

Invitation to Participate in Research

The value in the network: How parents/ caregivers of primary school-aged children with disability use services and supports

We are seeking volunteer research participants to learn about how parents/caregivers of primary school-aged children with disability use services and supports; how this fits in with their family life; and what makes it easier or harder for them to make use of the resources they have available. This research is part of a PhD study being carried out by Jane Adams, supervised by Dr Angela Dew and Professor Leanne Dowse from the School of Social Sciences at UNSW Sydney.

Would the research study be a good fit for me?

The study might be a good fit for you if:

- You live in one of the following areas of NSW:
 - * Nepean and Blue Mountains
 - * Western Sydney
 - * Central Coast
 - * Northern Sydney
 - * South Western Sydney
 - * Southern NSW
- You are a parent/ primary caregiver for a child with disability, aged 6 to 12 years and at primary school.
- It has been at least three years since your child was diagnosed with a disability.
- Your child has had an individual NDIS package for at least 12 months.
- You are in touch with services from at least two different service providers, not including your child's school.
- You are willing to be interviewed. (Note: Each parent/primary caregiver in your family will be invited to be interviewed individually. However, some or all of the interviews can be conducted with both parents together if that is your preference).

What would happen if I took part in the research study?

If you decide to take part you would participate in 3 interviews with the researcher, over 6 months. There is also an optional fourth interview, which you may choose to participate in.

The overall structure of the interviews is provided below:

	Time	What will happen in the interview
Core components of the research: If you participate, you will be asked to participate in each of these		
Interview 1	2 hours	The researcher will ask you about your family life, the activities you and your family are involved in, and how you manage your family life.
Interview 2 (2-3 weeks later)	2 hours	The researcher will ask you about the services and supports in your life, and the relationships you have with services and supports related to your child with disability. The researcher will work with you to develop a diagram of your service and support network (sociogram).
Interview 3 (6 months later)	1 hour	The researcher will interview you about any changes in your family life and service and support network since the first interview, how you have managed those changes, and what made it easier or more difficult.

Optional part of the research: After the three core interviews are completed, the researcher will discuss whether you would like to participate in a fourth interview to explore a particular feature of your network in greater detail. This interview would take approximately 1 hour. **A separate consent form will be provided for the optional interview if you choose to participate.**



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If you feel that other items, such as documents or objects, would help the researcher to understand how you use services and supports, they could also form part of the study. You do not have to do this.

If you require an interpreter, the research team will arrange one for the interviews and phone conversations and will pay the costs associated with this.

Will I be paid to take part in the research study?

There are no additional costs associated with participation in this research study, nor will you be paid.

If you would like more information or are interested in being part of the study please contact:

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This research has been reviewed and approved by The University of New South Wales Human Research Ethics Committee. If you have any complaints or concerns about the research study please email humanethics@unsw.edu.au or phone +61 2 9385 6222 quoting the following number HC180454.