

PARENTAL UNDERSTANDING OF AUTISM IN RELATION TO THE CHILD'S INDIVIDUAL CHARACTERISTICS

Human Sciences Research Centre University of Derby

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study looking at how parents understand autism in relation to the individual characteristics of their children on the autism spectrum. You can take part if you are over the age of 18 years and have a child or adolescent who has received a formal diagnosis of autism (ASD) from a paediatrician, clinical psychologist or similar healthcare professional.

Why is this research being done?

Understanding how parents view their child's strengths, abilities and unique characteristics might be related to their and their family's well-being and to good coping skills. This can help us develop an individualised autism profiling tool to describe the strengths and abilities of the child in the wider context of autism and comorbidities. The output of the tool will inform decisions for intervention and support strategies that are particular to the needs of the child and the family.

Who is doing this research?

This study is being conducted by PhD Candidate Alexandra Karousi and her academic supervisory team Dr Simon Bignell, Dr Sigrid Lipka and Dr Christopher Barnes at the University of Derby.

Why have I been invited to participate?

You have been invited to participate as you have identified yourself as a parent/caregiver of a child or adolescent, who has received a formal diagnosis of autism (ASD).

Please note that you cannot take part in this research if:

- You are under 18 years of age.
- You do not have a child with autism or your child has not been diagnosed by a paediatrician, clinical psychologist or similar healthcare professional.

What does taking part in the research involve?

We are exploring how parents' experiences and views of autism are related to the individual characteristics of their children and whether this relates to parenting self-efficacy, well-being and to good coping skills. This can help us develop a means to improve the ways in which parents can manage the challenging behaviours seen in autism and have a good quality of life. The study involves completing some questions that will take approximately 20 minutes. At the end of the survey, we will ask you if you would like to take part in further research and in particular, if you would consider taking part in a face-to-face or Skype interview in about *four weeks'* time so we can identify emerging factors

of interest to the area being researched. You do not need to take part in this second part of the research study if you do not want to and can still participate in the online survey.

What do I do if I am interested in taking part in the research?

If you wish to take part and meet all the inclusion criteria, you simply need to click the consent statement and you will then be able to fill in the questionnaire.

What happens if I change my mind about taking part?

Although your input to this research will be extremely valuable, participation is voluntary and should you decide you no longer want to take part you are free to withdraw from the study. You do not need to provide any reasons for this. You can withdraw questionnaire data up to **four weeks** after completion of the survey. Just email Alexandra Karousi with the unique identification number you will be asked to provide when you start the survey.

You may also withdraw during the study, just close the browser and no data will be saved. You will not be contacted by the research team again. This will not affect your right to make contact with the team should you wish to discuss any aspect of the research in the future or ask for more information about the study.

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What happens if I decide not to take part?

It is your choice whether you take part in the research or not. Participation is voluntary. There are no consequences to not taking part.

What will happen to the information that I give?

The information will be stored securely on a password protected computer or encrypted data storage device and only the researchers will have access to it. Results of the study will be disseminated at conferences and in peer reviewed journal articles. All information will be anonymised and so you will not be identifiable. If you provide contact details to be considered for the second part of the study, these details will be used only by the research team.

Use of your data and your rights.

Researchers will be collecting data from your participation in this study. We need these data to understand parents' views of autism in relation to the individual characteristics of their children with autism, and whether this relates to parenting self-efficacy, well-being and quality of life; and also in the public interest of enhancing academic research. This is the legal basis on which we are collecting your data and while this allows us to use your data, it also means we have obligations towards you to:

- Not seek more information from you than what is essential and necessary for the study;
- Make sure that you are not identified by the data by anonymising it using ID codes;
- Use your anonymised data only for the purposes of this study and for any relevant publications that arise from it;
- Store data safely in password-protected databases to which only the named researchers have access;
- Not keep your information for longer than is necessary (usually for seven years);
- Safely destroy your data by shredding or permanently deleting them.

The University of Derby 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. Researchers on the project with access to the data are highly qualified and experienced and have been very careful to ensure the security of your data. The study was approved for its ethical standards by The University of Derby Human Sciences Research Ethics Committee. However, in the unlikely event that you feel you need to make a complaint regarding the use of your information, you can contact the Data Protection Officer at the University of Derby: James Eaglesfield (01332) 591762 or the Information Commissioners Office 0303 123 1113. Further information about the project can be obtained from Alexandra Karousi (01332) 592559 at the University of Derby, Kedleston Road, Derby DE22 1GB.

Where can I get more information about this research?

If you would like more information about this research, please contact Alexandra Karousi at a.karousi1@unimail.derby.ac.uk or at the address below.

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THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.