

Participant Information Sheet

Research title: Building Better Support Systems for Children with Disabilities Aged 0-8 Years

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Ethics approval number: 2026/HE011161

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Thank you for your interest in participating in this research project. Please read the following information about the project so that you can decide whether you would like to take part in this research. Please feel free to ask any questions you might have about your involvement in the project. You can also talk to someone you trust before deciding if you want to participate.

Participation in this research is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you would not need to give any explanation for your decision to stop participating.

Your decision whether you take part, or not to take part, or to take part and then withdraw, will not affect your relationship with The University of Queensland.

What is the purpose of this research?

The research project is about children’s access to disability support, including through the National Disability Insurance Scheme (NDIS), school-based supports, and other sources. The research also seeks to understand families’ experiences seeking support for children with disabilities, developmental delays, or who are neurodivergent.

The research is funded by the University of Queensland, and conducted in partnership with The University of Sydney and community organisations including the Australian Research Alliance for Children and Youth (ARACY), Children and Young People with Disabilities Australia (CYDA),

Queensland Advocacy for Inclusion, Cerebral Palsy Alliance, Down Syndrome Australia, Thriving Queensland Kids Partnership, and BUSHKids.

What does participation involve?

If you agree to participate, you will be asked to complete an online 'core' questionnaire which will take about 15 minutes. In the questionnaire, you will be asked to complete questions on your child's disability, your experiences seeking support for your child, and your family background. In addition to the 'core' questionnaire, you may elect to participate in additional optional sections dealing with related topics, including disability policy reform, financial issues, carer mental health and social support, access to sleep support, and your views about how disability support could be made better.

What are the possible benefits of taking part?

Your responses will help to better understand support needs for children with disabilities or who are neurodivergent. In appreciation of your participation, you may elect to participate in a prize draw after completing the questionnaire to win 1 of 10 \$100 gift cards. To participate in the draw, you will need to provide a valid email address. Terms and conditions for the prize draw [can be found here](#).

What are the possible risks and disadvantages of taking part?

You will be asked to respond to questions about your child's disability, disability support, and your family circumstances. It is possible that this may be distressing to some parents/carers. If you need support, you can contact Beyond Blue (1300 22 4636 – <https://www.beyondblue.org.au/>) or Lifeline (13 11 14 – <https://www.lifeline.org.au/>).

What will happen to the information about me?

By completing the survey, you consent to UQ collecting and using your information as set out in this Participant Information Statement. Information obtained in connection with this project will be retained and disposed of in accordance with relevant University of Queensland policies and State and National regulations. For further information regarding the management of research data and information, you may refer to UQ's [Research Data Management Policy](#).

Any information obtained in connection with this research project that can identify you will remain confidential. Confidentiality will be maintained by storing data stored securely on the University of Queensland Research Data Manager, a secure digital storage facility. If you elect to provide an email address it will be stored separately from anonymous survey data. Only the researchers listed in this information sheet will have access to data from the research project. Nobody will know that you participated in the research project. Anonymous survey data will be stored for 7 years and then deleted.

If you elect to provide an email address and do not consent to be contacted for future research, your email address will be securely stored until completion of the prize draw and dissemination of research findings, and then deleted.

If you elect to provide an email address and consent to be contacted for future research, your email address will be stored securely for 3 years and then deleted.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

The collected data may be used again for secondary/future research. Identifiable data will not be used in this way.

Any information obtained during the research project is subject to inspection (for the purpose of verifying the procedures and the data) by the relevant authorities and authorised representatives of The University of Queensland, or as required by law. Designated University individuals (data stewards or custodians) may also have access to the information for the purposes of ensuring long term retention and disposal. By completing the survey, you authorise release of, or access to, this confidential information to the relevant research personnel and authorities as noted above.

Personal Information

The personal information collected for this research project includes: email address and demographic information.

Collection – Your personal information is collected for the following purposes. **Email address:** administering the prize draw, sharing findings with participants, and re-contacting participants who elect to be contacted for future research. **Demographic information:** understanding how experiences of disability support differ across diverse families.

Use – Your personal information will be used for the purpose of the research project and any other purpose described in this Participant Information Sheet.

Storage and security – Your personal information will be maintained confidentially by ensuring appropriate access and security is applied to the research project data. Your personal information will be accessed by authorised research staff, authorised staff of UQ (for the purposes of managing data holdings) and third parties as described in this Participant Information Sheet and the Consent Form.

Disclosure – Your personal information will only be disclosed in a manner consistent with this Participant Information Sheet and the Consent Form. Your personal information will remain confidential and will not be disclosed to a third party without your agreement, or as required by law.

You have the right to request access to the personal information about you that is collected and stored by the research team. If you are seeking to update or correct any information, it is recommended that you liaise with the research team in the first instance (see contact details at the top of this information sheet).

You are also able to request amendment via a University of Queensland Right to Information and Privacy officer (rti@uq.edu.au). For further information regarding the management of your personal information, please refer to UQ's [Research Data Management Policy](#), [Privacy Management Policy](#) and [Privacy Management Procedure](#).

What will happen if I decide to withdraw?

Your participation in this research is voluntary, and you are free to stop participating at any time without needing to provide an explanation. Because the survey is completed anonymously, if you stop participating prior to completing the survey, or elect not to provide an email address, the researchers will be unable to identify your data and it cannot be removed. If you have provided an email address and wish to withdraw from the study, you may do so by emailing the lead researcher (m.oflaherty@uq.edu.au), in which case your data will be deleted and not used in any further

research. If you stop participating or withdraw from this study, you will you would not receive any penalty or bias as a result, however you will be ineligible to participate in the prize draw.

If you decide to stop participating or withdraw, we will not collect additional data or information from you. Any data, samples and information already collected may be retained as described in this Participant Information Sheet to ensure that the results of the research project can be measured properly and to comply with relevant regulations. If you decide to stop participating or withdraw, the data already collected may be used in analysis unless you have provided an email address and request that we delete your data as described above.

Can I hear about the results of this research?

If you elect to provide an email address, you may choose to receive a summary of the results from the research project. Findings from the research project will be communicated in articles and policy briefs.

Who can I contact if I have any concerns about the project?

Questions about the nature of this project and participation in it should be directed to the research team (see top of information sheet for details).

This study adheres to the principles of the National Statement on Ethical Conduct in Human Research. The study has received ethics approval in accordance with the review processes of The University of Queensland. You are free to discuss concerns regarding this study or your participation in it with the research team, but if you would like to speak to an officer of the University not involved in the study, you may contact the Human Research Ethics Team via email humanethics@research.uq.edu.au or phone (see contact details at: <https://research-support.uq.edu.au/research-support/ethics-integrity-compliance/contacts>).