



# **Supporting the Woman Supporting the Mother Study**

**Wednesday 29th June 2022**

**Webinar and Website Launch**

**Research Centre for Children & Families**

Funding provided by the National  
Disability Research Partnership,  
hosted by the University of  
Melbourne and funded by the  
Department of Social Services



THE UNIVERSITY OF  
**SYDNEY**



# Acknowledgment of Country

- Ami Newland is a Dharug woman from New South Wales
- She is now living with her family on the land of the Nukunu people in South Australia
- She was supported to keep her youngest child with her by Intellectual Disability Rights Service (IDRS)
- Ami is a co-researcher on the project. She has been part of other research with the University of Sydney team.

# Welcome and overview

- Hear about the study
- Hear from co-researchers with lived experience
- Hear from an Expert Advisory Group member
- Launch of website and resources
- Q & A

## **About the partners**

# University Research Team

- ❖ We are **disability researchers**.
- ❖ We worked on **Healthy Start**. It was an Australian first (2005-2012)
- ❖ It helped workers learn how to support parents with intellectual disability.
- ❖ Susan and Margaret worked on the **Bumpy Road** project with WASH House, Rachel, and some co-researchers (<https://www.bumpyroad.org.au/>)



Susan Collings



Margaret Spencer



Gabrielle Hindmarsh



Hannah Wilkinson



Nikki Wedgwood

# The partners



Women  
With  
Disabilities  
Australia  
(WWDA)



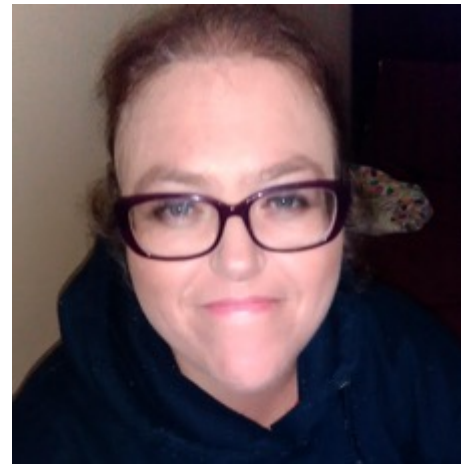
## Parents as research experts



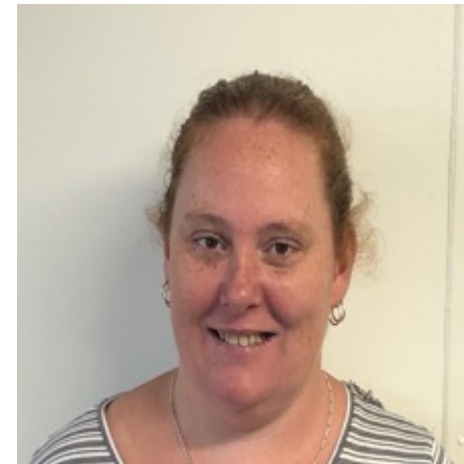
Rachel Tozer - parent facilitator.  
She has a lot of experience  
working with parents with  
intellectual disability



