National Disability Research Partnership

Proceedings from the National Disability Research Partnership (NDRP) Evidence to Action Event: *Doing research together, 'Supporting inclusive and collaborative research partnerships'* October 2025

Acknowledgement of Country

"*As we gather to discuss important issues for people with disability, we acknowledge the strength, resilience, cultural wisdom of First Nations people with disability. We know we are on First Nations land and we respect the First Nations people from this land. First Nations people have lived here for many, many years and we share this land. We honour and respect all First Nations people and elders and ancestors, and their stories have so much to teach us.*" – Mary Sayers, CEO, NDRP

Introduction

About the National Disability Research Partnership

The National Disability Research Partnership (NDRP) is an independent not for profit organisation. Our Board, committees and staff, are majority people with disability. We work in partnership with people with disability and their organisations, researchers, advocates and government. . Our role is to support strong, inclusive research that can drive real change in policy and practice.

Mobilising evidence for action

One of our key strategic objectives is to mobilise evidence for action. Mobilising evidence for action means quality research is used to inform real world changes that make a difference for people with disability. This means findings from research are used to improve policy, practice and programs.

One of our initiatives is to hold 'evidence to action' events. In these events we host discussions about a certain topic related to the NDRP Research Agenda. This includes what we know from the research, what we don't know, and what further research is needed. The goal of these events is to work together and inform future research and policy directions.

This document

This document has:

- overview of key themes discussed at our third event held on October 13, 2025,
- points from each session including quotes,
- attendee numbers and feedback,
- main messages,
- resources, supports, and thanks.

About the event

The third event in the Evidence to Action series, "Doing Research Together: Supporting Inclusive and Collaborative Research Partnerships", convened on 13 October 2025, brought together disability sector professionals, researchers, advocates, and people with lived experience. The event aimed to foster stronger, more inclusive research partnerships that drive meaningful change in policy and practice.

The program was structured around seven sessions, including short presentations, myth-busting discussions, and examples of good practice. Speakers from advocacy organisations shared practical insights on building respectful, inclusive research partnerships. Resources such as the video on the Advocacy basics, and the NDRP Resource Pack were provided to support ongoing learning and collaboration after the event.

Launching the DANA Report

Dr Cherry Baylosis from Disability Advocacy Network Australia (DANA) launched the new report, "*Co-Design Partnerships: A Mutual Exchange*". Cherry's session focused on the importance of inclusive and collaborative research partnerships, and the leadership and contribution of advocacy organisations, including disabled persons organisations and disability representative organisations can provide in research. She emphasised the benefits for partnerships built from the outset based on shared purpose, trust, and accessibility, and highlighted how disability-led research, shaped by lived experience, drives genuine change for communities.

Quote: ***" The key finding … is the importance of mutuality where the partnerships between people that typically do the research benefit but also, most importantly, so do people with disability and the broader community as well." Cherry Baylosis***

Figure 1 Key findings from the DANA Report



Two-way learning

Researchers listening through difference, reflecting on biases, and using trauma-informed approaches

Partnerships as mutual learning, knowledge flows both ways



Co-define, co-design, co-create

Shared decision-making from start to finish

Co-authoring, co-facilitation, and accessible outputs



Distribution of resources

Partnerships requiring fair sharing of time, money, and data

Session 3, *Advocacy 101: Who's who and what they do*, was facilitated by Dr Jade McEwen and speakers shared their organisation's role, priorities, and insights into how researchers can collaborate effectively with advocacy organisations. They emphasised that genuine collaboration means shared power, early involvement, and sustained commitment.

Diana Piantedosi – Women with Disabilities Australia (WWDA)

"When it comes to partnering with researchers, we do so quite intentionally. We often receive requests to share surveys or advertise calls for participants, but we won't do this unless we've been meaningfully involved throughout project development."

"Involving us early in the formative stages of project design actually sets your research up for success. We can help shape your questions, support recruitment, and ensure your findings resonate with community."

Luke Nelson – Inclusion Australia

"We often work with researchers to make it easier for people with intellectual disability to understand and take part in research — from Easy Read materials to co-developed summaries and guides."

