



INFORMATION LEAFLET

SENSORY PROCESSING PATTERNS AND ACTIVITY CHOICES PROJECT



You have been invited to take part in a Research Project, which aims to determine if there is a link between a child's sensory preferences and the range of activities in which he/she chooses to participate.

The Project also aims to determine difference in sensory processing and activity choices between children with autism and children who do not have autism. This leaflet will give you further information about the Project. You can then decide if you would like to take part.



CENTRE FOR AUTISM
MIDDLETOWN

WHY HAVE YOU BEEN INVITED TO PARTICIPATE?

You are invited to take part in this Project because you registered to be a member of the Research Panel established by Middletown Centre for Autism. You may also have been invited because you registered interest through the Centre's website.

WHO IS CONDUCTING THE PROJECT?

The Sensory Processing and Activity Choices Project will be carried out jointly by Middletown Centre for Autism and University of Ulster. The Centre will be responsible for conducting the research with parents of children with autism, while the University will be responsible for conducting the research with parents of children who do not have autism.

The Centre was established by the Department of Education and Skills in the Republic of Ireland and the Department of Education in Northern Ireland to support the promotion of excellence in the development and co-ordination of education services to children and young people with autism.

WHAT ARE THE CRITERIA REQUIRED FOR REGISTERING TO TAKE PART IN THE SENSORY PROCESSING AND ACTIVITY CHOICES PROJECT?

In order for you to be eligible for registration in the Sensory Processing and Activity Choices Project, the following criteria must be met:

- Your child must have a formal diagnosis of autism or Asperger Syndrome.
- Your child must be aged between 4 and 11 years old.
- Your child must attend nursery/primary/special school.
- Your child must not have any difficulties such as ADHD, dyslexia, physical disability (e.g. cerebral palsy) or sensory impairments (e.g. visual/hearing impairment).

The Research Team at the Centre will then make a selection based on:

1. The eligibility criteria.
2. The sample required to meet gender and age matching comparisons between children with and without autism.

Please note that registration to participate does not guarantee selection. This study is also based on only one child per household.

WHAT WILL THE SENSORY PROCESSING AND ACTIVITY CHOICES PROJECT TELL US?

The purpose of the Sensory Processing and Activity Choices Project is to determine if there is a link between a child's sensory preferences/dislikes and the activities in which he/she chooses to participate. It will allow us to:

- Examine if there is a common pattern of sensory preferences and dislikes in children with autism.
- Examine if there is a common pattern of activities chosen by children with autism.
- Identify if there is a link between sensory preferences and chosen activities of children with autism.
- Compare the sensory preferences of children with and without autism.
- Compare the activity choices of children with and without autism.
- Questions regarding your family circumstances e.g. employment status are also collected to determine any potential relationship with your child's activity choices.

WHAT HAPPENS IF YOU DECIDE THAT YOU WISH TO TAKE PART IN THE PROJECT?

After reading this information leaflet, if you decide that you wish to take part in the Sensory Processing and Activity Choices Project, you should do the following:

STEP ONE:

Go to www.middletonautism.com/sp

STEP TWO:

Complete the online registration form. The online form will automatically let you know whether you are eligible to participate in the Project.

STEP THREE:

If you have been eligible to participate in the Project, the Centre will send you a letter of invitation in addition to a consent form and two questionnaires which provide information about your child. The completion of the questionnaires should take no more than approximately 15 minutes to one hour to complete.

These will include: **1.** The Sensory Profile Caregiver Questionnaire
2. Participation & Environment for Children & Youth (PEM-CY)

Prior to completion of these questionnaires, go to www.middletonautism.com/sp where you will have access to a short presentation which will assist you. You can also contact the Research Team at the Centre on 0044 (0) 283751 5758 for assistance if required. You should complete and return the two questionnaires and the consent form using the **FREEPOST** address outlined in your invitation letter.

STEP FOUR:

Once the questionnaires and consent forms have been returned to the Centre they will be analysed. You will be sent a copy of *Asperger Syndrome and Sensory Issues: Practical Solutions for Making Sense of the World* by Brenda Smith Myles. This is a useful book for children with Autism and Asperger Syndrome. You will also be invited to attend a training session on 'Sensory Processing and Autism' which will be delivered by a qualified Occupational Therapist from the Centre.

The questionnaires are for research purposes only to establish if there is a link between children's sensory preferences and their activity choices. You will not receive an individual report regarding your child. If you have any concerns following the completion of the questionnaires, you will be able to contact staff in the Centre to request advice by telephone or e-mail.



WHAT IS SENSORY PROCESSING?

Sensory processing is a term used to describe how people perceive, interpret and respond to sensory stimuli e.g. sounds, sights and smells in the surrounding environment. All individuals perceive and respond differently to sensory stimuli, and everyone has different sensory preferences and dislikes. For example, some individuals seek movement while others may feel nauseous in response to excess movement. This, then, affects how individuals engage with the environment in daily activities.

The Sensory Processing and Activity Choices Research Project aims to determine if the sensory preferences and dislikes of children affects the activities in which they choose to engage. Research and literature indicates that many children with autism have significant preferences for daily activities (e.g. play and leisure activities), whilst actively avoiding other activities. This Project will examine if these activity choices are affected by sensory preferences and dislikes.

BENEFITS FROM TAKING PART

You will be contributing to a better understanding of how children with autism process sensory information and how this may then, affect their preferred choice of activity. This will provide information on the types of activity we should be offering to children with autism to increase their participation in play, leisure and social activities.

POTENTIAL RISKS TO YOU WHEN TAKING PART

The Sensory Profile and the Participation & Environment for Children & Youth (PEM-CY) are both written questionnaires, which are designed to be quick and simple to complete. Participation in the Project should therefore not cause any risk or negative impact. Completion of the questionnaires may raise concerns for some parents about their child. Attendance at the information sessions on 'Sensory Processing and Autism' will provide you with strategies to understand and address your child's sensory processing differences. If you continue to have concerns, you may contact a member of staff in the Centre at any time.

CONFIDENTIALITY

Results from the questionnaires will be treated in the strictest confidence. Data will be used exclusively for research purposes. Your child's personal details will not be identified in any published reports, papers or at research conferences. The Centre may use the information provided for the purposes of this current research project, or future projects, but in all situations will respect the confidentiality commitments given in this confidentiality statement. Following completion of this Project, all personal data will be destroyed.

YOUR RIGHTS

If you have completed a consent form but later decide that you no longer wish to be part of the Sensory Processing and Activity Choices Research Project, you have the right to withdraw from the Project at any time. In this case, please inform a member of staff in the Centre. You will still be able to attend information sessions on 'Sensory Processing and Autism'.

If there are any other questions or concerns that you have about taking part in the Project, please contact the Research Team at the Centre:

Email: research@middletownautism.com **Telephone:** 0044 (0) 28 3751 5750

THANK YOU

Middletown Centre for Autism would like to thank you for being part of this Project. Your participation will help both educational and health professionals to better understand the strengths and needs of children with autism.

