



studio **A** Artwork by Meagan Pelham

National Centre of Excellence in  
Intellectual Disability Health (the Centre)

# Annual Report

2024 -2025

 National Centre  
of Excellence in  
Intellectual  
Disability Health

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# Introduction

## Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to Elders both past and present. We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

## Acknowledgements

The Centre acknowledges the rich and diverse lived experiences of people with intellectual disability. We acknowledge with appreciation all the people and families who have shared their stories which have informed the **National Roadmap for Improving the Health of People with Intellectual Disability** and the work of the Centre.

We extend our thanks to everyone who contributed to making this report, including the leadership teams from across the consortium, our partner and collaborator organisations, the Learn and Lead Group, the First Nations, National and International Advisory Committees, and our Council.

The National Centre of Excellence in Intellectual Disability Health receives core funding from the Australian Government Department of Health, Disability and Ageing to support the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

## Cover image

Artwork by Meagan Pelham



**studio A**

# About the Centre



National Centre  
of Excellence in  
**Intellectual  
Disability Health**

# Vision and values

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our work is guided by our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

# Who we are

The Centre builds on the work of 9 consortium organisations.

We are co-led by people with intellectual disability, consortium leads and an independent council.

Our work is informed by national and international advisory committees that include:

- people with intellectual disability, supporters and families
- health and disability professionals
- researchers and educators
- advocates
- government, policy and decision makers
- First Nations people and organisations.

We work in partnership with people and organisations around Australia through our Partner and Collaborator Networks, National Clinicians Network and national network of people and families.

Our work is delivered by organisations across Australia.

## Many Organisations, One Vision

This shared approach to governance and delivery supports knowledge exchange, fosters cross-sector collaboration and drives change.

# What we do

The Centre works to improve health care for people with intellectual disability and plays an important role in delivering the National Roadmap for Improving the Health of People with Intellectual Disability.

This includes:

## 1. National Leadership and Advocacy

We bring together people and organisations who want better health care for people with intellectual disability.

Together we:

- Share ideas and experiences
- Identify national priority issues
- Raise awareness of the health needs of people with intellectual disability
- Drive advocacy and change at a national level.

## 2. Research Translation and Capacity Building

We build skills and knowledge in research.

We do this by:

- Identifying the most important research and data needs
- Analysing health data
- Providing advice to research bodies
- Turning research findings into practice to improve health care for people with intellectual disability.

## 3. Health Service Improvement

We work to help make services better.

We do this by:

- Promoting ways of working that are based on evidence
- Supporting the health workforce to learn about intellectual disability through training and information.

## 4. Knowledge Hub

The Centre is also a national source for knowledge, information and advice.

We are co-designing an interactive online platform to share evidence-based health resources, and tailored information.

# How we work

## Connect and collaborate

We bring together people with intellectual disability, families and supporters, health and disability workers, researchers, advocates, policy and decision makers for ideas exchange and collaboration.

### *Together we*

## Build evidence

Build evidence about the issues and what makes a difference, drawing on data, research and the voices people with intellectual disability.

## Create real-world solutions

Use evidence to create real-world solutions including policy, clinical models, frameworks, training and resources.

## Promote and advocate

Promote and share these solutions and advocate for their adoption across the healthcare system to create lasting change.

# Year at a Glance

## Engagement and Advocacy

### 327 Activities

245 stakeholder meetings

55 presentations delivered

18 submissions

9 letters of correspondence with key decision makers



**6 online events**  
- **1,504** attendees

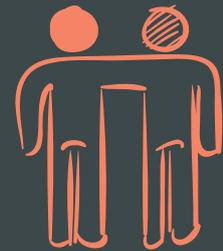


**18 submissions**  
and consultations



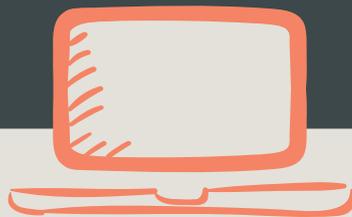
**65 seed funding**  
applications

**50+**  
**people**



with intellectual disability actively contributing to the work of the Centre

Website



**81% increase**  
in website page views

**119% increase**  
in unique visitors

LinkedIn



**Over 1.4 million**  
impressions on LinkedIn

# Letter from the Director

It is my great pleasure to present the Centre's first Annual Report.

