

## An Invitation to take part in a research project



My name is Cirlei Ioris and I am a MSc student in Public Health at University of West of England (UWE). I am undertaking a research study and I would like to invite you to take part in it. But before you decide, 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 carefully and discuss it with others if you wish. Ask me 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.

Thank you for taking the time to read this information.

**1. Study title:** The mental health needs of adults with Asperger Syndrome and High Functioning Autism: a parental perspective.

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

The purpose of my study is to explore parents' views about the mental health needs of adults with High Functioning Autism (HFA) and Asperger Syndrome (AS). Results from this study will contribute to better understanding the needs of adults with HFA/AS, and could potentially help to inform policy makers and practitioners as to how they can best support people with autism in order to improve their mental health and quality of life.

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

You have been invited to take part because you are a parent of an adult (over 18 years) who in addition to having Asperger Syndrome or High Functioning Autism also has mental health problems. You may have been sent an email with information about this study or seen it on an advertisement on a website. I aim to speak with 10 to 12 parents.

### **4. Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you decide to take part, you are still free to withdraw at any time without giving a reason.

### **5. What will happen to me if I take part and what do I have to do?**

If you are interested in taking part, I will ask you to email me or text me on my work mobile (see my contact detail below). I will then call you to answer any questions you may have. We can discuss a suitable place that we could meet, that is convenient for you.

Before the interview, I will ask you to sign a consent form. I will go through this with you in case you have any questions about it. I will also ask you for permission to record the interview.

The interview may last between 45min to 60min. We will be talking about your views regarding the support you/your son or daughter have received and the type of support you think you/ your son or daughter would benefit from. We will also be talking about the everyday challenges you may face in caring for your autistic son or daughter and the strategies you may have found/developed by yourself to support them.

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

I am aware that you have been or may have been through difficult times and talking about this may cause you some distress. During the interview, you can stop at any time and take as much time as you need to continue, if you wish. Please remember that participation is voluntary and you have the right to withdraw at any time.

If you decide to withdraw, I will ask you to notify me through email. I will then remove from the study all the information from your interview, and the transcripts will be destroyed. The only thing I will require if you decide to withdraw from the study is that you do it the latest a month before I need to complete my research, which needs to be submitted by 12th December 2017 (See below for my email address).

### **7. What are the possible benefits of taking part?**

This study aims to give parents a voice about their views on the needs of people with autism and mental health. Your experiences and views may contribute to a better understanding of what type of support is needed to be in place for adults with High Functioning Autism and Asperger Syndrome.

### **8. What if something goes wrong?**

If you have a complaint or a concern about this study, you can discuss it with me in the first instance. You also can contact my supervisor Dr Noreen Hopewell-Kelly (see below for her contact details).

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

Yes. All your personal information will be protected. Your name and identifying details will be changed when transcribing the interview. You will be identified only by codes and I will be the only person with access to the un-anonymised information. The only identification in the dissertation will be your parental status and your child's gender and age as this information may be important when analysing the data collected.

All information will be stored on a password-protected laptop and the interview will be deleted soon after the transcription.

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

I will write up a dissertation for my Masters in Public Health qualification, which will be placed in the library at UWE. I hope to share the findings among health and social care providers, groups and organizations with an interest in this issue. The findings of this study may also contribute to the development of further research on this important topic. However, I cannot guarantee that it will definitely have this outcome.

I would like to assure you that none of the participants will be identified in any publication or dissemination of the findings of this study.

### **11. Who is organising and funding the research?**

I discuss the organisation of the research with my supervisor, Dr Noreen Hopewell-Kelly. This research has not received any funding and it is for academic purposes only.

### **13. Contact for Further Information**

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