"Many people with disability find it hard to access the research world because it isn't always inclusive. I want to give a big shout-out to the NDRP for making it easier and encouraging researchers to truly include people with disability in this work."

Melanie Chatfield – Blind Citizens Australia (BCA)

"Accessibility for people who are blind or vision impaired is key. Exclusion from information and participation is still our number one discrimination issue."

"If your research involves designing a product, engage with us early and include user testing from the start. Make sure people with different experiences of blindness and vision impairment help shape the design and development."

Julian Laurens – People with Disability Australia (PWDA)

"When you work with us, you're drawing on the voices of our members and our lived experience across systemic, individual and project advocacy."

"Partnerships with DPOs take time because we're accountable to our members and Board. Respecting those timelines and maintaining good communication makes the relationship work."

Session 4, *Building Respectful Partnerships*, was chaired by Professor Linda Steele (University of Technology Sydney) and explored four myths about co-design between researchers and advocacy organisations. Speakers drew on lived experience to show what respectful, disability-led partnership looks like.

Myth #1: "One meeting is co-design."

Megan Spindler-Smith – People with Disability Australia

"Co-design is a relationship — a process of shared ownership from the first question to the outcome. It's sustained, collaborative, and grounded in power sharing." "True co-design means people with disability shape the questions, not just answer them."

Megan reminded attendees that co-design is not a box to tick, but a method of working that demands shared power, time, and commitment. She emphasised that lived experience must be recognised as lived expertise, applied and respected throughout every stage of research.

Myth #2: "It's quicker to do it ourselves."

Jenny Karavolos – Australian Autism Alliance

"Trying to save time by designing a project alone often ends up costing time — and the right solution. The real speed comes from starting together, not catching up later."

Jenny illustrated this myth with her "late invitation" story, showing how projects that approach advocacy organisations too late in designing the research lose both quality and impact. She called for early and equal partnerships that prevent tokenism and strengthen research from the outset.

Myth #3: "Advocacy groups only represent a few voices."

Jeremy Muir and Sarah McInnes – Physical Disability Australia

"Advocacy organisations like PDA represent far more than a few voices. Our work is grounded in ongoing consultation, peer networks, and community evidence across Australia. We don't claim to speak for everyone, but we work hard to include as many voices as possible, amplifying the collective concerns and aspirations of our community."

Jeremy and Sarah challenged the assumption that advocacy organisations are narrow in scope. They explained that representative advocacy is built on rigorous engagement and accountability to diverse communities, making it a vital form of evidence and expertise.

Myth #4: "Advocacy organisations are too busy to be involved meaningfully."

Martin Butcher – National Centre for Disability Advocacy

"Advocates aren't too busy to engage — they're too under-resourced to do it for free. When time, clarity and fair funding are built in, advocates are keen to collaborate. We need researchers as much as researchers need us. With the right support, meaningful engagement is absolutely possible."

Martin explained the pressures faced by small advocacy organisations and individual advocates, many of whom balance direct client work with systemic advocacy. He urged researchers to plan ahead, be clear about expectations, and resource collaboration fairly.

In Session 5, ***Resourcing Partnerships Fairly***, Mary Sayers returned as session guide, joined by Michelle Keogh (People with Disability Australia) and Dr Amy Conley Wright (Inclusion Australia). Together they explored how sharing time, money, and information fairly is essential to real partnership.

This session confronted the toughest element of co-design – money. As Mary Sayers noted, *"money is always the hard part."* Advocacy organisations are approached repeatedly by researchers with strong ideas but little or no funding to support their involvement. Amy and Michelle explored why this pattern persists and how fair resourcing is central to inclusion, impact, and trust.

Dr Amy Conley Wright – Inclusion Australia

As an academic and advocate, Amy highlighted how it is important for researchers to recognise the invisible costs that organisations carry.

"We have high staff costs that may not be visible to everyone… We need time to prepare materials or partners to come to us with high-quality accessible materials."

