

Parent/Guardian Information Statement

Family Survey



THE UNIVERSITY OF
SYDNEY

Research Study: Community participation for children with a disability (0-14 years) and their families in Australia

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1. What is this study about?

We are conducting a study on how children with a disability and their families participate in activities in the community in Australia. Activities might include going to a museum, playing a sport, going for a walk or to the beach, going to an event or a place of worship, going shopping or going out to a restaurant.

Taking part in this study is voluntary. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by Dr Genevieve Johnsson (University of Sydney, Plumtree) and Sylvana Mahmic (Plumtree).

The Commonwealth Government of Australia, Department of Social Services is funding this project associated with this research. There are no financial benefits for researchers.

3. Who can take part in the study?

Participation in the family survey will be open to caregivers who:

- currently live in Australia
- have a child with developmental delay or disability aged 0-14 years in their care
- currently or would like to participate in activities in the community
- are able to read and write sufficiently in English, or have the support of a translator

4. What will the study involve?

If you decide to take part in this study, you will be asked to complete an online survey. There are some questions you may be able to ask your child. The survey will take about 15-20 minutes.

5. Can we withdraw once started?

Being in this study is completely voluntary and your family does not have to take part. Any decision will not affect current or future relationships with the University of Sydney, the researchers, or anyone else at Plumtree. Any information that you have we have already collected will be kept in our study records and may be included in the study results if you decide to withdraw mid-survey.

6. Are there any risks or costs?

It will not cost you anything apart from your time to complete the survey. We do not see that there will be any personal risk in completing the survey. The only risk is if you become upset telling us about your experiences. If you or your child become upset during or after doing the survey, you can contact Lifeline on 13 11 14 or Kids helpline 1800 55 1800. These organisations have trained people who can listen and give you support.

7. Are there any benefits?

Your information will help us understand how children with a disability and their families participate and feel included in the community, and the things that make it hard to feel included. You can also choose to go into the draw to win a \$50 Booktopia voucher for your family. Your entry information will be kept separate from your survey response.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you and your family for the purposes of this study. Any information provided to us will be stored securely and we will only disclose it with your permission, unless we are required by law to release information.

We are planning for the study findings to be published. This may include in journals, conference presentations, policy briefs and factsheets. Every effort will be made to protect individual identity by using different names. We may also use the information from this survey for other research projects. You will be asked permission in the survey for us to do this. You can say no and still participate in the research.

9. Will I be told the results of the study?

You and your family have a right to receive feedback about the overall results of this study. A summary of the survey results will be on the Plumtree website in December 2022. We are unable to provide individual feedback to families due to the anonymity of the survey.

10. What if I would like further information?

You can contact Dr Genevieve Johnsson to talk about the research and to ask questions genevieve.johnsson@sydney.edu.au

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2022/127] according to the *National Statement on Ethical Conduct in Human Research (2007)*.

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:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep