

## **INFORMATION LEAFLET FOR PARENTS/ CARERS – FOCUS GROUPS**

### **ASSIST (Autism Spectrum Social Stories in Schools Trial)**

#### **What is the purpose of this study?**

Social Stories™ are an intervention designed by Carol Gray (2000) to help with children with autistic spectrum disorder (ASD). A story book using pictures and simple language places the child in a story with positive social coping. By regularly reading or hearing a story in which they star, the child learns to adopt specific social skills. There has been no research on their use in mainstream schools. The aim of our study is to add to earlier small scale research to develop a manualised Social Stories™ intervention to help ASD children with their behaviour, in mainstream schools.

To do this we would like to gather information relating to the optimum design and use of Social Stories in children and young people with autism spectrum disorders. We would like to ask a small group of parents/carers, teachers, clinicians and young people about the best way to design and use Social Stories™ with ASD children. This “user group” will provide their experiences of and views on using Social Stories. These findings, alongside those of other autism experts, will be used to develop a Social Story™ writing toolkit for use in mainstream schools.

#### **Why have I been approached?**

You have been approached as the parent/carer of a child with an Autistic Spectrum Disorder who is 16 years of age or under and has previously used Social Story interventions with your child.

#### **Do I have to take part?**

You and your child are under no obligation whatsoever to take part. It is entirely voluntary. You and your child are free to withdraw from the study at anytime, without explanation. It is entirely voluntary. If you do agree to participate you can stop at any time, without explanation, we will use the information collected so far and stop collecting any further information. If you decide not to take part in or withdraw from the study this will not stop you receiving treatment from NHS services in any way.

#### **What will happen if I take part?**

This study will develop a manual for parents and teachers on how to develop and deliver a Social Story. We are interested in your experiences of using Social Stories in the past because we need to check that the manual we develop is based on your experience and views.

If you are happy to be involved you and your child will join a small group of parents to discuss your experiences using Social Stories, your views on writing Social Stories and what you think makes a good Social Story. You will be asked to look over a manual designed for parents and teachers to guide them in making Social Stories and asked your opinions on it.

With your permission we will record what you say using audio or video and a special researcher (qualitative researcher) will collect information to provide to an expert (academics, clinicians and parents) who will develop a manual on how to use Social Stories.

We plan to have around six meetings, three for the user group and three with the user group and “expert” group made up of researchers. The joint user/ expert group meetings will be conducted at the University of York and the rest at Lime Trees. We will assist with organizing transport and pay travel costs. Dr Barry Wright, Dr Chris Williams and other researchers will be available should you require further assistance or advice. Some members may also be asked to participate in one individual interviews to provide additional information to help the researcher ensure that the focus groups discuss the most important topics.

### **What do I do if I want to take part?**

If you are happy for both you and your son/daughter to take part in this study, please contact David Marshall, who is one of the researchers on the study or send us completed consent forms in the enclosed stamped-addressed envelope.

### **What are the possible benefits of taking part?**

This study will provide information about the effectiveness of Social Stories™ for children with ASD in mainstream schools and will help develop a toolkit for other parents to use. You may also benefit from hearing the experiences of other parents, teachers, young people and clinicians using Social Stories.

### **What are the disadvantages of taking part?**

We don't think that children in the study will have any side-effects from the stories. Some might not like using the stories. It is important for us to know who chooses not to carry on using the stories, and if possible why not.

### **What happens when the research study stops?**

No specific individual will be named in any research or reports produced. Confidentiality will be maintained. Any information kept will be done so anonymously. Once the overall results have been discovered, they will be published in a medical journal and copies will be given to the local community

through local professionals and support groups. All information collected about you will be destroyed after 6 months and all the information about the study will be destroyed after 10 years.

### **Will my information be kept private?**

Yes. If videos are used, they will be deleted after being transcribed. When we write down information that you or your child tell us we will give you a number. We will use this number instead of your name so no-one will know the information is about you. When we have finished the study we will write reports about it, but these reports won't have your name on them. It is up to you if you want to tell your family or friends about the research.

### **Will anyone else know I'm doing this?**

We will keep your information private. This means that we will only tell those who have a need or right to know. Wherever possible, we will send out information that has your name and address removed. Data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research.

### **Who is organising and funding the research?**

The research has been organised by Lime Trees Child, Adolescent and Family Service in York, which is part of the NHS. It has been financially supported by a special research grant. A group called Leeds East ethics committee checks that it is a fair and well conducted study.

