

The National Disability Research Partnership (NDRP) Evidence to Action Event – 1 May 2025

What we learned about using knowledge to drive change for people with disability

Acknowledgement of Country

"I'd like to begin by acknowledging the Traditional Owners of the lands on which we meet today. We pay our respects to Elders past and present, and to First Nations people joining us today. At the NDRP, we recognise the strength, leadership and resilience of First Nations people with disability. We know that First Nations people have always been researchers, knowledge holders and truth-tellers. As we come together to talk about knowledge and action, we honour their traditions of sharing, learning and community wisdom." — Mary Sayers, NDRP CEO

Our work to drive disability-led change

Our vision is for disability-led research to improve rules and everyday processes for people with disability in Australia.

Our purpose is to support people with disability to take part in disability research. This research will build evidence for rules and process that promote the rights of people with disability.

To achieve this, one of our main goals is to make sure quality research leads to real world changes that help people with disability. This means making sure people use findings from research to make better rules and programs to support people with disability.

We hold events called 'evidence to action'. In these events, we discuss topics related to the <u>NDRP</u> <u>Research Agenda</u>. We talk about:

- what we know from the research
- what we don't know
- what research we still need.

The goal of these events is to work together to advise future research and rules.



About the event

We had our second 'evidence to action' event on 1 May 2025.

This event focused on sharing and using knowledge in ways that can change what people's decisions and actions. We call this knowledge mobilisation. It is an important part of our work to make sure research creates real change.

The event brought together people with disability, researchers, policy makers and advocates to talk about this topic.

Our panel of experts included:

- Mary Sayers, CEO of the NDRP
- Professor Erin Wilson
- Associate Professor Lorna Hallahan
- Professor Kirsten Deane

What people shared

Erin Wilson gave the keynote speech at the start of the event. She explained that knowledge mobilisation isn't just about writing a report at the end of a project. It's about involving people with disability from the very start of the research through to the end. She shared examples and challenged everyone to think about who research is for, how it's used and what difference it makes.

We also looked back on the <u>SHUT OUT Report</u> from 2009. The report included powerful feedback from around Australia that helped shape Australia's first National Disability Strategy. Kirsten Deane and Lorna Hallahan also spoke about the report. They were both Deputy Chairs of the National People with Disability and Carer Council that guided the report development.

Madeleine Clarke helped guide the panel. She is a disabled early career researcher and advocate. Madeleine reminded us that people with disability are often buried in research and erased from their own stories. She spoke about the fear and responsibility of working with people's lived experience.

Kirsten and Lorna shared the story behind the report. They talked about how it captured the voices of thousands of people with disability and pushed for big changes to how important systems work. They spoke about:

- the need to honour people's stories
- avoiding causing harm when asking for feedback
- ensuring governments truly listen and act.



Main themes

Throughout the event, speakers and attendees talked about how to build genuine relationships between researchers, people with disability and decision-makers. The key message was that research must be inclusive and accessible, and we must use it.

Knowledge mobilisation must happen from the beginning

Knowledge mobilisation is a way of thinking. It is a process that must be part of the project from the very start. It's not something that happens at the end of a project.

High-quality research must be designed with action and use in mind.

Policy makers are more likely to use research if they are part of developing it. Giving them a report at the end is not enough.

'As soon as you start asking people questions about their lives, you start to mobilise that knowledge.' – Lorna Hallahan

'Knowledge mobilisation isn't what happens at the end. It must be built in from the start.'

— Erin Wilson

Working together and building trust is important

It is important to build and keep trust with people with disability, policy makers and researchers.

Research is more relevant and accessible when people with disability are involved at every stage of a project. Working with people with disability also helps more people use the research findings.

We need to respect experiences of trauma

Researchers must invite people to share personal stories and be respectful when they include them in their work. Personal stories help bring evidence to light and help us work towards our goals.

People shared painful and deeply personal stories in the SHUT OUT report. The process lacked support for people who shared and listened to personal stories. This created a risk that these people could experience their trauma over again.

'People with disability are being buried in research and almost erased from their own narrative... The terror and the responsibility that comes with doing this kind of work is real.'

- Madeleine Clarke



People with disability are experts and leaders of change

'Lived experience' is not enough. People with disability can also be experts in analysis, research and advocacy.

The best insights often come from those living through the issues, like people with disability.

'Evidence alone is not enough—you need stories to make it come alive, to make people say: 'Okay, I heard that. What do I need to do?' – Kirsten Deane

Research and policy must stay flexible

Deciding on research questions or policy problems too early can lead to incorrect findings or missing more urgent issues.

We must not let people force us to look at complex problems in simple ways. People who make policies must be prepared to work with complicated situations where there are many different voices and views.

Impact happens in unexpected ways

Knowledge mobilisation has power when people use research in ways we may never see.

