



1,000 Families study

Secondary caregiver 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.

Secondary 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 will be recruiting a large number of families (at least 1,000 Families) to take part in this research. We would also like to follow families over time, 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 secondary parental caregivers of children with intellectual disability (learning disability or learning difficulties) between the ages of 4 and 15 years 11 months of age to take part in this research. Secondary parental caregivers might not be the child's father, but would be the adult who cares for the child with intellectual disability but not as much as the primary caregiver. The secondary caregiver might include a grandparent or the mother's partner. Fathers may be biological, adoptive, or step fathers. 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 are a parent or parental caregiver of a child with intellectual disability aged

between 4 and 15 years 11 months of age and 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 the secondary caregiver, 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.

If you agree, we will 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.

We plan to follow up with 1,000 Families Study families in about two years' time. If you agree, we will contact you again then to ask if you would like to take part in this follow-up research. At that stage, we would ask you to complete the online survey again.

Do I have to take part in the research?

You are under no obligation to participate in the research, your involvement is voluntary. You can complete the online survey but not give us permission to invite you to take part again in two years' time.

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 various parts of the study, you do not have to answer any questions that you do not wish to answer.

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.

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 during 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 will keep your personal data for three years so that we can invite you to take part in the research study again in approximately two years' time. At that time, we will check again if we can approach you again in the future. Your anonymised responses to the survey questions 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 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 ; Ms. 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