### **Who can I contact if I want general advice about taking part in research, or want to make a complaint?**

Leeds and York Partnership NHS Foundation Trust Research and Innovation Unit can help if you want general advice about taking part in research. You can e-mail them at [REDACTED] or telephone on [REDACTED]. The Patient Advice and Liaison Service can give advice if you want to make a complaint. You can e-mail them at [REDACTED] or telephone them on [REDACTED]. You can also visit their website: <http://www.nyypct.nhs.uk/AdviceInformation/PALS/index.htm>

### **Who can I contact if I want to learn more about this study?**

If you would like any further information please contact Dr. Barry Wright [REDACTED]  
[REDACTED] or Dr. Chris Williams [REDACTED]

Thank you for reading this. If you have any questions please ask.

# CONSENT FORM FOR PARENTS/CARERS – FOCUS GROUP

## ASSIST (Autism Spectrum Social Stories in Schools Trial)

I have seen and read a copy of the patient information leaflet explaining the research study

I have had an opportunity to ask questions about the research

I understand that by participating in this research my child and I will join a small group of parents, teachers and clinicians to discuss my experiences using Social Stories. These sessions may be audio or video recorded.

I understand that if the researchers are concerned about my child's emotional health at any point they will discuss what to do next with both myself and my child.

I understand that I can discuss the research with a researcher at any time if I would like

I know that the research information will be kept strictly confidential. When the results are published no individual will be identified in any way

I understand that any data from the research will be securely kept for 10 years and then destroyed.

I know that taking part in this research is entirely voluntary. I know that if I or my child does not wish to take part I can stop being part of the research at any time, without providing a reason. This will not stop us receiving treatment from NHS services in any way.

I understand that relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research. I give permission to these individuals to have access to my child's medical records.

If I have any questions or concerns about the research I know I can contact Dr. Barry Wright   
 or Dr. Chris Williams

**I agree for my child and I to take part in this research study**

Name of young person: ..... (Block capitals)

Name of parent/carer: ..... (Block capitals)

Signature of parent/guardian: ..... Date: .....

Project explained and consent obtained by: .....

Signature of researcher: ..... Date:.....

**Thank you for your help**

# INFORMATION LEAFLET FOR PARENTS/ CARERS- PILOT STUDY

## ASSSIST (Autism Spectrum Social Stories in Schools Trial)

### **What is the purpose of this study?**

Social Stories™ are an intervention designed by Carol Gray (2000) to help with children with Autistic Spectrum Disorder (ASD). A story book using pictures and simple language places the child in a story with positive social coping. By regularly reading or hearing a story in which they star, the child learns to adopt specific social skills. There has been no research on their use in mainstream schools. The aim of our study is to add to earlier small scale research to develop a manualised Social Stories™ intervention to help ASD children with their behaviour, in mainstream schools.

We have reviewed studies already done on Social Stories™ by other research teams and have asked parents and carers about the best way to design and use Social Stories™ with ASD children. A small group of parents and carers joined other autism experts to develop a Social Story™ writing toolkit for use in mainstream schools.

The next stage of the study involves comparing the manualised Social Stories™ intervention that has recently been developed with the normal treatment. The information you provide us with on your experience of using the Social Stories manual will inform how it can be made better for families in the future.

### **Why have I been approached?**

You have been approached as the parent/carer of a child with an Autistic Spectrum Disorder.

### **Do I have to take part?**

You and your child are under no obligation whatsoever to take part. It is entirely voluntary. You and your child are free to withdraw from the study at any time, without explanation. If you do agree to participate, you can stop at any time, without explanation, we will use the information collected so far and stop collecting any further information. If you decide not to take part in or withdraw from the study this will not stop you receiving treatment from NHS services in any way.

### **What will happen if I take part?**

Interested families and teachers will be invited to meet a researcher for further information. If you would like to take part you will be asked to use a manual developed by the research team on using Social Stories. You will walk through the manual with your child, and with guidance from the manual, develop a Social Story.

At the end of the pilot study, you will be asked to take part in an interview about your experiences of using the Social Stories™ manual. You may also be asked to complete some questionnaires at this point. These results will be passed on to a writing group who will use your experience to further develop the manual for use by other families in the future.

Dr Barry Wright, Dr Chris Williams and other researchers will be available should you require further assistance or advice.

### **What do I do if I and my child want to take part?**

If you are happy for both you and your son/daughter to take part in this study, please contact David Marshall, who is one of the researchers on the study or send us the completed consent forms in the enclosed stamped-addressed envelope.

### **What are the possible benefits of taking part?**

Using the Social Stories™/ standard stories may help your child with their behaviour. This study will provide information about the effectiveness of Social Stories™ for children with ASD in mainstream schools. Free workshops on the writing and use of Social Stories™ will be provided.

### **What are the disadvantages of taking part?**

We don't think that children in the study will have any side-effects from the stories. Some might not like using the stories. It is important for us to know who chooses not to carry on using the stories, and if possible why not.

### **What happens when the research study stops?**

No specific individual will be named in any research or reports produced. Confidentiality will be maintained. Any information kept will be done so anonymously. Once the overall results have been discovered, they will be published in a medical journal and copies will be given to the local community through local professionals and support groups. All information collected about you will be destroyed after 6 months and all the information about the study will be destroyed after 10 years.

