



Parent and Guardian Information Sheet for 10-17 years

Study Title: The Sensory Experiences of Autistic Adolescent Females

You are being invited to take part in a research study. Before you decide whether or not to consent, it is important that to understand what the research is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that might not be clear to you. Make sure that you are happy before you decide to give consent. Thank you for taking the time to consider this invitation.

This study is taking place as a Sensory Integration Masters research project at Ulster University by Eleanor McStay, (Specialist Speech and Language Therapist, Middletown Centre for Autism).

1. What is the purpose of the study?

The study aims to find out about the sensory experiences of autistic females aged 10-19 years, and how their sensory experiences might affect school and home life. Sensory experiences relate to how sensory information is processed (sensory processing) from the environment and from within the body. 85-95% of autistic people experience sensory processing differences which can impact on life at home, school and in the community.

We are collecting responses from autistic females aged 10-19. Responses from those aged 10-17 will be provided by parents/guardians. Those aged 18-19 years provide consent for themselves as adults.

2. Why have I been invited?

You have been invited to take part because you are a parent or guardian of a female, aged 10-17 years old with an autism diagnosis and who may experience sensory processing differences.

3. Do I have to take part?

It is up to you and your daughter to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep.

If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason.

If you choose to take part, please email mcstay_fearon-e@ulster.ac.uk. We will arrange a short call via Zoom to verify your age and give you an opportunity to ask any questions you might have about the study. After this, a link will then be emailed to you to access a survey.

4. What do participants have to do to take part?

You will be asked to complete an online survey. The survey will ask questions about your daughter's sensory experiences across the eight sensory systems: touch, smell, taste, hearing, vision, movement, deep pressure and interoception.

The survey is designed so that you only answer questions about the relevant sensory systems to your daughter. It has taken, on average, 20 minutes for others to complete but it might take longer or shorter, depending on how many sensory systems impact your daughter.

As this study aims to understand the personal experiences of autistic adolescent females, it would be preferable to complete the survey together with your daughter as much as possible, so that her words are captured. Your daughter should be able to reflect and comment on her own experiences, to ensure that her sensory experiences are described in her words.

You can support your daughter to complete the survey. You might decide to read the questions for her, help to type her responses, help her to take a break and come back later or complete the survey jointly with her.

Only completed surveys will be included for data analysis. Incomplete surveys will, therefore, be excluded from the final data analysis. This is to ensure that the data reflects an accurate picture of the sensory experiences of the target population.

5. Risks and/or disadvantages?

Some females may find it tiring or distressing to answer questions about some personal sensory experiences. Some parents or guardians might find it emotionally distressing to hear some of the personal sensory experiences of their daughter.

You and your daughter can take a break at any time during the survey. She can come back to it after a break. You both can decide not to answer a particular question if it causes too much distress.

If your daughter becomes upset, she can talk with a friend, family member or other trusted person (i.e., teacher) about what has made her distressed. You might also seek support from a friend or family member to talk about what has been emotionally distressing for you. You can access support through your GP if you wish to talk to a professional about what has made you or your daughter distressed.

If you wish to withdraw from the study, you can without giving a reason. Any data already submitted after withdrawal cannot be deleted as it is anonymous but only completed surveys will be included for data analysis.

6. Are there any possible benefits in taking part?

There are no direct benefits in taking part. By taking part you and your daughter will be adding her personal experience to the evidence base for sensory experiences for autistic adolescent females.

7. What happens when the study ends?

At the end of the data collection period, the survey answers will be analysed. Themes will be explored and written up as part of the MSc project paperwork. The researcher will email the results to participants who wish to receive these. Participants wishing to receive the results can submit their email address by following a link at the end of the survey. Participants will submit their email addresses on this separate link to maintain confidentiality with the data. Email addresses will be stored in confidence on the Ulster University secure server in a document which is only accessible by the student.

8. Will my taking part in this study be kept confidential?

Ulster University is committed to protecting the rights of individuals in line with General Data Protection Regulation (GDPR) guidelines. In research, this means ensuring that measures are taken to protect participants' data. Data will be held securely on the Ulster University encrypted server. The data gathered is stored for 10 years, with access only by the chief investigator and student. Data will be held in confidence and any information that might identify you will be removed prior to publication as required under Data Protection legislation and in line with GDPR guidelines.

However, Freedom of Information legislation requires access to certain non-personal or generalized data. For example, if there is a child protection discloser, the researcher has a duty to follow up on this information.

Ulster University's GDPR can be found at this link:

https://www.ulster.ac.uk/data/assets/pdf_file/0006/286008/GDPR-Policy.pdf/nocache

9. What will happen to the results of the study?

The results will be analysed and written up for marking as part of researchers MSc. Following this, the study will be written up for publication in a peer reviewed journal.

10. Who is organising and funding the research?

The study is taking place as a master's research project through Ulster University. The researcher's employer, Middletown Centre for Autism, has funded the researcher's master's studies.

11. Who has reviewed this study?

Autistic females have reviewed the survey questions and this Participant Information Sheet. Researchers at Ulster University and Middletown Centre for Autism who are knowledgeable in the subject area have also provided feedback.

The study has been reviewed by an ethics committee in accordance with the University procedures. You can contact the University Research Governance section for further details if required.

12. Who should I contact if I have concerns about the conduct of the study?

Concerns about how the study is being conducted can be made by contacting the Ulster University Research Governance Department on +44 28 9536 5123.

13. Contact details

If you have questions or want additional information, please contact the researcher at mcstay_fearon-e@ulster.ac.uk

Version 5

03/01/2023