

## PARTICIPANTS INFORMATION SHEET

### **Research study: Mental ill-health: self-reported barriers to accessing services for adults with autism.**

My name is Alison Martin; I am currently undertaking a M.A. in Autism at Sheffield Hallam University. You can contact me via email at [b2045623@my.shu.ac.uk](mailto:b2045623@my.shu.ac.uk) if you have any question or difficulty with regard your participation in this research.

You are being invited to take part in a research study. Before you decide to participate is important for you to be fully aware of the purpose of the study and what it will involve. This briefing sheet aims to give you the information you need to make that decision.

Please be aware that I receive formal supervision in the conduct of this research. My supervisor, Jill Smith ([jill.smith@exchange.shu.ac.uk](mailto:jill.smith@exchange.shu.ac.uk)) is available to be contacted by you if you want to make an complaint.

#### WHAT IS THE PURPOSE OF THE STUDY?

- The government have produced guidelines to ensure that people with autism receive 'the right support at the right time' during their lifetime.
- This study aims to collect the views of people with autism/Aspergers Syndrome on how they access support when they have periods of mental ill-health, for example, depression, anxiety.
- It also aims to identify any improvements that could be made to local services; it will not have the power to make any changes but information from this study will be shared with the Local Autism Strategy Group with a view to making better use of the services that exist.

#### DO I HAVE TO TAKE PART?

You do not have to take part; the choice is entirely yours and your decision will not be held against you in any way.

#### WHAT WILL HAPPEN TO ME IF I TAKE PART?

- You will receive a link to a short on-line survey that you will be asked to complete and submit. The survey will ask for your consent to take part and then ask you some questions about your experiences of getting support when you need it for any mental ill-health concerns you may have had or have now.
- If you want to stop and change your mind at any point of the survey you can do this; just do not submit the survey.
- You will also be able to withdraw the use of your completed survey **without giving a reason** by letting me know before 30.06.16
- If you would like to receive a summary of the findings, discussion and recommendations identified in the research study once the dissertation has been completed, you will be able to let me know.

- If you would like me to come into your college and talk to you (on your own, as part of a group or with a trusted mentor) about taking part in the study then you can let me know – but you do not need to do this and can make a decision based on the information in this briefing sheet if you would prefer.

#### WHAT ARE THE POSSIBLE BENEFITS TO TAKING PART IN THE STUDY?

- You will have the opportunity to tell your 'story' and have your voice heard through self-reporting.
- Historically many research studies into autism have not involved those with autism but have instead asked for information from other informants, such as parents, carers and professionals. It is important that the views of those with autism are listened to so that life experiences can be improved.

#### WHAT ARE THE POSSIBLE DISADVANTAGES OF TAKING PART?

The survey aims to be written in a supportive manner; however, it is possible that thinking and writing about any difficulties you have experienced could make you feel upset. If this is the case, you can stop at any time. You can talk to a trusted person at college or at home, and there are details included at the bottom of these sheet of agencies where you can obtain further support.

#### WILL MY PARTICIPATION AND THE DATA COLLECTED BE HELD IN CONFIDENCE?

- It will not be possible for anyone other than myself to know who you are.
- I will code your survey with a participant number and only these numbers will be used in the report. It will not be possible for anyone reading the report to identify you.
- Your completed survey will be stored electronically in a password protected folder on a password protected computer.
- Any printed-out information will be kept in a locked drawer. At the end of the research study (December 2017) all surveys and data will be destroyed.

#### INFORMATION I SHALL NEED TO GET STARTED

The on-line survey can be found at: **[www.facebook.com/AutismMH](https://www.facebook.com/AutismMH)**

Agencies who can offer you support are:

- Your College pastoral support team
- First Response Service – Dial 111 and take option 2 (Cambridgeshire and Peterborough NHS Mental Health crisis support
- CPFT Psychological Wellbeing Service – self-referral team tel. 0300 300 0055 or [www.cpft.nhs.uk](http://www.cpft.nhs.uk)
- Contact your G.P.