Since October 2023, the Centre's nine consortium organisations have worked hard to quickly establish a new national organisation. A major early achievement has been creating an inclusive governance structure and way of working that places people with intellectual disability at the heart of everything we do.

Our governance now includes an independent Council, First Nations Advisory Committee, the Learn and Lead Group (representing lived experience), International Committee, National Advisory Committee, and a Management Committee comprising representatives from the nine consortium organisations and members of the Centre's leadership team. Bringing together so many people and perspectives is no small task, but the collective expertise is invaluable and underpins our commitment to collaboration.

We have built a strong multidisciplinary team and launched our new brand and website, bringing our vision to life.

Cross sector-collaboration and systemic change is critical to achieving our vision. To progress collaboration and systemic change, we convened a network of 56 partner and collaborator organisations, held our inaugural online conference and have been working closely with decision-makers across government, health services, and regulatory bodies to implement our Driving Change Strategy.

We commenced three foundational pieces of work in health service capability: a model of care scoping review, an analysis of best practice in leading development of health system capacity and an audit of resources focused on improving health services for people with intellectual disability. These pieces will provide a solid platform for future work.

Our highly specialised data work was undertaken by researchers across the consortium. This work develops our ability to understand, using large datasets, how to know who has an intellectual disability, how people use services, what the health outcomes are, and what health gaps need to be addressed for people with intellectual disability. This work will continue through FY26 bringing us closer to filling critical gaps in the evidence base to better track, understand and respond to health needs and outcomes for people with intellectual disability.

As a key action under the Roadmap, we are creating an interactive online space, The Knowledge Exchange Hub (KEH), through a collaborative design process featured in this report.

In June we launched our flagship podcast for health professionals, Excellence in Practice: Voices for Better Care, which continues to receive excellent feedback.

Our work to build research capacity has included the production of webinars, the development of a culturally safe and inclusive research strategy, working on a research translation strategy and national co-designed research priorities, and inclusive research training. This training has already been piloted for research staff across the Centre and will be rolled out to the sector in the coming year.

We also began developing a new strategy for the Centre. This strategy will guide our work from 2025 to 2028 and will set the course for the next stage of our journey.

I hope you enjoy reading more about the work of the National Centre of Excellence in Intellectual Disability Health. As a Centre, we are excited to share this work with you and hope you are inspired and greatly encouraged.

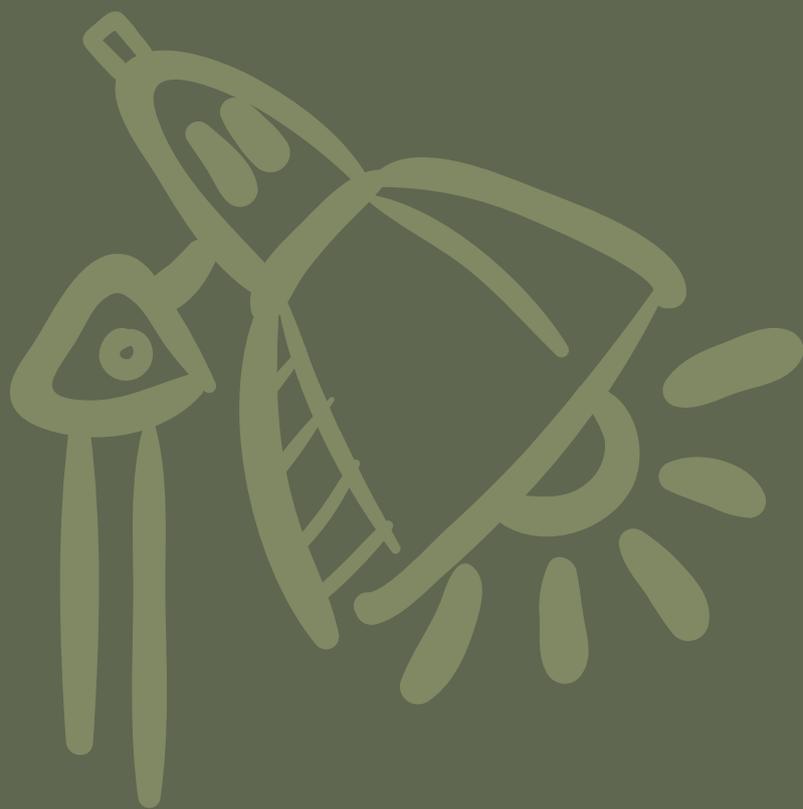
Your engagement with our work is invaluable as we continue our collective journey towards more inclusive and impactful health services and outcomes for people with intellectual disability.

