

# Big Learning Disability Survey: Supporter guidelines



## About the survey

Mencap is running the first national survey of people with a learning disability in 15 years.

This will be a chance for people with a learning disability to tell us about their everyday lives and experiences. We will be asking questions on topics that people with a learning disability have told us are important to them, such as health, relationships, employment and inclusion. The results will help Mencap to provide better support and further improve the lives of people with a learning disability.

## Survey participants

The survey is for adults (aged 18+) with a learning disability who live in the UK. Some people with a learning disability will be able to complete the survey by themselves. Other people might need some help to complete the survey. They might need a support worker, carer, family member, friend or somebody else to support them.

## Tips for supporters

Thank you for offering to support somebody to complete the survey. We have put together some tips to make this easier for you:

### 1. Decide where the conversation should take place

Before getting started with the survey, talk to the individual about where they want to complete it. It is important that this is a place where the individual feels comfortable enough to talk about their life and experiences. This may be a place where there is enough privacy or a place that they are already familiar with.

### 2. Make sure the individual feels at ease

It is essential that the individual feels at ease when they are completing the survey. Before you start, discuss how you are going to fill in the survey. Some people might want to read and fill in the survey themselves, whereas others might want you to do this. Allow enough time for them to answer each question – they should not feel under pressure to complete the survey as quickly as possible. Take breaks if needed, and maybe put the kettle on before you get started!

### 3. Make it feel like a conversation

If you can make filling in the survey more of a conversation, then this will make it much more fun! Rather than just reading out the questions and answer options, you can talk around the topics and encourage respondents to answer questions **in their own words first** before prompting them with the answer options. The answer they give is likely to be quite close to one of the answer options provided in the survey. Of course, everybody is different, and so you will need to adapt the style of the conversation to the person!

### 4. Use picture response scales if needed

You will see that some questions in the survey use response scales, such as a 5-point scale from 'Strongly agree' to 'Strongly disagree'. Some people might find it easier to answer these questions using pictures. On the following pages, we have created some picture scales for you to use to help people to answer these questions.

If an individual does not seem to understand the response options, even when using the picture scale, then please skip these questions.

### 5. Read through or practice beforehand

You might like to read through the survey questions before supporting somebody to fill it in. Or you might like to practice administering the survey with a colleague, family member or friend before supporting somebody to fill it in.

## Gaining and maintaining informed consent

It is essential that you ask the individual whether they are happy to take part in the research. Before doing so, you need to go through the 'information about this survey' section at the very beginning of the survey. This will help you to provide the individual with important information about things like confidentiality, and how Mencap will use any data collected. After you have gone through this information with the individual, please check whether they have understood and retained it.

It's really important that you explain there will be no bad or negative consequences if somebody decides not to take part, to skip a question or to stop answering questions at any time.

Whilst you are supporting the individual to complete the survey, please check they are happy to continue as you go on. Somebody may change their mind mid-way through, and they should be able to stop answering the questions if they want to.

## Reporting concerns

For most people, completing the survey will give them an opportunity to talk about how their life is now and the things that will help to improve this. However, it is possible that whilst you are supporting somebody to complete the survey, they will disclose something concerning.

Please report any concerns to Carla Barrett, Mencap's Research Manager, by emailing [carla.barrett@mencap.org.uk](mailto:carla.barrett@mencap.org.uk). If you work for Mencap or another organisation, please additionally follow all relevant protocols and safeguarding policies, as appropriate.

## Further sources of support

To get support you can contact **Mencap's Learning Disability Helpline**. It offers free advice and support for people with a learning disability, their families and carers. Just phone **0808 808 1111** or email [helpline@mencap.org.uk](mailto:helpline@mencap.org.uk)

If you're in **Northern Ireland**, phone 0808 808 1111 (and select option 2) or email [helpline.ni@mencap.org.uk](mailto:helpline.ni@mencap.org.uk)

If you're in **Wales**, phone 0808 808 1111 (and select option 3) or email [helpline.wales@mencap.org.uk](mailto:helpline.wales@mencap.org.uk)

You can also talk to **Mencap's Research team** about any of the topics included in this survey. Email: [research@mencap.org.uk](mailto:research@mencap.org.uk)



Strongly  
agree



Agree



Neither  
agree nor  
disagree



Disagree



Strongly  
disagree





Very good



Good



OK



Bad



Very bad