary research and advocacy to resolve the unanswered questions.



# Racial and Ethnic Disparities in Healthcare: Issues in the Design, Structure, and Administration of Federal Healthcare Financing Programs Supported Through Direct Public Funding

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## INTRODUCTION

An examination of the relationship between racial disparities in healthcare and public healthcare financing may strike some as ironic, given the well-documented role that programs such as Medicare and Medicaid have played in reducing racial and ethnic disparities in healthcare access and health outcomes (Congressional Research Service, 1993; Committee on Ways and Means, 1996; Davis and Schoen, 1978; Moon, 1993; Starr, 1982; Smith, 1999; The Henry J. Kaiser Family Foundation, 1999). But in the face of a significant and ongoing health gap between minority and non-minority individuals, it is worth considering whether the manner in which public financing programs are administered has the potential to contribute to one of the nation's most sobering and enduring public health problems.

This paper begins with a background and overview that briefly describe Medicare and Medicaid (and its companion SCHIP program) and roles in financing healthcare for minority persons. It then turns to a more extended analysis of the kinds of administrative choices made under these programs that have the potential to contribute to the problem of health disparities, either by tolerating or tacitly countenancing access, treatment and quality differentials or by failing to act affirmatively to minimize the possibility of differentials.

This paper examines issues in federal and state administration of health programs rather than the legislative design of the programs themselves. Several limitations and caveats should be noted at the outset. First, the association between race and poverty makes it difficult to disentangle

the two factors. Administrative choices that adversely affect poor patients are also more likely to create problems for minority patients. The literature is replete with studies of race-associated healthcare disparities; regardless of payer source, income, or other characteristics unrelated to healthcare need, racially linked health disparities appear to be one of the most unfortunate constants of the American health system (U.S. Civil Rights Commission, 1999; Mayberry et al., 2000; Gaskin and Hoffman, 2000; Weinick et al., 2000). Minority patients perceive barriers and racism within the health system, and at least some research suggests that these perceptions appear to be borne out by discernible differences in how health professionals interact with minority patients (The Henry J. Kaiser Family Foundation, 1999; La Viest et al., 2000; Lillie-Blanton et al., 2000; Einbinder and Schulman, 2000; Schulman et al., 1999). Furthermore, studies confirm the independent role of race in healthcare (Mayberry et al., 2000). At the same time, it is difficult to separate healthcare administration choices that harm poor people from those that harm members of racial and ethnic minority groups. This is particularly true in the case of programs such as Medicaid, where coverage is specifically aimed at the poor and medically indigent.

Second, even if U.S. lawmakers were to enact a totally reformed system that utilizes a single payer with common coverage and payment rules, research from other nations suggests that minority and poor residents nonetheless would continue to experience reduced healthcare access and poorer health outcomes. The literature on disparities in healthcare access is replete with examples of disparate access to care and disparate utilization of health services (Mayberry et al., 2000; Lillie-Blanton et al., 2000). The most recent example can be found in a 2001 Surgeon General's report examining racial and ethnic disparities in the use of mental health services by members of racial and ethnic minority groups, which speculates on the underlying causes of disparity in access, utilization and quality and concludes that the principal factors are cost, poor services in poor communities, cultural and communications barriers, fear of the health system, and general overall problems in the relationship between patients and providers (U.S. Department of Health and Human Services, 2001). This focus on provider/patient communication difficulties, fear of the system, and cultural isolation in healthcare appear to be recurrent themes throughout the literature on healthcare disparities.

Furthermore, the evidence on disparate access to care even where insurance is technically not a barrier is hardly unique to the United States. For example, studies of the apparently common practice of using government-sponsored community health clinics in nations with national health systems typically point to the need for such service delivery interventions because of access barriers related to race, ethnicity, culture, and poverty

(Hawkins et al., 2000). Consequently, even aggressive efforts to reduce disparity-causing choices in the administration of healthcare financing programs could nonetheless continue to leave minority and low-income patients with unequal access.

Third, even substantial incremental reforms that improve existing programs but leave them intact inevitably would leave millions of Americans dependent on sources of healthcare financing that are perceived as other than “mainstream,” and thus subject to the misapprehensions that enrollment in “lesser” programs brings with it. The data reviewed for this study suggest that incremental reforms would leave a racially and income-identifiable group of Americans disproportionately enrolled in forms of healthcare financing that are less attractive to healthcare providers because they cover less, pay less, and carry unpleasant connotations and associations, such as bureaucratic hassles and the status of a “poor people’s program.”<sup>1</sup> This lesser form of coverage in effect validates on business grounds what may be underlying prejudicial leanings on the part of members of the medical care industry.

Finally, and as noted at the outset, any assessment of the limitations of directly financed public insurance programs such as Medicare and Medicaid must be read against a backdrop of their extraordinary accomplishments over the past three and a half decades. Since their inception, Medicare and Medicaid have literally remade the American healthcare system for minority Americans, opening access that previously had been denied. At the time of their enactment, white Americans were hospitalized 27% more frequently than African Americans and members of other minority groups, and in the case of elderly persons, the racial gap stood at 70%. By 1975, the gap had narrowed to 4% overall and 14% among the elderly (Davis and Schoen, 1978). Research also has pointed to the connection between the decline in U.S. infant mortality rates and the advent of Medicaid, which made pregnancy related care available and accessible to the poorest women (Davis and Schoen, 1978; Congressional Research Service, 1993).

Data on access to and use of healthcare by income and insurance status suggest that Medicaid has eliminated healthcare access and utilization disparities among children and non-elderly adults, particularly when utilization data are adjusted for reduced health status; indeed, poor Medicaid beneficiaries appear to use care at rates greater than the poor with

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<sup>1</sup> At one time, dependence on Medicaid was viewed by health providers and policymakers as stigmatizing. As Medicare has become increasingly complicated and overall payment has declined in relation to the overall cost of care, anecdotal evidence suggests that reliance on Medicare (either alone or in combination with Medicaid) may be producing similar reactions within the health system.

private insurance, presumably because of the program's broad coverage rules and strict limits on cost sharing, discussed below (Congressional Research Service, 1993). Although the source of care differs, Medicaid beneficiaries have been shown to be significantly more likely to have a usual source of care (Congressional Research Service, 1993). Medicare and Medicaid have been directly credited with the desegregation of U.S. hospitals, nursing homes, and other healthcare institutions, as providers rapidly moved to eliminate the techniques of discrimination in order to be able to participate in government health programs (Smith, 1999).<sup>2</sup>

Despite these limitations, it is important to understand the extent to which the administration of publicly funded health coverage has the potential to perpetuate, intensify, or implicitly validate differential treatment of minority Americans.

### Background and Overview

Medicare and Medicaid represent enormous advances in American social welfare policy. The joint product of an extraordinary convergence of social, policy, and political circumstances that have been chronicled at length and in multiple dimensions by numerous experts (Fein, 1986; Marmor, 1970; Moon, 1993). Medicare and Medicaid not only opened the health system to previously uninsured persons but changed American healthcare itself by supplying the financing needed to achieve the enormous leaps in medicine and technology that the nation has witnessed over the past 40 years.

For purposes of issues that are dealt with in this paper, it is important to remember the context in which Medicare and Medicaid were enacted. As Marilyn Moon has observed, "[t]he rules that were established to govern Medicare did little to disrupt or change the way healthcare was practiced or financed in the United States." In his seminal history of the federal government's efforts to address race discrimination in American healthcare, David Barton Smith describes the civil rights environment in which Medicare and Medicaid were enacted, with *de jure* race discrimination in healthcare having only recently ended, and with Southern Members of Congress threatening to derail passage of Medicare if its funding were used under Title VI as a lever to force healthcare integration (Smith,

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<sup>2</sup> These techniques included such devices as denying admission to patients without staff physicians while simultaneously denying admitting privileges to minority physicians or physicians working at publicly funded clinics located in medically underserved communities, segregating the wards and wings of hospitals and nursing homes, placing strict numerical limits on minority patients admitted or served, demanding insurmountable pre-admission deposits (akin to a poll-tax), and refusing to participate in certain government insurance programs, particularly Medicaid (Rosenbaum et al., 2000).

1999). In its efforts to secure Medicare's enactment, the Johnson Administration effectively promised that Medicare funding would not be used as a basis for Title VI enforcement against physicians in individual practice and thus as a means of achieving changes in the behavior among medical professionals.<sup>3</sup> This promise had major implications for the autonomy of American medicine and was consistent with the overall hands-off approach of the original Medicare legislation when it came to altering the behavior of physicians. The Administration made good on its promise by interpreting Medicare physician payments as a form of indemnity coverage, which lacked the requisite nexus to federal funding to produce Title VI enforcement jurisdiction—which hinges on the receipt of federal financial assistance. Despite the virtual end of Medicare as an indemnity-style program (physicians now are effectively required to accept direct, assigned Medicare payments as a condition of participation through the use of payment penalties for those physicians who refuse assignment), succeeding administrations never have issued an outright reversal of this original interpretation of the program in a Civil Rights Act context.<sup>4</sup>

While both Medicare and Medicaid are quite complex, Medicaid is especially so because of its cash welfare assistance roots, as well as its uneasy perch atop a honeycombed federal-state system of program authority. It is not possible to understand how the design and administration of the programs (as well as the more recent SCHIP statute) could potentially create disparities without a basic familiarity with the programs and their relationship both to other payers as well as to each other.

### *Medicare*

Medicare is a federally administered social insurance program that finances a defined set of health benefits for individuals who qualify for coverage (i.e., individuals who are entitled to Social Security Old Age or Disability Insurance benefits, children and adults with end-stage renal

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<sup>3</sup> Of course no similar promise was made with respect to Medicare payments to hospitals, whose desegregation already had been forced by the courts. Smith presents a marvelous overview of the Johnson Administration's near-superhuman effort to achieve compliance agreements with all Medicare-participating hospitals by the date of Medicare implementation, only six months following enactment.

<sup>4</sup> The hesitation to extend civil rights statutes to office-based health professionals on the basis of their participation in federal healthcare financing programs continues today. In 2000, the federal government released guidelines clarifying existing civil rights act standards as they apply to healthcare access among persons with limited English proficiency. Included in the regulations was clarification that physicians would be considered subject to these standards if they participated in Medicare and Medicaid. By the spring of 2001, nearly all of the major private medical groups were meeting with White House officials demanding the repeal of the guidance.

disease, and certain individuals who are permitted to purchase coverage). In 2000, Medicare outlays reached \$216 billion (Congressional Budget Office, 2001) and total program enrollment stood at over 39 million (HCFA, 2001a).

Medicare is federally administered according to uniform standards, most of which are found in extensive regulations governing the program. The program consists of three parts (A, B, and C). Part A (Hospital Insurance) is paid for through a payroll tax-based trust fund; it covers inpatient and outpatient hospital services, post-hospital extended care services, home healthcare, and hospice benefits. Part B (Supplementary Medical Insurance) is financed through a combination of premium payments and general revenues. Part B covers physician and other medical services, outpatient hospital care, home health services, certain preventive services, clinical diagnostic laboratory services, ambulatory surgical services, and outpatient mental health services.

Part C of Medicare, enacted in 1997, established the Medicare+Choice program as a means of encouraging enrollment in managed care arrangements and to modernize and strengthen the regulatory framework for Medicare managed care (Rosenblatt et al., 1997; 2001). Medicare contains significant cost-sharing requirements, including both deductibles and coinsurance.

While Medicare is federally administered, private insurers (known as carriers and intermediaries) conduct the day-to-day business of provider enrollment, claims payment, and coverage decision-making. Qualified managed care organizations, known as Medicare+Choice providers, carry out broad contractual responsibilities for the federal government.

Both the Medicare statute and implementing regulations establish conditions of participation for medical care institutions and professionals; indeed, much of the Medicare legislation is devoted to the establishment of standards of participation for health professionals, hospitals, other institutions and suppliers, and the managed care industry. Medicare also specifies a range of formulas for provider compensation in the case of hospital care, physician and medical care, and payments to managed care entities. State health agencies, accreditation bodies, and peer review organizations conduct provider certification and oversight activities.

Medicare was founded on the notion of health system freedom for both providers and patients alike. Physicians, hospitals, health professionals and suppliers have discretion over whether to participate in the program at all (although most U.S. physicians and virtually all hospitals and qualified nursing homes and home health agencies do so). Furthermore, providers can decide the extent of their participation, limiting their involvement for example to patients who once were privately insured and now depend on Medicare exclusively or primarily.

In a similar vein, a hallmark of Medicare from a beneficiary perspective is its free-choice-of-provider guarantee. It is probably safe to say that Medicare beneficiaries are the last remaining group of insured Americans who are given a choice with respect to how they use healthcare. Beneficiaries can elect to enroll in a Medicare+Choice plan if one is available;<sup>5</sup> alternatively, they can elect to remain in the “fee-for-service” system, obtaining medical and healthcare from the participating physician, healthcare institution, or other health professional of their choice.

While the concept of free choice among participating health providers exists in theory, in practice there are problems, although none so severe as those faced by Medicaid beneficiaries. When these problems are combined with various structural shortcomings in the Medicare program, they create a potential for barriers, particularly in the case of lower income beneficiaries, who are significantly more likely to be members of a racial or ethnic minority group. Medicare coverage is limited, omitting crucial services such as prescribed drugs and cost sharing is high, with monthly premiums in the case of Part B coverage and significant deductibles and coinsurance. Furthermore, because Medicare was modeled on the “major medical” health insurance plans that existed at the time of enactment (and that still dominate the insurance market), it fails to cover long-term services necessary to the management of chronic and serious physical and mental health conditions that extend beyond an initial acute phase of illness.

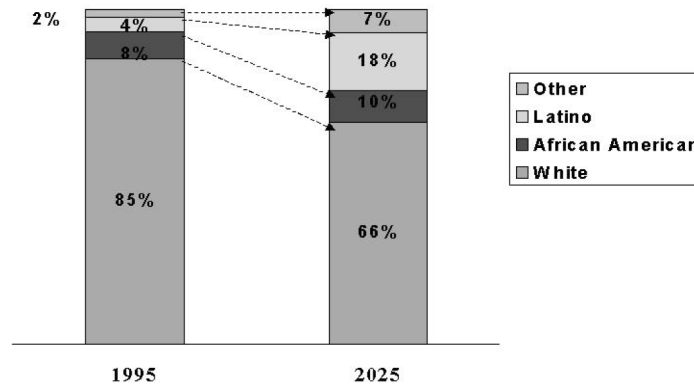
Figures 1 through 4 illustrate the nature and extent of the dilemma facing minority Medicare beneficiaries. Figure 1 shows that members of racial and ethnic minority groups, who are at significantly greater risk of poverty, represent a sizable and growing part of the Medicare population. By 2025, minority persons will constitute 33% of the Medicare population, up from 15% in 1995.

Figure 2 provides an overview of the health status of Medicare beneficiaries by race and ethnicity and shows that regardless of condition, minority beneficiaries are more likely to experience significant limitations in health status. Latino and African-American beneficiaries are more than one-and-a-half times more likely to be in fair to poor health. They also are at significantly greater risk for one or more limitations in activities of daily living (ADLs) and cognitive impairments. This health risk profile suggests a higher need for services.

Figure 3 shows the enormity of the poverty gap between minority and non-minority beneficiaries. In 1997, African-American and Latino

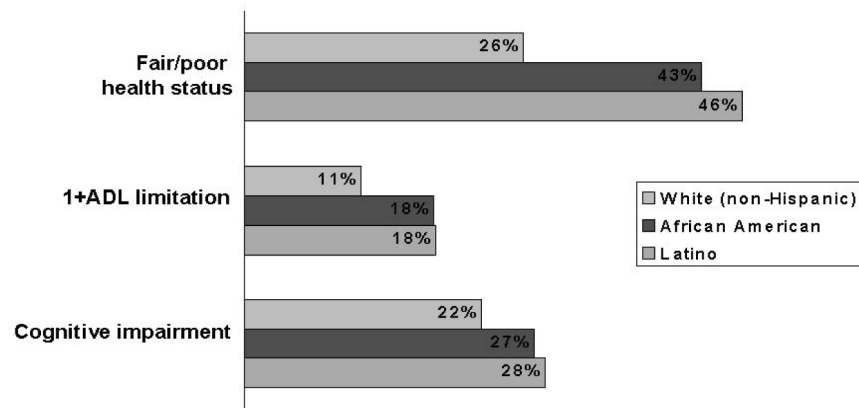
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<sup>5</sup> In recent years participation in Medicare+Choice has eroded significantly, chiefly as a result of limitations on the payment formula enacted in 1997, as well as increased regulatory participation standards (Rosenblatt et al., 2001).



Note: "Latino" refers to U.S. residents self-describing as being of Hispanic origin, regardless of country of birth or citizenship. "Other" includes Asian-Pacific Islanders, American Indians, Eskimos, and Aleuts.

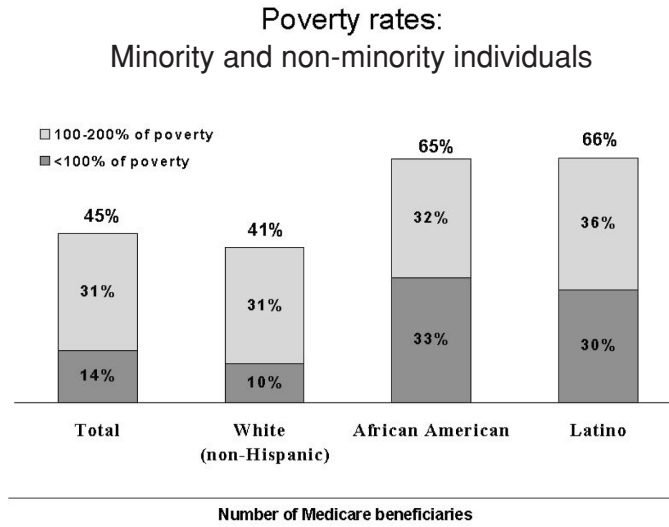
**FIGURE 1** Racial and ethnic minority Americans as a share of the elderly population: 1995–2025. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for The Henry J. Kaiser Family Foundation.



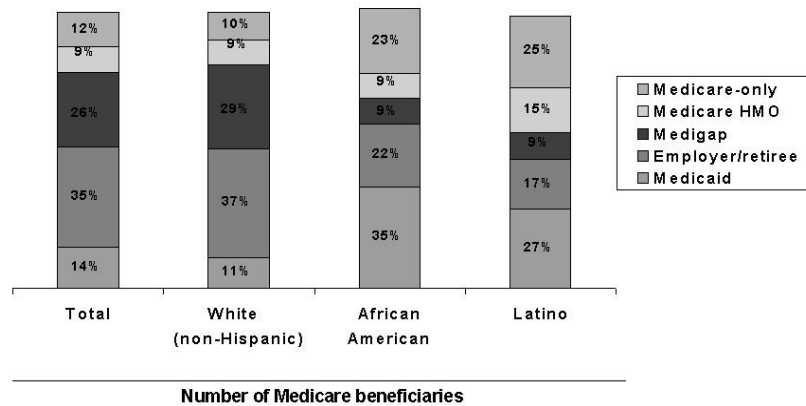
Note: "Latino" refers to U.S. residents self-describing as being of Hispanic origin regardless of country of birth or citizenship. Excludes other races (Asian-Pacific Islanders, American Indians, Eskimos, and Aleuts).

**FIGURE 2** Health problems and long-term care needs: minority and non-minority individuals. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for the The Henry J. Kaiser Family Foundation.





**FIGURE 3** Poverty rates: Minority and non-minority individuals. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for The Henry J. Kaiser Family Foundation.



**FIGURE 4** Supplemental insurance coverage: Minority and non-minority Medicare beneficiaries. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for the The Henry J. Kaiser Family Foundation.

beneficiaries were over three times more likely to be poor and more than one-and-a-half times as likely to have low incomes overall. That year, two-thirds of African-American and Latino beneficiaries were poor or near poor.

Figure 4 shows the healthcare financing implications of the deep poverty among minority beneficiaries. In 1995, white Medicare beneficiaries were one-and-a-half times more likely than African-American beneficiaries and twice as likely as Latino beneficiaries to have additional coverage through an employer-sponsored health plan and three times as likely to have private Medigap coverage. Conversely, minority beneficiaries were twice as likely to be exclusively dependent on Medicare and about three times as likely to depend on Medicaid as a supplemental source of health coverage.

These statistics suggest that minority Medicare beneficiaries are poorer and sicker, are at significantly greater risk for serious healthcare under-financing, and are far more likely to depend on sources of supplemental financing less acceptable to providers. Minority beneficiaries are more likely to lack employer-sponsored or other private coverage, significantly more likely to depend on Medicare alone, and far more likely to depend on Medicaid as a source of supplemental coverage. Because minority beneficiaries represent a rapidly growing proportion of the overall Medicare population, the consequences of these problems are more likely to become clear and pronounced.

### **Medicaid and the State Children's Health Insurance Program (SCHIP)**

The largest and most complex of all federal grant-in-aid programs, Medicaid is a means-tested entitlement that creates three interlocking sets of enforceable legal rights. The first is states' right to open-ended federal financing for their medical assistance and program administration costs. The second is an eligible individual's right to coverage for a defined set of benefits. The third is a legally enforceable providers' right to participate in Medicaid if qualified and to be paid for the care they furnish (Rosenbaum and Rousseau, 2001).

In fundamental respects, Medicaid is the mirror image of Medicare. Medicaid is rooted in welfare principles in that its origins were as a companion to federal cash welfare assistance programs for certain poor families with "dependent" children, indigent elderly and disabled persons, and certain "medically needy" persons whose characteristics connect them to a federal welfare category (e.g., age, disability, dependent children) (Congressional Research Service, 1993; Schneider et al., 1998; Rosenbaum and Rousseau, 2001). These mandatory coverage categories have been expanded over the past 35 years to include "poverty level" (i.e., low income)

children and pregnant women regardless of family composition or disability status, and low-income Medicare beneficiaries whose poverty level incomes prevent them from either purchasing supplemental Medigap coverage or paying Medicare's premiums, deductibles and coinsurance out of pocket. Beyond these minimum coverage groups, the law gives states the option of covering literally dozens of additional eligibility groups consisting of persons who bear some relationship to the mandatory groups but who are not poor enough to qualify for coverage outright. Despite the many eligibility expansions that have occurred over the past two decades, Medicaid is still associated with coverage of the poor. After 35 years, the program remains a selective and restrictive source of coverage, reaching only approximately half of all poor individuals.

Despite the fact that Medicaid's roots are in welfare, its importance as a health payer can hardly be overstated. In 1998, Medicaid was a source of health insurance for 40 million persons (Congressional Budget Office, 2001). The vast majority of individuals insured through Medicaid are persons without access to employer or other private health insurance benefits; they are individuals who because of age, disability, or dependency lie outside the furthest limits of the private health insurance market (Rosenbaum and Rousseau, 2001).

Medicaid is an integral part of the American insurance system not only because of whom it covers, but also because of what it finances. Unencumbered by the conventions of private insurance, Medicaid is capable of covering populations and services that lie outside essential structural insurance limitations that flow from the problems of "avoidable risk" and "moral hazard," and that are embedded in the notion of "fair discrimination" (Rosenblatt et al., 1997; Rosenbaum and Rousseau, 2001). In its role as an insurer of both uninsured and uninsurable populations and services, Medicaid effectively attempts to compensate for the structural and financial limitations of the world's largest voluntary healthcare market.

Medicaid melds state design and administration choices within a broad federal framework that contains many options and a few absolutes. The program is designed and administered by participating states in accordance with broad federal standards. As a matter of federal law, state welfare agencies bear final legal responsibility for Medicaid eligibility determinations, but the law permits any state agency to act as the responsible "single state agency"<sup>6</sup> for overall program accountability purposes.<sup>7</sup>

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<sup>6</sup> 42 U.S.C. §1395a(a)(4)

<sup>7</sup> Approximately half of all states share ongoing administrative responsibilities with county governments; even in these states however, the single state agency has a non-delegable obligation to administer the program within federal requirements.

In many states, agencies other than welfare agencies, such as public health agencies, public healthcare financing agencies, and social welfare agencies, are the named single state agency (Commerce Clearinghouse, 2001).

The federal Medicaid statute, which has been described by courts as one of the most complex social welfare statutes ever conceived,<sup>8</sup> contains minimum standards regarding eligibility, benefits and coverage, patient cost sharing, and program administration (Congressional Research Service, 2001). Minimum provider participation and payment rules also are specified; since the repeal of the so-called “Boren Amendment” in 1997,<sup>9</sup> federal Medicaid provider payment formula standards have been diminished, but certain standards remain in place.<sup>10</sup>

As noted, states that elect to participate in Medicaid must extend coverage to certain categories of individuals, known as the mandatory categorically needy. These groups consist of “AFDC-related” families with children,<sup>11</sup> certain former welfare recipients, elderly and disabled recipients of Supplemental Security Income, certain low-income Medicare beneficiaries (for Medicare cost sharing only), and “poverty level” pregnant women and children. States have numerous expansion options, of which the most important for purposes of this paper is the option to extend coverage to any adult with a Medicaid-eligible child (Rosenbaum and Maloy, 1999). In the absence of special federal demonstration authority under §1115 of the Social Security Act, states do not have the option to extend coverage to non-elderly, non-disabled adults without Medicaid-eligible children (Rosenbaum et al., 1999b).

Persons who are eligible for Medicaid are legally entitled to apply for assistance and have the right to a prompt determination of eligibility.<sup>12</sup>

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<sup>8</sup> See, e.g., *Lewis v City of New York*, 2001 WL 540657 (2d Cir., May 22), in which the court began its decision regarding Medicaid eligibility among undocumented pregnant women and by noting that Medicaid’s complexity required that it offer a “regrettably detailed review of the lengthy history of this action as well as the evolution of Medicaid law as it pertains to prenatal care and aliens.”

<sup>9</sup> The Boren Amendment guaranteed hospitals and nursing facilities payment in accordance with a specific cost-related payment methodology. This methodology created an enforceable legal right and was thus highly unpopular among states. *Wilder v Virginia Hospital Association*, 496 U.S. 498 (1990). In 1997 Congress repealed the Boren Amendment as part of the Balanced Budget Act, Pub. L. 105-33.

<sup>10</sup> For example, federal law continues to set minimum, cost-based payment rules for federally qualified health centers, rural health clinics, and hospices.

<sup>11</sup> In 1996 when the Aid to Families with Dependent Children program was repealed, Medicaid was amended to preserve this “AFDC-related” category in order to avoid the loss of Medicaid coverage among individuals no longer entitled to cash welfare. Despite this effort, Medicaid enrollment declined steeply, as welfare recipients were pushed off the program and eligible persons, caught in welfare diversion efforts, were denied the opportunity to enroll (Ellwood and Ku, 1998; Rosenbaum and Maloy, 1999).

<sup>12</sup> 42 U.S.C. §1396a(a)(8).

States must make provision for application at certain “outstationed” locations in addition to local welfare offices.<sup>13</sup> If found eligible, individuals must be furnished with medical assistance with “reasonable promptness.”<sup>14</sup> This “reasonable promptness” requirement has in recent years been interpreted by courts to apply not only to evidence of coverage but to medical care itself.<sup>15</sup> Because Medicaid creates an individual legal entitlement in eligible persons, the law conditions the denial, reduction or termination of benefits and coverage on compliance with relatively rigorous due process requirements (Rosenblatt et al., 1997; 2001). These protections apply not only to persons receiving care in ambulatory fee-for-service settings but, under legal agency theory, to residents of private long-term care institutions as well as managed care organization enrollees (Rosenblatt et al., 1997; 2001).

Medicaid benefits are perhaps the broadest ever granted through an insurance program. This is particularly true in the case of children, who are entitled to all forms of federally funded medical assistance, special preventive benefits, vision, dental and hearing care, and whose coverage must be furnished in accordance with a “preventive standard” of medical necessity (Rosenbaum and Rousseau, 2001). For beneficiaries other than those medically needy individuals who “spend down” to eligibility, cost sharing can be nominal at most, and certain groups are entirely exempted (Schneider and Garfield, 2000).

Ostensibly, Medicaid beneficiaries are entitled to freedom of choice in the selection of their medical provider.<sup>16</sup> The Medicaid freedom of choice provision was added in 1967, after initial state implementation of Medicaid suggested that states were relying exclusively on publicly operated health systems to furnish care (Starr, 1982; Stevens and Stevens, 1974). However, notoriously low provider participation has been a hallmark of the program for decades (Stevens and Stevens, 1974; Congressional Research Service, 1993). As a result, Medicaid beneficiaries continue to rely disproportionately on publicly supported systems of care such as public hospitals, health centers, and public health agencies.

<sup>13</sup> 42 U.S.C. §1396a(a)(55).

<sup>14</sup> 42 U.S.C. §1396a (a)(8).

<sup>15</sup> See, e.g., *Boulet v Celluci* 2000WL 1030398 ( MA, 1st Cir.) *Cramer v Chiles* 33 F. Supp. 2d 342 (FL, 11th Cir., 1999), *Doe v Chiles*, 136 F. 3d 709 (11th Cir, 1998), *Lewis v New Mexico Dept of Health* 94 F. Supp. 2d 1217 (NM, 10th Cir, 2000) *Benjamin v Ohl* (WV, 4th Cir., 1999) *King v Sullivan* 776 F. Supp. 645 (RI, 1st Cir., 1991) *King v Fallon* 801 F. Supp. 925 (RI, 1st. Cir., 1992). *McMillan v McCrimon* 807 F. Supp. 475 (IL, 7th Cir., 1992) *Sobky v Smoley* 855 F. Supp. 1123 (CA, 9th Cir., 1994).

<sup>16</sup> 42 U.S.C. §1396a(a)(23).

In recent years, this so-called “freedom of choice” guarantee has been significantly curtailed. Since 1997, states have been given the express design option of requiring enrollment in some form of managed care arrangement as a condition of coverage for most beneficiaries.<sup>17</sup> As of 2000, total Medicaid enrollment in managed care stood at 18.8 million persons, 55.8% of the Medicaid population and a 40% increase since 1996 (HCFA, 2000).<sup>18</sup> The addition of this state option to mandate managed care enrollment came after two decades of state experimentation with mandatory managed care, an effort that was actively encouraged by the Clinton Administration (Rosenbaum et al., 1999a). As of 1999, virtually all states did so for some or most of their beneficiary populations, using either risk style comprehensive managed care service arrangements (akin to commercial HMOs) or more modest primary care case management systems.

Although freedom of choice has never been a reality for beneficiaries and now is limited as a matter of law as a result of managed care, federal law historically has provided an additional protection. This protection, known in the law as the “equal access” requirement, requires states to ensure that Medicaid beneficiaries have basic equality in access to care. Specifically, the equal access provision requires that payments be “sufficient to enlist enough providers so that care and services are available under the plan at least to the extent . . . as to the general public.”<sup>19</sup> Read literally, this provision requires equality in access, even though the actual *source* of care may be different because of differences in provider participation.

Federal Medicaid law affords states considerable discretion in the design and operation of their state programs. As a result, state plans vary—at times dramatically—in who qualifies for coverage, the level and range of services to which individuals are entitled; participation rules for providers and provider compensation; and methods of administration, such as enrollment procedures, service delivery, and quality oversight. In recent years, Congress has enacted numerous reforms to give states even more flexibility with respect to who is covered, for what services and benefits, and through which type of arrangement. State responses to these flexibility options are quite literally all over the map, with certain states maintaining extremely broad programs and others doing only slightly more than the mandatory minimum. It is fair to say that because of the

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<sup>17</sup> The Balanced Budget Act of 1997, Pub. L. 105-33, §4701 et seq.

<sup>18</sup> HCFA, Penetration Rates from 1996-2000: National Summary Table; accessed June 2, 2001, at <http://www.hcfa.gov>.

<sup>19</sup> 42 U.S.C. §1396a(a)(30). The leading case in the field is *Clark v Kizer* 758 F. Supp. 572 (1990), holding California’s payment structure unlawful as a matter of law for its failure to produce a sufficient number of participating dentists.

long-term care financing pressures that have dominated Medicaid for decades, states that maintain limited programs with only modest adoption of coverage options have tended to adopt those options that relate to the provision of long-term institutional care, rather than the coverage options that are designed to extend access to community residents.

States also have broad flexibility in the area of coverage design, at least in the case of adults. State plans can adopt significant “amount, duration, and scope” limitations on classes of covered benefits. So other than in the case of children, states are relatively free to adopt any definition of medical necessity they choose as long as it meets minimum tests of reasonableness.<sup>20</sup> However, the basic Medicaid entitlement has been interpreted to mean that coverage decisions conducted by state agencies and their contractors (such as managed care entities, home health agencies, and long-term care institutions) must be based on individualized determinations grounded in relevant and reliable evidence. Unlike employer benefits, decisions cannot turn on the irrebuttable application of generalized practice guidelines.<sup>21</sup>

With respect to provider participation and compensation, states have broad discretion. State agencies can fashion their own participation standards and as long as the standards do not discriminate against an entire category of practitioners whose practice is authorized under state law, states have near total control over provider rules. The same is true with provider compensation: State agencies generally are free to adopt whatever payment methodologies they choose. With the above-noted exception of payments to certain types of clinics and to hospices, states have broad discretion over both payment formulas and provider participation standards.

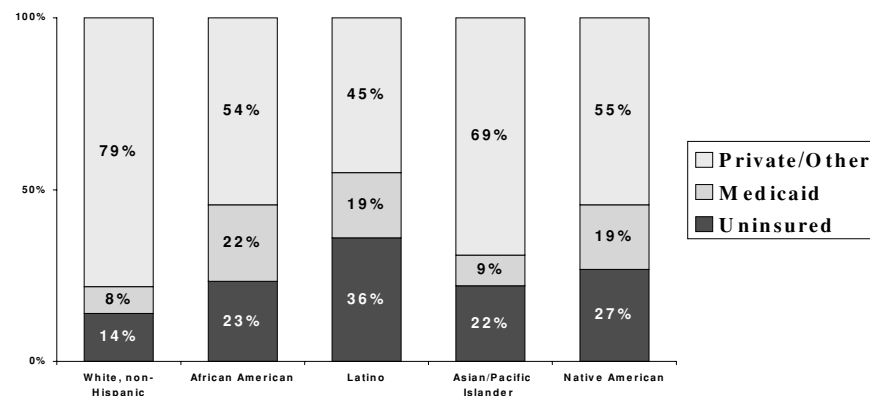
As of 2000, all states<sup>22</sup> participated in Medicaid. Federal Medicaid contributions to approved state plans accounted for nearly 60% of all funds spent on medical assistance. Medicaid’s role in the financing of American healthcare is key overall and particularly strong in certain respects. In 1998 Medicaid covered approximately 20% of all children and financed one-third of all U.S. births. The program accounted for nearly 50% of all

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<sup>20</sup> See, e.g., *Cowan v Myers* 232 Cal. Rptr. 299 (Cal. App., 1986), cert. den. 484 U.S. 846 (1987) in which the California Supreme Court upheld a medical necessity standard under the California Medicaid program (known as MediCal) that limited coverage to services “to protect life, to prevent significant disabilities or illness, or to alleviate severe pain.”

<sup>21</sup> *Massachusetts Eye and Ear Infirmary v Commissioner of the Division of Medical Assistance* 705 N.E. 2d 592 (Mass., 1999) in which the Supreme Judicial Court struck down denials of coverage and payment to providers that were based on irrebuttable treatment guidelines that prohibited individualized decisions as to the medical necessity of in-patient hospital care in particular patients’ cases.

<sup>22</sup> In this context the term state includes the District of Columbia, as well as the commonwealths of Puerto Rico and the Virgin Islands and the trust territories.



**FIGURE 5** Health insurance status, by race and ethnicity, 1997: Total Nonelderly Population. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for The Henry J. Kaiser Family Foundation.

