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## **The 'Hidden Sense': Targeting the proprioceptive system to improve target behaviours for children with Autism Spectrum Disorder**

### **PARTICIPANT INFORMATION STATEMENT**

#### **(1) What is this study about?**

You are invited to take part in a research study about improving undesirable behaviour of children with Autism Spectrum Disorder (ASD). The study aims to explore the effectiveness of a parent-implemented daily program of activities with proprioceptive input on behaviours for children with ASD and co-occurring sensory modulation difficulties.

You have been invited to participate in this study because you are a parent of a child with ASD. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

#### **(2) Who is running the study?**

The study is being carried out by the following researchers:

- Dr Yu-Wei Chen, Occupational Therapist, Lecturer, University of Sydney
- Victoria Jarman, Occupational Therapist, Postgraduate Student, University of Sydney

Victoria is conducting this study as the basis for the degree of Master of Health Science (Developmental Disability) at The University of Sydney. This will take place under the supervision of Dr Chen.

### **(3) What will the study involve for me?**

Your involvement in the study will include completing a questionnaire for screening to determine if your child has sensory over-responsiveness, discussions with us to identify and create goals for a target undesirable behaviour for your child, daily recording of your child's undesirable behaviour via an application on a smart device and implementation of intervention activities daily with your child.

The intervention will involve using one type of sensory based intervention, proprioception. Proprioception is provided to a child when they activate, or move, a muscle, especially against resistance. Therefore, activities where your child is pushing, pulling, carrying, lifting, chewing, sucking or gaining another form of resistance are proprioceptive activities. Proprioception is the most calming type of sensation when provided to the body and unlike other sensory stimuli, children are rarely sensitive to proprioception. Therefore, the study will use proprioceptive input to help children to calm their bodies and in turn reduce their undesirable behaviours. You will facilitate proprioceptive activities with your child during daily routines, such as, when your child is playing, doing homework, or tasks around the house.

We will train and guide you through implementation of the activities, including how and when to facilitate them with your child. You can continue other therapies for your child during the research however these interventions must not be addressing the target behaviour agreed upon for the research. You will be provided with an opportunity to review the results from the research for your child.

### **(4) How much of my time will the study take?**

The research period will last 9 weeks. You will be required to score your child's behaviour daily for the 9 weeks and implement the intervention for 5 weeks. Training will be provided within the intervention period.

### **(5) Who can take part in the study?**

You will need to meet the following criteria to participate in the study:

- Parent of a child with aged 3-12 years with a primary diagnosis of ASD (additional diagnosis of mild global developmental delay, mild intellectual disability, ADHD/ADD, anxiety, sensory processing disorder, language delay accepted).
- Reside in South Eastern Sydney
- Speak fluent English (parent)

### **(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by talking the researchers.

If you decide to withdraw from the study, we will not collect any more information from you. Please let us know at the time when you withdraw what you would like us to do with the information we have collected about you up to that point. If you wish your information will be removed from our study records and will not be included in the study results, up to the point that we have analysed and published the results.

**(7) Are there any risks or costs associated with being in the study?**

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

**(8) Are there any benefits associated with being in the study?**

We cannot guarantee that you will receive any direct benefits from being in the study. We hope that the results from the study will contribute to knowledge about using sensory based intervention to address undesirable behaviours of children with ASD. This information may help researchers to develop intervention strategies that can improve undesirable behaviours for children with ASD.

**(9) What will happen to information about me that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

**(10) Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

**(11) What if I would like further information about the study?**

When you have read this information, Victoria Jarman will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Victoria Jarman at [vjar1807@uni.sydney.edu.au](mailto:vjar1807@uni.sydney.edu.au)

**(12) Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback when completing the consent form. This feedback will be in the form of a one page summary. You will receive this feedback after the study is finished.

**(13) What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [*INSERT protocol number once approval is obtained*]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*