Warm Regards,

**Julian**  
Director  
National Centre of Excellence  
in Intellectual Disability Health



# Highlights



# Innovation Seed Funding Grants 2025

## Nurturing inclusive innovation in intellectual disability health

In early 2025, the Centre launched its inaugural Innovation Seed Funding Grant round to support inclusive, co-designed initiatives in intellectual disability health. Focus areas included mental health, primary and preventative health, models of care, and care pathways.

The response was outstanding, with applications showcasing innovation, a strong commitment to collaboration and co-design. The round highlighted the work happening in this space, across sectors.



## Congratulations to the five successful grant recipients, whose projects are now underway:

- Aruma is developing animated micro-learning videos to boost health literacy and encourage preventive care.



- Murdoch Children's Research Institute is co-designing a health checklist for people with cerebral palsy and intellectual disability to support better care coordination.



- Pharmaceutical Society of Australia is creating workshops and Easy Read resources to help people understand and manage their medications.



- Western New South Wales Local Health District is working with Aboriginal communities to build culturally respectful models of care.



- Women's and Children's Health Network is evaluating dental transition pathways from paediatric to adult disability services in South Australia.



# Driving Change

## National leadership and advocacy for better health care

The Centre's Driving Change team rapidly progressed from establishment to action, embedding advocacy as a core function of the Centre and fostering collaboration across sectors.

The Driving Change strategy and engagement plan were developed and endorsed. The strategy provides a clear framework for the Centre and partners and ensures alignment with the National Roadmap. It also stipulates that people with intellectual disability are included in advocacy and their voices heard in conversations and decision making about health care.

As part of the Driving Change strategy, the Centre is supporting people with intellectual disability, their families and peak representative organisations to advocate for better health care.

Advocacy training has been developed and held for all Centre staff. The team are also working closely with the Learn and Lead Group to drive their work and uplift their advocacy skills.

The team also launched support for peak bodies in other states and territories to implement the Driving Change strategy. Partnerships were formed this year with Developmental Disability WA (DDWA) and the South Australian Council for Intellectual Disability (SACID). These organisations were provided with funding and support to develop capacity in health advocacy. This ensured deliverables were met and local voices amplified in the lead up to state elections. This support will continue in the coming years to other states/territories as part of the Driving Change strategy. This is to ensure we are building a nuanced understanding of local health issues around the country and helping to build our collective voice.

The team sought to influence policy by making 10 submissions, written correspondence, and were successful in holding 54 meetings with key stakeholders, addressing key priorities such as the National Oral Health Plan and the National Health Reform Agreement.

From inception to implementation, the Centre has established itself as a catalyst for collaborative systemic advocacy, building momentum for long-term improvements in health care for people with intellectual disability.

# Learn and Lead Group

## Shaping the Centre through lived experience

The Learn and Lead Group is made up of people with intellectual disability from around Australia. The group provides a strong voice in shaping the Centre's work.

A nationwide recruitment campaign that attracted over 50 applicants resulted in the recruitment of passionate individuals, selected through a rigorous process.

Fortnightly meetings in early months were focused on building trust, exploring advocacy, and setting shared values. The group wrote their own Acknowledgement of Country, now proudly spoken at every meeting.

“I have a voice in leadership, in operations, in management, and it's actually listened to and accounted for. As well as being someone that people go to for advice because of my experience.”

- Learn and Lead Group Member

In March 2025, members came together in Sydney for a powerful in-person gathering, where they contributed to the Centre's three-year strategy, took part in advocacy training, and developed their public speaking skills.