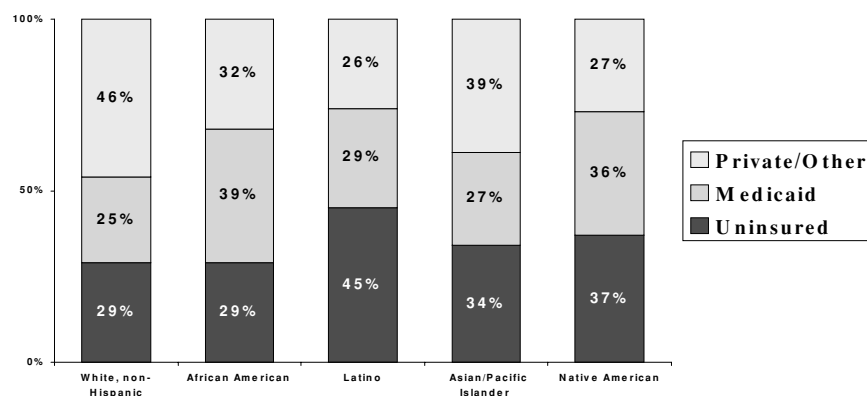
nursing home care, and over a third of all funds received by such “core” safety net providers as public hospitals and federally funded health centers (Rosenbaum and Rousseau, 2001; IOM, 2000).

In general, Medicaid is a principal source of healthcare financing for minority Americans. Figure 5 shows that in 1997, the program covered one in five non-elderly African Americans, Latinos, and Native Americans compared to fewer than one in ten non-elderly white Americans (The Henry J. Kaiser Family Foundation, 1999). Figure 6 shows, the reliance on Medicaid versus private insurance is equally pronounced when only low-income beneficiaries are considered. In 1997, nearly half of all white, non-Latino beneficiaries had access to private insurance compared with only 32% and 26% of African-American and Latino beneficiaries, respectively. Concurrently, dependence on Medicaid was higher among minority populations, even when only low-income persons were considered.

Unlike Medicare, the federal government does not systematically collect or analyze Medicaid recipient and expenditure data on the basis of race, nor does it require states to do so; so far, efforts to force such collection as a means of enforcing Title VI of the 1964 Civil Rights Act have failed<sup>23</sup> (Rosenbaum et al., 2000). However, the limited data that are available suggest significant racial and ethnic disparities in the level of care received by recipients. These disparities, illustrated in Table 1 below, have been noted in the program virtually since its inception (Davis and Schoen, 1978).

<sup>23</sup> In *Madison Hughes v Shalala*, 80 F. 3d 1121 (6<sup>th</sup> Cir., 1996), plaintiffs unsuccessfully sought to require the Secretary of HHS to compile Medicaid recipient and payment data on the basis of race and ethnicity. Their argument was that Title VI enforcement was impossible without such data.





**FIGURE 6** Health insurance status, by race and ethnicity, 1997: Low-income nonelderly population. Low-income is defined as 200% below the federal poverty level. SOURCE: Urban Institute analysis of the March 1998 Current Population Survey, prepared for The Henry J. Kaiser Family Foundation.

SCHIP: In 1997, Congress amended the Social Security Act to add a new Title XXI program known as the State Children’s Health Insurance Program (SCHIP). SCHIP is a federal grant-in-aid statute that specifically creates no legal entitlement in individuals. Instead, SCHIP entitles states to a defined sum (subject to aggregate annual national and state-specific limits) that can be used to furnish “child health assistance” to “targeted low-income children.” The term “targeted low-income children” applies to children under age 19 who are neither eligible for Medicaid nor covered by any other form of “creditable” health insurance coverage as the term is used under the Public Health Service Act (HCFA, 2001b).

States may use SCHIP allotments to expand Medicaid coverage (in which case all Medicaid rules apply). Alternatively, SCHIP permits states

**TABLE 1.** Medicaid Payments per Recipient, by Race (1998)

Race	Dollar Payment Levels
White	4609 (100%)
American Indian/Alaskan Native	3297 (71%)
Black	2836 (62%)
Asian/Pacific Islander	1924 (42%)
Hispanic	1842 (40%)

SOURCE: Healthcare Financing Administration, unpublished data, published in Rosenbaum, et al., 2000.

to establish separate programs that operate directly under the authority of the SCHIP statute, which in structural design bears only passing resemblance to Medicaid. States have near total discretion over the benefits they furnish and the manner in which they furnish coverage. Although coverage options are broad, the minimum coverage rules need only satisfy a benchmark that is tied to the commercial insurance market rather than the broad coverage rules of Medicaid. Certain preventive benefits also must be covered and cost sharing (up to a statutory maximum) is permitted.

For purposes of this paper, perhaps the most notable aspect of SCHIP is that states may elect to use their funds to expand Medicaid, establish a wholly separate program for “targeted” children, or adopt a hybrid of the two. As of 2000, 34 states had adopted separately administered SCHIP programs that operate directly under Title XXI authority. The remaining states used their funds to expand Medicaid, thereby retaining a single form of health insurance coverage for lower-income children.

Federal law permits states to establish separate SCHIP programs that stand apart from Medicaid not only in terms of their benefit packages and cost sharing rules, but also in terms of their organization and service delivery arrangements. SCHIP contains no minimum standards regarding the relationship between the administration of a Medicaid plan and a separately administered SCHIP plan. States are free to contract with completely separate providers and health plans, cover different benefits, pay different rates, and so forth. Preliminary research beginning to emerge from state SCHIP programs indicates that in states with separately administered SCHIP programs (i.e., not a Medicaid expansion) the Medicaid child population is likely to be a minority one, while children enrolled in SCHIP are somewhat more likely to be white (Edwards, 2001).

### **Health Disparities and Medicare and Medicaid Administration**

This section of the paper considers various issues in the administration of Medicare, Medicaid and SCHIP that potentially affect the issue of health disparities in access, quality and outcome. In reviewing these materials, it is important to bear in mind that there can be acts of either *commission* or *omission* where healthcare financing programs are involved. Acts of commission involve affirmative choices on the part of federal agencies (or state agencies, in the case of Medicaid) to adopt operating rules that have the potential to create or perpetuate disparities. An act of omission, on the other hand, entails the failure to elect an option related to program structure or administration that could conceivably reduce the potential for disparities.

There is virtually no evidence regarding the relationship, if any, between the existence of health disparities and acts of either regulatory com-

mission or omission in Medicare and Medicaid.<sup>24</sup> Nonetheless, even a passing acquaintance with the realities of the health system and the dynamics of healthcare allows one to hypothesize regarding the types of administration practices that could potentially contribute to the problem of disparities.

The systemic choices reviewed here are ones that arise from the administration of existing programs rather than from their basic legislative framework. Put another way, the issues addressed here focus on how programs are administered, not how they are designed by Congress. Even the act of identifying systemic choices in public program administration that have disparity-creating *potential* probably can be viewed as highly controversial. This is because many of the types of discretionary conduct discussed here fall within the administrative discretion of agencies. But this analysis is predicated on the notion that quite apart from the *legal* requirements of the non-discrimination provisions of the Title VI statute and regulations, there is reason to be sensitive to those structure and design choices in government financing that, while perhaps not violative of Title VI (even under a broad effects test), nonetheless give pause because of their possible consequences.

Seven distinct problems in program administration are identified and discussed: 1) Medicare policies regarding conditions of participation and their impact on low income Medicare beneficiaries; 2) Medicare policies that potentially underlie the problem of racially disparate health outcomes among similarly insured Medicare beneficiaries; 3) issues related to the design of Medicaid eligibility standards and enrollment arrangements; 4) Medicaid provider compensation; 5) administration choices related to the administration of separate SCHIP programs; 6) issues related to quality management and improvement; and 7) contractually sanctioned provider discrimination in Medicaid managed care.

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<sup>24</sup> The Hospital Survey and Construction Act of 1946 (the Hill Burton Program) presents an analogous situation to this type of examination of the potentially racially adverse impact of public healthcare financing regulatory and administration choices. In 1979, federal Hill Burton regulations were revised to restructure program operating standards in order to eliminate the potentially racially disparate impact of previous rules. Prior rules had permitted Hill Burton hospitals to engage in practices that could lead to adverse regulatory consequences. Examples of these practices were vividly illustrated in the seminal case, *Cook v Ochsner Foundation Hospital et al.* 61 F.R.D. 354 (1972), which documented practices such as refusal to participate in Medicaid, the use of pre-admission deposits, and the refusal to admit patients who did not have a private physician with staff privileges. All of these practices were viewed by most facilities as lawful under existing Hill Burton regulations. Following extensive hearings, the Department of Health and Human Services revised the rules because of their potential to cause both exclusion and segregation (Rosenblatt et al., 1997).

*1. Medicare conditions of participation applicable to physicians and their impact on low-income Medicare beneficiaries*

Federal Medicare regulations permit Medicare-participating physicians to select their patients at will. As a result, the federal power to set conditions of Medicare participation has failed to address the issue of low-income Medicare beneficiaries, who risk serious access barriers unless they can locate providers that also participate in and will accept Medicaid as a supplemental source of payment for uncovered deductibles and coinsurance and necessary but uncovered services.

Only a small proportion of all Medicare-participating physicians and managed care organizations also participate in Medicaid. The refusal of Medicare-participating hospitals and nursing homes to participate (or participate fully) in Medicaid has been identified as both an actual and potential violation of Title VI of the 1964 Civil Rights Act (Rosenbaum et al., 2000). Despite the existence of a parallel problem in the case of other health providers, the federal government has not attempted to systematically lessen the problem of Medicaid non-participation that occurs among Medicare-enrolled physicians<sup>25</sup> and health plans.

The refusal by physicians, managed care companies and other providers to participate in Medicaid, at least in the case of low-income Medicare patients who need Medicaid to “perfect” their Medicare coverage, has a disproportionate adverse impact on minority beneficiaries because of their higher representation among poor beneficiaries and their lower level of private coverage. Without the ability to use supplemental Medicaid coverage, patients would face the choice of foregoing treatment by a non-Medicaid-participating physician or paying out-of-pocket uncovered premiums, deductibles and coinsurance. As a practical matter of course, this second option is out of the question.

The problem of non-participation in Medicaid, at least in the case of low-income Medicare beneficiaries, is exacerbated by state Medicaid payment choices in response to the Balanced Budget Act of 1997. This gave state Medicaid programs the option of limiting payments for services covered under both programs to the nearly always lower Medicaid rate rather than the higher Medicare rate. Previously, a physician who chose to par-

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<sup>25</sup> Indeed, as noted above, despite the transformation of Medicare from an indemnity payment system to one in which most physicians participate directly, there are no formal regulations regarding the status of direct Medicare payments to physicians as a source of federal financing for Title VI enforcement purposes, although references to this effect are contained in 2000 OCR guidance on services to individuals with limited English proficiency. Regardless of whether Medicare participation by physicians is deemed to be the receipt of federal assistance for Title VI purposes, it establishes a basis to regulate their conduct toward poor patients who depend on Medicaid supplemental insurance.

ticipate in both programs could be assured that Medicaid would cover at least those deductibles and coinsurance requirements imposed under Medicare (i.e., that Medicaid would pay up to the Medicare payment rate). This is no longer the case; state agencies now have the option of capping their payments at the normal Medicaid rate which, given the low payment levels under Medicaid, are depressed even in relation to already low Medicare physician payment levels.

*2. Medicare administration issues underlying racial disparities in health outcomes among similarly insured Medicare beneficiaries*

Much of the literature on race-based health disparities focuses on disparate access to certain types of treatment among similarly situated hospitalized beneficiaries and other beneficiaries undergoing medical treatment (U.S. Civil Rights Commission, 1999). In considering how Medicare's structural dimensions might contribute to these disparities, it may be important to focus on the utilization review process that is used by Medicare (and virtually all other insurers) to control access to advanced inpatient care. In the modern health system, utilization review approval is a prerequisite to virtually all advanced care. While the literature on the actual dynamics of utilization review is slender, case law suggests that a basic element of utilization review is the extent to which a physician is willing to aggressively advocate for the needs of a patient as part of the treatment approval process.<sup>26</sup> As a result, successful navigation of the utilization review process in the case of complex treatments may hinge to a significant degree on the existence of a "committed sponsor" relationship of the type explored by Duff and Hollingshead in their seminal study of physician/patient relationships (Duff and Hollingshead, 1968).

Low-income beneficiaries may be far less likely to have access to a health specialist who is a "committed sponsor" and thus may fare less well within Medicare utilization review. Low-income Medicare patients, who are disproportionately minority, face barriers to physician acceptance for the reasons explored above. Furthermore, those primary care physicians who do treat lower-income beneficiaries in ambulatory settings and who may be able to help link a patient to specialty care may lack the collegial and referral relationships with medical specialists and specialized treatment centers that committed sponsorship in the specialized inpatient

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<sup>26</sup> In *Wickline v State of California* 239 Cal. Rptr., 810 (Cal. App., 1986), petition for review dismissed, 741 P. 2d 613 (Cal., 1987) the court specifically addressed the liability of physicians who fail to act as committed sponsors for their patients in response to an adverse utilization review decision.

setting demands.<sup>27</sup> To the extent that a committed sponsor relationship is lacking, so too might be the aggressive advocacy integral to better ensuring that complex treatments ultimately are judged to be medically necessary and appropriate under prospective and concurrent review.

In sum, in a world in which successful navigation of utilization review acts as a precondition to access to highly specialized in-patient procedures, patients without committed sponsors may fare less well in the utilization review process. Inadequate direct access to specialists because of low acceptance rate coupled with dependence on primary care physicians who lack significant collegial networks may reduce the likelihood that once admitted, a patient will be under the care of a “committed sponsor” specialist who can help pave the path through the utilization review process. If “committed sponsorship” of the type observed by Duff and Hollingshead a generation ago continues to play an equally vital role in the modern world of healthcare quality, particularly given the more aggressive efforts to control access to care found in utilization management and prospective case review, then the inability of lower income patients to attach to a committed specialist (or be attached to one through a collegial referral) may have a major impact on the outcome of Medicare utilization review.

### *3. Administrative choices in setting Medicaid eligibility standards and enrollment arrangements*

Studies suggest that individuals and families place great value in the Medicaid program (Stuber et al., 2000; Kaiser Commission, 2000). At the same time, research also suggests that the manner in which states administer their programs creates serious problems of stigma. The stigma perceived by families can be traced to how they are treated by two distinct groups: The individuals who enroll them in the program (and the settings in which they work) and healthcare providers (discussed below). To the extent that states’ choices in eligibility and enrollment cause stigma, it is probably safe to assume that this consequence falls disproportionately on minority beneficiaries, given their disproportionate dependence on the program and the actual or perceived problem of prejudicial attitudes and beliefs within the underlying health system.

Although Medicaid contains a number of specific requirements related to program administration, states also have broad latitude in how

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<sup>27</sup> Indeed, in discussing specialist referrals with physicians in practice at federally funded community health centers, the author has heard on innumerable occasions about the difficulties these physicians have in locating specialists who will accept and aggressively manage their referrals as a result of financial and other considerations.

they design their plans. A state can extend Medicaid to the entire low-income population regardless of disability, age, work status, or the presence of dependent children. Federal financial participation is available for all low-income individuals other than non-elderly, non-disabled adults without children. In other words, with the exception of childless, working-age adults, federal financial participation can be claimed for all low- and moderate-income children and adults, thereby removing the perception that Medicaid is only for welfare recipients and families that choose not to work (Rosenbaum and Rousseau, 2000; Schneider et al., 1998).

State flexibility does not stop at the point of eligibility design. Even though only welfare agencies can by law render a formal eligibility determination, these agencies' involvement in the actual eligibility determination process can be rendered virtually invisible (Cohen Ross, 2000). Enrollment arrangements can be established in out-stationed locations (e.g., health clinics, physicians' offices, the work place, churches, supermarkets, etc.). Applications can be extremely short in any state that elects to determine eligibility on the basis of income alone. Other than proof of legal status or citizenship, program rules require virtually no written verification or documentation of eligibility factors (i.e., affirmance of eligibility is sufficient). Enrollment periods can be set to last for a duration of 12 months, with full federal financial participation available for children regardless of any change in eligibility status during the 12-month period. Redeterminations of eligibility can be accomplished completely by mail, using "passive" procedures that automatically renew coverage in the absence of evidence to the contrary.

In short, a state can design its program to virtually eliminate all of the stigma-producing events that arise from the eligibility, eligibility determination, and enrollment process itself. Federal financial participation is available for most groups of individuals. Furthermore, the federal government in recent years has been relatively generous about granting states the authority to conduct federally funded demonstrations that de-categorize program eligibility (Rosenbaum et al., 1999).

The leader in this effort to transform Medicaid from a "welfare piggyback" program to a true public insurance program has been Medicaid, whose program now serves individuals without access to employer coverage, as well as persons who need subsidization in order to secure benefits available through their employers. States that have taken active steps designed to produce destigmatizing program structures that move Medicaid away from welfare and toward a more neutral public insurance stance are Oregon, Tennessee, Arizona, and Rhode Island. At the same time, many states retain a dated version of Medicaid, strictly limiting coverage and enrollment options and forcing the program to run like welfare. This choice helps perpetuate attitudes and beliefs on the part of provid-

ers, persons in need of assistance with insurance (and who does not need assistance with insurance costs today?), policy makers, and the public at large that while it is acceptable to subsidize individual health benefits through deep tax breaks, a direct subsidy is a mark of shame.

#### 4. *Administrative choices in payment of Medicaid providers*

It is perhaps safe to say that the best-known problem plaguing the Medicaid program is its notoriously low payment rates. A recent GAO study documented the practice on the part of business consultants of encouraging physicians to “ration ‘certain lower paid patients’ and ‘tell some of the higher paid patients to come right on in’” (GAO, 2001). According to taped consultant interviews that were played at a Senate hearing at which the results of the GAO investigation were presented, the following conversation occurred:

Referring to the advice a consultant gave a physician practice, the consultant joked, “So what we said about to do there, you have to ration your Medicaid, and if anyone calls from Blue Cross/Blue Shield, you say, ‘When do you want to come in? We’ll come and get you.’” The consultant said that one way of discouraging Medicaid patients while welcoming private pay patients whose insurance policies often reimburse at higher rates, is to give Medicaid patients the most inconvenient appointment times while saving the most popular appointment slots for private pay patients.<sup>28</sup>

Low rates, whether set for physicians, pharmacies, managed care organizations, nursing homes, home health agencies, or other health suppliers have several potential effects, all of which fall with disproportionate impact on minority patients. First, low rates make it impossible for any provider but those that are heavily dependent on Medicaid revenues (e.g., core safety net providers such as public hospitals and health centers, children’s hospitals, and nursing facilities) to participate in the program. The loss of revenues as a result of steep contractual allowances is simply so steep that any significant level of participation becomes economically out of the question for other than small classes of providers. Second, as the GAO study illustrates, low rates also induce fraudulent practices aimed at rationing care, discouraging access, discriminating in the provision of services, and excluding patients from practices.

