



PARTICIPATE IN RESEARCH

Information for Prospective Participants
– Parent/Caregiver – Cycle 1 –

Autism CRC Middle Years Behaviour Support Project

Research team contacts

Principal Researcher: Dr Beth Saggers Associate Professor

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What is the purpose of the research?

This project is being undertaken as part of the Autism Cooperative Research Centre (www.autismcrc.com.au) and is about middle years learners (aged 9-16 years) on the autism spectrum (ASD) and with complex needs who attend schools in rural, remote, Indigenous and alternative settings (including distance education and home education).

One aspect in Cycle 1 of the project is to capture data from parents, educators and students themselves in alternative settings to address the following:

- 1) Why parents whose children have a diagnosis of autism, or suspected diagnosis of autism, in the middle years of schooling decide to choose alternative education settings for their children?
- 2) What additional support and resources do educators, parents and students on the spectrum in alternative educational settings perceive is required for education success and how does this influence support in more mainstream inclusive settings?

The data collected in this cycle of the project will help inform more inclusive and supportive approaches to students with more challenging or complex needs on the autism spectrum. It will also inform professional support provided to educational settings, and possibly parents in home education, through a tele-classroom consultation (TCC) approach in Cycle 2 of the project.

Are you looking for people like me?

The research team is looking for:

- Caregivers of middle years' learners (9-16 years) who are exhibiting complex behaviours and/or high impact social, emotional and behavioural needs impacting on their schooling.
- Families of middle years' learners on the autism spectrum being educated in alternative settings (including distance education and home education).

What will you ask me to do?

Your participation will involve:

- Completing a questionnaire that will take approximately 20-30 minutes of your time.
- Depending on your willingness to be contacted, participating in a follow-up interview that will take approximately 45 minutes.
- Students will be recruited via their parent/caregiver. Therefore you will be required to assist your child in understanding the purpose of the study, and provide consent in the first instance for your child to be approached to participate. While a parent/caregiver may participate in Cycle 1 without the child's involvement, and a child may participate without

their parent or caregiver's involvement, parents/ caregivers will need to be aware of their child's participation and, depending on the age of the child and the child's capacity to consent, will either provide consent on behalf of their child with the team then seeking assent from the child, or if the child is deemed by the parent/caregiver as having the capacity to consent the team will seek consent from the child to participate.

Are there any risks for me in taking part?

There are minimal risks associated with your participation in this research project.

All data collected and analysed is considered low risk. However, there is some risk of discomfort or distress for students and their families in reflecting on their withdrawal from mainstream schooling or difficulties experienced in sourcing a suitable educational setting.

As such, a key foreseeable risk is one of possible discomfort and inconvenience. You may feel some discomfort:

- When being interviewed.
- In the time you have to take to participate in surveys and interviews.

It should be noted that if you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty.

Are there any benefits for me in taking part?

There are no immediate, specific benefits for participants in Cycle 1. This phase of the research may have benefits for participants as this information can be used to inform future support approaches that may be implemented. All participants from Cycle 1 will have the opportunity to download the report from the Autism CRC website.

Will I be compensated for my time?

No, but we would very much appreciate your participation in this research and although it is unlikely this project will benefit you directly, it may benefit educators and allied health professionals by developing resources and professional development modules to support the inclusion of students on the autism spectrum and complex needs.

Who is funding this research?

The project is funded by Autism CRC (www.autismcrc.com.au) however they will not have access to personally identifying information about you that may be obtained during the project.

I am interested – what should I do next?

If you would like to participate in this study, for details of the next step, please contact:

Beth Saggers b.saggers@qut.edu.au **07 3138 9615**

You will be provided with further information to ensure that your decision and consent to participate is fully informed.

Thank You!

QUT Ethics Approval Number: 1800000949