From April 2025, Learn and Lead members moved from planning to action, shaping health resources, providing input on advocacy priorities, advising on the Knowledge Exchange Hub, and ensuring accessibility at Centre events.

Their influence extends beyond the group; members have chaired webinars, featured in podcasts, reviewed grant applications, joined national committees, and co-presented at major conferences. Some have taken on paid roles within the Centre, Consortium member organisations and beyond.

The members of the Learn and Lead Group have made a big contribution to the Centre. We are grateful for their time and expert advice and look forward to continuing to work together.



# Excellence in Practice: Voices for Better Care

Championing inclusive health care,  
one conversation at a time

In June 2025 the Centre proudly launched its flagship podcast Excellence in Practice: Voices for Better Care.

Designed as a practical resource for healthcare workers, the series has quickly attracted a broad audience across major podcast platforms.

Hosted by Ricky Kremer and Raylene Griffiths, and featuring guest experts, the podcast shines a spotlight on the health inequities experienced by people with intellectual disability, why these inequities must change, and what better care looks like in practice.

Each episode blends professional and lived experience expertise. By amplifying diverse voices and sharing evidence-based strategies, the podcast is helping to build awareness, shift attitudes, and inspire action across the health and allied health sectors. We will continue to expand the series, strengthen partnerships, and grow our national audience committed to delivering equitable, person-centred care.





**Fresh and in...** 9 Jul 2025

★★★★★

showl\_

So great to hear voices of people with lived experience of intellectual disability interviewing health care workers and diving deep into issues that affect them personally. Highly recommend for health care professionals!

**Love this p...** 25 Aug 2025

★★★★★

Podcast fan 17

What an incredible listen. Beautifully hosted and really interesting and informative. Brilliant.

# Inaugural Centre Conference

Bringing sectors together to build  
momentum for change

In August 2024, the Centre hosted its first national conference, an online event that brought together voices from across Australia to tackle the big issues in intellectual disability health.

Over two days, 980 attendees explored key themes including challenges to health equity, cultural safety and inclusion, and innovation in healthcare.