Low payment rates in effect encourage and validate bad provider conduct. To the extent that the attitudes and beliefs regarding minority pa-

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<sup>28</sup> BNA, 2001. Unscrupulous Consultants Tell Providers how to Cheat Third Party Payers, GAO Finds, *Health Care Policy Report* 9:26 (July 2, 2001), pp. 1037-1038.



tients remain significant matters within the provider community, grossly low payment rates offer a ready-made excuse for non-participation that rests entirely on neutral economic grounds. This excuse is particularly available to urban healthcare providers who are plentiful in number to the point of saturation in more affluent communities. As Table 2 illustrates, because of the high concentration of minority individuals in the poorest large city neighborhoods, this refusal to participate also has its greatest adverse impact on minority beneficiaries who ultimately are starved for access in the midst of plenty.

Table 2 shows the marked racial and ethnic patterns of urban poverty in the largest cities. While the concentration of urban poverty increased for all races between 1970 and 1990, by 1990, 83% of all urban African-American poor persons resided in census tracts that could be labeled as poor, while nearly 42% resided in high-poverty census tracts. Latino poverty concentrations were somewhat less pronounced but decidedly elevated above overall rates. In 1990, 68% of all poor persons residing in the nation's 100 largest cities were either African American or Latino, and an astonishing 87% of all poor persons residing in these cities' highest

**TABLE 2** Concentration of Poverty—100 Largest Cities, 1970-1990

		1970	1980	1990
<b>Total</b>	# poor	7,542,479	8,133,277	9,392,953
	% poor	14.5%	16.7%	18.3%
	Poor in poverty (>20%) tracts	4,156,543	5,178,509	6,466,097
	% poor in poverty tracts	55.1%	63.8%	68.8%
	Poor in high poverty (> 40% poor) tracts	1,240,855	1,828,576	2,650,142
	% in high poverty tracts	16.5%	22.5%	28.2%
	<b>African American</b>	# poor	3,182,881	3,428,593
% population poor	27.7%	27.2%	29.9%	
Poor in poverty (>20%) tracts	2,567,429	2,837,386	3,328,652	
% poor in poverty tracts	80.7%	82.5%	83.2%	
Poor in high poverty (> 40% poor) tracts	895,920	1,157,537	1,664,872	
% in high poverty tracts	28.1%	33.8%	41.6%	
<b>Latino</b>	# poor	966,413	1,575,569	2,394,890
% population poor	23.2%	26.2%	21.7%	
Poor in poverty (>20%) tracts	664,375	1,162,367	1,842,990	
% poor in poverty tracts	68.8%	73.8%	77.0%	
Poor in high poverty (> 40% poor) tracts	196,202	378,832	650,747	
% in high poverty tracts	20.3%	24.0%	27.2%	

SOURCE: Fossett and Perloff, 1999.

poverty urban census tracts were members of these racial and ethnic groups. These statistics underscore the particularly serious impact that provider non-participation in Medicaid and depressed Medicaid payment levels potentially could have on minority beneficiaries' access to care.

Low provider compensation rates have other pernicious effects as well. The failure of Medicaid programs to include capital payments in their compensation rates to safety net providers that so frequently anchor poor communities seriously limits their ability to engage in the level of renovation, facility and practice improvement, and overall technical up-keep that is essential to maintaining a safe and good quality healthcare environment. Equipment cannot be updated or replaced as needed. Building space essential to the expansion of capacity (along with greater employment opportunities in poorer neighborhoods) cannot be added. Supplies cannot be maintained. And finally, the recruitment of personnel and health professionals becomes even more difficult because of the depressed working conditions.

The federal Medicaid equal access requirement described previously does not guarantee precisely the same *pattern* of access that privately insured persons have. But it does require that states maintain payment levels that are reasonable to enlist sufficient providers to achieve an equal overall level of access to care. Related to this equal access requirement is the requirement that medical assistance be furnished promptly, a basic operating rule that in recent years, as noted earlier, has been used to expand access to care, particularly in the case of persons with disabilities. Other than isolated litigation efforts designed to challenge grossly low provider payment levels, this basic requirement of the program has attracted no attention other than from the nation's governors who have periodically called for its repeal.<sup>29</sup> The federal government has done virtually nothing with the provision, and there are virtually no guidelines that interpret how to apply the equal access requirement or what is expected in terms of state implementation (e.g., specific data collection to measure levels of access where disparities in health outcomes are pronounced, affirmative efforts to increase rates, or affirmative efforts aimed at attracting healthcare providers in high need communities).

##### 5. Administration of separate SCHIP programs

As noted earlier, SCHIP permits states to use their allotments to establish and operate separate SCHIP programs. Research on SCHIP is just

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<sup>29</sup> Under pressure from the governors, the Balanced Budget Act of 1997 repealed specific equal access provisions related to obstetrical and gynecological care but left the overall requirement in tact.

underway, but several issues are becoming apparent. First, in many states with separate programs, the SCHIP population is whiter than the Medicaid population because of racially identifiable poverty distribution. Minority children simply are more likely to be extremely poor, and thus any state with a separately administered SCHIP program is more likely to have a SCHIP population that is white in relation to its Medicaid population. As the inner-city data presented earlier underscore, SCHIP and Medicaid children also are likely to reside in different communities, with Medicaid children more concentrated in inner-city poor neighborhoods, and SCHIP children (those with incomes about twice the federal poverty level), throughout a metropolitan area.

Thus, even without taking any step other than deciding to set up a separate SCHIP program, a state that does so likely faces a situation in which its Medicaid children are more likely to be minority children, and its SCHIP children are more likely to be white.

This racial skewing of children receiving public insurance into two sub-groups may pose problems in and of itself, since these patterns create racial imprimaturs for the programs. Added to this problem however, is the fact that early research conducted by the George Washington University Center for Health Services Research and Policy, as well as anecdotes from around the country, indicate that states with separate programs are permitting their physicians to participate in SCHIP but not Medicaid, permitting managed care organizations and insurers to sell to SCHIP agencies but not to Medicaid, and even paying better rates under SCHIP and not Medicaid. These choices in design and administration obviously have the potential to take a bad situation and make it far worse, labeling minority children as members of substandard health coverage arrangements reserved for minorities and outside of the healthcare mainstream. No federal regulations address this problem.

*6. Administrative choices in establishing conditions of participation and quality of care measurement; self examination by federal and state governments*

The final problem is one that affects Medicare, Medicaid, and SCHIP. There is very little in the conditions of participation under these three programs that requires or finances the efforts of healthcare providers to take systematic steps to examine enrollment and utilization patterns in relation to the demographics of the communities in which they serve, and undertake affirmative steps to improve access to their services. Limited conditions of participation under federal Medicare and Medicaid managed care regulations do require that participating managed care organizations make certain efforts to address access to care in their service ar-

eas.<sup>30</sup> But there is no affirmative obligation on the part of either providers as a condition of participation or participating states in the case of Medicaid and SCHIP to collect and analyze health data on access and utilization by race, examine health outcomes by race, examine patterns of healthcare administration that conceivably could contribute to racially identifiable outcomes, or take affirmative steps to attempt to remedy these problems through restructuring of healthcare delivery arrangements.

Notably, state Medicaid programs are far ahead of the federal government in the case of managed care organizations; their contracts with managed care organizations typically contain extensive access requirements related not only to networks but to hours, locations of services, cultural competency and translation services, and other steps designed to remove barriers that disproportionately could affect minority enrollment and utilization (Rosenbaum et al., 1997; 1998; 1999a). Only in the case of the federally funded community health centers program does one find federal policies aimed at engendering this type of careful self-examination by health providers on an ongoing basis to determine whether access to care is appropriate. Not since the federal government undertook such an effort in the mid-1970s as part of its revision of Hill Burton hospital regulations<sup>31</sup> has there been this type of careful self-assessment of the federal government's (or state governments') payment practices or the practices of federally assisted providers. Indeed, in the case of Medicaid, the federal government neither collects nor requires much racial data.

*7. Administrative choices in the design of managed care systems: contractually sanctioned discrimination in provider networks*

As noted previously, federal law provides states with broad leeway in the design of their managed care arrangements and selection of managed care contractors. Despite the "equal access" provisions in the Medicaid statute (noted above), most state contracts with managed care organizations do not expressly prohibit contractors' provider networks from engaging in what can be termed "contractually sanctioned discrimination," i.e., permitting network providers under a general duty of care to all plan members to nonetheless refuse to treat the Medicaid sponsored members of the plan (Rosenbaum et al., 1997). The issue of segregated provider networks (i.e., networks operated by Medicaid participating

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<sup>30</sup> The Medicaid managed care regulations are now in suspense by the Bush Administration. Medicare+Choice regulations require merely that a provider network be "sufficient to provide adequate access to covered services to meet the needs of the population served." 42 C.F.R. §422.112(1).

<sup>31</sup> See note 25, *supra*.

managed care organizations that subdivide members based on sponsorship status) has been the subject of both speculation and actual legal challenges (Rosenbaum et al., 2000). Anecdotal discussions with physicians and other health professionals who participate in managed care plans suggest a great unwillingness on their part to accept Medicaid-sponsored members into their practices, either because of payment differentials or because of discomfort with Medicaid-sponsored members.<sup>32</sup>

As serious as network provider discrimination might be at the primary care stage, in communities with health centers, safety net provider clinics, and other sources of primary care for medically underserved populations, there may be enough primary care access to overcome the worst tangible effects of internally sanctioned discrimination (although the long-lasting tangible and intangible effects of contractually sanctioned discrimination could never fairly be calculated). At the point of specialty care however, the real and immediate impact of sanctioned network discrimination could be enormous, since permitting specialists to refuse to accept or treat referred Medicaid-sponsored plan members is tantamount to the denial of specialty care. Unless a managed care organization was to literally run two entire specialty networks, contractually sanctioned discrimination against Medicaid beneficiaries could have an incalculable effect on access to specialized services. Because of disproportionate minority representation within the Medicaid-sponsored managed care enrollee population, the impact would be felt most heavily by minority patients.

Regulations issued by the Clinton Administration in January 2001 and applicable to Medicaid managed care systems prohibit contractually sanctioned provider discrimination against Medicaid patients within Medicaid-participating managed care organizations.<sup>33</sup> On August 20, 2001, the Bush Administration suspended these rules.<sup>34</sup> The Administration simultaneously proposed new regulations that seek to relax certain of the requirements imposed on state agencies and managed care organizations

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<sup>32</sup> This position on the part of providers serves to at least informally dispel any notions that managed care would somehow erase healthcare access differentials based on sponsorship. Medicaid-only managed care plans are the norm in many communities, and in communities in which MCOs that do business across sponsors are in the market, separate Medicaid-only subsidiary operations may be common. There are many reasons to maintain a special Medicaid subsidiary, because the specifications of a Medicaid contract offer differ enormously from those found in a commercial agreement. Furthermore, the geographic isolation in which beneficiaries may live (particularly in the case of inner city residents) may justify enhanced provider networks in order to ensure adequate access in underserved communities. These affirmative reasons for maintaining a separate Medicaid business are a different matter from doing so in order to isolate and separate Medicaid customers.

<sup>33</sup> 42 C.F.R. 438.206(d)(7).

<sup>34</sup> 66 Fed. Reg. (August 17, 2001).

under the January 19 rule.<sup>35</sup> One of the rules eliminated in its entirety is the regulation that explicitly prohibits discrimination against Medicaid beneficiaries. The implicit message sent by the repeal of this express anti-discrimination provision is that while general compliance with civil rights laws remains a requirement,<sup>36</sup> contractually sanctioned discrimination based on payer status is no longer specifically prohibited.

It is conceivable of course that the Health and Human Services Office for Civil Rights (OCR) could conclude upon investigation that federal civil rights regulations are violated by contractually sanctioned discrimination against Medicaid patients by network providers.<sup>37</sup> To date however, OCR does not appear to have taken such a position, nor has it developed standards to clarify the legality of this practice under Title VI. Furthermore, by relying on general Title VI sanctions rather than expressly prohibiting patient “redlining” by member sponsorship status, the Administration essentially foregoes an opportunity to set an explicit standard designed to directly address an identified problem issue in Medicaid managed care that has the potential to hurt not only all Medicaid beneficiaries but disproportionately harm minority patients. Putting aside Title VI, the repeal of such a regulation appears to have direct implications for the enforceability of the equal access provisions of the Medicaid statute themselves.

### Discussion

There is no question regarding the contribution that public financing programs have made to improving health and healthcare for minority Americans. At the same time, the data presented in this paper underscore the disproportionate dependence on these programs that minority individuals maintain, as well as their vulnerability to heightened health risks and reduced access to healthcare because of their poverty and where they live. Together Medicare, Medicaid, and SCHIP pumped better than \$350 billion into the American healthcare system in 2000. At the same time, a review of key issues in program administration, such as treatment of low-income Medicare beneficiaries, Medicaid eligibility and enrollment practices, provider recruitment and payment, conditions of participation for health providers, and overall program management by both agencies and

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<sup>35</sup> 66 Fed. Reg. 454564 (August 20, 2001).

<sup>36</sup> The NPRM does not repeal the January 19 rule requiring compliance by MCOs with Title VI as well as other applicable federal civil rights statutes.

<sup>37</sup> In light of the recent Supreme Court decision in *Alexander v Sandoval*, 121 S.Ct. 1511 (2001), the ability of beneficiaries to directly challenge such discrimination as a violation of the Title VI regulations is thrown into doubt, as are the discriminatory effects regulations themselves.

participating providers reveals that little has been done to make affirmative use of this vast purchasing leverage to both promote and finance customization of the healthcare to better meet the needs of minority patients and blunt or minimize prejudicial attitudes. Indeed, if anything, stigmatizing enrollment arrangements and dramatically low payment levels have not only tacitly sanctioned provider and system aversion but have affirmatively encouraged the rejection of lower income patients. Even in SCHIP, where the entire population is lower income, emerging information suggests that states are unwittingly creating a dynamic that encourages the racially identifiable treatment of children within the publicly financed health system.

What will it take to fix these problems? Two issues—financial and political—need to be addressed. First, making the programs more oriented to minority patients will require significant financial investments. Destigmatizing Medicaid's eligibility and enrollment arrangements not only requires funds to underwrite eligibility expansion but would also, if past reform efforts are any gauge, result in greater enrollment rates and would thus push program costs up. Medicaid payments are so depressed that even modest proportional increases in payments necessitate major outlays, and Medicaid provider participation research suggests that modest rate increases in fact result in little change in the system.

While money is always a problem, and can be expected to become increasingly so in an era of declining rates of government revenues, the financial problems actually pale in comparison to the two awesome political problems that arise in any restructuring discussion: the healthcare industry and state governments.

Restructuring Medicare and Medicaid administration to emphasize orientation toward minority patients and beneficiaries as a condition of federal financial participation means confronting the fundamental character of both programs. As Marilyn Moon has observed, the context for enactment of the programs was that they would require nothing of health providers (Moon, 1993). The promises made at the birth of Medicare and Medicaid (and once again at the birth of SCHIP) were that participation would be voluntary and that few if any conditions of participation would be imposed. Despite the presence of direct government financing, providers could continue to select their patients and their markets, and to a greater or lesser degree could continue accountable and open to minorities.

The act of literally pulling physician payments out of Title VI enforcement authority in 1965 is emblematic of the delicacy with which government payments were overlaid on the healthcare system. To the extent that anyone believes that provider attitudes regarding government regulation of their health practices have softened, one need only look at the

recent dust-up over the Office for Civil Rights Limited English Proficiency Guidelines, when dozens of prominent provider groups in April 2001 joined together to actively protest to the White House the application of these guidelines to healthcare.

It is true that much has changed since 1965. Providers now are in managed care networks and are obligated to accept as patients the members who select or are assigned to them.<sup>38</sup> Payment arrangements are now direct rather than indemnity in nature. Old racial barriers and attitudes certainly have softened if not dissipated. But the notion of telling Medicare-participating physicians that they must participate in Medicaid at least to the extent that they serve low-income Medicare beneficiaries would strike most persons as an utterly radical idea and one that lies beyond the furthest reaches of permissible payer leverage over the health system.

The other political behemoth is state governments. States always have operated Medicaid with substantial levels of autonomy; this autonomy has grown over the years, as the power of governors has increased and as succeeding administrations have lessened their regulatory enforcement of the Medicaid statute. Were a federal agency to suddenly impose a series of regulatory requirements related to eligibility and enrollment design, provider compensation, and assessment of program impact on minority families, the federal officials prescribing such changes probably would be regarded as daft and most likely would lose their jobs.

Where does that leave policy in this area? The enormous difficulty of achieving changes of the magnitude described here means that the effort to make changes will only work if they are constantly placed in front of policy makers and program administrators and if the changes that are identified as potentially beneficial are tied to incentives. Congress might consider extending additional levels of compensation to both state agencies and providers that take steps to orient programs toward minority patients and away from practices that result in segregation, exclusion, and denial of care. Also necessary is sufficient health services research to support the claim that certain healthcare financing decisions and service arrangements are at least associated with better (or poorer) access to healthcare and health outcomes among minority beneficiaries.

There are certain practices that appear to create so much disparity that careful consideration should be given to how to stop them.

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<sup>38</sup> In this regard, it is important to note that provider challenges to “all products” clauses have meant that in practice, managed care companies that sell their products to both public and private payers may in fact set up separate subsidiaries that do Medicaid business with separate networks or else may maintain separate networks for their Medicaid customers (Rosenblatt et al., 1997; 2001).



Above all is the refusal of providers to participate in Medicaid in the case of low-income Medicare beneficiaries and the tendency of separately administered state SCHIP programs to segregate white, near-poor children from minority poor children in access and coverage. Both of these practices, as well as the practice of permitting Medicaid managed care plans to treat enrollees through separate networks, appear to directly countenance a form of payer segregation that comes close, at least in principle, to segregated waiting rooms and hospital wings. The elimination of these practices should be matters of first priority for federal and state policy makers.

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# The Impact of Cost Containment Efforts on Racial and Ethnic Disparities in Healthcare: A Conceptualization

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## INTRODUCTION

Like all developed countries, the United States continues to battle high and rising health care costs. In the mid to late 1990s, U.S. health expenditures as a percentage of gross domestic product had temporarily stabilized for the first time in decades, albeit at a level almost 30% higher than in any other country (Anderson and Hussey, 2001). More recently, however, there has been a resurgence in health care cost inflation, with some indications (unproven, as yet) that we are entering another era of double-digit annual increases.<sup>1</sup> This resurgence appears to have been caused by a number of factors, including a spike in demand for pharmaceuticals, increasing consumer dissatisfaction with heavy-handed cost containment techniques used by managed care organizations, and the inability of payers to squeeze additional savings from provider payments.

