

External Stakeholders Participant Information Statement

Research Title: Positive Behaviour Support delivered via Tele-practice

You are invited to participate in a research project conducted by staff at Autism Spectrum Australia (Aspect) in partnership with the University of Sydney.

About this form

This Participant Information Statement tells you about this research project. It explains what will happen if you take part.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

Knowing what is involved will help you decide if you want to take part in the research. Please read this statement carefully and be confident that you understand what it says before you agree to participate. If you have any questions about the project, please ask one of the researchers named below.

If you decide you want to take part in the research project, you will be asked to give verbal consent prior to data collection. By giving verbal consent you are telling us that you understand what you have read, that you consent to take part in the research project as described below and that you consent to the use of your personal information as described below.

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

Who is organising and funding this research project?

This research project is being conducted by Autism Spectrum Australia (Aspect) in partnership with the University of Sydney. The findings from this research will form part of the information used to develop a set of resources on the delivery of positive behaviour support via telepractice (Funded by the NDIS Quality & Safeguards Commission).

Research team

- Chief Investigator (University of Sydney): Dr. Kim Bulkeley, kbulkeley@sydney.edu.au
- Co-Investigator (University of Sydney) and Lead Researcher (Aspect): Genevieve Johnsson, 0400 503 489, gjohnsson@autismspectrum.org.au

Is this study approved?

This study has been approved by the:

- HREC [#2019_403, Approved 22/7/2019]
- Aspect Research Approvals Committee [#1912A, Approved 28/8/2019]

What is this research about?

The purpose of the study is to investigate the feasibility and acceptability of a positive behaviour support (PBS) service delivered to participants on the autism spectrum and their local support teams in regional and remote areas via videoconferencing technology. For an interim period while face to face services are impacted by the COVID 19 Pandemic, participants will be included if they reside in any location of Australia. Online service delivery of PBS is recognised as an option that is underutilised in current service models. We will ask you as an external stakeholder with experience of tele-PBS to give us your views about your experience of delivering and/or receiving an online service to help us understand the benefits and challenges of this approach to PBS service delivery.

Who is eligible?

Participants in the study include eligible children and young persons (see below), as well as their caregivers, local support team members (therapists and community support workers), and Aspect PBS practitioners.

Eligible participants are children and young persons diagnosed on the autism spectrum aged 4-17 years who are presenting with behaviours of concern. Children and young persons in regional and remote areas (and for an interim period while face to face services are impacted by the COVID 19 Pandemic, in any location) of Australia will be able to receive tele-PBS services (tele-PBS). Another group of participants will receive in-person PBS services where they are locally available (in-person).

Children and young persons in the tele-PBS group must have reliable access to an internet connection and technology (computer or device) for participating in online sessions.

Children and young persons may be deemed ineligible if they are in need of intensive support that is outside of the scope of the Aspect PBS Practitioner e.g. needing medical intervention including prescription of medications and/or psychiatric treatment. These participants will be referred to an organisation within their local community e.g. community mental health.

Participation in the current study is also open to external stakeholders who have received or delivered PBS services via telepractice. This may include individuals with a disability and their caregivers, PBS Practitioners, and PBS managers.

What am I being asked to do?

External stakeholders will be invited to a half an hour interview with researchers via telephone or face to face. Interviews will be conducted at a mutually convenient time.

What are the benefits of taking part in this research?

The major benefit of this research is that Aspect and the broader disability sector can investigate and understand the successful application of Positive Behaviour Support via tele-practice. This may increase PBS services delivered to caregivers and their local support team, especially in regions that it is unavailable in a face-to-face format. This may result in improved outcomes in parent empowerment, quality of life, and behavior.

The research will also provide insight into the delivery of PBS services delivered via technology as compared to in-person services and understand the role of the PBS practitioner to ensure this service meets the needs of its participants in the future. In addition, this research will contribute to the development of resources for families and practitioners to support the quality of tele-PBS practice.

What are the costs and risk for me in taking part in this research?

There are no other personal or financial costs associated with participating in this research except for time spent participating in interviews (All participants - approximately 30 minutes).

There is minimal potential for emotional distress as a result of participation in this research, i.e., when participating in interviews about experiences with tele-PBS. We will endeavour to minimise and manage this risk through sensitive questioning and by directing you to counselling and support services in the local community as needed.

If you become upset or distressed as a result of your participation in the research project, we encourage you to contact Lifeline (13 11 14), Parentline (1300 30 1300), or Kids Helpline (1800 55 1800). These services have trained volunteers ready to listen, and provide support and referrals if necessary. You are free to withdraw from the study at any time.

We will ask you to give us information to identify you

Researchers will ask you to provide general information about you to help with analysing the interviews from a larger group of people. You may also provide identifying information in the course of the interview with the researcher that will be included in the analysis. All information will be de-identified before being included in reports or research summaries.

What will happen to the information I provide?

By providing verbal consent in the phone interview for this study, you agree that the research team can collect and use the personal information that they collect about you for this research project. Any information obtained in connection with this research project that can identify you will remain confidential.

Research data including audio recordings from phone interviews and interview transcriptions will be stored electronically in the University of Sydney Research Data Store under password protection. Access to this research data store will be by named investigators only.

A summary report will be provided to all participants. The final research report will be de-identified and distributed to Aspect Therapy and Research. Results of the study will be provided in a written journal article and submitted to a relevant journal. Results may be presented at relevant conferences.

If your responses can be identified individually you will have access to this data if you request it, in accordance with privacy laws. Any information that you provide can only be disclosed if (1) it is to protect you or others from harm, (2) a court order is produced, or (3) you provide the researchers with written permission.

Can I get a copy of the results of the study?

Once the research has been completed, participants can request a written summary report by contacting Genevieve Johnsson (Lead Researcher).

What if I don't want to take part, or want to withdraw after I take part?

Participation in this research is entirely voluntary. You may also withdraw from the research at any time while it is in progress without any disruption to your relationship with the researchers. If you do so, there are **no** disadvantages, penalties or adverse consequences for you and your relationship with Aspect or any other organisation or service, and you do not need to give a reason. If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data

collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

If you decide to withdraw from the project, please notify a member of the research team. You have the right to have any questions answered by the research team at any time.

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 [#2019_403] and Autism Spectrum Australia [#1912A]. 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: ro.humanethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile)

You may also contact the Aspect Research Approvals Committee. Please quote the study title and protocol number.

The Manager, Aspect Research Approvals Committee, Autism Spectrum Australia

- Telephone: +61 2 8868 8508
- Email: research@autismspectrum.org.au

Participant Consent Statement

Researchers will confirm that you have read, understood and agree with the following at the start of the interview.

By taking part in an interview regarding the above research project, I declare that:

- I have read the above or someone has read it to me in a language that I understand
- I understand the purposes, procedures, benefits and risks of the taking part in the research
- I have had an opportunity to ask questions and I am satisfied with the answers I have received
- I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the interview without affecting my future relationship or care with Aspect or University of Sydney.
- I understand I can request feedback on the study results at any time in writing via email or verbally at the start of the interview