National Centre of Excellence in

**Intellectual Disability Health**

National

**Conference**

21-22 August 2024



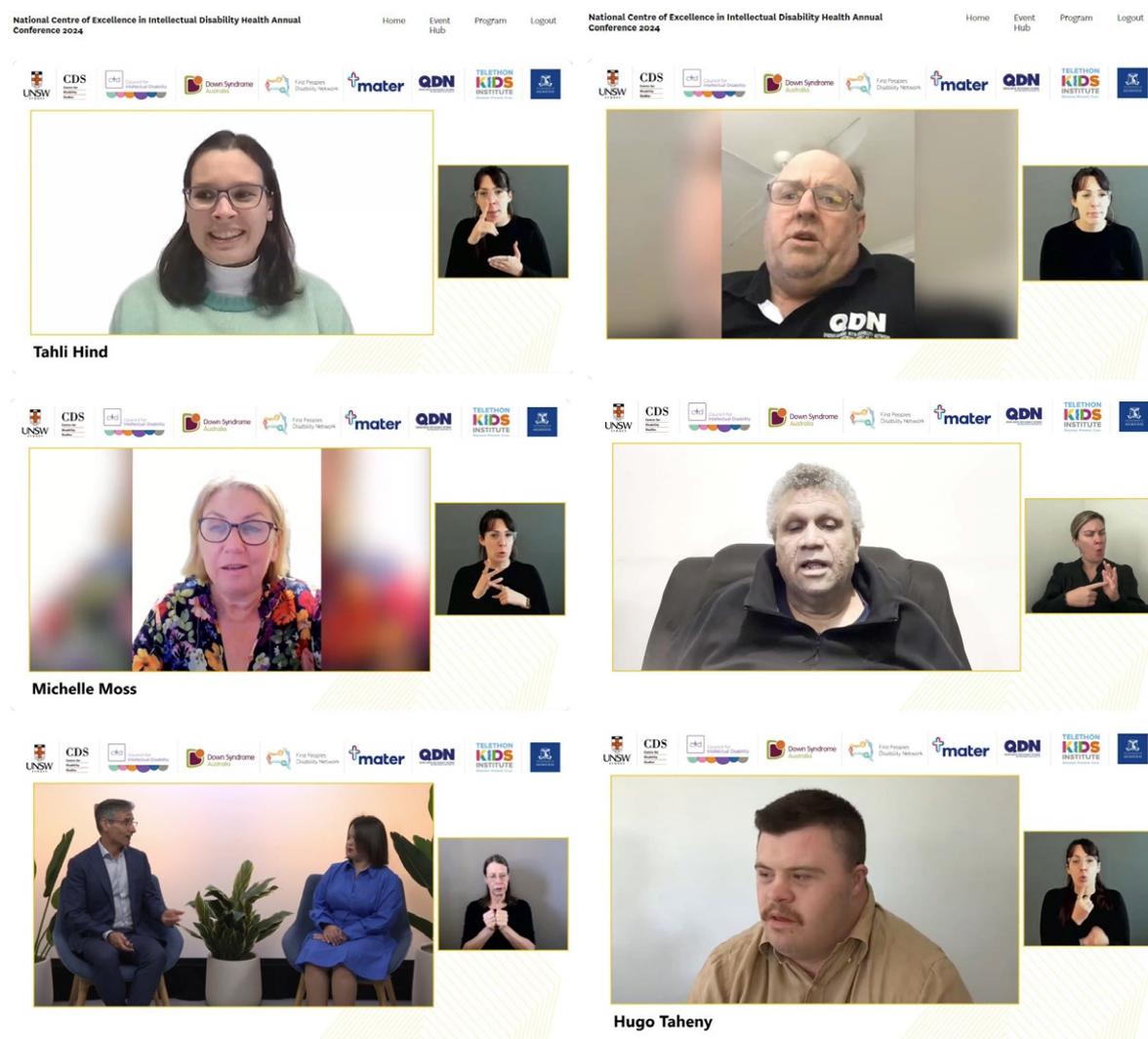
“I really liked the mix of presenters, the genuine involvement and leadership of people with disability and the championing of lived experience. I liked the strong messages that came through about what is needed in the health system and acknowledgement of the gaps.”

- Conference Attendee

The conference attracted a diverse audience: including 325 participants from the health sector, 241 from the disability sector, 238 people with lived experience, families and carers, 91 representatives from government agencies 85 researchers and academics

Feedback was overwhelmingly positive, with attendees highlighting the number of expert speakers with intellectual disability and the breadth of topics as standout features.

This free event marked an important milestone for the Centre, creating a national platform for collaboration, learning, and action. By amplifying lived experience voices, the conference set the tone for the Centre's commitment to inclusive, evidence-based change.



# Co-Designing a Knowledge Exchange Hub

Putting people and communities at the heart of health information

The co-design of the Knowledge Exchange Hub (KEH) brought together people and communities from across Australia to shape a new digital platform for sharing, contributing to and connecting with health information.

At the heart of the project was a commitment to placing lived experience at the centre of design, delivery, and decision-making. The KEH Advisory Group, formed in August 2024 to co-design the

“At its core, the KEH responds to urgent and long-standing challenges: fragmented health information, systemic exclusion, and inaccessible services. It seeks to build a trusted, inclusive space where people with intellectual disability can find, understand, and contribute to health knowledge that directly affects their lives.”

- Patsie Frawley, Lead

platform, has over 50 members including people with intellectual disability, families, supporters, professionals, researchers, and advocates.

Through drop-in sessions and workshops both in person and online, the group worked to co-create a platform that is accessible, inclusive, and has the potential to transform how health knowledge is created, shared, and accessed.

Embedded in the project was First Nations consultation and co-design. The Centre's First Nations Team worked in partnership with community consultants and communities to ensure cultural safety is central to the Hub's design and future use.

The Knowledge Exchange Hub will be more than a website, it will be a trusted space for learning, sharing, and connecting. We look forward to launching the Hub and continuing to work alongside people and communities to shape its future.



Living Well artwork created by participants at a Knowledge Exchange Hub consultation in Alice Springs, with support from Disability Advocacy Service and NPY Women's Council.

