

Being on the Autism Spectrum – Understanding the Journey in Tasmania

Information sheet for focus group participants

I. Invitation

You are invited to participate in a study that will give you the opportunity to voice your experiences being on the autism spectrum, or being the parent/guardian of a child on the spectrum. The study will comprise a number of focus groups held around Tasmania, and you will be able to nominate the most appropriate session for you.

The study has been commissioned by the Tasmanian Autism Advisory Panel (AAP), who have been meeting since 2014 with the aim of developing a long term strategy for improved services for people on the spectrum. The AAP has broad representation, including from private practitioners, local advocacy organisations, government and community service providers, family and carers, and most importantly, people on the autism spectrum. You can read about the roles and responsibilities of the AAP, as well as communiques released after each of their meetings here:

http://www.dhhs.tas.gov.au/disability/autism_panel

The AAP has asked independent consultants Banks Spencer Consulting to undertake the study on their behalf. Banks Spencer Consulting has previously worked with the autism community on behalf of Autism Tasmania. The consultants you will be working with are:

- Adele Spencer, Project Lead
- Sarah Clark, Research Assistant

Banks Spencer Consulting have no links to either the Tasmanian Government or any service providers, and as such are entirely independent.

This work has been funded by the Tasmanian Government.

2. What is the purpose of this study?

The purpose of the study is to understand how people on the autism spectrum, their families and carers, access services in Tasmania, including:

- Understanding current diagnosis and referral processes
- Access to support services, including via the National Disability Insurance Scheme
- Access to community services, including transport, health services, emergency services and education

3. Why have I been invited to participate?

Organisations that have been identified as being involved in the autism community have been asked to share advertisements inviting individuals to participate in this study. Adults who identify being on the autism spectrum, or parents/guardians with children of any age on the autism spectrum are eligible to participate. It is hoped that by advertising widely that the study will attract participants with a broad range of experiences.

Should you decide to participate, your participation will be entirely voluntary and will not affect your relationship with the Tasmanian Government Department of Health and Human Services or any of the support services provided to you, or your child. There will be no consequences to you or your child should you decide not to participate. Further, if at any stage during the focus group you decide that you would like to withdraw, you will also be able to do so without any consequences to you or your child.

4. What will I be asked to do?

The first step will be to confirm with the consultants that you would like to participate in the study (details at end of this information sheet). Your preferred contact information will be confidentially stored by the consultants, so that they can keep you up to date with where the focus group will be held, what time and so forth. Once you have attended the focus group, all your contact information will be destroyed.

When you contact the consultants, you will be asked to nominate which focus group session you would like to attend from the following options:

- Burnie
 - Pre-school (0-5 years)
 - School aged (6-18 years)
 - Adult (over 18 years)
- Hobart
 - Pre-school (0-5 years)
 - School aged (6-18 years)
 - Adult (over 18 years)
- Launceston
 - Pre-school (0-5 years)
 - School aged (6-18 years)
 - Adult (over 18 years)

Each of the focus groups will comprise between three and twelve participants. If fewer or more participants register for a session, alternate arrangements will be made to either combine with another session, or hold an additional session. The consultants will advise you of the specific location and time once this has been arranged.

During the focus groups, participants will be asked a series of questions. The questions will be about your experiences and opinions. You may have a lot to say about something; please be sure to let

other participants speak. The consultant will moderate the session to ensure that all participants can be heard. The focus groups are anticipated to last between an hour and an hour and a half.

Questions will be simple and ask things like 'how were you / was your child diagnosed on the autism spectrum?' And, 'what services have you accessed?'

As you talk, notes will be taken about the content of the discussion. Notes will not be attributed to participants so that all data that is compiled will be anonymous.

5. Are there any possible benefits from participation in this study?

Data collected from the focus groups will inform a report written for the AAP and Tasmanian Government. Recommendations may be made about how services could be better provided for people on the spectrum.

No benefits are anticipated for individual participants.

6. Are there any possible risks from participation in this study?

There is a risk that during the focus group that you may become distressed by recounting your experiences, or listening to someone else's.

Should this happen, you may find it useful to talk with a counselor from one of the following organisations:

- beyondblue – 1300 22 4636 (24 hours, 7 days a week)
- Carers Tasmania – 1800 242 636 (9am – 5pm weekdays)
- Lifeline – 13 11 14 (24 hours, 7 days a week)
- SANE – 1800 18 7263 (9am – 5pm weekdays)

If during the focus group you become distressed and would like to leave, you may do so at any time. Raising your hand before leaving the room will alert the consultants that you would like someone to sit with you. In this instance, the Research Assistant will accompany you out of the room and sit with you.

7. What if I change my mind during or after the study?

Your participation in this study is entirely voluntary. Even after you consent to participate, you may withdraw at any time with absolutely no consequences. If during the focus group session you would like to leave, you may do so at any time. You do not have to provide an explanation as to why you would like to leave, and the consultants will not follow this up with you.

If during the course of the focus group session you say something that you would not like recorded, please let the consultants know and it will be removed. However, once the focus group has concluded, any comments that have been recorded will not be able to be removed. This is because comments will not be identified and it will not be possible to isolate and extract them from the notes taken during the session.

8. What will happen to the information when this study is over?

The notes that are taken during the focus group will be stored on the premises of the Tasmanian Government Department of Health and Human Services for a period of five years. After this time they will be destroyed. The notes will only be able to be accessed by the Tasmanian Government Department of Health and Human Services, Disability and Community Services Directorate.

The matters raised during the focus group will be kept confidential, and not identifiable in any of the notes. However, while all focus group participants will be asked to respect the confidentiality of other participants, this cannot be guaranteed.

9. How will the results of the study be published?

The findings from the focus groups will inform a short report from the AAP to the Tasmanian Government, which will be made public via the AAP website:

http://www.dhhs.tas.gov.au/disability/autism_panel

There will not be any identifying information contained within the report. It is anticipated that the report will be public within six months from the conclusion of the study.

10. What if I have questions about this study?

If you have any further queries or would like to agree to participate in the study, please contact Adele Spencer via bs@banksspencerconsulting.com or 0450 889 036.

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H16334.

This information sheet is for you to keep. You may wish to refer back to it before the focus group. To participate in the study, you will need to sign a consent form. Copies of this information sheet and the consent form will be available at the focus group sessions.