Mothers' stories: Experiences of mothers who have a child with autism in mainstream school.

PARTICIPANT INFORMATION SHEET

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

Introduction

I am a PhD student and lecturer in Occupational Therapy in Trinity College Dublin. This project is researching the occupational lives of mothers who have children with autism in mainstream school. **Occupation in this research project does not refer to work but refers to all the things you do, need/want to do**. I would like to understand what you do that is meaningful to you and whether or not you feel you experience occupational injustice i.e. that you are not able to do things you need/want to do because of, for example, time, resources, supports, obligations and gender.

Why I am doing the project:

I am doing this project because I want to examine the relationship between what you do/cannot do and the fact that you are a woman and mother of a child with autism. I believe our roles and obligations in life can facilitate, or deprive us, from doing things that are essential to us being ourselves. I feel it is important to understand how life is for other people so that we can learn how to support them.

Why you have been asked to take part:

You have been invited because you are a mother of a child in mainstream school who has autism. I feel that you can contribute much to my understanding and knowledge of the (occupational) lives of these mothers generally.

What you will have to do if you agree to take part:

If you agree to take part, I will ask you to sign a consent form and we will have an interview where I will ask you for your story. The interview method I am using is open-ended. I will not have pre-set questions but, after you tell me your story, I will ask you to tell me some more about the issues you have raised. The interview might last about 1½-2 hours and will be at a place of convenience to you, including the option of having it virtually (e.g. via Skype). If you agree, I will record the interview.

I may wish to meet you again for a shorter second interview to clarify issues and ask you specific questions. You can participate in the first interview and decline to participate in the second. I will ask you to sign a new consent form if you are being interviewed a second time.

Your participation in the project will remain confidential and your information anonymous:

Your name, your story and responses to the questions will not be disclosed to other parties. I will use a number of code to identify you rather than your real name. Only I will know this number and will not share it with or given to anyone else. I will use a pseudonym in any write up or publication of the project and will ensure that no clues to your identity appear. Any extracts from what you say that are quoted in the write up will be entirely anonymous. If you say anything that might reveal who you are, I will remove this from the write up and instead refer to it in general terms. Your story will be used for the purpose of this project only and will not be used in any other project without your explicit consent.

What happens to your information:

Following your interview I will transcribe, or employ an approved service to transcribe, the recorded interview. No audio recordings will be made available to anyone other than the research/research team and transcriber, nor will any such recordings be replayed in any public forum or presentation of the research. The soft copy of this transcript will then be held in an encrypted file on a password protected computer and the hard copy will be stored in a locked cabinet to which I alone have access. The information you share will always be kept private, be held for no longer than seven years, and then both hard and soft copies will be destroyed. Your information will be used in no other study without your explicit consent. The study will comply with the General Data Protection Regulation (GDPR) 2016 at all times.

The advantages of taking part:

There may be no direct benefit to you, but you may enjoy sharing your experiences and opinions. Your participation will help me know more about the occupations and any joys or injustices experienced by mothers with children with autism so I can write, teach and speak about it in an informed way.

Any disadvantages of taking part and what:

There is a risk that you may share some personal or confidential information that you do not wish to speak about or that you may feel uncomfortable talking about. However, I do not wish for this to happen. At any time you may decline to answer any question or stop the interview.

You do not have to take part in the study:

Your participation in this project is entirely voluntary. You are not obliged to take part. You may withdraw at any time during the interview or project and have your interview recordings destroyed. You may request to omit individual responses or for changes to be made to your answers.

Provisions for debriefing:

I will give you an opportunity at the end of the interview to add to, withdraw or clarify responses. Additionally, if you wish, I will give you a copy of the interview transcript. At this point you will have the opportunity to request that any information you have shared is removed and I will do so. If you become upset during interview we will take a break and resume the interview when you are ready and willing. If you become upset after the interview, there are a list of support groups below that you are advised to contact. You may also contact the researcher to debrief.

Services that offer support for if the participant becomes upset at any point in the project:

- DUBDOC Out of Hours GP Service: Telephone: 01 4545607
- GP Out of Hours Service Nationally: http://www.hse.ie/eng/services/list/3/outofhours/GPOOH.html
- Samaritans: http://www.samaritans.org/how-we-can-help-you/contact-us or call: 116 123 (ROI)
- ASPIRE Directory of Supports: http://www.aspireireland.ie/cmsWP/directory-of-service/

In the extremely unlikely event that illicit activity is reported I will be obliged to report it to appropriate authorities.

What happens next?

If you think you might be interested in taking part in this research please contact me via email (sarah.quinn@tcd.ie) or phone (0852561494). I can then answer your queries. You should take a week to consider participating. Only when you are ready, would we arrange an interview.

Researcher's details:
Sarah Quinn; email: sarah.quinn@tcd.ie; tel: 085 2561494

Supervisor's details:
Dr. Gillian Wylie; email: wylieg@tcd.ie; tel: 01 8964788

Data Protection (GDPR)

Data Controller: Trinity College Dublin

Data Processor's Contact Details: Sarah Quinn; email: sarah.quinn@tcd.ie; phone: 0852561494

Data Protection Officer's Details: dataprotection@tcd.ie; phone: 018968486

- Your data will be used as part of the research on the 'Mothers' stories: Experiences of mothers who have a child with autism in mainstream school'.
- Your data (information) is being processed for the purpose of legitimate interest (Article 6;1(f), General Data Protection Regulation, 2016) and for the purpose of scientific research purposes (Article 9;2(j), General Data Protection Regulation, 2016).
- Researchers Sarah Quinn and Dr. Gillian Wylie (supervisor) will have access to your data which gathered during this study.
- Your data will be assigned a code. The keycode will be placed in a locked cabinet in Sarah Quinn's office in Trinity Centre of Health Science in a separate location from all hardcopies of your information.
- The data will be stored for 7 years in line with Trinity College Dublin policy and then destroyed.
- Electronic files of data will be stored on encrypted files on password protected computer.
- It would be impossible to conduct this research without processing of your data, therefore data processing is necessary. Data processing is any operation which is performed on personal data, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction (Act 4(2), General Data Protection Regulation, 2016).
- Measures will be taken to reduce risk when processing the data, however should a data breach occur, this may cause you harm. This harm will be significantly reduced as your data will not have any identifiable information on it. Instead of your name, a code number will be used on your interview transcripts. Other names you reference will also be delated and the information you shared referred to in general terms. If necessary, you have the right to lodge a complaint with the Data Protection Commissioner and with TCD's Data Protection Officer (contact details can be found at the top of this document.
- Until data is analysed by the researcher, you have the right to the following;
    - to request access to your data and a copy of it in an accessible/portable format.
    - to have any inaccurate information about you corrected or deleted.
    - to have personal data deleted.
- Your data will used for this research only and will not be used for any other research without your explicit consent.

Further information: You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Sarah Quinn who can be telephoned at 085 256 1494 or Dr. Gillian Wylie at 01 896 4788. If the researcher team learns of important new information that might affect your desire to remain in the study, Sarah will tell you.