

Study Title: A society fit for autistics: overcoming the barriers, challenging stereotypes and enabling autistics to take their place in the world

Investigators: We are a group of seven autistic people who have received funding from Disability Research on Independent Living and Learning (DRILL) from lottery money to carry out this research. Marion Hersh and Sharon Elley are a senior lecturer and lecturer at the Universities of Glasgow and Leeds. Michael Dawson and David Cowan are involved in projects for autistic people in Glasgow and Panda Mery in London. Zyggy Banks supports autistic students at the University of Leicester. Callum Watson is an assistant psychologist who has formerly supported autistic students. Michael, David, Panda, Callum and Zyggy are all employed as research assistants by the University of Glasgow.

The Study: The aim of the study is to answer the following two questions:

1. How do autistic people use strategies, including logic, reasoning and rules, to understand social situations, other people's reactions and empower themselves?
2. What are the barriers, including stereotypes, misconceptions and systemic issues to autistic people using their strengths and appropriate strategies to understand and participate in decision making, the economy and community?

We will use the results to produce recommendations for autistic people and decision makers and service providers.

Procedures, confidentiality and anonymity:

We have already obtained a lot of useful information from a questionnaire. We are now interviewing about 50 autistic people to investigate issues arising from the questionnaire responses in more detail. The interview will be based on a list of themes rather than specific questions. We hope this will encourage you to state your own views rather than reflect back ours. The themes will include diagnosis, employment and job search, the benefit system, education, sensory issues and the medical system. However, we recognise that not all themes will be relevant to all participants. The interview will also include questions about four to six scenarios relating to types of situations that you have experienced. Short descriptions will be provided both verbally and in writing. After each description and any questions to clarify the scenario you will be asked questions about how you would respond in the situation and what methods or strategies, if any, you would use to determine your response.

As well as face to face interviews, there are options for doing interviews on the phone or in writing. Please let us know if you would like to do this and/or if you would like to be sent the list of themes in advance. Contact details are below.

This consent form and any identifying information you provide, for instance contact details to be sent the results of the research, will be stored separately from your responses. Your responses will be analysed totally anonymously. They are completely confidential. Only the seven researchers (Marion, Sharon, Michael, Richard, Callum, Zyggy and Panda) and Marion's assistant (currently Kathleen McNally) will see them.

Voluntary participation: Participation is completely voluntary. You should not feel under any pressure to respond. You can decide to withdraw at any point during the interview. This could mean ending the interview at any point, but allowing us to use your answers or ending the interview and not allowing us to use your answers.

Benefits and risks: The main benefits are contributing to better understanding of

1. how autistic people use strategies, including logic, reasoning and rules, to understand social situations, other people's reactions and empower themselves?
2. the barriers, including stereotypes, misconceptions and systemic issues to autistic people using their strengths and appropriate strategies to understand and participate in decision making, the economy and community.

We will use the results of the research to make recommendations to autistic people and service providers and decisions makers, aimed at changing the experiences of autistic people, removing barriers and increasing their empowerment. We will also apply for a further project to investigate practical implementation of some of the strategies identified. We hope that the results of the project would contribute to making a real difference in the lives of at least some autistic people. However, this difference will not be noticeable for a number of years. There are no risks.

Publication: We will be producing reports and would like to submit the results for publication in an international journal. We might use brief quotes from your comments, but they will be anonymous. We will make sure that no-one can guess your identity.

Ethical approval: We have received ethical approval from the Ethics Committee of the College of Science and Engineering of the University of Glasgow.

Further information: Please contact us if you have questions or would like further information about our research. Do also contact us if you would like a copy of our published results. We will store the contact addresses separately from the results.

Contact details:

Dr Marion Hersh: marion.hersh@glasgow.ac.uk. Biomedical Engineering, Rankine Building, University of Glasgow, Glasgow G12 8LT.

Dr Sharon Elley: S.T.Elley@leeds.ac.uk, School of Sociology and Social Policy, Social Sciences Building, University of Leeds, Leeds, LS2 9JT

Callum Watson: callumwatson@hotmail.com

Panda Mery: panda.mery@glasgow.ac.uk

Thank you for much for considering participation in our study

Consent: I am checking the box to confirm that

1. I have read and understood the above information.
2. I understand that my participation is voluntary, and that I can withdraw from the study at any time without having to give a reason to the researcher.
3. I understand that my data will be kept anonymous and that no information that identifies me will be made available to others.
4. I understand that I can contact the researcher for this project by email to receive more information and/or a summary of the results.
5. I agree to a recording being made of the interview solely for the purpose of analysing the results.

6. I agree to participate in this study.

Signature of participant

Date

Signature of researcher

Date