### **Will my information be kept private?**

Yes. When we write down information that you or your child tell us we will give you a number. We will use this number instead of your name so no-one will know the information is about you. When we have finished the study we will write reports about it, but these reports won't have your name on them. It is up to you if you want to tell your family or friends about the research.

### **Will anyone else know I'm doing this?**

We will keep your information private. This means that we will only tell those who have a need or right to know. Wherever possible, we will send out information that has your name and address removed. Data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research. Your child's general practitioner will also be informed that (s)he is taking part in this study.

### **Who is organising and funding the research?**

The research has been organised by Lime Trees Child, Adolescent and Family Service in York, which is part of the NHS. It has been financially supported by a special research grant.

### **Who has reviewed the study?**

Before any research goes ahead, it has to be checked by a research ethics committee. These are people who make sure the research is safe and fair. Leeds East ethics committee have done this.

### **Who can I contact if I want general advice about taking part in research, or want to make a complaint?**

Leeds and York Partnership NHS Foundation Trust Research and Innovation can help if you want general advice about taking part in research. You can e-mail them at [REDACTED] or telephone on [REDACTED]. The Patient Advice and Liaison Service can give advice if you want to make a complaint. You can e-mail them at [REDACTED] or telephone them on [REDACTED]. You can also visit their website: <http://www.nyypct.nhs.uk/AdviceInformation/PALS/index.htm>

### **Who can I contact if I want to learn more about this study?**

If you would like any further information, please contact Dr. Barry Wright [REDACTED] or Dr. Chris Williams [REDACTED]

Thank you for reading this. If you have any questions please ask.

# CONSENT FORM FOR PARENTS – PILOT STUDY

## ASSIST (Autism Spectrum Social Stories in Schools Trial)

I have read the leaflet about this research.

I have had the opportunity to ask any questions that I have about the research.

I understand that by participating in this research I will be working with my child and their teacher using the new Social Stories™ manual.

I understand that at the end of the Social Stories intervention I will take part in an interview about my experiences of taking part in the study and using the Social Stories™., I understand that I may be asked to complete some questionnaires.

I understand that if the researchers are concerned about my child's emotional health at any point they will discuss what to do next with both myself and my child.

I know that the research information will be kept strictly confidential. When the results are published, no individual will be identified in any way

I understand that relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research. I give permission to these individuals to have access to my child's medical records.

I know that taking part in this research is entirely voluntary I know that if I or my child does not wish to take part we can stop being part of the research at any time, without providing a reason. This will not stop us receiving treatment from NHS services in any way.

I give permission for the researcher to contact my child's GP and inform them that my child is taking part in this study.

I understand that any data from the research will be securely kept for 10 years and then destroyed.

I understand that I can contact the Research Team at Lime Trees [REDACTED] if I want to ask any more questions I have about the research.

**I agree for my child and I to take part in this research study**

Name of young person: ..... (Block capitals)

Name of parent/guardian: ..... (Block capitals)

Signature of parent/guardian: ..... Date: .....

Project explained and consent obtained by: .....

Signature of researcher: ..... Date: .....

Thank you for your help



# INFORMATION LEAFLET FOR TEACHERS – FEASIBILITY STUDY

## ASSIST (Autism Spectrum Social Stories in Schools Trial)

### What is the purpose of this study?

Social Stories™ are an intervention designed by Carol Gray (2000) to help children with Autism Spectrum Disorder (ASD). A story book using pictures and simple language places the child in a story with positive social coping skills. By regularly reading or hearing a story in which they star, the child learns to adopt specific social skills. There has been little research on their use in mainstream schools. The aim of our study is to add to earlier small scale research to develop a manualised Social Stories™ intervention to help ASD children with their behaviour, in mainstream schools.

We have reviewed studies already done on Social Stories™ by other research teams and have asked parents and carers about the best way to design and use Social Stories™ with ASD children. A small group of parents and carers joined other autism experts to develop a Social Story™ manual for use in mainstream schools.

The next stage of the study involves comparing the manualised Social Stories™ intervention that has recently been developed with standard stories. This research will provide evidence on the effectiveness of the Social Stories™ intervention.

### Why have I been approached?

You have been approached as the teacher of a child with an Autism Spectrum Disorder in a mainstream school who is 15 years of age or under.

### Do I have to take part?

You are under no obligation whatsoever to take part. It is entirely voluntary. You are free to withdraw from the study at any time, without explanation. If you do agree to participate you can stop at any time, without explanation. We will use the information collected so far and stop collecting any further information if you do decide to withdraw. If you decide not to take part in or withdraw from the study this will not stop the child receiving treatment from NHS services in any way.