This paper argues that the prevailing cost containment methods have the tendency to cause more harm to racial and ethnic minorities than to others. It might be argued, then, that one way to avoid problems resulting from cost containment would be to eschew it as a policy goal. The point is not a trivial one. If individuals or their third-party payers wish to

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<sup>1</sup> One indication is the rate of growth in costs of two prominent purchasing cooperatives. In 2001, premiums for the Federal Employees Health Benefits Plan (FEHBP) increased by 10.5%, and costs for the California Public Employees Retirement System (CalPERS) rose by 13% (which was divided between premium increases and higher levels of patient cost sharing). These figures were obtained from <http://www.opm.gov/pressrel/2000/fehb%20open%20season%202000.htm> (FEHBP) and <http://webmd-practice.medcast.com/Z/Channels/39/article60467> (CalPERS).

spend more on health care and consequently, less on other things, why should they be stopped—particularly when it seems increasingly clear that certain new medical devices, products, and procedures can improve the quality and length of life?

There are several reasons why. First, additional health care spending has significant opportunity costs. A dollar spent on health cannot be spent on other things like education, housing, or consumer goods. Second, there are various ways in which the health care market is imperfect that may lead to more spending than is desirable. Unlike other goods and services, health care services are often well insured, which insulates consumers from facing their true cost. In addition, because consumer information is often poor, people may demand medical goods and services in part because of strong advertising, or because they are “induced” to do so by providers who have a pecuniary incentive to increase demand. Third, government now pays for almost half of U.S. health care spending. Even though the United States is now going through a period of unprecedented budget surpluses the future of social programs is nevertheless worrisome, particularly for Medicare, which faces more recipients and fewer contributors when the “baby boom” generation retires. Finally, one of the major reasons that the number of uninsured persons continues to rise in the United States is because of health care costs. The ability of employers to offer insurance coverage, as well as workers’ ability to enroll when it is offered, is dependent on how much each has to pay for coverage. Rising costs have been shown not only to reduce employers’ ability to offer coverage, but also to dampen demand by employees to enroll in such coverage when it is offered (Cooper and Schone, 1997).

Thus, there are strong reasons to believe that we as a society should attempt to control health care costs. One of the major challenges is to design ways of doing so that not only preserve quality care, but also do not aggravate—and perhaps can even reduce—existing racial and ethnic disparities in care.

The purpose of this paper is to analyze how existing cost containment mechanisms may have a differential negative impact on racial and ethnic minorities. The next section provides a simple framework for categorizing cost containment strategies. The following section examines how various cost containment efforts may negatively affect racial and ethnic minorities as compared with other groups. The conclusion section discusses ways in which some of the problems raised here can perhaps be ameliorated.

### **COST CONTAINMENT STRATEGIES**

There are numerous ways in which one can classify strategies aimed at controlling a nation’s health care expenses. The one adopted here is

from Ellis and McGuire (1993), who distinguish between “supply-side” and “demand-side” cost sharing. According to these authors, the major feature of demand-side approaches is that “patients must pay more in co-payments and deductibles,” whereas supply-side methods “seek to alter the incentives of health care workers to provide certain services” (Ellis and McGuire, 1993, p. 135). A third—managed competition—is also discussed. Managed competition, more so than the other strategies, emphasizes both demand- and supply-side measures for containing costs.

### Demand-Side Approaches

In the traditional economic model, demand is paramount. Of course, to obtain a market equilibrium of price and quantity, it is necessary to consider both demand and supply. Beyond that, however, the role of supply is rather passive. If, for example, demand increases, resulting in a higher market clearing prices and higher profits, firms will increase supply to meet this demand and reap these profits. In contrast, changes in supply are not supposed to influence people’s demand.

The passive role of demand stems in large part from the economic model’s reliance on consumer sovereignty—the assumption that people make better choices for themselves than others, such as government, can make for them. But many observers doubt that health care meets the necessary requirements for the proper functioning of a market. If this is the case, then relying on consumer sovereignty may not result in the best outcomes for society. Especially noteworthy are strong externalities,<sup>2</sup> poor consumer information, the influence and market power of physicians, and the belief by many that people deserve health care irrespective of their ability to pay.<sup>3</sup> As a result, more policy tools in health care have focused on the supply side, as described below.

There are two major tools available for containing costs through demand. One mentioned by Ellis and McGuire (1993) is patient cost sharing. If people have to pay more, it is generally assumed that they use

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<sup>2</sup> Externalities exist when one person or organization’s production or consumption has effects on others. Positive externalities imply that these activities help others; negative externalities lead to harm. Immunizations are a classic example of a positive externality. They help not only the recipient, but also others who are less likely to get a disease if more people are immunized. Free markets under-provide positive externalities because the recipient must bear the full cost even though others are benefiting. Industrial pollution is an example of a negative externality because pollution reduces the quality of life for others. Free markets over-provide pollution because the producers of it do not bear its associated costs.

<sup>3</sup> For a discussion of 15 assumptions necessary for a free market to result in the best health care system, see Rice (1998).

fewer services, a finding almost always supported in the health care literature. There are, in turn, two ways in which cost sharing is traditionally applied to consumers: by paying for insurance premiums, and by paying coinsurance, co-payments, and/or deductibles when they receive services. During the 1990s, the consumer expenditure towards cost sharing in job-based coverage was fairly steady in real dollars, although there was a shifting in these expenses to higher premiums and lower co-payments (Gabel et al., 2001).

An instance where there is less support for the hypothesis that cost sharing reduces utilization is in the case of services provided by physicians *after* a patient has commenced a new episode of care. One of the more overlooked but intriguing findings of the RAND Health Insurance Experiment, the pre-eminent study of consumer demand for health care services, is that co-payments had a substantial impact on whether or not patients sought care for an illness, but little discernible effect on how much care they received once they sought medical attention (Manning et al., 1987; Newhouse, 1993). Apparently, it is the physician who controls resource usage once an episode of care commences. This means that in considering the role of patient cost sharing, it is important to realize that its major impact is on reducing the number of episodes of care for which medical care is sought rather than the cost of care per episode.

The other tool available for containing costs through demand is giving people better information. This information can pertain to particular services (e.g., informing people what services are medically appropriate) or to insurance itself (e.g., letting them know the price and quality of alternative insurance choices that may reflect different benefits, provider networks, etc.). The idea is to facilitate consumer sovereignty so that peoples' demand is informed, and therefore, most optimal for meeting their intended purposes.

Providing consumers with more information has been one of the major developments in the health care services market in recent years. The main avenue has been by supplying consumers with information about the quality of alternative health plan choices, although there has also been some movement towards reporting on the quality of hospital and physician groups as well. Parallel to that, there has been a vast expansion of medical information available to the lay public through the Internet, even though the accuracy of this information is, by its nature, often suspect. Whether the availability of such information does in fact lead to better consumer choices is a hotly debated topic, and the resolution is still up in the air. Some published studies have found little impact of quality information on bettering consumer choice (Chernew and Scanlon, 1998), although others have found a positive impact (Mukamel and Mushlin, 1998).

### Supply-Side Approaches

Most tools that have been used to control health care costs focus on the supply side. These approaches, in general, are aimed at getting providers such as hospitals and physicians to change their behavior, rather than focusing on the patient's behavior. To give a few examples:

- Public programs, notably Medicaid, traditionally have paid physicians very low fees to treat patients. The result—and in some instances, perhaps the intent—is to dissuade physicians from providing more services to program beneficiaries.
- Utilization review and practice guidelines are aimed at ensuring that physicians provide services that are seen as medically appropriate.
- Diagnosis-related groups (DRGs) and capitation try to instill in hospitals and physicians, respectively, an incentive not to over-provide services. They do this by paying a fixed sum of money for care regardless of how many services are actually performed.
- Supply and technology controls attempt to limit the number of hospitals, doctors, or capital equipment in the system as a means of controlling overall usage.

Space does not permit a detailed description of the prevalence of each of these, although it should be noted all except the last (supply and technology controls) are commonly employed in the United States. To illustrate a single example, we focus here on one of the more controversial ones: the use of capitation to pay physicians. Under capitation, the physician receives a fixed amount of money per patient over a period of time such as a year, irrespective of how many services are provided. These capitation payments often include not only the services provided by primary care physicians, but their referrals to hospitals and specialists as well. A positive way to view the consequences of capitation is that there is an incentive for physicians to provide preventive care but not to over-utilize marginally useful services. On the negative side, capitation may lead physicians to stint on providing useful services.

Recent data on its prevalence is provided by a 1999 national survey conducted by Mathematica Policy Research, Inc. for the Medicare Payment Advisory Commission (2000). Table 1 shows how primary care physicians are paid by health plans, and Table 2 shows the same information for specialists. Within the table, “withholds” refers to the situation whereby some of the physician’s remuneration is held back and paid only if certain cost containment goals are met, such as keeping down hospitalization and referrals. “Bonuses” are extra payments that can be based on the meeting of individual or group utilization goals, high patient satisfaction, etc.



**TABLE 1.** How Health Plans Pay Primary Care Physicians

	All Plans	California Markets	Midwest Markets	Northeast/ Mid-Atlantic Markets	Southeast/ South Central Markets
Predominant payment method for primary care physicians					
Fee-for-service	24.7%	1.2%	23.2%	29.6%	50.9%
Without withholds or bonuses	15.1%	1.2%	2.3%	10.5%	50.9%
With withholds or bonuses	9.7	0.0	20.9	19.1	0.0
Capitation	61.2%	59.5%	74.3%	69.2%	41.0%
Without withholds or bonuses	29.2%	30.7%	36.5%	31.6%	17.8%
With withholds or bonuses	32.0	28.8	37.8	37.6	23.2
Salary	14.1%	39.4%	2.5%	1.2%	8.0%
Without withholds or bonuses	13.3%	39.4%	0.0%	0.0%	8.0%
With withholds or bonuses	0.8	0.0	2.5	1.2	0.0

Capitation is by far the most common method used in paying primary care physicians (Table 1), with an estimated share of 61% of HMOs relying primarily on it. Fee-for-service is second with 25%, and salary is third with 14%. Withholds and bonuses are used about half of the time in capitation and about one-third of the time in fee-for-service, but are rarely used in salary arrangements. The results differ a great deal by geographic

**TABLE 2.** How Health Plans Pay Specialists

	All Plans	California Markets	Midwest Markets	Northeast/ Mid-Atlantic Markets	Southeast/ South Central Markets
Predominant payment method for specialists					
Fee-for-service (total)	75.3%	35.9%	100.0%	94.7%	80.2%
Without withholding or bonuses	52.2%	23.8%	57.2%	73.0%	56.6%
With withholding or bonuses	23.1	12.1	42.8	21.6	23.6
Capitation (total)	13.3%	25.1%	0.0%	5.3%	19.8%
Without withholding or bonuses	7.1%	12.0%	0.0%	4.1%	10.7%
With withholding or bonuses	6.2	13.1	0.0%	1.2	9.0
Salary (total)	11.4%	39.0%	0.0%	0.0%	0.0%
Without withholding or bonuses	11.4%	39.0%	0.0%	0.0%	0.0%
With withholding or bonuses	0.0	0.0	0.0	0.0	0.0

area. California, for example, is far more likely to use salary to pay primary care physicians, mainly due to the presence of Kaiser Permanente, a large group model HMO. Fee-for-service arrangements are almost unheard of in California, but make up half of the arrangements in southern markets and about one-fourth in the other regions.

In contrast, except in California, fee-for-service is the most common method of paying specialists (Table 2). This method accounts for 75% of the market nationally, and over 90% in much of the country. Capitation of specialists accounts for 13%, and salary, 11%. As before, salary is far more common in California than elsewhere. The presence of withholds and bonuses is comparable to those reported for primary care physicians.

Strong financial methods for controlling costs in managed care are far more prevalent in the payment of primary care physicians. Only 15% of primary care physicians were paid on a fee-for-service without any bonuses or withholds, compared with 52% of specialists.

The study also examined the types of performance measures used by health plans to adjust payments to primary care physicians. It found that quality measures were used most often (68%), followed by consumer surveys (48%), utilization and cost measures (46%), patient complaints (42%), and enrollee turnover rates (23%). On average, between 6%-10% of compensation was affected by physician's performance on these measures (Medicare Payment Advisory Commission, 2000).

### **Managed Competition**

Managed competition combines both demand and supply-side incentives to control costs (Enthoven, 1978; Enthoven and Kronick, 1989). Under managed competition, health plans compete with each other for enrollees. Payers such as employers or government provide a fixed amount of money to the enrollees to purchase insurance. The payers also provide information on alternative plan costs and measures of quality and enrollee satisfaction. If enrollees choose a more expensive plan, they have to pay additional premiums out of pocket. These are the parts of managed competition aimed at the demand side. Health plans, in turn, need to keep their costs down to remain competitive, and one way they can do so is to pay providers in a manner that induces them to control costs. They may also use techniques such as utilization review. These are the aspects of managed competition aimed at controlling costs through the supply side.

Managed competition was part of the failed Health Security Act proposed by the Clinton Administration, but many aspects of it have been adopted by some private payers. Most notable is the practice of offering employees a fixed contribution towards a menu of health plans. Research has shown that this can save payers considerable amounts of

money. One problem, however, is that health plans that rely on fee-for-service medicine may obtain a sicker group of enrollees, which eventually may lead to these types of plans being priced out of the market (Buchmueller, 1998).

### **COST CONTAINMENT AND RACIAL AND ETHNIC DISPARITIES**

This section is divided into two parts: demand-side approaches for containing costs and supply-side approaches. Within each, I will indicate how the use of these techniques is likely to affect racial and ethnic disparities in health care.

Before proceeding, it is important to discuss a potential limitation of this analysis. Although I make an effort, when possible, to isolate (both conceptually and empirically) the impact of race and ethnicity from other sociodemographic characteristics, sometimes this is not possible or even desirable. Race and ethnicity are often correlated with socioeconomic status, and both of these “variables” are related to various measures of health care outcomes.

To anticipate an example discussed in more detail below, higher cost-sharing requirements are more of a financial burden on those with low incomes. They either result in more income being spent on services, or fewer services being purchased. Racial and ethnic minorities have, on average, lower incomes than whites, so they tend to be more adversely affected by cost sharing. Thus, race/ethnicity is not the cause of the problem—low income is—but those in these subgroups of the population nevertheless bear a disproportionate burden. In other instances described below, however, race appears to be the true cause of disparities. One obvious example is the discussion of racial stereotyping on the part of some physicians.

### **DEMAND-SIDE APPROACHES**

The two main demand-side approaches to containing costs—patient cost sharing and consumer information—are discussed in turn.

#### **Patient Cost Sharing**

Patient cost sharing, in the form of coinsurance, deductibles, and co-payments applied at the time of service usage, is more common in the United States than in the rest of the world. It also seems to be the cost-containment method of choice among a disproportionate number of health economists in the United States. The genesis of this belief may lie,

in part, in the RAND Health Insurance Study, a vast social science experiment conducted between 1974 to 1982, and described in Newhouse (1993). One of the main findings of the study was that consumer demand was indeed sensitive to out-of-pocket costs in that people who had to pay more for services at point-of-service were considerably less likely to seek medical care. Furthermore, in general, the researchers found little evidence that lower cost sharing resulted in better health outcomes (although there were some positive effects, particularly for some procedures undergone primarily by blacks, as discussed below).

These results have been used in conjunction with traditional economic theory to demonstrate that higher cost sharing improves a countries' social welfare (Feldman and Dowd, 1991). The point was made forcefully by Manning and colleagues (1987), who asked whether the cost of the RAND Health Insurance Study (over \$200 million in today's dollars) was worth it.

*[W]e believe that the benefits of this particular experiment greatly exceeded the costs. . . . Between 1982 and 1984, there was a remarkable increase in initial cost sharing in the United States, at least for hospital services. For example, the number of major companies with first-dollar charges for hospital care rose from 30 to 63 percent in those two years, and the number of such firms with an annual deductible of \$200 per person or more rose from 4 to 21 percent. Although it is impossible to know how much of this change can be attributed to the experimental results, the initial findings of the experiment were published . . . and given wide publicity in both the general and trade press. In certain instances a direct link between changes in cost sharing and the experimental results can be made (Manning et al., 1987, p. 272).*

Because the experiment showed that increased patient cost-sharing reduced medical expenditures, the researchers estimated that under the most optimistic scenario, the eight-year experiment could have paid for itself in a week.

But why is the lower utilization that results from cost sharing supposed to make society better off? It is because the extra services that people use when they have full insurance are assumed to bring about less in the way of benefits. Economic theory posits that people will buy something up until the point that the benefit of the last unit purchased equals the cost. With full insurance, the money price of services is zero; it is therefore assumed that the last service consumed has almost zero value. When this low benefit is compared with the cost of production, there is a "welfare loss" associated with the production and consumption of the service—it costs more to produce than the person (and therefore, society) gains.

This theory has two key implications: society will be better off if people pay higher cost sharing amounts<sup>4</sup> and cost sharing requirements should be highest for services that are more price sensitive. The latter argument is a bit more complicated. If the possession of insurance leads to a large increase in utilization, then welfare loss will be larger because more services will be purchased where the additional costs exceed extra benefits. Thus, one would improve social welfare by assessing higher patient coinsurance rates for such services, thereby reducing usage. In contrast, if utilization rates are not very sensitive to the possession of insurance, then there is little welfare loss, and less need to charge high coinsurance rates.

These are strong policy recommendations, and it is important to understand their basis. The traditional economic model assumes that people make well-informed choices that maximize their own utility. Thus, in making the decision to buy or not buy a service, they are implicitly evaluating the utility or gain they would receive from the service against its cost or co-payment.

