

Attachment 4

Group 2 Patient Sheet The information sheet will be the first page of an Online survey link (survey.ac.uk) sent to mothers who have expressed an interest in attending the coaching intervention.

Online Mums' group: Coaching mothers of children with sensory integration difficulties: A collaborative service development. A pre-feasibility study.

We are exploring better ways to support mothers of children with sensory integration difficulties (SID) based on current evidence and feedback from mothers themselves. This group will help mothers to identify areas of concern in everyday family life and to develop strategies and techniques to address them. Learning and supporting others within the group is part of this process. At this stage we are developing this approach therefore Mothers taking part in the group will also be helping to shape future groups for others, by giving feedback about the group itself and the questionnaires used to evaluate it.

Who is carrying out the study?

My name is Susan Allen. I am an occupational therapy clinician and lecturer, and am currently completing a PhD at the School of Psychology and Clinical Language Sciences, University of Reading, with Dr Fiona Knott (f.j.knott@reading.ac.uk) and Dr Amanda Branson (a.branson@reading.ac.uk). The focus of my PhD is working towards improving services for families of children with SID.

What do I need to do?

1. **Consent form and demographics:** In the first instance, you will be asked to complete a consent form (below). Then there will be a questionnaire that asks you about yourself and your child. The survey will allow you to navigate forwards and backwards and pause at any time until you have finished it. The survey will take



approximately 10 minutes to complete. Participation is voluntary. You have the right to withdraw at any time.

2. **Pre-session questionnaires:** You will be contacted by Sue Allen who will share details of the pre-session questionnaires. We will ask you to complete a Sensory Processing Measure for your child, and a questionnaire about your child's participation in daily life. We will ask you to identify what you would like to get out of the group. We will also ask you to complete forms about your level of stress and how competent you feel. These questionnaires can be completed online or face to face.

3. **Mums' group:** You will be sent an invitation to attend an online MS teams group from 9.30 to 11am on Monday. The group will be attended by up to 6 mothers of children who present with sensory integration difficulties that affects everyday life. You will be invited to share your experiences and identify areas of everyday family life which you would like to change.

We know that, when mothers gain understanding and are empowered, the outcomes for both themselves and their child improve. The role of the occupational therapist will be to facilitate you in problem solving rather than telling you what to do, this is also known as a coaching approach.

We plan to record sessions to check that the researcher has followed the coaching process correctly. We will audio record any feedback given at the end of the final session. The recordings will be held on the University One Drive and deleted at the end of the study.

4. **Post group questionnaires:** Following completion of the group, you will be asked to repeat the pre session questionnaires. Finally, we will ask you to complete an online survey on what was helpful and how you think the group could be improved for other mothers in the future.

Will your information be confidential?

Yes. The online survey platform has end to end encryption. Your replies from the online survey will be downloaded anonymously onto an Excel spreadsheet which will be stored on the University One Drive. Any paper forms will be digitised and destroyed once uploaded. Uploading of information will be through the Primary Investigator's password protected computer, then stored on the University One Drive. No information about your identity or the identity of your child will be shared. Information provided will be stored securely and reviewed annually after the completion of this study in line with university guidelines, other than video recorded information which will be deleted at the end of the study. This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Who can I contact if I have any queries about taking part in the study?

If you have any queries please contact:

Susan Allen s.c.f.allen@pgr.reading.ac.uk

Click to link for full data protection information (this will be held as final page of online questionnaire)

Data protection statement

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or, in writing, to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law, we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependent on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your

personal data.

If we have included any additional requests for use of your data, for example, adding you to a registration list for the purposes of inviting you to take part in future studies, this will be done only with your consent where you have provided it to us and should you wish to be removed from the register at a later date, you should contact s.c.f.allen@pgr.reading.ac.uk

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details are to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>

You also have a right to complain to the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance