The Lives of People with Profound and Multiple Learning Disabilities in the UK

Information Sheet
For Carers from the Coronavirus and People with LD Study

Thank you for your interest in taking part in the 'Lives of People with Profound and Multiple Learning Disabilities in the UK' study.

What is this information about?

Previously you took part in the 'Coronavirus and People with Learning Disability Study'. At that time you gave us permission to contact you about future research. One of the learnings from the COVID-19 research was how important it is to understand the unique needs of people with profound and multiple learning disabilities (PMLD), and the needs of their carers.

Listening to the concerns expressed by carers, we have designed this survey specifically about the lives of people with profound and multiple learning disabilities (PMLD) across the UK. We want to know more about the lifestyle of people with PMLD, and we want to know how we can better support them in the future.

Who are we?

We are the same research team from the COVID-19 study (including researchers from the University of Birmingham, Manchester Metropolitan University, the University of South Wales, the University of Glasgow, and Queens University Belfast). Our focus for this new research is solely on people with PMLD and their carers. This research is funded by the Baily Thomas Charitable Fund.

How many families are we looking for?

We want to recruit around 350 family carers of people with profound and multiple learning disabilities who will complete an online survey. Carers must be 18 years of age, or older, to take part. We know that some adults with learning disabilities are not able to talk to researchers and we would like to thank you for taking part on behalf of the person with a learning disability that you care for. This information will help you decide if you want to take part in the research. Take time to decide if you want to take part. Ask us any questions that you may have.

Why have you been invited?

You have been asked to take part because you took part in the Coronavirus and People with Learning Disabilities study, you are a family carer who supports someone aged 14 or older who has profound and multiple learning disabilities, and you previously gave us permission to invite you to take part in future research.

If you do decide to take part in this research, we would like to compare how things are now with your responses to the COVID-19 study survey. We will only do this with your consent. The responses to the previous surveys are managed by Dr Sue Caton at Manchester Metropolitan University (MMU). If you are happy for us to be able to compare with your past survey responses, we would need your permission for Manchester Metropolitan University to share your information with us at the University of Birmingham. The same researchers from MMU are involved in this survey, but data is now being managed at the University of Birmingham. If you are happy for us to be able to compare with past surveys, we would need your permission for MMU to share your information with us at the University of Birmingham. You will be asked in the survey to agree or not agree to Manchester Metropolitan University sharing your COVID-19 survey responses with the University of Birmingham. You do not have to give your permission for your information to be shared and compared, and your decision will not impact on any other aspect of the survey.

What will I have to do?

You will be asked to complete an online survey. The survey may take up to 45 minutes to complete, and you can stop for breaks at any time and return, using the same link, to where you left off.

What will I be asked about?

The survey will be similar to the survey you completed previously and will ask questions about different aspects of the life of the person you care for (e.g., questions about health, well-being, living circumstances, cost of living, and access to services and supports). The survey will also ask some questions about you and your well-being.

Do I have to take part?

It is up to you to decide. When you start the survey you will be taken to a page where you will be asked if you consent to taking part. If you change your mind about taking part, you can stop and exit the survey.

Are there any risks if I participate?

There are not any risks to taking part. If you feel any distress when you answer the questions, you can close the survey and come back to it at a later time, or you can leave the study. If you feel distressed after you answered the survey or if you need any help, please contact:

In England and NI: Mencap Learning Disability Helpline: phone: 0808 808 1111,
Email: helpline@mencap.org.uk.

In Wales: Mencap Cymru: 0808 8000 300

In Scotland: Enable Scotland: Phone: 0300 0200 101, Email: enabledirect@enable.org.uk

Are there any advantages if I participate?

We hope you will think it is interesting and enjoy completing the survey. The researchers will find things out and share the study findings with people and organisations who can make things better for people with learning disabilities. Everyone who completes the survey will be offered a chance to be included in a prize draw, and ten winners will each receive a £50 gift voucher. The draw will be held when the survey is finished.

What information about me will you collect and why?

We will collect some personal information about you (this might include your name, email) to allow us to contact you about the study's findings and possible future research. We will also collect your responses to online survey questions about the person with learning disabilities that you care for. Data will be collected between June and October 2026.

How will my information be stored and how will you look after it?

For the new survey, your data will be stored and managed at the University of Birmingham. Data will be kept within the Qualtrics software. Qualtrics data will be downloaded weekly and stored on a University of Birmingham secure password protected server.

How will you use my information?

Data from the survey will be analysed using SPSS software to report on the lives of people with learning disabilities. Participants will be anonymous in all reports and other project outputs.

Will my data be sent anywhere else, or shared with other people or organisations?

Qualtrics data will be downloaded, pseudo-anonymised and kept at the University of Birmingham for data analysis. The University never sells personal data to third parties. Personal data will not be shared.

The only instance in which we may have to breach confidentiality is if you were to disclose that you or somebody else was at risk of harm. In this circumstance, we would have a legal responsibility to pass this information on to appropriate services. Where possible, we would endeavor to discuss this with you first and ensure you are aware of available support services.

When will you destroy my information?

The data and your personal data will be stored safely for 10 years. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

Data Protection Law

The way we look after your information is ruled by UK law. Under UK law, we need to have a very good reason for using your information (this is called a 'lawful basis'). Sometimes, we might also want to use sensitive information about you, like information about your health, religion and ethnic background. This is called 'special category information'. We collect all this information from you to help with our research, which aims to benefit everyone because we believe that it is in the 'public interest'.

You have the right to make choices about your information under UK law. If you have any questions or would like to ask us to do something with your information, you can ask the researcher (contact details are below).

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within four weeks of completing the survey, we will make sure this is done. If you ask us to delete data after this point, we might not be able to.

What will happen to the results of the research study?

We will share the results of the study with participants, organisations that support people with learning disabilities, policy makers, and other researchers. We will tell people what we find out in different ways such as reports, social media, presentations, academic journal articles.

Who has reviewed this research project?

The Humanities and Social Sciences ethics committee at the University of Birmingham has reviewed and approved this project. The Baily Thomas Charitable Fund has reviewed and funded this research.

Who can I contact about this study?

If you have any questions about the research, please contact:

Dr Peter Mulhall (pmld-survey@contacts.bham.ac.uk)

If you have any comments or concerns about the research you can talk to the Principal Investigator: Professor Jill Bradshaw (j.bradshaw.2@bham.ac.uk).

If you want to complain about the research, you can contact:
The Ethics Team (uobstudyoversight@contacts.bham.ac.uk).

If you are unhappy about how your data is managed?

If you are not happy about how we managed your personal data, you can contact the University of Birmingham's Data Protection Officer,Legal Services, The University of Birmingham, Edgbaston, Birmingham B15 2TT, Email: dataprotection@contacts.bham.ac.uk Telephone: +44 (0)121 414 3916

You have the right to complain directly to the UK Information Commissioner's Office if you would like to complain about how we process your personal data:

https://ico.org.uk/global/contact-us/