She shared how the NDRP-funded *Safe Homes Project* worked well because resources, access and trust were built in from the start, allowing Inclusion Australia's policy officers, people with intellectual disability, to act as co-researchers.

Michelle Keogh – People with Disability Australia (PWDA)

Michelle reframed funding as respect, not overhead.

"When you resource partnerships fairly, you're not paying for a nice-to-have. You're investing in the lived experience and networks that make research stronger."

She emphasised budgeting for staff time, access supports and longer timelines.

"Fair resourcing isn't just about money; it's about access, respect and recognising that partnerships bring value to both sides. Funding is a critical part of making it happen, but the funding alone won't 100 percent make it happen." (Michelle)

Session 6, ***Lessons from Practice***, was led by Professor Dennis Petrie (Monash University) and featured Dr Tess Altman and Dr Liz Hudson (Children and Young People with Disability Australia), alongside Dr Catherine Smith (University of Melbourne). They reflected on examples of partnership success, challenges, and lessons for future collaboration.

Dr Tess Altman (Children and Young People with Disability Australia – CYDA)

Tess shared lessons from *Safety Beyond Barriers*, a co-designed project with the Australian Institute of Family Studies and funded by the NDRP. The partnership reshaped how both organisations approached research ethics. CYDA's emphasis on relational safety and accessibility combined with AIFS's formal ethics processes and subject matter expertise to create an "*ethics ethos*" that ran through the project. Joint development of the ethics application strengthened mutual learning, refreshed traditional templates, and modelled how co-design can be embedded from proposal to implementation.

Dr Liz Hudson (CYDA) and Dr Catherine Smith (University of Melbourne)

Liz then reflected on their long-standing collaboration, with Dr Catherine Smith (University of Melbourne) and Professor Helen Dickinson (UNSW). Liz highlighted the power of combining advocacy's community reach with academic rigour: "*That dual authority is very powerful*."

Catherine emphasised reciprocity and capacity building: the partnership enabled young people to critique and contextualise findings, while researchers became more accountable to lived experience. Together, they ensured results were quickly mobilised into policy submissions, briefings and media— "*the work doesn't sit on a shelf*."

Both acknowledged challenges: mismatched timelines, limited resources, and differences in language and tone. Their strategies included early expectation-setting, routine reflection, valuing each other's strengths, and ensuring the closing of "*the loop*" by sharing outcomes with participants.

Catherine concluded, "*Partnerships are gloriously messy—but when purposeful communication and respect sit at the same table, research grows legs and moves.*" Liz added, "*When advocates and researchers work side by side, we achieve far more than either could alone.*"

The event concluded with Session 7, a ***Closing and Next Steps*** reflection facilitated by Mary Sayers, inviting attendees to share one action they would take forward.

Table 1: Lessons from research-advocacy partnerships

What works	What gets in the way	What we're learning
Shared purpose and mutual respect: Partnerships grounded in trust, accessibility and lived experience.	Partnerships formed too late or without early involvement led to tokenism and missed impact.	Start together, not later, co-design is a relationship, not a meeting.
Early and equal involvement: Advocacy organisations help shape research questions, methods and outputs from the beginning.	Researchers approach advocacy groups only for recruitment or dissemination, not shared ownership.	Early collaboration builds relevance, credibility, and community resonance.
Accessibility and inclusion: Co-developed materials, Easy English or Easy Read formats, user testing and diverse representation strengthen quality and reach.	Accessibility costs, short timelines, or limited planning make meaningful inclusion difficult.	Budgeting for access supports and building accessibility into every stage improves research integrity.
Representative advocacy: DPOs and DROs bring evidence grounded in extensive community consultation and accountability.	Misunderstanding that advocacy organisations "only represent a few voices."	Representative advocacy is rigorous evidence, it amplifies collective experience, not just individual stories.
Fair resourcing: Funding, time and access supports are built in from the start.	Partnerships expected to be "in-kind" or unfunded; unrealistic timelines.	Fair pay and planning signal respect and make genuine co-design possible.
Long-term relationships: Returning partnerships build trust, efficiency and deeper understanding.	High staff turnover, shifting priorities, or one-off projects erode continuity.	Sustained collaboration allows learning across cycles and strengthens institutional memory.
Ethical co-design: Shared development of ethics processes and safety frameworks.	Traditional ethics templates don't fit co-designed research; slow committee processes.	Co-designed ethics can reshape institutional standards and embed lived experience as expertise.
Reciprocity and reflection: Both sides build capacity, are transparent and hold each other accountable.	Mismatched language, pace and communication styles between advocacy and academia.	Routine reflection, clear expectations and valuing each other's strengths sustain partnerships.
Purposeful communication: Honest, transparent dialogue about goals, timelines and outputs.	Limited time for relationship-building or unclear roles.	Communication is the foundation of respect, plan time for it as part of the work.
Shared action and impact: Research findings translated into submissions, briefings and advocacy tools.	Research "sits on a shelf" if not accessible or actionable.	Build dissemination, knowledge mobilisation and sharing results with-community is every project plan.

