

Supplementary Materials 12

**QUESTIONS ABOUT YOU, YOUR FAMILY, AND
PLANNING AHEAD**

Please create your individual participant number.

To do this, write your initials and the day of your birth e.g. if your name was John Smith and your birthday was on the 15th of March, your participant number would be JS15.

Please write this here:



About you

Relationship to person with learning disabilities

- father
- mother
- brother
- sister
- other (please describe) _____

Gender _____

Date of birth _____

Ethnic group:

Tick one only

White

- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy or Irish Traveller
- Any other white background (please describe) _____

Mixed / Multiple ethnic group

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed background (please describe) _____

Asian / Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background (please describe) _____

Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black/African/Caribbean background (please describe) _____

Other ethnic group

- Arab
- Any other ethnic group (please describe) _____

Prefer not to say

How would you describe your health?

On a scale of 1 (very poor health) to 10 (very healthy) _____

If you would like to share more details about your health, please do so below:

Do you anticipate that the current main carer (this may be you or someone else) is still able to provide care in 5 years' time? (*not anticipating any unexpected events*)

- Yes, we can most probably carry on for at least 5 years
- Not sure – I am worried that it will become too much for the main carer
- No, probably not

If you would like to share more details, please do so below:

About your family member with learning disabilities

Gender _____

Age _____

Does s/he have autism?

Tick one only

Yes

No

Not sure

Does s/he have Down Syndrome?

Tick one only

Yes

No

Not sure

Does s/he have dementia?

Tick one only

Yes

No

Not sure

Does s/he have a diagnosed mental health condition (e.g. depression)?

Tick one only

Yes

No

Not sure

To what extent is s/he able to make someone who doesn't know him/her understand what s/he wants or needs (either with or without words)?

Tick one only

Not at all (has unique communication that is only understood by those who know him/her well)

To some extent (can make some needs known, but not others)

Completely – well able to communicate

Not sure

How often does s/he display behaviours that have been or could be described as 'challenging' (e.g. hurting themselves or others, throwing things, eating inedible objects, or other behaviours)

On a scale of 1 (never) to 10 (all of the time) _____

If you would like to share more details, please do so below:

Who else lives in the household?

Please describe their living situation below:

About planning ahead

How concerned are you about your family's future living/caring situation?

On a scale of 1 (not at all concerned) to 10 (extremely concerned) _____

If you would like to share more details, please do so below:

How prepared do you feel for future changes in your family's circumstances (including living and caring set-up)?

On a scale of 1 (not at all prepared) to 10 (fully prepared) _____

If you would like to share more details, please do so below:

During the past six months, to what extent have you, or your family, taken steps or action for planning ahead?

On a scale of 1 (none at all) to 10 (significant steps) _____

If you would like to share more details, please do so below:
