

Participant Information Sheet

The Needs Project: A Study of Autistic Children's Educational and Family Needs

Invitation

Before you decide whether or not to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. A member of the team can be contacted if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Introduction

We are conducting a research study to better understand why some autistic children struggle to thrive in education and other settings. This research aims to identify the factors contributing to the challenges autistic children face, with the goal of identifying and developing targeted support.

Purpose of the study

Many autistic children experience significant difficulties in all types of education, even with additional support.

This study aims to:

- Identify the specific needs of autistic children
- Understand the factors that contribute to challenges in managing day-to-day living
- Develop the rationale for evidence-based strategies to support them

Why have I been chosen?

You are invited to take part as you have identified yourself to be a parent/carers of an autistic child aged 7 years to 16 years.

Do I have to take part?

Taking part is entirely voluntary and refusal or withdrawal will involve no penalty or loss, now or in the future.

What will happen to me if I take part?

If you choose to participate in this study, you will be asked to complete a detailed survey about your child's:

- Educational abilities and experiences
- Functional abilities



- Mental wellbeing and behaviour
- Engagement with leisure pursuits
- Family experiences

We will also ask about caregiver strain and your experiences as a parent/carer of an autistic child, and how much support you have.

The survey should take up to 90 minutes to complete. There is a mixture of question types; most questions are multiple-choice, with occasional free-text responses.

What do I have to do?

To take part you will answer questions on a secure online platform called Qualtrics. If you require any reasonable adjustment or help in completing the survey, please get in touch.

Are there possible disadvantages and/or risks in taking part?

There are no foreseeable risks associated with participating in this study. However, completing the survey may take time and effort. The survey includes questions about your wellbeing including your mental health, which may be uncomfortable for some people. To support you, we will provide information on UK national mental health resources and helplines for adults.

What are the possible benefits of taking part?

1. By participating in this study, you will help improve the understanding of the needs of autistic children. This knowledge may lead to better support, services, and awareness for these children and their families.
2. At the end of the survey, you will have the option to save a summary of scores based on your responses to the questionnaires covering how your child is sleeping, managing emotions, managing demands and their sensory experiences.
3. You can also opt-in to receive updates about the study and research findings.

Will my taking part in this project be kept confidential?

All information collected will be kept strictly confidential. Survey responses will be stored online in Qualtrics under the Cambridge University site license and only made available to approved researchers. Data will be analysed on computers located at the Autism Research Centre (18b Trumpington Road, Cambridge, CB2 8AH). Data will be stored for up to 5 years after the completion of the study. If you choose to provide your email address, (which is optional) for future follow-up studies, your email address will be stored separately to your responses in a secure server.



All data collected will be stored according to Data Protection Legislation. All data will be stored in password protected files on the University Network and will only be accessible by the research team. All applicants for the study have completed GDPR training.

Information about how the University uses personal data can be found at: <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>.

What if I want to withdraw from the study?

Participation in this study is completely voluntary and you may withdraw at any point. However, since we are not routinely collecting personally identifiable data, please be aware that we will not be able to identify or remove your survey responses after you withdraw. This means that partial survey responses may still be recorded and included in the data analysis once you begin the survey. If you choose to provide your email address, (which is optional) for future follow-up studies, you may request to withdraw, and we will be able to remove your responses from the data.

What will happen to the results of the research project?

After completing the survey, you will see an End of Survey Message that includes a link to an optional Contact Form, allowing you to receive the study findings once available. If you prefer not to share your contact details with us, you can visit our website (www.autismresearchcentre.com) for updates on ongoing projects and published scientific papers.

Research will be presented at conferences and written up in journals. Results are normally presented in terms of groups of individuals. If any individual data are presented, the data will be totally anonymous, without any means of identifying the individuals involved. Data collected during the course of the project might be used for additional or future research questions that arise.

Who is organising and funding the research?

The study is funded by existing grants held by the Autism Research Centre, University of Cambridge. The principal investigator's employment is funded by North East London NHS Foundation Trust.

Ethical review of the study

The project has been reviewed by the University of Cambridge Psychology Research Ethics Committee and received a favourable opinion.

Contact for further information



Autism Research Centre
Department of Psychiatry
Douglas House
18b Trumpington Road
Cambridge CB2 8AH
www.autismresearchcentre.com

Principal Investigator – Dr Jenny Parker email jp2096@cam.ac.uk



Autism Research Centre
Department of Psychiatry
Douglas House
18b Trumpington Road
Cambridge CB2 8AH
www.autismresearchcentre.com