



Participant Information Leaflet for Primary Caregivers

Version 3 (19/11/21)

Study Title: Cerebra 1,000 Families Study (Wave 3)

Investigator(s): Professor Richard Hastings, Caitlin Murray, Caitlin Williams

Introduction

Thank you for previously taking part in the 1,000 Families Study. You are invited to take part in the third wave of the study. Before you decide if you'd like to take part, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

The University of Warwick is responsible for this research. The research has received funding from the charity Cerebra and from the University of Warwick.

What is the study about?

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, and families have taken part in two waves of data collection thus far. We would now like to follow up with families for a third wave of the study, because it is important to understand how families change over time and adjust in different ways to having a child with intellectual disability.

What would taking part involve?

You have been invited to take part in this research because you indicated that you were happy to be contacted to take part in the third wave of the research and are a parent or parental caregiver of a child with learning (intellectual) disability living in the UK.

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 (a paper version is available via post upon request) 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 survey to take about 20-30 minutes to complete in total. To say thank you for your time, we are offering all primary caregivers who complete the survey the option to receive a

£10 voucher. If you would like to receive the voucher, this will be either an Amazon voucher by email or, if you do not want to receive an Amazon voucher, we can provide a One4All voucher by post, which can be used in over 130 retailers.

Do I have to take part?

No. Participation in this study is completely voluntary and choosing not to take part will not affect you in any way. You can also choose to withdraw your participation without giving a reason by contacting one of the research team. Further details about withdrawing from the study are provided later in this information.

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. We understand that some questions within the survey may feel like they don't apply to you and/or your family. It has been several years since we began Wave 1 of the 1000 Families Study and we know that over that period, families have grown and changed, but we continue to ask the same questions to be able to look at changes across time. If some questions do not apply to you/your family, please feel free to choose the best answer, or to leave the question blank. We also welcome feedback on the study and survey questions, and our contact details can be found later in this document. You do not have to answer any questions that you do not wish to answer, and you will still receive the £10 voucher for completing the online survey even if you have not answered every question.

What are the possible benefits of taking part in this study?

Involvement in this research provides an opportunity to share your and your family's experiences of raising a child with learning 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. Your participation in this study will make a valuable contribution to UK-based family and disability research. In addition, offering a £10 voucher is our way of saying thank you for continuing to participate in the research and an appreciation of the time you have spent.

What are the possible disadvantages, side effects or risks, of taking part in this study?

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. Based on feedback from families during Wave 1 and 2 of the 1000 Families Study, we have removed questions that may have caused 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: 0808 808 3555, Family Lives 0808 800 2222
Mencap Cymru: 0808 8000 300

Expenses and payments

As mentioned, all primary caregivers who complete the survey will be offered a £10 voucher to say thank you for your time. This will be either an Amazon voucher or a One4All voucher. Primary caregivers have the option of whether they would like to receive the voucher or not.

Will my taking part be kept confidential?

Yes, all information about you will be handled in confidence and all information will be kept securely (on a secure University server). Information from the study will only be seen by the research team. Your data will be collected via an online survey (Qualtrics) or through a paper copy if you request this. The survey asks you to provide your postcode, as well as your personal identification number that we will provide. This information enables us to link your responses across the different time points of the 1000 Families Study. This data will be kept separate from all other data and protected on a secure University of Warwick server, and only the ID number will remain with the research data.

The survey asks you to provide your postcode. We would like this information because we can then get other information from the UK Census about the area in which you live. We will also initially use this information along with your personal identification number to link Wave 3 responses with Wave 1 and 2 responses. You do not have to provide this information. Postcodes will be kept separate from all other data and protected on a secure University of Warwick server.

The survey also asks if you are willing to be invited to potential future waves of the study, and/or additional related future research projects. This includes your name, email address, 'phone number and postal address. This data will be kept separate from all other data and protected on a secure University of Warwick server. If you choose to opt-in to the newsletter providing updates on the study, your email address will also be kept separate from all other data and protected on a secure University of Warwick server. Only members of the research team directly involved with contacting families will have access to this data.