It should be stressed that not all economists “buy into” the application of this theory to health care. For example, Ellis and McGuire (1993) write, “[We] are skeptical that the observed demand can be interpreted as reflecting ‘socially efficient’ consumption, [so] we interpret the demand curve in a more limited way, as an empirical relationship between the degree of cost sharing and quantity of use demanded by the patient” (p. 142). Evans (1984) notes: “The welfare burden is minimized when there is no insurance at all” (p. 49). And if one takes this reasoning very far, Reinhardt (1992) points out that this logic will always find that the country with higher patient cost-sharing requirements will have the more efficient health system. Thus, the U.S. system would be deemed more efficient than the Canadian system or any of a number of European systems, not because of a comparison of outcomes to costs, but rather simply from the fact that the U.S. imposes higher patient cost sharing, which in turn reduces utilization.

The implications of relying on patient cost sharing on racial and ethnic minorities are extremely important. Simply put, cost sharing results in de facto discrimination, for several reasons. First, in cases where racial and ethnic minorities are not deterred by the requirements, cost sharing

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<sup>4</sup> It is actually a bit more complicated. Excess insurance is assumed to lower social welfare, but the existence of insurance also raises welfare because “risk averse” individuals want protection against having to face catastrophically high medical expenses. The Feldman/Dowd study concludes, however, that the welfare loss from excess insurance far exceeds the additional utility conveyed by owning insurance.

constitutes a much higher average burden. In 1998, median household income for whites was a about \$41,000, compared with \$25,000 for blacks and \$28,000 for Hispanics (U.S. Census Bureau, 2000, p. 466).

Second, certain racial and ethnic minority groups are in poorer health. As a result, they have a greater need for services. If they use them, then the problems associated with high cost sharing and low incomes are magnified for minorities compared with whites, who are both healthier and wealthier. To give some examples among the total population, 8% of whites rate their health as fair or poor, compared with 16% of blacks and 13% of Hispanics. Age-adjusted hypertension rates are about 50% higher among blacks than whites. Both blacks and Hispanics have about twice the rate of untreated dental caries as whites (U.S. National Center for Health Statistics, 2000, pp. 232, 234, 270). Among Medicare beneficiaries, 42% of black beneficiaries, and 44% of Hispanics rate their health as fair or poor, compared with 25% of whites. Similarly, members of both minority groups are twice as likely to have diabetes. Two-thirds of black Medicare beneficiaries have hypertension, compared with half of whites (Gornick, 2000).

Third, in many cases cost sharing *is* a deterrent to necessary service usage. Thus, racial and ethnic minorities do not receive the care they need, in part because they simply can't afford the costs. The RAND Health Insurance Experiment did find some instances in which lower cost sharing improved health status. Some of these included:

- Low-income families at elevated risk benefited the most from free care. The reduction in diastolic blood pressure among lower-income persons who were judged to be at an elevated risk for hypertension was 3.3 mm Hg, compared with only 0.4 mm Hg for similar people with higher incomes (Brook et al., 1983).
- Low-income persons in poor health who were given free care had the largest reduction in serious symptoms (Shapiro et al., 1986).
- Among children of poor families who were at the highest risk, those with free care were less likely to have anemia than those in the cost-sharing plans (Valdez, 1986).

Gornick (2000) has also shown the large disparities in service usage between whites and racial/ethnic Medicare beneficiaries, which are doubly of concern because these numbers do not adjust for the poorer health status of the latter. Blacks use 82% as many office visits and 77% as many specialist services as whites, and are only half as likely to get flu shots. In contrast, they are far more likely to get services that tend to result from seeking care too late. For example, amputations of lower limbs are more than triple among blacks compared with whites.

It is not possible to know how many of these disparities are due to price; indeed, there are racial and ethnic disparities in health care utilization, as well as differences by social class in countries that have comprehensive health insurance. In the case of Medicare, though, the evidence of a price effect is strong. We know from the RAND Health Insurance Experiment that cost sharing matters, and other studies have also shown that having supplemental insurance is a major determinant of service utilization as well (McCall et al., 1991; Ettner, 1997). Minorities are far less likely to have supplemental insurance. Whereas only 9% of whites on Medicare lack any form of supplementation, the figures for blacks and Latinos are 27% and 16%, respectively (Pourat et al., 2000).

Finally, racial and ethnic minorities are hurt by cost sharing because they can benefit most from preventive care—due to their worse health status and lower use of such care. As noted above, the traditional theory posits that cost sharing should be highest for services that are most price sensitive, and indeed, the RAND Health Insurance Experiment found prevention and dentistry to be among the most price-sensitive services (Newhouse, 1993).<sup>5</sup> Application of this theory would therefore discourage usage of preventive care, an area in which racial and ethnic minorities have both the greatest need and ability to benefit.

Of all of the cost-containment methods reviewed in this section, patient cost sharing is the one I believe is most problematic for racial and ethnic minorities. The reasons are best summarized by Evans and colleagues (1993):

*The primary effect of substituting user fees for tax finance is cost shifting—the transfer of the burden of paying for health care from taxpayers to users of care. . . . [P]eople pay taxes in rough proportion to their incomes, and use health care in rough proportion to their health status or need for care. The relationships are not exact, but in general sicker people use more health care, and richer people pay more taxes. It follows that when health care is paid for from taxes, people with higher incomes pay a larger share of the total cost; when it is paid for by the users, sick people pay a larger share. . . . Whether one is a gainer or loser, then, depends upon where one is located in the distribution of both income . . . and health. . . . In general, a shift to more user fee financing redistributes net income . . . from lower to higher income people, and from sicker to healthier people. The wealthy and healthy gain, the poor and sick lose (Evans et al., 1993, p. 4).*

The other form of patient cost-sharing is the premiums paid by individuals and families for health insurance. There has been a great deal of research indicating that premiums affect consumers. They do so in two ways. First, as premiums rise, individuals are less likely to purchase

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<sup>5</sup> This was true in the 25-95% patient coinsurance range but not the 0-25% range.

health insurance policies offered by their employers (Cooper and Schone, 1997; Kronick and Gilmer, 1999). Second, there is much research to indicate that choice of health plan is extremely responsive to premiums (Cutler and Reber, 1998; Buchmueller, 1998). Because racial and ethnic minorities have, on average, lower incomes than whites, we would expect that their enrollment in insurance plans would also be lower. In 1999, 75% of whites had job-based health insurance coverage, while this was true of only 58% of blacks and 47% of Latinos (Brown et al., 2001).

The second issue is whether higher premiums may force a disproportionate number of racial and ethnic minorities to choose health plans that are of lower quality. This is an intriguing issue and will be discussed next.

### Consumer Information

The second demand-side approach to cost containment is relying on consumer information. As noted earlier, this is manifested mainly by comparisons of the benefits, costs, and quality of health plans, as well as consumer satisfaction. Indeed, the major assumption of most “pro-competitive” health initiatives in both the private and public sectors is that consumers are capable of using this information to make good plan choices.

Whether this strategy works well is a subject of much debate. The federal government has invested considerable funding and research firms have invested considerable energy in formulating ways of presenting and disseminating such information through such initiatives as the Consumer Assessment of Health Plans (CAHPS, see <http://www.ahcpr.gov/qual/cahpfact.htm>) sponsored by the Agency for Healthcare Research and Quality). Furthermore, there have been major private initiatives such as the Health Plan Employer Data and Information Set (HEDIS) developed by the National Committee for Quality Assurance (see <http://www.ncqa.org/Programs/HEDIS>). In addition, organizations such as the Pacific Business Group on Health have published extensive data on HEDIS and other measures of quality and satisfaction (see <http://www.pbgh.org>).

Although these efforts are admirable, the reliance on consumer information to make health plan choices disproportionately harms certain racial and ethnic minorities in relation to whites. The groups that are disadvantaged are those who have lower levels of education, and especially individuals whose primary language is not English. In 1999, 26% of whites age 25 had a four-year college degree, compared with 16% of blacks and 11% of Hispanics (U.S. Census Bureau, 2000, pp. 43, 46). Although it is difficult to find comparable data for those whose primary language is not English, the rates are undoubtedly lower. Research by Hibbard and col-



leagues (2001) shows a strong relationship between more education and understanding comparative information about health plans up until age 80.

One might argue that even though racial and ethnic minorities are disadvantaged by strategies that rely on good consumer information, there is little to be done except to improve education (both in general as well as education targeted to understanding things like report cards). This is too narrow a viewpoint. Few other countries rely on consumers to make choices among competing health plans. It is quite possible to organize a health care system whereby everyone has the same health plans and cost containment efforts are focused on things other than demand-side strategies. We evaluate some of these in the next section.

### SUPPLY-SIDE APPROACHES

This section is divided into four parts, each reflecting a different set of supply-side approaches for containing costs: low physician fees; capitation and DRGs; utilization review and practice guidelines; and supply, technology, and expenditures controls.

#### Low Physician Fees

Traditionally, states have paid physicians very poorly for treating Medicaid patients. Economists have constructed conceptual models to help explain how physicians would be expected to respond. One such model is that of a "price discriminating monopolist," in which physicians can receive different amounts of revenue from different groups of patients (Sloan et al., 1978). One implication of the model is that physicians will treat the most lucrative patients first, and once that market is exhausted, treat others, as well. They will not tend to treat patients whose costs exceed revenues. Thus, we would expect that Medicaid patients might have trouble finding a doctor willing to treat them. In addition, different physicians have different costs and face different levels of demand. Those physicians who are better trained, more specialized, etc. tend to have higher costs, especially when including the value of their time. The model would predict that these more costly physicians would also tend to avoid low-revenue patients such as those covered by Medicaid.

Most studies have shown just such effects. Medicaid patients are less likely to have access to physicians in their outpatient practices, as well as to specialists and others who may be perceived as more qualified (Mitchell, 1991). This, in turn, results in differential access problems for minorities. Whereas 6% of whites have Medicaid coverage, 19% of blacks and 14% of Hispanics do. Blacks are more than 30% more likely to use an

emergency room than whites because it is less likely that their regular place of care is a physician office (U.S. National Center for Health Statistics, 2000, pp. 340, 267).

A way to avoid this problem is to have all insurers pay the same amount to physicians, which is known as an “all-payer system.” Such a system exists in several European countries, as well as in Japan. When each patient has equal value to a physician, the latter no longer has a financial incentive to choose one type of patient over another. However, he or she may still prefer certain patients based on non-financial criteria, an issue explored next.

### Capitation and DRGs

These strategies are combined because the incentives are similar. Under DRGs, hospitals are paid an amount of money for an in-patient stay that is, in most cases, completely unrelated to how many resources are used to treat the patient. Under capitation, physicians receive a fixed amount of money per patient per year, again largely unrelated to subsequent resource usage. It might be argued that DRGs do not affect physician decision making because they apply to how the hospital—rather than how the doctor—is paid. This ignores the fact that hospitals use a number of strategies to make physicians cognizant of the hospital’s financial incentive. These range from informing the doctor how long the patient has stayed in relation to the average for that DRGs, all the way to withdrawing privileges to practice in the hospital.

In and of themselves, capitation and DRGs should not favor one racial or ethnic group over another. Hospitals receive the same DRG payment for a white and a Latino patient; doctors get the same capitation fee for whites and blacks (although different insurers may pay differing amounts, and have different racial/ethnic mixes of enrollees). Rather, the issue is more subtle. It is possible that the financial pressure exerted by these payment methods will result in physicians cutting back their services differentially—and that this differentiation is related to race and ethnicity.

Consider the case of capitation. A physician who is capitated has an incentive to enroll more patients in his or her practice, and under certain schemes, may also have an incentive to control the number of hospital and specialist referrals. One scarce resource is the physician’s time. Thus, there is a potential incentive to do less for the patient.

It is important to recognize that research on this topic has yet to reach any consensus. Reviews of the literature by Miller and Luft (1997, 2001), one of which includes literature up to the year 2000, lists just as many studies finding that HMOs provide better quality care and worse quality

care. However, this does not provide direct evidence, because here we are specifically considering the impact of capitating the physician. Unfortunately, to my knowledge there have been no studies that have directly assessed the impact of physician financial incentives on the actual quality of care delivered.

Let us suppose, though, that a physician does feel the need to control how much time he or she spends with the patient and/or number of referrals. How could this manifest itself into racial and ethnic disparities? There are at least three possibilities. First, there could be overt discrimination, with the physician willfully favoring his or her racial/ethnic group over others. Although certainly possible, this has not been considered the major driving factor by most researchers.

A second and somewhat related explanation is that physicians stereotype minority patients. One particularly interesting study of this possibility was conducted by van Ryn and Burke (2000), who surveyed physicians' attitudes after patients received an angiogram in 10 New York state hospitals. They were asked questions about perceptions on such things as the patient's intelligence and education, pleasantness, self-control, and rationality. They also were asked to rate patients on likely compliance with medical care, drug and alcohol use and lifestyle, as well as the likelihood that they would sue.

In general, physicians rated whites higher than blacks on most dimensions—even after the researchers controlled for the appropriate variables. Overall, they found that black patients:

*“were more likely to be seen as at risk for noncompliance with cardiac rehabilitation, substance abuse, and having inadequate social support. In addition, physicians rated Black patients as less intelligent than white patients, even when patient sex, age, income, and education were controlled. Physicians also report less affiliative feelings towards black patients” (van Ryn and Burke, 2000, p. 821).*

The authors posit an explanation for these results. It may be that physicians have stereotypes about racial and ethnic minorities, and apply these generalizations to individuals in the group. They write:

*“Physicians may fail to correctly incorporate individual diagnostic data, instead being swayed by their beliefs regarding the probabilities of individuals in a socio-demographic category having a given characteristic. In this way, physicians' understanding of epidemiological evidence regarding population-based likelihoods may function as stereotypes, and be applied to assessments and perceptions of individuals regardless of actual individual characteristics. It is possible that this is especially likely when population-based statistics are con-*

*sistent with dominant biases. . . . This suggests that physicians are applying general race differences to their impressions of individual patients and failing to incorporate disconfirming individual information" (van Ryn and Burke, 2000, pp. 822-823).*

Interestingly, this could result in a circle. Because physicians are pressed for time under capitation, stereotyping leads to less care to racial and ethnic minorities. In this regard, the study found physicians spent more time with white than black patients. These patients, in turn, may not be receiving as good advice on care, and furthermore, may feel alienated from the physician. As a result, they may reveal less information to the physician or seek care less often.

A third and related reason that racial and ethnic minorities might fare worse in a DRG or capitated environment is through "statistical discrimination." This concept has been applied to health care by Balsa and McGuire (2001). In essence, the authors argue that physicians' decisions result from the inability to interpret information about the patient. If they feel they know less about a patient's symptoms or needs, they will be less certain that a particular course of treatment is appropriate. Under strong financial pressures such as those generated by DRGs and capitation, physicians may therefore favor the patients for whom information is less ambiguous. To illustrate, they note that "a white male doctor might have an easier time interpreting the signal, 'doc, it really hurts' from a white male patient than from a black woman patient, or from a Latino woman patient" (Balsa and McGuire, 2001, p. 1). Indeed one would expect particularly large effects among patients whose native tongue is not English.

I have argued that there are several reasons to believe that the incentives of managed care could differentially harm the care provided to racial and ethnic minorities. An interesting test of this hypothesis was conducted by Tai-Seale and colleagues (2001), who focused on a group of Medicaid beneficiaries who were forced into HMOs. From this natural experiment, they found that compared with whites who were forced into HMOs, blacks "experienced declines in relative use of physician services (among both adults and children) and an increase in relative use of the ER among children" (Tai-Seale et al., 2001, p. 56). They further note that, "while the reduction in service use in itself is not necessarily a sign of poor access or discrimination, it is the difference in the decline of relative service use between African-American and white beneficiaries that warrants further investigation" (p. 57). The findings therefore are consistent with the belief that financial incentives that encourage physicians to reduce resource usage under managed care differentially harm racial and ethnic minorities.

### Utilization Review and Practice Guidelines

Utilization review is a practice engaged in, usually but not always by health care payers, to monitor whether a particular service is appropriate for a patient in a specific instance. It can be done prospectively (requiring that a hospital admission be approved in advance), concurrently (during a hospital stay), or retrospectively (reviewing services already rendered by a physician as part of a “practice profile”). Traditionally, utilization review has been thought of as a cost containment method because it was originally applied to fee-for-service medicine, in which there often is a financial incentive to over-provide. But it can also be used in a capitated environment to ensure that enough services are being delivered.

In contrast, practice guidelines are designed to reduce inappropriate variation in the provision of medical services (Wennberg and Gittelsohn, 1982; Rutledge, 1998). Their implementation can lead to the provision of more or fewer services, depending on how prevailing practice patterns compare to the norms recommended in the guidelines.

Practice guidelines should result in a reduction of racial and ethnic disparities. Since the guidelines are agnostic with regard to race and ethnicity, following those guidelines should result in standard care across these groups. A potential problem arises when guidelines are used not as a way of enhancing quality, but as a way to reduce costs. In such instances, they begin to resemble utilization review. Many of the problems described in the previous section also apply here.

Suppose that a multispecialty group practice has contracts with a number of network-model HMOs and wishes to monitor the resource usage of its physicians. Further suppose that, as a way of controlling costs, it uses practice guidelines but alerts physicians that they are deviating from the guidelines only when they are performing more services than recommended in those guidelines. It does not let them know when their utilization is lower than the specified levels (unless they are so deviant that there is a risk of malpractice).

Under this scenario, physicians are likely to feel pressured to control their provision of and/or recommendations for additional services. If this is the case, then for the reasons discussed under the capitation/DRG section, they are likely on average to provide relatively fewer services or recommendations for services to racial and ethnic minorities.

It is worth noting a particular study on physicians’ recommendations for managing chest pain conducted by Schulman and colleagues (1999). Physicians at national meetings were recruited to participate in a study in which they viewed videos of patients and were then asked to assess whether they would recommend cardiac catheterization. The patients on the videos were actually actors, all of whom were directed to follow scripts

in identical manners. In addition, each of these “patients” was identified as having the same occupation and health history. Each physician participant was randomly assigned to see and hear one such video. The study found that both women and blacks were much less likely to be recommended for cardiac catheterization than men and whites. The odds ratios for both were 0.6, and the odds ratio for black women (compared with white men) was 0.4.

This study seems especially relevant because it shows how physicians are likely to ration when they are under pressure—as a result of utilization review or the inappropriate application of practice guidelines—to keep costs and referrals down. These supply-side techniques therefore also have the potential to aggravate racial and ethnic disparities.

