

How parents were experts on the project

What we wanted to know

We wanted to know how the NDIS **and** family support services work together to help parents with intellectual disability and their children

What we did to find out

We asked parents with intellectual disability to be **co-researchers**.

These mothers with intellectual disability had:

- Had 'lived' experience with the NDIS and family support services
- Had been part of the Bumpy Road study
- Joined an Expert Advisory Group

The **Expert Advisory Group** was:

- Four researchers at the University of Sydney
- Six co-researchers with lived experience
- Two people from family support services
- Two disability advocates
- A parent facilitator

How we worked together

The Expert Advisory Group met six times on Zoom to talk about the project.

The co-researchers also met together to practice speaking up in a group

The University of Sydney researchers told the Expert Advisory Group what it found.

The co-researchers told the Expert Advisory Group what they thought about:

- What the NDIS and family support services did that **was** good
- What NDIS and family support services did that was **not** good
- How services could work together to give parents better support

What we did to tell other people what we found

The Expert Advisory Group talked about how to share the information we found.

We decided to:

- Record a **webinar** – to tell people about what we had done
- Make a **website** – to share information with parents and families, NDIS and family support workers, governments, researchers, and others.
- Create two **tip sheets** – one for parents and one for workers
- Filmed four **videos** – where the co-researchers did interviews about:
 - What it is like to be parent
 - Who kinds of support they got
 - What happens if they did not get the right support
 - What workers need to know about the right support