

Information Sheet: The Autistic label- a help or hinderance?

Thank you for considering participation in our research project, which aims to explore individuals experiences of those been given or identify with the Autistic label, looking specifically at the transition of entering into the adult/working world. This information sheet is intended to provide you with details about the study to help you decide whether you would like to participate. Please take your time to read through the information, and feel free to ask any questions before making your decision.

Purpose of the study

The purpose of this study is to investigate and build upon already existing research regarding experiences and perceptions of young adults with or those who identify with the Autistic label as they navigate the transition to adulthood. For many this transition can be influential for establishing one's own identity and place within society. Therefore, qualitative research methods in the form of interviews will be conducted to explore the lived experiences uncovering the potential barriers or facilitators and opportunities young Autistic adults encounter during the transition to adulthood. With a deeper understanding, the findings from this research project could be utilised to inform future interventions and policies to further promote positive outcomes and quality of life for young adults with an Autistic label.

Participation and Interview procedures

It is completely up to you as to whether you do decide to take part. If you do decide to take part you will given this information sheet as well as a consent form in which you will be required to sign.

This research project will be completed on 3rd September 2024 with data collection commencing between April-July. Any communication will only be regarding the research, you will not be contacted for any other reason, apart from arranging an appropriate time for interviewing. For this research project participants will be given the opportunity to decide on their preference for the format of interview. Online platforms (google meet), or in person interviews will both be available lasting approximately 1 hour. After the interview is conducted participants will have up until 31st of July to withdraw from the research. You do not have to give a reason, and there will be no negative consequences from withdrawing from the research. If this applies please contact sgpearce1@sheffield.ac.uk.

The interview will last approximately 1 hour using a semi-structured approach. The interview will be split into 2 halves with a break in the middle. The first half will be discussing childhood and school experiences, and the second half will be discussing young adulthood and employment/work life experiences. Some topics will include:

- Personal view of adopting and identifying with the Autistic label
- How you think others perceive the Autistic label (family, peers as well as those in authority)
- How readily available support is offered in each life stage
- Opportunities the Autistic label provides
- Any barriers faced when identifying with the Autistic label and how these could and were removed

Whilst there are no immediate benefits for those participating in the project, it is hoped that through your participation your experiences can help to shape and make suggestions for

future change within the field of disability studies to continually improve outcomes for all young Autistic adults. By taking part there also shouldn't be any harm caused but again there is also no obligation to answer any question you do not feel comfortable discussing. And should you find any discussion distressing you can request to pause or stop the interview if you wish to do so. Here are some links for where you can receive additional support in this case.

- Samaritans- <https://www.samaritans.org/>
- National Autistic Society- <https://www.autism.org.uk/what-we-do/help-and-support>
- Mind- <https://www.mind.org.uk/information-support/helplines/>

Data collection and protection

Interviews will be recorded via the online Google meet platform. These files will be saved into an encrypted U-drive. The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. All the information that we collect about you during the course of the research will remain strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. Therefore I ask that participants provide a pseudonym which will be used in the research to ensure your identity is anonymised. Confidentiality of data will be ensured unless a safeguarding concern is raised which will require escalation to the Safeguarding lead (Rob Begon). All personal data will be destroyed after the formal completion of my master's degree, approximately the end of 2024.

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

Ethical approval

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by The School of Education department

Short form of information sheet

- Title- The Autistic Label- A help or hinderance?
- Aim of study- To explore the experiences of those given or identify with the Autistic label, focusing on the transition from childhood to adulthood.
- Participation is voluntary and you can drop out of the research project up until 31st July
- You will only be contacted in regards to the study by email
- Interview process
 - You can decide to either meet in person or do it online
 - Lasting 1 hour with break
 - First half talking about childhood, second half talking about young adulthood
 - Research questions such as: how you and others perceive the autistic label, barriers and opportunities and the support available
 - There is no obligation to answer a question if you do not feel comfortable in sharing

- Should you find the interviews distressing here are links to helplines- <https://www.samaritans.org/>, <https://www.mind.org.uk/information-support/helplines/>
- Data is controlled by University of Sheffield and will remain confidential unless a safeguarding concern is raised that requires escalation to the study supervisor

Contact Information

Should you wish to make a complaint or raise a concern about the research project then please get in contact with the supervisory researcher- Rob Begon (r.begon@sheffield.ac.uk). However if you are concerned with the handling of personal data in this research project please be advised to visit the University's Privacy Notice- <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>

Should you wish to ask any further questions or show an interest in taking part in the study you should get in contact with the lead researcher- **Shona Pearce** (sgpearce1@sheffield.ac.uk) or the study supervisor- **Rob Begon** (r.begon@sheffield.ac.uk)

Thank you for taking the time to read through this information sheet. I look forward to hearing from you if you wish to take part! (You will be able to keep this sheet and will be required to sign the consent form if you do sign up.)

Read the information and consent form to help to decide if you want to participate