****College of Health and Life Sciences

Department of Clinical Sciences

**Participant Information Sheet**

**Study title:**

Research Exploration: Participation of Children with Autism – Emphasis including Associations and Impacts of Environment, Sibling Comparisons, and links to Sensory Behaviour

**Invitation Paragraph:**

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please feel free to email the researchers (information seen below) if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

In the world of ASD, participation has been studied before, focusing on various topics such as physical activity, hobby preference, social participation, and high education (Simpson et al., 2019; Russell, Healy and Braithwaite, 2019; Jansen et al., 2017; Orsmond et al., 2013). This research continues to happen because participation in meaningful activities helps living life to its full potential (Imms et al., 2016). Yet, participation is a complex construct with many areas that are still left unresolved (Imms et al., 2016). The aim of this study will be to explore specific aspects of participation within the ASD population that have not been covered in past literature.

More and more studies point to the fact that children are less in nature and that the content of children's nature experiences is different than before. Although the changes in children's use of nature seem to be extensive, we have limited knowledge of how this may impact children with Autism Spectrum Disorder (ASD). Results from this survey will, therefore, be able to help fill an important knowledge need. The purpose of this study is to look at the possible facilitators and barriers in natural, play-space environments for children with ASD. We will also look at the sensory aspects of the environment that support and inhibit the child’s participation in play.

Studies have been done before to look at how participation can be affected in play with peers, siblings and during school activities. However, none of these studies look at participation in comparison to another child in the family. The second part of the study will be comparing participation in children on the spectrum to their typically developing sibling.

It is known that children on the spectrum present with various sensory behaviours. The third part of the study focuses on looking at relationships between sensory behaviour and participation. Specifically, this study will explore constructs of participation like frequency, engagement and independence and look for links to behaviour. This is important as findings can inform interventions.

 As participants, the questionnaire should take 30-45 minutes to complete. This study is open to participants who have children on spectrum with or without siblings.

The data will be gathered through an anonymous online survey. Upon completion of the survey, you will be eligible to enter a raffle for a £20 Amazon gift card.

**Why have I been invited to participate?**

You have been invited to participate because you are a parent/ primary guardian of a child with ASD (under the age of 16). You may also have at least one other child without ASD.  Both parents/ primary guardians who **do** and **do** **not** have children with siblings are encouraged to participate. All participants will be of adult age (18 years or higher.)

**Do I have to take part?**

As participation is entirely voluntary, it is up to you to decide whether or not to take part. You have the right to decline or withdraw from this study and doing so will in no way influence or adversely affect you. If you do decide to take part, you will be given this information sheet to keep and you may be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time up until 25/06/2020 and without having to give a reason. However, because the survey is anonymous once it has been submitted, you will be unable to withdraw your results.

**What will happen to me if I take part?**

As a participant, your data will be used for the purpose of a master’s dissertation at Brunel University. The anonymized data may be used in future publications within the parameters of the university and will always remain confidential. The survey can be completed at a convenient time and place (at school or at home). The questions consist of multiple-choice and short-answer responses that should be answered to the participant's complete knowledge or honesty.  After you have completed the survey, there is an option to participate in a raffle where you have a chance of receiving a 20£ gift card to Amazon.  This raffle will not be anonymous, as we will need your email if you are selected to deliver the prize. The emails will not be shared with anyone outside the research team and will be deleted after the winner has been selected. This data is separate from the answers given in the survey. In the survey, your answers will remain anonymous.

**Are there any lifestyle restrictions?**

There are no known lifestyle restrictions when participating in this survey

**What are the possible disadvantages and risks of taking part?**

There are no anticipated disadvantages or risks associated with taking part in this study. However, there are questions that may cause minor psychological discomfort if the subject area is sensitive around the child in question.  For example, questions about attention, distractibility or how your child responds when frustrated.

**What are the possible benefits of taking part?**

There are no known individual benefits of taking part in this study; however, your results will contribute to research needed in this particular field.

**What if something goes wrong?**

As the nature of the questionnaire there are no foreseeable risks; however, if you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone’s negligence, then you may have grounds for legal action, but you may have to pay for it. If you have concerns about your child while taking the online questionnaire, please contact your child’s teacher. If you have any concerns about the online questionnaire, please contact the researchers (information shown below.) You may also contact the Brunel University Ethics Team (information shown below.)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will always be kept strictly confidential. Raw data will be kept up until publication date/ submitting to the University. The questionnaire is submitted anonymously.  Any information about you which leaves the University will have all your identifying information removed. With your permission, anonymized data will be stored and may be used in future research – you can indicate whether or not you give permission for this by way of the Consent Form.

If during the course of the research evidence of harm or misconduct come to light, then it may be necessary to break confidentiality. We will tell you at the time if we think we need to do this, and let you know what will happen next.

**Will I be recorded, and how will the recording be used?**

You will not be recorded while taking this questionnaire.

**What will happen to the results of the research study?**

The results will be used as part of several master’s dissertations. Your anonymized responses will be added to a database for analysis at Brunel University. Once published you will be able to obtain the results with the specific journal the result published. You will not be identified in any report or publication unless you specifically request it.

**Who is organising and funding the research?**

The research is being organised by the principle researchers: Kristina Fenske-Vincent , Mikayla Pillar, Lomarshini Anand with Professor Dido Green in conjunction with Brunel University London.

**What are the indemnity arrangements?**

Brunel University London provides appropriate insurance cover for research which has received ethical approval.

**Who has reviewed the study?**

This study has been approved by The College of Health and Life Sciences Research Ethics Committee and is part of MSC Brunel University London.

Research Integrity

Brunel University London is committed to compliance with the Universities UK [Research Integrity Concordat](http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/the-concordat-to-support-research-integrity.pdf). You are entitled to expect the highest level of integrity from the researchers during the course of this research.

**Contact for further information and complaints:**

**Researchers’ name and details**

Kristina Fenske-Vincent – [1804315@brunel.ac.uk](mailto:1804315@brunel.ac.uk)

Mikayla Pillar - [1830758@brunel.ac.uk](mailto:1830758@brunel.ac.uk)

Lomarshini Anand Bangalore Muthukrishna - [1939376@brunel.ac.uk](mailto:1939376@brunel.ac.uk)

**Supervisor name and details**

Supervisor: Dido Green- [Dido.Green@brunel.ac.uk](mailto:Dido.Green@brunel.ac.uk)

**For complaints and concerns, Chair of the Research Ethics Committee:**

College of Health and Life Sciences Research Ethics Committee Chair – Professor Christina Victor ([Christina.Victor@brunel.ac.uk](mailto:Christina.Victor@brunel.ac.uk) )