# Consortium, Council and Advisory Committees



## Consortium Organisations

Centre for Disability Studies

Council for Intellectual Disability

Down Syndrome Australia

First Peoples Disability Network Australia

Queensland Centre of Excellence in Autism and Intellectual Disability Health

Queenslanders with Disability Network

The Kids Research Institute Australia

University of Melbourne

University of New South Wales

## Council Members

Judy Huett (co-chair)

Eileen Baldry (co-chair)

Adrienne Torda

Angus Graham

Donna Best

Jaquie Mills

Jessica Smith

Nora Shields

Rhys Nagas

Tania Harris

## Management Committee

Kate Allred

Anna Ashenden

Kirsten Deane

Jenny Downs

Kitty-Rose Foley

Patsie Frawley

Sophie Howlett

Anne Kavanagh

Ricky Kremer

Michelle Moss

Mary-Ann O'Donovan

Ellen Skladzien

Preeyaporn Srasuebkul

Julian Trollor

## Learn and Lead Group

Beck Biddle

Greg Bonyhady

Ally Gillies

Ray

Tessa Douglas

Hayley Mills

Ana Nguyen

Audrey O'Connor

Susan Olson

Andrew Tabakovic

## First Nations Advisory Committee

Mo Billy

Charlotte Bridges

Sarah Cattermole

Barbra Drummond

Paul Knight

Tennille Lamb

Charlene Mundine

Associate Professor Glenn  
Pearson

Madeleine Prasad

Uncle Willie Prince

Justen Thomas

## National Advisory Committee

Christine Bigby

Andrew Cashin

Jenny Karavolos

Rebecca Kelly

Nick Lennox

Trudy Lin

Catherine McAlpine

Uncle Willie Prince

Jacki Small

Kerry Stubbs

Gavin Burner

Gavin Burner was a member of the National Advisory Committee. We acknowledge Gavin's passing and offer condolences to his family and friends. We deeply appreciate Gavin's incredible leadership and the lasting impact he made on the intellectual disability community.

## International Advisory Committee

Darryl Barrett

David Bathgate

Gyles Glover

Chris Hatton

Tony Holland

Seth Keller

Yona Lunsky

Paula McGowan

Cathy Rice

## Partners & Collaborator Organisations

Australian Association of Developmental Disability Medicine (AADDM)

Ability First

Achieve Australia

Aruma

Australasian Society for Intellectual Disability (ASID)

Australian Commission for Safety & Quality in Health Care

Australian Indigenous Doctors' Association

Australian Psychological Society

Australian Society of Special Care in Dentistry

Autism CRC

Autism Spectrum Australia

Carers NSW

Central and Eastern  
Sydney PHN

Cerebral Palsy Alliance

Congress of Aboriginal and  
Torres Strait Islander Nurses  
and Midwives (CATSINaM)

Country to Coast PHN

Curtin University

Deakin University

Dietitians Australia

EdHealth Australia

Endeavour Foundation

Fragile X Association

Inclusion Melbourne

Independent Community Living  
Australia

Indigenous Allied Health  
Australia

La Trobe University

McCallum Disability  
Services

Microboards Australia

Monash Health

Murdoch Children's  
Research Institute

National Association of  
Aboriginal and Torres Strait  
Islander Health Workers and  
Practitioners (NAATSIHWP)

National Disability Services

Northcott

NPY Women's Council

NSW Health

NT Department of Health

Professional Association of  
Nurses in Developmental  
Disability Australia (PANDDA)

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Pharmaceutical Society of  
Australia  
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Primary Health Tasmania  
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Queensland Health  
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SA Intellectual Disability Health  
Service  
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SAL Consulting  
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Scope  
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Speech Pathology Australia  
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Swinburne University of  
Technology  
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Sydney Children's Hospital  
Network  
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Sydney Local Health District  
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Sydney Local Health District  
(SIDMHOS)  
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The University of Notre Dame  
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University of Queensland  
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University of Sydney  
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University of Technology  
Sydney  
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Victorian Dual Disability  
Service, St Vincent's Hospital  
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WA Department of Health  
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Western NSW Local Health  
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Western Victoria PHN  
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