Participant Information Sheet

Name of school: School of Education, Language and Psychology

Title of study: Mapping autistic adults' social identity

Introduction

You are invited to take part in this study about the experiences of autistic individuals. I am a postgraduate researcher at York St John University and I am interested in learning about the lives of autistic adults, in part because I am autistic myself. This research is being carried out as part of my PhD qualification, under the supervision of Drs Brett Heasman, Lorna Hamilton and Ruth Knight.

Please read the following information about the study, then take time to carefully decide whether you wish to take part. Please feel free to ask any questions you may have about the research before making your decision.

What is the purpose of this investigation?

The purpose of this study is to investigate autistic adults' experiences and feelings about identity across social settings.

This is something which would be beneficial to learn about as much existing research into autistic people's identity focuses on specific experiences of 'autistic identity' in isolation, whereas I am interested in gaining a more holistic view of your identity as a person, and how your experience may change across different settings.

Do you have to take part?

Participating in this study is voluntary. If you do decide you would like to take part, you can withdraw at any time up to and during the interview, and can withdraw your data up to 2 weeks after your interview has taken place. Simply contact me if you want to do this, my details can be found at the bottom of this information sheet in the Researcher Contact Details section.

What will you do in the project?

As part of this study you will first be creating an eco -map to help visualise some of your recent social experiences. An eco-map is a simple diagram originally designed to visualise relationships. There is no right or wrong way to create this, and I will be there to assist you if you want.

You will then take part in a semi-structured interview, this is an interview where the questions are less defined and more open ended to allow you to discuss your experiences. In this interview you will be asked questions about your experiences with identity in social situations, your feelings about these experiences, and how you feel they impacted you. These questions will be guided by the information in your created ecomap.

You will also be invited to contribute during the data analysis to ensure your thoughts and feelings have not been misinterpreted. This will involve communicating with me via a method you are comfortable with (eg call, email, video). Any contribution is not mandatory.

Why have you been invited to take part?

You have been invited to take part in this study as you are an autistic adult.

What are the potential risks to you in taking part?

This study involves speaking to the researcher about personal feelings and experiences. This could be stressful if you find it difficult to communicate verbally sometimes or find conversation causes anxiety. Any information you give during the interview is voluntary, and you do not have to discuss any topic you find distressing.

You can withdraw from the study at any point before and during your interview. You can also choose to withdraw your data up to 2 weeks after your interview if you decide you no longer want to participate. You can do this by contacting me or my academic supervisors.

What happens to the information in the project?

Your interview audio will be recorded. After this it will be transcribed. During transcription any information which may be used to personally identify you will be removed, and you will be referred to by a pseudonym.

Your interview recording and transcripts will be stored on a password protected university drive only accessible by me and my supervisors. After transcription the recordings will be destroyed. Your data will then be analysed and written up.

If you have any questions/concerns about the way we are collecting and using your personal data please contact the University by emailing: gov.compliance@yorksj.ac.uk.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

What happens next?

If you decide you would like to take part in the study, you will be asked to sign a consent form to confirm this. Otherwise, thank you for your interest, there is nothing more you need to do.

This investigation was granted ethical approval by the York St John University Research Ethics Committee.

Researcher contact details:

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If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Dr Sharon jagger

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