



## **Sexuality, Autism, and Young People and Families study Information for Participants in the research project**

### **1. Study title**

Mothers' Perspectives about the Sexual Understanding and Development of their Children with Autism and a Moderate or Severe Learning Disability

### **2. Invitation**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with friends or relatives if that would be helpful for you. We are also very happy to answer any questions that you might have or give you more information that you might want. Our contact details are at the end of this document. Please take time to decide whether you or not you wish to take part.

### **3. What is the purpose of the study?**

The sexual understanding and development of young people with Autism and a learning disability is something that is not usually given much attention. Yet this is a vital part of growing up for all young people. This is an area of concern to mothers as well, particularly as they play a very significant role in supporting the development of their child's sexual understanding. However, there has been little research about mothers' views.

In this study we want to find out about mothers' experiences and views. We hope that this will lead to better support for families and the young people themselves.

It is hoped that the insight into mothers' views will help with the provision of sensitive support to families, and help schools, colleges and health professionals to work more effectively in partnership with them.

### **4. Why have I been chosen?**

You have been asked to take part in the study because an organisation in contact with you thinks that you are a mother of a young person with Autism and a learning disability in the right age range for the study (16-25 years). We are hoping to recruit around 6 to 12 participants for this study.

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

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. You will be given the information sheet and a copy of your consent form to keep. If you do decide to take part you are still free to withdraw at any time without giving a reason. Deciding not to take part will not impact any other aspect of your relationship with University of Glasgow or the voluntary organisation that you receive a service from.

**6. What will happen to me if I take part?**

The researcher, Rebecca Pryde, will arrange to meet with you in the premises of the voluntary organisation you receive a service from, or on University of Glasgow premises, whatever is more convenient for you. We will ask everyone to complete an interview, this could take from 60 – 90 minutes. The questions will include a description of your family, your views on your child's sexual development, how you and your child have coped with their sexual development and some of the challenges you have faced and sources of support you have received in regard to sexuality. You can stop the interview at any time, to take a break or if you decide you no longer want to take part.

**7. What do I have to do?**

If you decide you want to take part in the study or you want to ask for further information, please contact the primary researcher using the contact details at the end of this information sheet.

If you are happy to be contacted in relation to this study, please tell the person that told you about the study. A member of administration team will then contact you within two weeks to check that you have all the information that you need. They will only contact you if you give permission to do so.

If you decide you do wish to take part, the researcher, Rebecca Pryde, will meet with you to ask you questions with regard to your child and their sexual development, which should last around 60 – 90 minutes. Although there will be a general structure to the interview, the information you give will guide the interview. You will be able to raise any other issues you want to discuss at the end of the interview. You will be able to take a break or stop the interview at any time.

**8. What are the possible disadvantages and risks of taking part?**

We do not anticipate that there will be any risk to you completing the interviews. However, we do recognise that this may be an emotive topic for you and if you do become distressed during the interview, you will be offered a break or to stop the interview at any time.

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

Whilst there will be no direct benefits to you, the study will improve our understanding of mothers' experiences and views. We will use the results from this study, along with findings from other research, to develop workshops for mothers and for professionals who work with young people with low functioning autism.

**10. Will my taking part in this study be kept confidential?**

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. We might use direct quotations from your interview in the final report, however, you will not be able to be identified by this information and you will need to provide consent in order for us to do this.

Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

**11. What will happen to the results of the research study?**

We hope to publish this article in a scientific journal. If this is the case, you will not be identified in this publication.

We hope that the results will provide a greater understanding of mothers' points of view. In turn, we hope that this understanding will help schools, colleges and health professionals to provide more sensitive support to families with regard to their sons and daughters' sexuality. We also hope that it will help professionals to work alongside families more effectively.

**12. Who is organising and funding the research?**

There is no specific funding for this research which is being organised by the University of Glasgow.

**13. Who has reviewed the study?**

This project has been reviewed by the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee.

#### 14. **Contact for Further Information**

If you have any further questions please contact Rebecca Pryde

By telephone: 07720 924 604

Or email: [r.pryde.1@research.gla.ac.uk](mailto:r.pryde.1@research.gla.ac.uk);

**Thank you for taking the time to read through this information sheet.**