### What will happen if I take part?

Children will receive all other treatment or support as usual. Parents, children and teachers will be asked to set goals with the help of a clinician and also complete questionnaires and a diary at three times: at the beginning of the study, six weeks into the study and four months into the study.

Depending on which school the child attends, they may be using the new Social Stories™ manual or spending the equivalent amount of time reading a story of similar length. This will be decided randomly by a computer.

A small group of participants will be asked to take part in an interview about their experiences of taking part in the study and using the Social Stories™/ standard stories.

.If your school is assigned to the group using Social Stories™ we will organise for you to attend a free workshop on the writing and use of Social Stories™ and provide you with a free manual on Social Stories™. If you are assigned to the group using standard stories, you will not be able to attend this workshop or receive the manual initially but both will be provided for you at the end of the study. Dr Barry Wright, Dr Chris Williams and other researchers will be available should you require further assistance or advice.

### **What do I do if I want to take part?**

If you are happy to take part in this study, please contact David Marshall [REDACTED] who is one of the researchers on the study or send us completed consent forms in the enclosed stamped-addressed envelope.

### **What are the possible benefits of taking part?**

Using the Social Stories™/ standard stories may help the child you teach with their behaviour. This study will provide information about the effectiveness of Social Stories™ for children with ASD in mainstream schools. Free workshops on the writing and use of Social Stories™ will be provided.

### **What are the disadvantages of taking part?**

We don't think that children in the study will have any side-effects from the stories. Some might not like using the stories. It is important for us to know who chooses not to carry on using the stories, and if possible why not.

### **What happens when the research study stops?**

No specific individual will be named in any research or reports produced. Confidentiality will be maintained. Any identifying information kept will be done so anonymously. Once the overall results have been discovered, they will be published in a medical journal and copies will be given to the local community through local professionals and support groups. All information collected about you will be destroyed after six months and all the information about the study will be destroyed after 10 years.

### **Will my information be kept private?**

Yes. When we write down information that you tell us we will give you a number. We will use this number instead of your name so no-one will know the information is about you. When we have finished the study we will write reports about it, but these reports won't have your name on them.

### **Will anyone else know I'm doing this?**

We will keep your information private. This means that we will only tell those who have a need or right to know. Wherever possible, we will send out information that has your name and address removed. Data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research.

### **Who is organising and funding the research?**

The research has been organised by Lime Trees Child, Adolescent and Family Service in York, which is part of the NHS. It has been financially supported by a special research grant.

### **Who has reviewed the study?**

Before any research goes ahead, it has to be checked by a research ethics committee. These are people who make sure the research is safe and fair. Leeds East ethics committee have done this.

### **Who can I contact if I want general advice about taking part in research, or want to make a complaint?**

Leeds and York Partnership NHS Foundation Trust Research and Innovation Unit can help if you want general advice about taking part in research. You can e-mail them at [REDACTED] or telephone on [REDACTED]. The Patient Advice and Liaison Service can give advice if you want to make a complaint. You can e-mail them at [REDACTED] or telephone them on [REDACTED]. You can also visit their website: <http://www.nypct.nhs.uk/AdviceInformation/PALS/index.htm>

### **Who can I contact if I want to learn more about this study?**

If you would like any further information please contact:

Dr David Marshall: T: [REDACTED] E: [REDACTED]

Dr. Barry Wright: T: [REDACTED] E: [REDACTED]

Dr. Chris Williams: T: [REDACTED] E: [REDACTED]

Thank you for reading this. If you have any questions please ask.

# CONSENT FORM FOR TEACHERS-FEASIBILITY STUDY

## ASSIST (Autism Spectrum Social Stories in Schools Trial)

*Please initial the box if you agree with the statement*

I have read the leaflet about this research.

I have had the opportunity to ask any questions that I have about the research.

I understand that by participating in this research I will be working with a child and parent using either the new Social Stories™ manual or spending the equivalent amount of time reading a story of similar length.

I understand I will be asked to set goals, keep a diary and complete questionnaires at three times,; at the beginning of the study, six weeks into the study and four months into the study.

I understand that I may be asked to take part in an interview about my experiences of taking part in the study and using the Social Stories™/ standard stories.

I know that the research information will be kept strictly confidential. When the results are published no individual will be identified in any way

I understand that relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities, or from the NHS Trust, where it is relevant to their taking part in this research.

I understand that any data from the research will be securely kept for 10 years and then destroyed.

I understand that I can meet Research Team at Lime Trees [REDACTED] if I want to ask any more questions I have about the research.

**I agree to take part in this research study**

*Please complete in block capitals*

Name of teacher: .....

Contact email address:.....Contact phone number:.....

School Name.....

Signature of teacher: ..... Date: .....

Project explained and consent obtained by: .....

Signature of researcher: ..... Date: .....

Thank you for your help