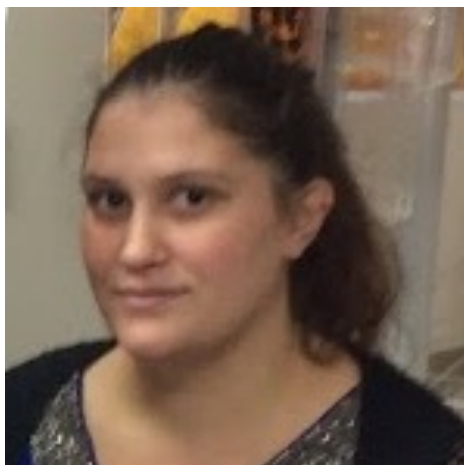
Margaret Roberts



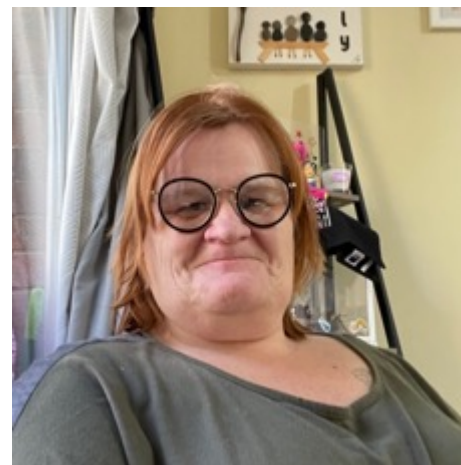
Chaya Hutchens



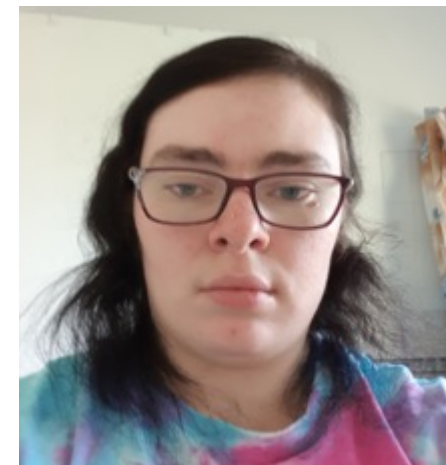
Lisa Bartulis



Ami Newland



Rachael Bartley



Renee Cross

About the co-design



# What we wanted to know

- How well does the NDIS **and** mainstream family support services work together to help parents with intellectual disability and their children?



# Why it matters

## Rights of parents with intellectual disability

- ❖ Rights to support with parenting skills

CRPD, National Disability Strategy

- ❖ May not get the right support –access issues, judgmental workers; disconnected services

- ❖ System failures  child protection  legal case  children in care

- ❖ Families living with disability a national priority

**National Framework for Protecting Australia's Children (2021-2031)**

# Expert Advisory Group

- ❖ University research team
- ❖ Co-researchers with lived experience
- ❖ Partner representatives
- ❖ Six meetings Sept 2021 – May 2022
- ❖ Meetings held on Zoom
- ❖ Researchers shared what they learnt
- ❖ Group reflections and break-out discussions

## Co-researcher support




- ❖ Extra time
- ❖ Practice speaking to the group
- ❖ Build confidence, group identity



# What information we looked at

## 1. Rapid evidence review

Evidence-based models of service integration (2006-2020)

Search = 4,639 articles  Titles/abstract screen = 27  Full text review = 16  Included studies = 6

## 2. Desk-based document review

- ❖ Websites of NDIS and NSW Department of Communities and Justice
- ❖ Google search for information about services for parents with intellectual disability

## 3. Bumpy Road interviews

- ❖ Re-read 8 written transcripts to search for references to services and other supports

# What we found out

## **Evidence for what works**

- ❖ Family-focused practice
- ❖ Practical skills and long-term support
- ❖ Key worker as go-between

## **Evidence about NDIS and mainstream family support**

- ❖ NDIS –disability type but not parent or caregiver status
- ❖ TEI - disability type but not caregiver status
- ❖ ‘Low satisfaction’ for NDIS participants with intellectual disability who are caregivers
- ❖ NDIS needs to train and offer specialised child protection workers
- ❖ Formalise an inter-agency collaboration between NDIS and mainstream family support services

(IAC report, 2019; Tarleton & Porter, 2012, Tarleton & Turney 2020; Young & Hawkins, 2006)

# What Bumpy Road participants said

- ❖ Unclear how to use NDIS plan for support with parenting responsibilities

*“No-one explained to me, ‘Oh, the NDIS package can help you”*

- ❖ Hard to join parents’ groups or parenting programs

*“I’ve learnt a lot of things over the years, but it’s hard to put them in place”*

- ❖ Need a disability advocate especially with child protection, reading documents

*“You’re in the dark and an advocate would have been very helpful”*

# **Reflections from the experts**

# Reflections from co-researchers





# Reflections from an advocacy expert

Leonie Hazelton  
Project Manager  
People with Disability Australia



**Launch of website and resources**

# Website and resources for parents



# What makes it hard to get help?

## Service problems for parents with intellectual disability



### Services do not work together

- you get NDIS. You do not get help to create a plan
- your family support worker does not understand your disability
- your family support and NDIS services do not talk to each other.

### Services do not work for you

- your main NDIS goal is to be a good parent
- your NDIS workers say they only help you. They cannot help you with your child
- your worker is rude and says your child is not safe
- you go to a parenting class. You do not feel welcome.

### Services do not stick with you

- you get short-term services only
- you get help to learn how to care for your baby. It stops before you are ready
- services are not around when your child gets older. You need help parenting your child at all ages and stages
- you get a good worker by chance not by choice. Good workers always move on.



