



1,000 Families study

Primary Caregiver Follow-up Study Information

Thank you for taking part in the 1,000 families study. Your participation in this study will make a valuable contribution to UK based family and disability research.

We estimate that the survey will take around 20 minutes for you to complete.

On the next page there is information about the study as required and approved by the NHS ethics committee. Please keep a copy of this information to read at a time of your convenience.

Primary caregiver Information sheet

We would like to invite you to take part in our research study. Before you decide to take part it is important for you to understand what the research would involve. Please take time to read the following information carefully. If there is anything that is unclear, or if you would like more information please contact us using the details provided at the end.

Purpose of the study

The aim of this study is to understand the experiences of family members living in the UK who care for a child with an intellectual disability (often called learning disability or learning difficulties in the UK). We wish to capture the experiences of parents/parental caregivers and any siblings. We have recruited over 1,000 families to take part in this research, including yourselves. We would now like to follow up with these families, because it is important to understand how families change over time and adjust in different ways to having a child with intellectual disability.

Who can take part?

We are inviting primary parental caregivers who participated in the first wave of the study and have children with intellectual disability (learning disability or learning difficulties) who are still between the ages of 4 years -15 years 11 months of age to take part in this research. Primary parental caregivers would be the adult who cares for the child with intellectual disability for most of the time. Parental caregivers may be biological, adoptive or foster parents. Your child with intellectual disability might also have other diagnosed conditions such as autism, Down syndrome, or other genetic syndromes. Your family must currently live somewhere in the UK. This research focuses on families whose child with intellectual disability lives with them for the majority of the time (more than half of a typical week). If your child with intellectual disability lives outside of the family home for the majority of the week (e.g., in a residential school placement) then this research study is not for you.

Why have I been invited to take part in the research?

You have been invited to take part in this research because you indicated that you were happy to be contacted to be invited to take part in the second wave of the study and are a parent or parental caregiver of a child with intellectual disability aged between 4 years - 15 years 11 months of age living in the UK.

What will happen if I take part?

Once you have read this study information, you will be asked to read some statements and to indicate your agreement to each one. We need to check that you agree to participate in the research. The online survey then includes questions asking about you and your family, your experiences as a parent, about your child with intellectual disability, and also about a sibling in the family if there is one. We expect the online survey to take about 20 minutes to complete in total. To say thank you for your time, we will also provide all primary carers who complete the survey with a £10 Amazon voucher.

If you agree, we will also send you updates about this research project and other research that we are carrying out about the experiences of families of individuals with intellectual disability.

Do I have to take part in the research?

You are under no obligation to participate in the research, your involvement is voluntary.

If you do agree to participate and then decide you no longer want to take part, you are free to withdraw. You do not have to provide a reason for wanting to withdraw from the study. You would have the option for any data you have provided up until your withdrawal to be removed from the study and destroyed.

You are able to withdraw yourself from the study even if another parent/caregiver from your household has also participated in the study.

Apart from the questions checking that you are happy to take part in the study, you do not have to answer any questions that you do not wish to answer, and you will still receive the £10 Amazon voucher for completing the online survey even if you have not answered every question.

Are there any possible benefits and risks of taking part in the study?

Involvement in this research provides an opportunity to share you and your family's experiences of raising a child with an intellectual disability. The information you provide will help us to understand more about families like yours, to share this information widely, and to inform ways to better support families. In addition, the £10 Amazon voucher is our way of saying thank you for continuing to participate in the research and an appreciation of the time you have spent.

We do not anticipate any risks to taking part in this research. The questions that we are asking have been used in several research studies before, and we have removed any that have tended to cause family members distress. However, it is possible that you will find some of the questions to be upsetting because we do ask

about your well-being and some of the difficulties faced by you, your family and your child with intellectual disability. We do also ask about positive experiences. If you are upset by any of the questions, you do not have to respond to them and you are under no obligation to continue with the survey.

If any of the survey questions make you concerned for yourself or another family member's well-being, we recommend that you make contact with your General Practitioner (GP) or one of the helplines listed below:

Mencap: 0808 808 1111, Contact a Family: 01332 557 975, KIDS: 0207 359 3635

How will the information you give to us be looked after?

All information that you provide as a part of this study will remain confidential, and we will store the information securely (in locked cabinets, or secure password protected computers) in an anonymised form. Access is restricted to the research team.

We will publish reports and give presentations about the results of the study. However, you will not be identified individually in any way as your responses will be pooled together with other participants and you will be assigned an anonymised study number. You and your family will not be able to be identified in any report or presentation about the study.

There are circumstances in which we would not be able to keep confidential something that you say. If you mention in the survey any information that suggests someone in your family, or you, is at risk of harm or has been subject to abuse, the researcher would have a duty to report this information to the appropriate authorities.

We also ask for your personal information (name, email, telephone). This will be kept secure and separate from the information you provide in the survey (so no-one can link your data to you). Personal data are requested for two reasons: (a) to update you about the findings of the study, and (b) to contact you if a future wave of the study takes place. The survey will ask if you would like to be kept up-to-date with our newsletter. If you provide your email address for this, it will only be used for newsletters and updates unless you have also specified you are happy to be contacted for future waves of the 1,000 Families study. If a future wave of the 1,000 Families Study does not take place, we will securely delete all personal data after 5 years from the date you completed the survey.

As mentioned previously, you can change your mind at any time and decide you no longer want to take part in the study, no longer are interested in participating in potential future waves of the 1000 Families Study, or no longer want to receive updates and newsletters. You do not have to provide a reason for this decision.

Your anonymised responses to the survey will be archived so that researchers in the future can carry out additional analysis of the data from the 1,000 Families Study. These researchers would not have access to your personal information and would have to agree to abide by appropriate ethical principles to do any new research.

Who is organising and funding the research?

The University of Warwick is responsible for this research. The research has received funding from the charity Cerebra, from the University of Warwick, and through the Economic and Social Research Council Doctoral Training Centre at the University of Warwick.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by a NHS Research Ethics Committee. A Research Ethics Committee is a group of independent people who review research to protect the dignity, rights, safety, and well-being of participants and researchers.

Further information and contact details

If you would like to ask questions before deciding whether to participate, please contact a member of the research team (Tel: 02476 524 139, Email: familyresearch@warwick.ac.uk).

If you are unhappy about any aspect of this research study, please contact the Chief Investigator Richard Hastings by mail, email or telephone (CEDAR, University of Warwick, Coventry, CV4 7AL; R.Hastings@warwick.ac.uk; 02476 522 197).

*If you would like to discuss the research, or ask any questions, with **someone who is not a part of the study team**, please contact; Dr. Samantha Flynn (Email: S.Flynn.1@warwick.ac.uk; 02476 524 139).*

This study is covered by the University of Warwick's insurance and indemnity cover.

Any complaint about the way that you have been dealt with during the study, or any possible harm that you might have suffered, should be directed to: the Head of Research Governance, Research & Impact Services, University House, University of Warwick, Coventry, CV4 8UW. Email-researchgovernance@warwick.ac.uk; telephone: 024 76 522746