### **Supply, Technology, and Expenditure Controls**

It is difficult to generalize about other countries, all of which have different health care systems and have relied on different methods of controlling costs. Nevertheless, if one were to risk doing so, it might be concluded that they rely much more heavily than the United States on “macro-level” supply-side strategies. Rather than looking at the particular services delivered,<sup>6</sup> they tend to stress (in varying degrees) system-wide policies such as regulating the supply of hospital beds, physicians, specialists, and medical technologies.

One of the most common methods of cost containment, especially for hospital and physician services, is the use of some kind of global budgets. These “tend to be prospectively set caps on spending for some portion of the health care industry” (Wolfe and Moran, 1993, p. 55). The exact meaning, however, varies from country to country. In some countries, such as Canada, hospitals receive an annual global budget to cover their entire operating budget. In Germany, there are regional budgets for different types of physician services. A survey of nine European countries found that all used some form of global budgeting. Most studies of global budgeting have found that global budgets do help control spending (Wolfe and Moran, 1993; U.S. General Accounting Office, 1991; Abel-Smith, 1992).

It would seem that the potential for racial and ethnic disparities could still exist under these macro-level policies, just as they did under the more micro-level supply-side strategies employed in the United States. Indeed, even countries with universal coverage and low patient cost sharing re-

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<sup>6</sup> This is not the case everywhere. Germany, for example, historically has compared individual physician utilization profiles to those of other physicians and, when there is a large deviation, informed the physician and sometimes even withheld reimbursement.

quirements have been unable to equalize access to care. To give some hypothetical examples consistent with the literature cited earlier:

- If the number of specialists are controlled, as is the case in many countries, then those that are in practice will experience excess demand for their services and may ration according to race and ethnicity.
- If the number of hospital beds or medical technologies are controlled, then these scarce resources may be rationed similarly.
- If there is a global budget on various sectors of the health system, each of these sectors will have to make its own allocation decisions. Again, there is little assurance that racial and ethnic disparities will be avoided.

Thus, whatever the merits or demerits of the cost-containment systems used in other countries, there is no assurance that importing them to the United States would be any less discriminatory than other supply-side strategies currently being used in this country. Perhaps the major lesson from other countries is that most do not rely on demand-side policies, which were earlier shown to have the potential to create large disparities. This theme is further examined below.

### Conclusions

Unfortunately, there are no easy answers to questions concerning how we can reduce racial and ethnic disparities in health care. This paper has shown that both demand- and supply-side cost containment methods have strong potential for aggravating existing inequities.

In some ways, the demand-side problem is more vexing. The core notion is that goods should be allotted according to ability to pay. Those who lack that ability therefore, will either use fewer services or spend much more of their income using them. Since racial and ethnic minorities have lower average incomes and, for most indicators, worse health status, demand-side cost containment policies tend to hit particularly hard.

There are no easy answers on the supply side either. Most papers on racial and ethnic disparities that show some form of discrimination on the part of physicians—however unintentional—suggest that they be told of current disparities in treatment as part of a broader effort to make them more “culturally competent” [see, for example, Brach and Fraser (2000) and van Ryn and Burke (2000)]. Needless to say, changes in deep-seated behavior of this kind will not take place overnight.

I would posit that the reliance on both demand- and supply-side cost containment strategies, particularly through the application of managed competition, makes the problems more acute in the United States than in

other countries. Managed competition relies on nearly all of the problematic cost-containment strategies outlined in this paper:

- Allocating services on the basis of ability to pay.
- Relying on consumer's understanding of complicated comparative information when choosing health plans.
- Pressuring providers through payment mechanisms such as DRGs and capitation.
- Monitoring the provision of services through a variety of utilization review mechanisms.

As noted, cost-containment methods used in others countries, which focus almost entirely on the supply side, do not offer a panacea for ending racial and ethnic disparities in health care. But they do shun the demand-side policies that have been embraced in the United States. Moving away from such policies is one tangible thing that the United States could do.

It really comes down to an issue of fairness. To ensure that individuals who are at a disadvantage have an equal probability of attaining good health, it is necessary to redistribute resources from those who have been more fortunate. Relying on ability-to-pay to allocate health care services, as noted earlier by Evans and colleagues (1993), does the opposite. Thus, while striving to increase the sensitivity of health care providers to existing inequities, we must not put further barriers in the way of racial and ethnic minorities receiving needed health care services.

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# Racial and Ethnic Disparities in Healthcare: An Ethical Analysis of When and How They Matter

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## INTRODUCTION

Recent health services research literature has called attention to the existence of a variety of disparities in the health services received by racial and ethnic minorities. As well, racial and ethnic disparities in health outcomes from various health services, including screening, diagnosis, and treatment for specific diseases or medical conditions have also been noted. Such findings provide the impetus for the consideration of two primary moral questions in this paper. First, when do ethnic and racial disparities in the receipt of health services matter morally? Second, when do racial and ethnic disparities in health outcomes among patient groups matter morally?

Our approach in answering these questions takes the form of two theses. Our first thesis, the *neutrality thesis*, is that disparities in health outcomes among patient groups with presumptively similar medical conditions should trigger moral scrutiny. Our second thesis, the *anti-discrimination thesis*, is that disparities in receipt of healthcare or adverse health outcomes among racial, ethnic or other disadvantaged patient groups should trigger heightened moral scrutiny. The theses are presented as lenses through which the morally salient features of health services can be viewed. Most theories of justice can accept some version of both the neutrality thesis and the anti-discrimination thesis. However, as we shall see, these theories differ in the nature and strength of their moral conclusions and in the reasoning they employ in reaching those conclusions.

The bulk of this paper will focus on the foundations of the theses, their relation to competing accounts of justice, and the considerations relevant to their moral analysis. In Section II, we articulate the moral foundations for the neutrality and anti-discrimination theses, and in Section III, we examine some potentially morally relevant considerations that inform the conclusions from the perspectives of alternative theoretical frameworks. Finally, in Section IV, we consider the moral implications of these findings for physicians and other healthcare providers.

The preliminary task, however, is to clarify several conceptual issues lurking in the formulation of the theses. Although the theses overlap in certain important respects, it is even more important to be clear about how they differ.

#### *Differences Between the Neutrality Thesis and the Anti-Discrimination Thesis*

The first conceptual distinction has to do with *who* is covered under the thesis. The neutrality thesis covers disparities in health outcomes among any patient groups with presumptively similar medical conditions and prognoses. By contrast, the anti-discrimination thesis refers specifically to a subset of what falls under the neutrality thesis—the special case in which the outcome disparities involve racial, ethnic or other disadvantaged patient groups.

The second conceptual distinction has to do with *what* is covered. The neutrality thesis covers only disparities in health outcomes. But the anti-discrimination thesis, which specifies that the disparity must occur in a disadvantaged social group, means that disparities in the healthcare services people receive, and not just the outcomes they experience, also matter.

The neutrality thesis is thus intended to cover any instance in which it is established that there are differences in outcomes among patient groups that are in relevant respects otherwise medically similar. If it was determined, for example, that white men with colon cancer had poorer survival rates than African-American men with colon cancer, then the neutrality thesis should trigger the same moral scrutiny as if the situation was reversed. In addition, this claim would hold even if it was clear that there were no differences in the medical services the two groups received. However, what if it was determined that white men were less likely than African-American men to have screening colonoscopies after age 50? As long as this disparity did not result in different medical outcomes, there are no moral implications under the neutrality thesis.

In contrast, the anti-discrimination thesis assumes that disparities in both health services received and disparities in health outcomes are independent and distinct reasons for moral concern when the disparities disfavor racial and ethnic groups. These groups are “morally suspect cat-

egories,” understood here as analogous to legally suspect categories in equal protection law. Under the anti-discrimination thesis, either type of disparity—alone or in combination—is treated as morally problematic as long as the disparity disfavors a morally suspect group. This is markedly different from the neutrality thesis, in which disparities in utilization are only problematic if they have a disparate impact on health outcomes.

Underlying the neutrality thesis is the implicit assumption that the moral value of medical interventions is generally instrumental. In other words, whether it is good or bad to receive or fail to receive a medical intervention depends on the impact each option would have on individual health and well-being. In the case of racial and ethnic minorities, however, a different moral value is at stake. The very fact that a minority population might receive fewer services believed to be beneficial suggests the potential for morally culpable discrimination. This is a significant moral concern in its own right, regardless of the medical consequences. Under the anti-discrimination thesis, disparities of either sort trigger an additional or heightened level of moral scrutiny beyond that warranted by health outcomes disparities generally.<sup>1</sup>

### Moral Foundations for the Two Theses

Thus far, we have merely articulated some of the implications of and analytic differences between the two theses and the implications of the differing forms of moral judgment that can flow from the use of either moral lens. In this section, we offer a philosophical defense of the two theses and link them to the more general theoretical foundations on which they rest.

A principle that has come to be known as the formal principle of equality is often the starting point for discussions as to when some sort of disparity or inequality in the way persons are treated (in a more general sense than meant in healthcare contexts) is morally problematic. It is a minimal conception of equality attributed to Aristotle, who argued that persons ought to be treated equally unless they differ in virtue of some morally relevant attributes. It is, of course, critical to determine in any particular context just which attributes are morally relevant and which are not. Often these determinations are matters of disagreement and controversy that can be traced to significant differences in rival theories of

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<sup>1</sup> We do not claim that the neutrality thesis and the anti-discrimination thesis offer an exhaustive account of the sources of value underpinning the broader range of moral concerns in healthcare policy. We have argued elsewhere that in addition to medical outcomes some arguments for universal healthcare may depend as much on their impact on aspects of human well being other than health (Faden and Powers, 1999).

justice. The degree of agreement across theories of justice on the matters under discussion in this paper is, therefore, surprising.

### *Libertarian Theories*

Consider first a type of theory of justice many would think least likely to agree with either the neutrality thesis or the anti-discrimination thesis. The libertarian theorist rejects any pattern of distribution as the proper aim of justice, arguing instead that whatever pattern of distribution emerges from un-coerced contracts and agreements is morally justified (Nozick, 1974). Moreover, coercive attempts by the state to enforce a preferred pattern of distribution are themselves viewed as unjust. To the libertarian, inequalities are counted as merely unfortunate and not unjust, unless they are the product of some intentional harm or injury.

Initially, one might think that the libertarian position leaves little room for objecting to disparities in health outcomes among patient groups, whether defined along racial lines or otherwise, or to disparities in the receipt of health services among racial and ethnic groups. As long as patient preferences are not overridden and no harm to those patients was intended, no injustice or other moral failing would obtain. Indeed, it seems highly unlikely that the libertarian could accept the neutrality thesis, failing to see any basis for demanding moral scrutiny merely because some patient groups fare less well than other patient groups.

The libertarian conclusion may well be different, however, when, as contemplated by the anti-discrimination thesis, the patient groups involve morally suspect categories. Some conceptual room is left open for endorsement of the anti-discrimination thesis, and that room is a consequence of the limited domain of moral judgment for which the libertarian theory is meant to apply. The libertarian view is primarily a theory of societal obligation, or what society collectively owes its members, and not a comprehensive moral doctrine spelling out the full range of individual or other non-governmental moral obligations. Libertarians often assert that particular individuals have duties of mutual aid, even fairly stringent ones, even though state coercion to enforce them would be unjust (Engelhardt, 1996), as do certain non-governmental institutions and professional bodies that assume certain social functions as part of their self-defined moral missions. Thus, even in the libertarian view, the failure of individuals and institutions to offer health services to all racial groups on an equal basis can be a significant basis for moral condemnation.

A point of particular significance for this discussion is that nothing in the libertarian view necessarily excludes the existence of parallel moral obligations that are role specific, such as those ordinarily obtaining between physician and patient. Such special obligations are often referred

to as agent-relative obligations. Some libertarians have argued that because of the existence of these agent-relative obligations, which in their view form the core of our moral requirements, coercive state action is morally condemnable. Such interference is said to be morally condemnable insofar as it may interfere with an individual's most basic agent-relative moral duties (Mack, 1991). The libertarian, therefore, may limit what government may do to enforce certain individual moral obligations, but it does not purport to be a comprehensive moral doctrine that effaces those individual obligations.

The upshot is that the libertarian view, even in its strictest form, need not reject a thesis asserting that disparities involving racial and ethnic minorities should trigger special moral scrutiny. However, libertarians will locate their judgment of moral failing in the failure of specific individuals or institutions to discharge their moral duties, not in the society at large. Nor would the libertarian necessarily see the moral problem as a failure of government to enforce neutrality in the receipt of care or achievement of the outcomes that specific individuals and institutions are properly committed to achieving.

In sum, even libertarianism, the theory of justice least compatible with the neutrality thesis, can substantially endorse the anti-discrimination thesis as applied to disparities in the receipt of services and in health outcomes. When using the lens of the anti-discrimination thesis, a libertarian might reach a more modest moral conclusion than the one we shall defend, and a libertarian does not endorse the more inclusive moral concern shown for disparities in health outcomes embodied in the neutrality thesis. However, in Section III, we explore some instances in which the libertarian view might agree with our conclusion that some patterns of racial and ethnic disparities should be counted as injustices, and not simply moral failings.

### *Egalitarian Theories*

A family of justice theories known as egalitarian theories offers more solid support for both the neutrality thesis and the anti-discrimination thesis, even as those theories diverge substantially in their theoretical foundations. Egalitarians, unlike libertarians, are intrinsically concerned with the existence of inequalities. Egalitarians themselves differ as to how much inequality they find morally tolerable, the reasons they find inequalities to be morally problematic, and the kinds of inequalities they consider to be the central job of justice to combat.

One strand of egalitarianism prominent in the bioethics and health policy literature borrows heavily from the work of John Rawls (Rawls, 1971). The first principle of the Rawlsian theory is that everyone should

be entitled first to an equal bundle of civil liberties (e.g., political and voting rights, freedom of religion, freedom of expression, etc.), which shall not be abridged even for the sake of the greater welfare of society overall. Secondly, everyone should be guaranteed a fair equality of opportunity. That principle of fair equality is given a robust, substantive interpretation such that permissible inequalities in such things as income and wealth work to the advantage of the least well-off segments of society. Fair equality of opportunity is thus a term of art, signaling more than a formal commitment to non-discrimination, but also an affirmative commitment to resources necessary to ensure that all citizens of comparable abilities can compete on equal terms. For Rawls, this commitment means a guarantee of educational resources sufficient for all persons to pursue opportunities such as jobs and positions of authority available to others within society.

Norman Daniels seizes on Rawls' core arguments (Daniels, 1985). He accepts the core Rawlsian framework but offers a friendly amendment to the Rawlsian theory. Daniels claims that once we acknowledge that there are considerable differences in the health of individuals and that the consequence of those differences is that individuals differ substantially in their opportunities to pursue life plans, we must relax Rawls' own assumption about the rough equality of persons. Once this assumption is relaxed, the theory has implications for how we think about healthcare resources. If, as Daniels argues, health is especially strategic in the realization of fair equality of opportunity, and that healthcare services (broadly construed by Daniels) make a limited but important contribution to health, then we derive a right to healthcare sufficient to pursue reasonable life opportunities. The logic of Daniels' account clearly lends support to the neutrality thesis in as much as disparities in health outcomes are precisely the sort of consequences that the principle of fair equality of opportunity treats as unjust and therefore, as proper objects of remedial governmental action.

In addition, Daniels' version of the Rawlsian theory can be seen as lending support for the anti-discrimination thesis, although this is not an element of Daniels' theory that he himself highlights. For example, the theoretical support for treating inequalities in health outcomes among racial groups as unjust, as distinguished from a rationale that makes inequalities among persons generally unjust because of their adverse impact on equality of opportunity, lies in its endorsement of Rawls' core notion of a formal principle of equality. Rawls and Daniels both start their discussion of equality of opportunity with the formal principle that morally irrelevant distinctions should not be employed as a basis for determining the range of life opportunities open to persons. Matters of race, gender, and the like are counted as irrelevant, so if their claims are plau-



sible, then even disparities in services received (as well as disparities in health outcomes) based on racial and ethnic categories warrant some moral scrutiny.

Other members of the egalitarian family of justice theories offer more direct support for both theses. The “capabilities” approach argues that it is the job of justice to protect and facilitate a plurality of irreducibly valuable capabilities or functionings (Sen, 1992; Nussbaum, 2000). Capabilities theorists, led by Amartya Sen, generate slightly different lists of the core human capabilities central to the job of justice, but all converge on the idea that a variety of health functionings, including longevity and absence of morbidity, are among those centrally important human capabilities. Unlike the modified Rawlsian concept, which makes the importance of health and hence healthcare derivatively important because of health’s especially strategic role in preserving equality of opportunity, the capabilities approach reaches similar conclusions about the intrinsic importance of health, and more directly, the goods instrumental to its realization. Based on Sen’s theory, inequalities among any of the core capabilities are matters of moral concern. Thus, as the neutrality thesis asserts, any finding of disparities in health outcomes should trigger moral scrutiny.

Among the core capabilities included on Sen’s list are capacities for all to live their lives with the benefit of mutual respect and free from invidious discrimination. Thus, support for the anti-discrimination thesis also flows naturally from the capabilities approach inasmuch as the value of equal human dignity and respect is of fundamental moral importance, as is health. Disparities in services received, no less than disparities in health outcomes, therefore trigger a heightened moral scrutiny under a theory that renders inequalities of both sorts morally problematic.

#### *Democratic Political Theory*

Libertarian and egalitarian theories are two broad theoretical traditions that at face value seem to have the greatest divergence in their implications. However, they have been shown to result in greater convergence, at least on the anti-discrimination thesis, than might otherwise be suspected. Apart from the (perhaps) unexpected convergence of two quite different comprehensive moral theories on the interpretation of the formal principle of equality, there are additional philosophical arguments favoring the anti-discrimination thesis that do not require taking sides with any comprehensive moral views.

Recent work in political philosophy by John Rawls begins with the assumption of what he calls a reasonable pluralism of comprehensive moral views (Rawls, 1993). In a democratic nation, persons motivated to reach agreement on the basic social structure, understood as shared basis

for social cooperation, will seek an overlapping consensus on some evaluative questions. That consensus will necessarily include a commitment to the view of each person as a free and equal citizen. While critics have questioned how much substantive moral content can be derived from this perspective, they generally agree that some underlying commitments are widely shared in any democracy (Gutmann and Thompson, 1996). Among them are the ideas that the interests of all should be given equal weight regardless of race, creed, color, gender or other attributes deemed morally irrelevant. Although such a notion does not settle the deeper moral question of which attributes are morally irrelevant, the crucial point is that such views form the bedrock of most Western democracies. Underlying this desire for equal respect and concern is the vague but powerful idea of human dignity and the importance we attach to equality of treatment for the least advantaged that the more powerful members of society have secured for themselves (Harris, 1988).