Only members of the research team will have access to data. However, in some instances, officials from regulatory authorities may need to access data for checking the quality of the research. All members of the research team and regulatory bodies are trained in data protection issues. Study research data will be kept securely for at least 10 years from the date of any publication which is based upon it in line with the University of Warwick's policies. Research data will be reviewed after 10 years to see if the data should be retained or can be deleted. No personal data will be transferred outside of the EEA. If researchers from outside the university are involved in future analysis of data from the 1,000 Families Study, they will not have access to any personal information and their work would be subject to ethical review and approval.

What will happen to the data collected about me?

As a publicly funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep your personal responses for at least 10 years from the date of any publication which is based upon it, and the data will be reviewed after 10 years to see if the data should be retained or can be deleted.

Research data will be pseudonymised as quickly as possible after data collection. This means all direct and indirect identifiers will be removed from the research data and only the participant number will remain. The key to identification will be stored separately and securely to the research data to safeguard your identify. As your data will be linked to your participant number, if you decide to withdraw your data, you would have the option for any

data you have provided up until your withdrawal to be removed from the study and destroyed. However, you would not be able to withdraw your data from any reports or academic papers already published (these will not have included any personally identifiable information).

Contact information collected during data collection for the purpose of invitations to future waves of the study will be kept, with your permission, for a period of five years to minimise the time period we retain personal information but to allow time for a future wave of the 1,000 Families Study to be started. If you request the withdrawal of your data following this 5 year time period, we will not be able to withdraw your data as we will no longer hold your personal details to identify your responses. Contact information for the purposes of sending vouchers will only be kept until the vouchers are sent out and will then be deleted.

While only members of the research team will have access to the research data, access to personal data (contact information, the key to identification, and postcode data) will be again restricted to only those on the research team who require access to that information for the purposes of contacting families.

Data Sharing

The University of Warwick has in place policies and procedures to keep your data safe. Data from this study may also be used for future research following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project. This is to enable researchers in the future to 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.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here:

<https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice> or by contacting the Legal and Compliance Team at GDPR@warwick.ac.uk.

What will happen if I don't want to carry on being part of the study?

Your participation in this study is completely voluntary. You are free to stop participating in the survey whenever you wish to, and this will not negatively affect you in any way. You do not need to answer any questions you are uncomfortable answering. You can close the browser with the survey at any point. If you would like to withdraw from the study, you can contact the research team to inform them that you no longer want to take part and/or be contacted regarding the study.

If you withdraw from the study, you will also be able to decide if you would like to withdraw data that has already been collected as we will have your ID number and contact details. Please note that if you withdraw from the study, it will not be possible to withdraw your data from existing reports or publications. If you request the withdrawal of your data following the time period where we keep your contact details, we will not be able to withdraw your data as we will no longer hold your personal details in order to identify your responses. To safeguard your rights, we will use the minimum personally-identifiable information possible and keep the data secure in line with the University's Information and Data Compliance policies.

What will happen to the results of the study?

The collective responses of everyone that completes the survey will be written up in reports and academic papers and will be made publicly available indefinitely. Results will also be disseminated at conferences in poster or oral formats. Reports and updates will also be provided in short summaries to families via our newsletter. You and your family will not be able to be identified in any report or presentation about the study.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC). **Reference number 197/20-21 AM01, date 19.11.21.**

Who should I contact if I want further information?

If you would like further information and/or have any questions, please contact a member of the research team at familyresearch@warwick.ac.uk and Caitlin Murray (Research Assistant) and/or Caitlin Williams (PhD student) at the Centre for Educational Development, Appraisal and Research, University of Warwick will be in touch.

Project lead and PhD supervisor for Caitlin Williams:

Professor Richard Hastings, Professor and Cerebra Chair of Family Research, Centre for Educational Development, Appraisal and Research, University of Warwick.

R.Hastings@Warwick.ac.uk

02476523638

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance

Research & Impact Services

University House

University of Warwick

Coventry

CV4 8UW

Email: researchgovernance@warwick.ac.uk

Tel: 02476 575733

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter: DPO@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Thank you for taking the time to read this Participant Information Leaflet