



UNIVERSITY OF
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The Open University

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Information sheet - Parent

Personality characteristics and cognitive abilities in children with an autism spectrum diagnosis and their parents

You and one of your children are being invited to take part in a study at the Autism Research Centre of the University of Cambridge and the Open University in Milton Keynes. Please consider taking part in this new research project.

What is the purpose of the research project?

The aim of the research is to examine to what extent children with autism resemble their biological parents on a series of tasks. This study may give us important insights in which characteristics are shared between parents and children and which features are not.

Who can take part in the study?

We are currently seeking the participation of very special families, who have two or more children with an autism spectrum diagnosis. The participation of such families is of extreme value to our research study, as it will help us to better understand the similarities and differences between parents and their children with autism. Please note that only one of your children will need to take part in the activities and tasks, in addition to both of you as parents.

What does the study entail?

We would like to invite both of you as parents and one of your children (aged between 6 and 18 years) with an autism spectrum diagnosis to participate in this project. The study will involve the completion of some questionnaires and assessments on a couple of mental tasks. Prior to the testing day, we will ask you (as parents) to complete some personality questionnaires. Depending on what you prefer, the testing day can either take place at your home, or you can visit our testing rooms in Cambridge or Milton Keynes. The testing session will take about 3 to 4 hours in total and you can take breaks during the session as you need to. We will start with a detailed interview that asks about your child's social and communication skills. You will then be given a brief IQ test, and we will ask you to complete three mental tasks. One task involves solving puzzles and two tasks concern the recognition of emotions in other people's faces. Before you do each task, full instructions will be provided and you will also get the chance to practice. Whilst you are completing the tests, we will also ask your child to do an IQ test and to complete the same tasks. Lastly, we will assess the strengths and difficulties of your child during a standardised assessment. We pay the travel expenses of your family and will in addition present you with a gift voucher of £25 as a thank you for taking part.

What about privacy and confidentiality?

The electronic data we collect will be stored on a secure computer network and any paper-based records will be stored in a secure filing cabinet. In the test results, you will not be identified by name, but by a code number. Your name and contact details will be kept in a separate and secured file. No identifying information will be linked to any of your test data, and all your personal information will be kept strictly confidential. Only members of the research group will have access to the data.

What will happen to the study results?

Results will be presented at conferences and written up in journals. Results will be presented in terms of groups of individuals. All data will be anonymous, without any means of identifying the individuals involved. After completion of the study, your family will be sent a newsletter detailing the results of the study.

What happens if I want to withdraw from the study?

You may withdraw at any stage without explanation and instruct us to destroy your data.

Who has reviewed the study?

The ethics protocol of this study has been reviewed and approved by the Psychology Research Ethics Committee of the University of Cambridge and the Open University Human Research Ethics Committee.

I have some more questions about the research. Who can I speak to?

Please contact **Edward Sucksmith** on 01223 746030 or email es504@medschl.cam.ac.uk.

Thank you for reading this.



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Information sheet - Child

Hello,

We would like you to help us by taking part in a study.

We want to find out how much children with autism are like their parents, and how they differ from their parents. For this study, we would like to ask you to complete some tests.

The first test is on paper and includes different puzzles and pictures. You will then complete two tasks on a computer. These involve looking at pictures of other people's faces. Lastly, a member of our team will ask you some questions about the things you like doing, and what you would like to do when you are older. Every task will be explained before you start and you will also get the chance to practice. You can take breaks from the tests when you need to.

After we have visited lots of families like yours, we will look at the results of the study for all families grouped together. We will send you a letter to tell you about these results. We will also talk about the study findings with other researchers and write about it in special books and magazines for scientists. We will not talk to anyone about your personal results. Your personal results on the tests will be kept on a computer and your results on the paper-and-pencil test will be locked safely in a cabinet.

If you feel uncomfortable about any of this then please tell us or tell your parents about it. If you don't want to take some of the puzzles and tasks, then you do not have to do it.

If you need to speak to someone about the study, you can phone **Edward Sucksmith** on 01223 746030 or email es504@medschl.cam.ac.uk.

Thank you for reading this.