Thus, although there is a diversity of possible justifications for the importance of health and healthcare services, there is widespread basis for agreement that inequalities in health outcomes that track racial and ethnic lines, especially when racial and ethnic lines also track other indices of social disadvantage, are ethically problematic. This feature of democratic theory, reflected also in equal protection law, justifies at minimum the added moral scrutiny required by the anti-discrimination thesis.

### **The Relevance of Causal Stories**

So far we have established that egalitarian theories, and in particular capability theory, provide moral justification for the neutrality thesis. Thus, even with a libertarian view, the failure of individuals and institutions to offer health services to all racial groups on an equal basis can be a significant basis for moral condemnation. Even if the moral scrutiny demanded by the neutrality thesis and the added moral scrutiny demanded by the anti-discrimination thesis are warranted, this is not the final word. All that has been established thus far is that governments and healthcare institutions have a moral obligation to investigate identified disparities. The key questions are how governments and healthcare institutions should interpret the moral meaning of the results of such an investigation, whether disparities should be considered injustices, and under what conditions. On many moral accounts, an evaluation of the explanations for the disparities is needed to make a judgment about whether the disparities represent an injustice. In other words, whether disparities in health outcomes or in the services patients receive constitute an injustice depends for some on the causal story that stands behind the disparity. Thus, while there may be wide agreement about the moral imperative to

investigate identified disparities, at least with respect to morally suspect groups, there is far less agreement about how to interpret the moral significance of the results of such an investigation.

The moral significance of causality is a difficult sticking point in moral philosophy. There is a natural inclination in theories of individual morality, as there is in law, to bind moral responsibility and causal responsibility together. We do not ordinarily think, for example, in law or morality, that an individual is morally culpable for adverse consequences arising from circumstances over which that individual had no control. Lack of causal efficacy is the end of the story for many assessments of moral and legal responsibility. Moreover, a judgment of causal responsibility is a threshold concern for many accounts of individual moral and legal responsibility, and the presence of some causal contribution to the harm of others opens the door to legal analysis. Theories of justice, however, are more varied and often more controversial than the individual model in their understandings of the relation between causal and moral responsibility.

#### *Libertarian Views of the Relevance of Causal Explanations*

Some theories of justice employ something similar to this individual moral responsibility model in their assessments of the justice of social institutions. Libertarians, for example, link a judgment of injustice to some intentional harm. That view holds that adverse consequences or disproportionate burdens borne by some individuals or groups as a consequence of the structure of social institutions do not warrant a judgment of injustice. The libertarian views these consequences for the most part as merely unfortunate, not unfair.

The libertarian view is an especially stringent rendering of the claim that moral responsibility for society and its political institutions is linked necessarily to a direct causal responsibility. It is a stringent standard as it demands that the causal connection be an intentional harm.

However, there is theoretical room for the libertarian to reach an even stronger conclusion that racial and ethnic disparities in health outcomes and the receipt of health services are morally condemnable failings of particular persons or institutions. In some cases, the libertarian can conclude that these disparities are injustices. There are at least three ways that the libertarian can reach such conclusions.

First, for the libertarian, patterns of inequality are not morally troubling in themselves. However, this assertion is qualified by the proviso that those patterns are morally unproblematic only as long as they are not the consequence of prior injustices in social exchanges or agreements. This nod to historical context is crucially important. If the social and institu-

tional history that causally contributes to present patterns of inequality are in and of themselves unjust, perhaps the result of past intentional harms whose adverse consequences remain today, then present patterns of inequality may be judged as unjust, and not merely a matter of moral failing of individuals or non-governmental institutions. There is nothing intrinsic to the libertarian view that makes it hostile to such historical claims regarding the legacy of racism, the intentional harms based on racial or ethnic prejudice, or the moral taint on the advantages obtained from such practices.

Second, for one brand of libertarian theorist, the constraint on coercive state appropriation of private assets for the purposes of achieving certain patterns of distribution does not entirely restrict what states can do with respect to redistribution. While private assets are put beyond the reach of states, not all resources are private. According to some libertarians, redistribution for the purposes of combating inequalities in the healthcare context are acceptable when it involves public resources or the decision to devote resources to activities that benefit the public at large. Medical education and the construction and operation of healthcare facilities are clear examples of public resources being invested deliberately for the promotion of the common good.

Even if the libertarian can argue that there is no antecedent duty to support such activities for the common good, the claim of allegiance to the state itself is said by some libertarians to depend upon strict neutrality between its citizens (Nozick, 1974). This requirement of neutrality clearly makes all disparities in services received, as well as disparities in health outcomes such as racial and ethnic health outcome disparities, unjust. If the neutrality requirement endorsed by some libertarians is a strict one, as it is in Nozick's libertarian theory, then the proper test of neutral state action is neutrality of effect on its citizens (Raz, 1986). Thus, one particular interpretation of libertarianism supports the neutrality thesis. Moreover, the moral failing associated with its violation is an injustice. Of course, not all libertarian theorists endorse the political neutrality thesis and accordingly, those libertarians would be committed neither to the neutrality thesis we have defended nor to the finding of an injustice if neutrality of effect is not achieved.

A third possible exception to the libertarian's general reluctance to see an injustice in any disparities in receipt of services or health outcomes, even in the case of racial and ethnic minorities, lies in the libertarian's account of what constitutes intentional harm. The typical definition of an intentional harm is one that is generated from a fully conscious or present-to-mind motivational stance. Therefore, overt racist actions would surely count as intentional harms. For example, if services were not offered to racial and ethnic minorities because of a conscious intention to make their

health outcomes worse, or as a deliberate assault on their dignity, these denials of services would count as intentional harms. In this narrow range of cases, the libertarian has no choice but to support the anti-discrimination thesis and conclude that the moral failings involved are injustices.

Less clear, however, is how the libertarian must account for more subtle, often unconscious, instances of racism. The resolution depends on the view of intention employed by the theory. In our judgment, nothing intrinsic to the libertarian theory rules out a more expansive account of what constitutes an intentional harm, even though the ideological thrust of most libertarian theories would be naturally resistant to any effort to look behind an agent's conscious state of mind. The libertarian would have to articulate a plausible rationale for adopting the narrow construal, and as long as the core intuition of what constitutes an injustice is tied to intentional harm, limits on the psychological transparency of an agent's own true intention would seem to need a persuasive argument for such a restriction.

#### *Brute Luck and Social Structural Egalitarian Views of Causality*

Other justice theories, including two prominent versions of egalitarianism, make the locus of causal responsibility an important consideration. Consider first a rather permissive standard sometimes referred to as the brute luck conception of justice (Scanlon, 1989). Brute luck theories count as an injustice all those inequalities that are not due to the choices of individuals. All inequalities that are beyond a person's control are therefore judged as brute bad luck and deserving of remedy, or if the inequality cannot be eliminated, compensation. Such theories take an indirect account of the causal story leading to the inequality in as much as the only inequalities society does not have to eliminate are those said to be chosen. While responsibility for some inequalities is laid at the individual doorstep, the brute luck standard holds society morally responsible for all inequalities that the individual did not bring on by his or her own choices. For example, the brute luck view recognizes that inequalities that result from genetics, ill health not brought on by lifestyle choices, and being born into a poor, uneducated family are all illustrative of inequalities that should be remedied by society. The brute luck theory can be contrasted with an alternative claim that attempts to reign in the moral responsibility of society for unchosen inequalities. The social structural concept argues that two conditions must be satisfied for society to incur an obligation to remedy inequalities: 1) the inequalities must not be the result of an individual's own choices; and 2) those inequalities must not be attributable to natural fortune that the society had no hand in creating. Examples of natural bad fortune, for which no social remedy is due, include genetic

differences and natural disasters. The focus is on the way social structures contribute to inequalities, and more specifically on the way that unjust social structures influence the creation of inequalities that reduce the life prospects of some people relative to others. Like the libertarian view, the social structural view demands proof that society had a causal hand in producing the inequality before it assigns society the moral responsibility for its elimination or reduction. The difference is that the social structural view does not require that the causal link between society and the inequality involve intentional harm. Instead, the social structural view adopts a less stringent requirement demanding only that the inequalities be an artifact or consequence of a particular social arrangement.

Let us next consider how the social structural and brute luck concepts might justify or limit the scope of application of a claim of injustice for disparities in health outcomes or health services. There are two important implications of the brute luck view. First, the brute luck standard provides robust justification for the injustice of inequalities that are covered by the neutrality thesis, but no special justification for the discrimination thesis. It would find all inequalities in health outcomes morally unjust, except for differences in health outcomes that are attributable to patient choice. The brute luck view reaches this conclusion independent of whether the inequalities are concentrated within racial and ethnic minorities or the majority ethnic and racial population. The fact that inequalities cluster along racial and ethnic lines or along lines of social disadvantage adds nothing to the moral assessment insofar as no further factual information of any sort (including some sort of causal story) is needed to find an injustice.

Second, because the brute luck concept is indifferent to any causal inquiry beyond the role of individual choice, the brute luck view can provide no special justification for viewing inequalities in health services as injustices. For example, the brute luck view is indifferent to whether inequalities in health outcomes between patient groups are a result of disparities in access to health services or the impact of differential socioeconomic status and educational background. Both generate social duties to reduce or eliminate disparities in health outcomes. The fact of brute, unchosen inequality is enough.

The social structural concept takes a different view. Attaching a judgment of injustice to disparities in services or outcomes along lines of racial and ethnic minority status—especially if burdened with other social disadvantages (the anti-discrimination thesis)—is entirely consonant with the social structural view. The claim of the neutrality thesis, which is that disparities in health outcomes that do not necessarily involve disadvantaged groups also constitute an injustice, also can be accommodated by the social structural view, but only if a different set of morally relevant

considerations can be brought to bear. Because the social structural view requires a causal story linking the social structure to health outcomes disparities, the case for injustice when disparities involve majority racial and ethnic patient groups would be more difficult to make than it would be for racial and ethnic groups who also experience broader social disadvantages. Even for these latter groups, a social structural view would necessitate the telling of a somewhat complex causal story to reach the conclusion that the inequalities are a matter of injustice and the responsibility of society to remedy.

#### *The Relevance of Individual Causal Responsibility*

A key question faced by libertarian, social structural, and brute luck theories is just how much of the causal story needs to be sorted out before deciding whether a disparity constitutes an injustice. All of these theories exclude from the realm of social responsibility inequalities generated by the choices and actions of individuals. But is this blanket exclusion plausible? This is where many of our most influential theories of justice appear ham-handed when compared with the kinds of moral intuitions that influence much of social policy in the United States and other industrial nations. For example, health insurance and welfare laws generally eschew fine-grained apportionment of individual, social and natural causal contributions to ill health. In many respects, health insurance plays the role of a kind of social safety net, catching those who fall through, regardless of the cause.

There are at least two potential explanations for why the moral foundations of many aspects of social policy do not fit well with some leading theories of justice. First, the apportionment of individual, natural, and social responsibility is, in practice, extremely difficult to disentangle. Second, because apportioning causal responsibility is often so hard to do, it is fraught with the risk of error and is potentially unfair. There is no doubt that these difficulties both explain and justify why public policy relies on moral lenses that deliberately leave some elements of the causal story out of focus. We think that the right mix of moral lenses leaves such differences out of account when examining health outcomes. This is the insight captured in the claim of injustice attaching to the inequalities coming under the scrutiny of the neutrality thesis. It is also the moral basis of public health, which finds any disparity in health outcomes to be morally problematic, regardless of who is affected. However, we argue that a special moral sensitivity to the constellation of race, ethnicity, and social disadvantage should be added back into the mix, especially when we have ample reason to believe that, although the precise causal story is complex, racial differences have made a dramatic contribution to the disproportional

tionate burdens that are an artifact of the social structure. This is the insight captured by the claim of injustice attaching to the inequalities coming under scrutiny by the anti-discrimination thesis.

From this stereoscopic vantage point we turn to a few examples of how patient choices and behavior fit into the arguments thus far. Although neither the neutrality thesis nor the anti-discrimination thesis rejects the notion that patient choices and actions make a moral difference in assessing the injustice of disparities in health outcomes, we deny that patient choice and behavior necessarily vitiate a conclusion of injustice.

Consider, for example, how that argument for the moral decisiveness of a patient's own choice to refuse treatment offered and recommended might seem to settle the issue of injustice once and for all. One possible explanation for some disparities in health services is that racial and ethnic groups exhibit different preferences for some types of medical care. Some groups may have higher aversion rates, for example, to invasive coronary care procedures. In some instances, preference differences make all the moral difference and a conclusion of injustice associated with disparities in the receipt of care may be rebutted. However, even if disparities in utilization rates are explained primarily by differences in uptake, rather than differences in offering, that is not necessarily the end of the matter. For example, gaps in mammography use between white and African-American women have closed considerably over less than a decade. This has been a consequence of public health education and outreach campaigns mounted on the assumption that gaps in knowledge and awareness, not merely a matter of differences in individual preferences or cultural values, accounted for differences in mammography rates.

Others have argued that minority aversion to the utilization of beneficial treatments might be based on a reasonable distrust of medical institutions and personnel (Randall, 1996). Whether such distrust is widespread is an empirical matter, and determining whether such distrust is reasonable lies beyond our task here. However, to the extent that the formation of preferences among racial and ethnic minorities is a product of a legacy of intentional discrimination that results in disparities in utilization and health outcomes, the fact that patient preferences account for all or some portion of those disparities does not obviate their injustice. If the preferences themselves are the fruit of a morally tainted history of institutional relationships, those who occupy positions of authority within those institutions have continuing moral obligations to ensure that patient preferences that are detrimental to racial and ethnic minorities are not systematically disadvantaging. In short, our view argues for looking behind or beyond mere preference in some instances to make a moral assessment of racial and ethnic disparities in the uptake of health services and in the resulting disparities in health outcomes.



Libertarian theories of justice, as well as most forms of egalitarianism, are mute on whether preferences must be taken at their face value. Many brute luck theorists believe that some preferences are beyond voluntary control and are instances of brute bad luck for which there is a duty to remedy (Cohen, 1993). The capability theorist also admits the possibility that some preferences are shaped by norms and institutions that involve unjust discrimination (for example, women's preferences for female circumcision). However, the idea of looking behind preferences is not the exclusive theoretical property of the brute luck theorist or any other particular theory. If the preferences themselves bear the moral taint of social structural injustices, then the social structural theorist cannot object. If the preferences bear the moral taint of intentional harms, then the libertarian cannot object. The difference is that each requires a different causal story to reach a conclusion of injustice when individual preference would ordinarily settle the moral matter in favor of there being no injustice.

Under all major accounts of justice, much of the work leading to a judgment of injustice involves getting the causal story straight, with some seeing overwhelming social determinants of such behaviors at work and others doubting the conclusiveness of the evidence and fearing the consequences of widespread belief in its truth. Although we lack the expertise to sort out these factual debates, our claim is a simpler one: there is too much at stake morally in ignoring the real possibility of some social structural causation. The demand for a precise apportionment of causal responsibility fails to take seriously the potential moral salience of the continuing effects of the legacy of racism and discrimination. Attaching a presumption of injustice to disparities in health outcomes that cluster along racial, ethnic, and socioeconomic lines is responsive to the need to fashion public policy with an awareness of the moral saliency of that legacy. Once again, we note that even the libertarian must attend to the importance of that history, for libertarianism is, in its own terms, a theory whose application is constrained by the assumption that patterns of inequalities are morally benign only when they emerge from a historical milieu in which injustices are not causally transmitted into the present context. In our view, few libertarians can claim that confidence when it comes to matters of race.

Moreover, at least for matters as central to human flourishing as health, we agree with the capabilities approach. The capabilities approach does not generally insist on the complete causal story to count disparities in health outcomes as instances of injustice. Moreover, the capabilities view demands additional moral scrutiny for racial and ethnic disparities in healthcare services and outcomes for moral reasons that have their foundation in capabilities other than health. These are capabilities that signal the importance of living a life as a free and equal moral person and enjoying the respect and dignity accorded to all citizens (Faden and Powers, 1999).

### **Implications for Physicians, Nurses and Other Providers of Health Care Services**

From the perspective of the health professional, the bottom line of this analysis can be summarized as follows. All the theories that we have reviewed have reasons to morally condemn disparities in health services and health outcomes involving racial and ethnic minorities. These theories have different reasons for reaching this conclusion, and they do not all agree that such disparities necessarily constitute an injustice. However, they all agree that race and ethnicity are morally irrelevant to the distribution of healthcare services and the outcomes with which these services are associated. Even from a libertarian viewpoint, the failure of individuals and institutions to offer health services to all racial groups on an equal basis can be a significant reason for moral condemnation.

In some respects, this is stating what is morally obvious. It is wrong for health professionals to discriminate on the basis of race or ethnicity. General moral duties of equal respect, as well as role-specific duties of the healing professions, obligate health professionals to accord equal consideration to each patient. The Hippocratic Oath requires physicians to apply treatments “for the benefit of the sick” and to “keep [patients] from harm and injustice” (Edelstein, 1967). The standard interpretation of the Hippocratic tradition concludes that such duties be applied impartially, and that no matter of personal preference or prejudice should compromise those duties with respect to any patient (Pellegrino and Thomasma, 1988). The Code of Ethics of the American Nurses Association similarly argues that the foundation of their professional duties rests in duties of beneficence impartially applied to all patients (American Nurses Association, 1985). Health care professionals are also obligated to address the moral context in which they work and to take responsibility for ensuring that equal respect and treatment is accorded by colleagues and by the healthcare organization where they work. To the extent that unconscious biases compromise their impartial duties toward their patients, there are derivative moral duties to identify and counteract those biases.

### **Conclusion**

One aim of this paper is to defend the view that racial and ethnic disparities are not merely matters of individual moral failing on the part of health professionals, but are also social injustices. Insofar as health professionals and professional organizations subscribe to this view, they should take a leadership role in advocating for interventions to reduce these disparities. It is here that good empirical data, capable of teasing apart the various factors that contribute to racial disparities, are critical.

Ethical arguments can justify the need for social action, but knowing precisely how to effectively intervene requires an integration of ethics with facts.

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