The impact of the SHUT OUT report went far beyond government. Advocates, families and allies used it to push for change.

Small group discussions

We ran small group discussions as part of the event. We designed these discussions to:

- gain insight from people's lived and professional experiences
- identify practical solutions to move research into action.

Each group was run by an experienced person and included a note-taker. They gave the group prompts to help people to reflect and stay focused on the discussion topic.

The discussions explored 5 themes:

- 1. Research policy partnerships
- 2. Sharing research in accessible ways
- 3. Community-led advocacy
- 4. Working together across different sectors
- 5. Overcoming barriers



The insights shared in the group discussions show deep knowledge and lived experience. They also show a strong, shared commitment to improving knowledge mobilisation.

People shared practical ideas and honest reflections about what is and isn't working and what the biggest opportunities are.

You can read the full list of insights in Table 1.

While these discussions showed valuable themes and potential directions, they are just the beginning. We need to do more work to:

- turn these insights into clear actions and partnerships
- make sure they work well with our guiding principles and Strategic Plan.

Table 1: Summary of small group discussion feedback

Following is a summary of what we heard during the small group discussions.

What we asked	What people shared	Possible solutions suggested
What works well when researchers and policymakers work together? What gets in the way? What needs to change?	Trust, working together from the start and understanding policy timelines matter. Barriers include short-term focus, strict rules about choosing services, lack of access to research and exclusion of people with disability.	 create resources for building policy partnerships early in research support research teams and governments to form relationships run workshops on how policies are made and tested.
What barriers make research hard to access? How to share research in different formats? Who needs research most?	Jargon and paywalls were key barriers. Accessible formats needed, including: • plain language • infographics • audio. It is important to involve target audiences and fund accessible formats upfront.	 People suggested we: create a guide to sharing accessible research results in ways relevant to the topic. This includes going beyond Easy Read fund accessibility planning in all projects and build a collection of accessible research examples.



What we asked	What people shared	Possible solutions suggested
How can research support lived experience advocacy? What's missing? How can community-led research create change?	Seeking too much feedback and controlling who can take part block meaningful involvement. Research must be inclusive and account for different and compounded experiences. Data should reflect real, diverse experiences and allow for systems of advocacy.	 support researchers to share and learn from each other. Fund training programs and fellowships for people with disability include different perspectives in community-led research. This includes perspectives from First Nations people, people of different genders and people from outside big cities provide better support to make sure community-led research is done in a fair way.
Who needs to be involved in knowledge mobilisation? How to build stronger links and supports?	Building long-term relationships takes time and resources. Different sectors have different information and use different terms for the same things. This makes it hard to work together. Solutions include: events that help new businesses grow working together on new ways to produce knowledge.	 People suggested we: develop tools for working across sectors. For example, research, policy and community sectors support long-term research partnerships across sectors host events to connect people and ideas for problem-solving.
What are common barriers? What has worked to turn research into action? What new ideas could improve this?	Translation isn't funded. Research often doesn't line up with budget cycles. Assumptions about people and languages makes research inaccessible. Need shared language and empathy.	 People suggested we: create a source of funding for research translation develop shared language glossaries provide coaching or small grants to test new ways to use what we learn from research.



Statistics from the event

People who signed up

- 148 people signed up for the event.
- 37% of people who signed up identified as living with a disability.
- 31% identified as a carer, family or kinship group member of a person with disability.
- 39% identified as a disability advocate.
- 37% identified as a researcher.
- 21% identified as being in a government or regulator role.
- 8% identified as a service provider.

People who took part

- 85% of people who signed up for event took part. This was 126 people.
- 26% of attendees responded to the survey. This was 33 people.

Ratings

The event received overwhelmingly positive feedback.

- 100% of people who responded to the survey rated the event as Excellent or Very Good.
- 73% of people rated the presentations and discussions 5/5
- 27% of people rated the presentations and discussions 4/5

Acknowledgments and thanks

The NDRP would like to extend our heartfelt thanks to all the:

- collaborators
- speakers
- panellists
- people who ran the small group discussions and people who took notes
- access and inclusion partners
- people who took part in this event and made it a success.

Supports

We acknowledge that some of the content may have been challenging. If you feel upset or need support, you can find a list of services on our website.



Contact information

We invite feedback on all aspects of our work. You can <u>fill out our event feedback survey</u>.

You can also contact us if you have any questions.

You can send us an email at info@ndrp.org.au.

You can call us on 03 9000 3813

You can visit our website at <u>www.ndrp.org.au</u>. To learn about our other events, visit our <u>evidence to Action page</u>.

You can visit our YouTube channel to watch a recording of the event www.youtube.com/watch?v=CflqaEfQBLQ&list=PLUcd97LtYOwqO7aTbHC6r88eqzxjdx2o2&index=2