

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 an autistic-led group consisting of autistic people and people with experience supporting autistic people. We 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. Zygy 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 Zygy 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

We have already obtained a lot of useful information from a questionnaire. We are now asking about 50 autistic people to carry out a diary exercise. This will cover interactions with other people in different situations, such as social situations, interactions with professionals, workplace situations, education and training situations. We will provide an instruction sheet which explains what information we would like you to record for each interaction. We suggest that you carry out the diary exercise for two months. However, you may want to extend this period if you are involved in less than 20 interactions during it. You can use a support person, friend or assistant to help you complete the diary, but they should not tell you what to write.

Confidentiality and anonymity:

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 anonymously. They are confidential. Only the seven researchers (Marion, Sharon, Michael, Richard, Callum, Zygy and Panda) and Marion's assistant (currently Kathleen McNally) will see them.

To enable us to contact you if we have any questions about your diary it would be helpful if you could put an alias (made-up name) on it and send this name and an email address separately. This information will be stored separately from the diary and only used to contact you in the case of questions.

Voluntary participation: Participation is completely voluntary. You should not feel under any pressure to respond. You can decide to withdraw at any point up to submission of the diary or up to a week later if you provide an alias and email

address. If you withdraw you could decide not to submit the diary. If you do so we would be grateful if you inform us, so we can recruit someone else. Alternatively you could decide to submit a diary for a shorter period or with some of the entries incomplete.

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 participate in this study.

Diary Exercise: Instruction Sheet

We are asking you to record all your interactions with other with other people in different situations, such as social situations, interactions with professionals, workplace situations, education and training situations. We suggest that you carry out the diary exercise for two months. However, you may want to extend this period if you are involved in less than 20 interactions during it.

Please be open with us and do not exclude interactions which were difficult or you feel you should have handled differently. Information of this type is helpful to us, we are not judging you and the analysis is anonymous.

For each interaction we are asking you to record the following:

1. A brief description of the situation, including where it took place, who else was present (relationship of person to you rather than names e.g. friend, advocate, social worker, teacher) and the overall subject e.g. meeting at work, discussion with friends
2. Your feelings about the situation e.g. looking forward to it, anxiety.
3. Any previous interactions with the other people and how they affected these feelings.
4. Any preparation for the situation.
5. Your involvement, including your responses and/or observing from the sidelines.
6. Any methods or strategies you used to help you to participate e.g. hiding your autistic trait, using learnt responses.
7. What you felt about using these methods or strategies
8. How successful you consider these methods or strategies in enabling you to participate.
9. Any methods or strategies you used to understand the situation, what other people said and did and what they felt about it/their emotions e.g. reasoning about the situation or reading body language
10. What you felt about using these methods or strategies
11. How successful you consider these methods or strategies in enabling you to understand the situation and what other people said and did and what they felt about it/their emotions.
12. Any other comments

You can provide your answers in note form and illustrate then with drawings, if that is easier. If you can, please type your diary on a computer or mobile device. If you write by hand, please make sure your writing is legible, as we do not want not to be able to read it.