**PARTICIPANT INFORMATION SHEET**

**Research Project:** What are parents’ experiences of discussing a genetic diagnosis with a young person with a learning disability?

You are being invited to take part in this research project, before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve.

Please take time to read the following information carefully and discuss it with others if you would find that helpful. As we will be discussing your family’s experience of using genetic information, you may wish to talk to your young person with a learning disability and a genetic diagnosis about your involvement before agreeing to take part.

1. **What is the purpose of this research project?**

This research project has been designed by Clare Jacobs as her dissertation project for the MSc in Genetic and Genomic Counselling. The aim of the project is to find out how families that have a young person with a learning disability (LD), that has a genetic cause, use the genetic information that they have been given.

As technology advances, we are likely to find more genetic causes for learning disability and families have identified that having a genetic diagnosis is helpful for them in accessing services, validating their experiences, for information and future reproductive choices. However, there is very little research around how families use that information to communicate with the young person with LD and whether it is helpful to the young person in understanding their disability.

I wish to find out what information is helpful to families and whether they feel adequately supported in disclosing and talking about genetic information to their young person. It is important that the experiences of families are known so that areas of practice can be developed.

1. **Why have I been invited to take part?**

You have been invited to take part because you are a parent or carer of a young person aged 10-24 years with a learning disability that may have a genetic cause. Recruitment of participants is through Unique and this is why you have received an invitation.

1. **Do I have to take part?**

No, your participation in this research project is entirely voluntary, if you decide to take part, you are invited to read this participant information form that outlines the study and I will send you a consent form. I will then contact you to discuss any questions that you might have. If you then decide that you would like to take part in the study you will fill in and return the consent form (by post or email). At the start of the interview, I will confirm that you are still happy to take part, if you no longer wish to take part you can withdraw from the study.

If you decide not to take part, you do not have to explain your reasons. You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

1. **What will taking part involve?**

If you decide to take part then you will be invited to discuss your views and experiences in an online interview, this would take place via a secure online platform. This interview would be held at a time that is convenient to you and would take approximately one hour. The interview would be recorded so that accurate records can be transcribed after the event.

1. **Will I be paid for taking part?**

No, there is no financial benefit from taking part.

1. **What are the possible benefits of taking part?**

There are no direct benefits to you from taking part in this research study. However, your contribution is important in helping us to understand the experiences of families. The results of this work will be disseminated and shared with genetic counsellors, with the aim of developing practice so that families’ experiences are recognised.

1. **What are the possible risks of taking part?**

It may be that talking about your young person’s genetic diagnosis will be upsetting for you. If you become upset, then the researcher will assist you and you can decide if you wish to continue.

If you find that you require further support, then Unique will provide support and signpost to other relevant support organisations.

1. **Will my taking part in this research project be kept confidential?**

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation.

Please see ‘What will happen to my Personal Data?’ (below) for further information.

As we will be discussing children and vulnerable adults it is possible that something may be disclosed that raises the possibility of a safeguarding concern. In this situation the research team may need to over-ride confidentiality and to disclose information obtained from you to statutory bodies or relevant agencies. Where appropriate this will be done with your consent.

1. **What will happen to my Personal Data?**

All personal data will be treated with great respect - some personal data will be collected from you on the consent form and I will also ask you to fill out a form with limited personal details about your family. When you have filled in these forms they will be scanned and stored on the Cardiff University Secure one drive and paper copies will be shredded.

Each participant will be allocated a number so that no identifying details will be used on interview transcripts. Any transcripts will be viewed on a password protected computer and stored in the Cardiff University Secure drive.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

* your rights
* the legal basis under which Cardiff University processes your personal data for research
* Cardiff University’s Data Protection Policy
* how to contact the Cardiff University Data Protection Officer
* how to contact the Information Commissioner’s Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection> Paper copies are available on request from the research team.

A Participant’s personal data will be stored on the Cardiff University’s secure drive for 5 years as per the University Records Retention Schedules and may be accessed by members of the research team and, where necessary, by members of the University’s governance and audit teams or by regulatory authorities.

Anonymised interview information will be kept for a minimum of 5 years but may be published in support of the research project, however no identifying characteristics will be used in publications.

If you choose to withdraw from the research project then any personal data collected up until the point of participant withdrawal from the research project will be destroyed. It will not be possible to withdraw any anonymised data that has already been published.

1. **What happens to the data at the end of the research project?**

At the end of the project the data will be disposed of in accordance with University processes and GDPR legislation.

1. **What will happen to the results of the research project?**

The aim of the research project is to inform the genetic counselling profession of families’ views. The intention is to publish the results of this research project in academic journals and present findings at conferences.

Verbatim quotes from anonymised participants may be used in papers or presentations but participants will not be identified in any report, publication or presentation.

1. **What if there is a problem?**

If you wish to complain, or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Clare Jacobs at [JacobsC2@cardiff.ac.uk](mailto:JacobsC2@cardiff.ac.uk) (Research student) or Celine Lewis [celine.lewis@ucl.ac.uk](mailto:celine.lewis@ucl.ac.uk) (Research Supervisor). If your complaint is not managed to your satisfaction, please contact the Chair of the School Research Ethics Committee Dr Ned Powell [PowellNG@cardiff.ac.uk](mailto:PowellNG@cardiff.ac.uk)

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

1. **Who is organising and funding this research project?**

The research is organised by Clare Jacobs a student on the Genetic and Genomic Counselling MSc at Cardiff University. The research is supervised by Dr Celine Lewis, Senior Behavioural Scientist at The UCL Great Ormond Street Institute of Child Health.

1. **Who has reviewed this research project?**

This research project has been reviewed and given a favourable opinion by Cardiff University School of Medicine Ethics Committee.

1. **Further information and contact details**

Should you have any questions relating to this research project, please contact Clare :

Clare Jacobs at [JacobsC2@cardiff.ac.uk](mailto:JacobsC2@cardiff.ac.uk)

**Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.**