THE UNIVERSITY OF  
**SYDNEY**

#### For more information contact:

The Research Centre for Children and Families,  
Sydney School of Education and Social Work  
e [rccf.research@sydney.edu.au](mailto:rccf.research@sydney.edu.au) w [sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html](http://sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html)

#### For more about the project: [rccf-parenting-disability.sydney.edu.au/](http://rccf-parenting-disability.sydney.edu.au/)

The *Supporting the Woman, Supporting the Mother* project was funded by the National Disability Research Partnership hosted by the University of Melbourne and funded by the Department of Social Services.

This resource was co-designed with six co-researchers who are mothers with intellectual disability.

# What makes it easier to get help?

## Tips for parents with intellectual disability



### You get the NDIS

Your NDIS **planner** is there to help you. You can ask a **friend or family member** to your plan meeting. They can help you to:

- get ideas for making goals
- decide what goes into your plan
- use your plan to be a good parent.

For NDIS information:  
<https://www.ndis.gov.au/understanding/what-ndis>

### You have an advocate

An advocate is not from the NDIS. You can ask for **an advocate** to:

- help you know about your rights
- come to meetings with you
- help you understand what things mean
- help you get information that you can read
- help you ask for things to be explained.

For an advocate:  
<https://pwd.org.au/>

### You get the right help

You can ask for help from your **Local Area Coordinator (LAC)** or you may get a **support coordinator** as part of your NDIS plan. They can:

- talk to you about different services
- show you how to use the NDIS portal
- help you match services to your goals
- explain the money in your plan
- link you into parenting groups or playgroups.

For parenting help:  
<https://raisingchildren.net.au/>



# What prevents service integration?

## Barriers to supporting parents with intellectual disability



### Mainstream services are not accessible

- parenting classes do not explain complex ideas in simple words
- lawyers and other professionals use technical jargon
- services expect all parents to have good literacy and communication skills
- feeling confused or judged can make parents disengage.

### Mainstream services do not understand disability

- intellectual disability is misunderstood and invisible
- disability training is not consistently offered to workers
- workers can see parents as resistant to help
- workers can blame parents for things beyond their control.

### Mainstream services do not help parents with disability support

- the NDIS portal is confusing to navigate
- finding the right services is a complex task
- understanding budgets takes good financial skills
- coordinating services takes good organisational skills.

#### For more information contact:

The Research Centre for Children and Families,  
Sydney School of Education and Social Work  
e [rccf.research@sydney.edu.au](mailto:rccf.research@sydney.edu.au) w [sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html](http://sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html)

#### For more about the project: [rccf-parenting-disability.sydney.edu.au/](http://rccf-parenting-disability.sydney.edu.au/)

The *Supporting the Woman, Supporting the Mother* project was funded by the National Disability Research Partnership hosted by the University of Melbourne and funded by the Department of Social Services.

This resource was co-designed with six co-researchers who are mothers with intellectual disability.

# What enhances service integration?

## Tips for supporting parents with intellectual disability



### Integrated services

- coordinate support to avoid gaps and overlaps
- communicate with parents about what they can and cannot offer
- involve NDIS support coordinators to ensure holistic support
- help parents get the most from their NDIS plan
- help parents find the best parenting and peer support groups for them.

For information about parents and parenting with intellectual disability:  
<https://www.parentingrc.org.au/programs/healthy-start/>

### Inclusive support workers

- listen to parents and respect their boundaries
- slow down, explain things clearly and check parents understand
- encourage parents to make good decisions
- celebrate with parents when they reach a goal
- communicate honestly and sensitively about their concerns.

For tips on how to work with parents with intellectual disability:  
<https://aifs.gov.au/cfca/2020/09/30/practices-support-parenting-parents-intellectual-disability>

# What are the next steps?

Dealing with gaps in reliable information about parents with intellectual disability

Prevents coordinated support

Prevents different government departments and programs from working together

Parents need access to advocacy as a right

This is essential when their parenting is being judged





# Questions ?



**Research Centre for Children and Families**  
Sydney School of Education and Social Work  
Faculty of Arts and Social Sciences

Website:

<https://www.sydney.edu.au/arts/our-research/centres-institutes-and-groups/research-centre-for-children-and-families.html>

Email: [rccf.research@sydney.edu.au](mailto:rccf.research@sydney.edu.au)

Email to register for our mailing list.