Resources

Below are the recordings, resources, and next steps.

Watch the event recordings:

1. Why advocacy partnerships matter – Session 1
2. Launch of the DANA Report – Session 2
3. Who's who and what they do – Session 3
4. Building respectful partnerships – Session 4
5. Resourcing partnerships fairly – Session 5
6. Lessons from practice – Session 6
7. Auslan interpreted version of Sessions 4–7

Explore the DANA Report

The report launched at the event — *Co-design Partnerships: A Mutual Exchange* — was commissioned by NDRP and developed by DANA with advocacy organisations.

Read or download the DANA Report

Access the NDRP Resource Pack

To build on the themes explored throughout the event, NDRP released a new Resource Pack on Supporting Inclusive and Collaborative Research Partnerships. It includes practical tools, templates, and examples for partnering with advocacy organisations, budgeting for access, and inclusive co-design.

- Watch the video explainer
- Download the Resource Pack (Word)

It is deliberately provided in a simple Word format so that users could copy, adapt, and share it in ways that best suit their teams or communities.

The pack includes:

- Who's who: an overview of DPOs and DROs, and how they differ from service providers.
- Tips for first contact: guidance on what to do when approaching an advocacy organisation.
- Tools and templates: a checklist for respectful engagement, a sample MoU, and a partnership budgeting template.
- Access and inclusion budgeting: advice on planning for costs such as interpreters, captioning, and support.
- FAQs: answers to common questions about co-design, ethics, and payment for lived experience.

Attendees

Event registrations

- 48% of total registrations self-identified as researchers
- 31% identified as a disability advocate
- 27% of registrants identified as living with a disability
- 13% identified as a carer, family or kinship group member of a person with disability
- 11% identified as a service provider
- 8% identified as being in a government or regulator role

Event engagement

- Attendance: The event had 134 attendees.
- Feedback: 26% of attendees responded to the survey (38 out of 149)

Event and presentations ratings

The event received overwhelmingly positive feedback with 92% rated the event as Excellent or Very Good and 68% gave the presentations and discussions a 5/5 rating; 27% gave 4/5.

Supports

While this event focused on doing research together, we acknowledge that some of the content may have been challenging. If you feel upset or need support, click here for services that can help.

Feedback

We invite feedback on all aspects of our work. Please access the event feedback survey here.

Acknowledgments and thanks

The NDRP would like to extend our heartfelt thanks to our collaborators, all speakers, facilitators, our access and inclusion partners, and attendees who made this event a success.

Contact information

National Disability Research Partnership
Email: info@ndrp.org.au
Phone: 03 9000 3813
www.ndrp.org.au Evidence to Action page
YouTube playlist

Additional resources for inclusive and respectful research partnerships

These resources can support researchers, advocacy organisations, and co-design partners to deepen their understanding of inclusive research, lived experience leadership, and accessible practice.

Area	Description	Link
Women with Disabilities Australia	What is advocacy? Standing up for your rights, Easy Read resource	Easy Ready resource link
Inclusion Australia	Guide to Inclusion for Policy Makers developed with people with intellectual disabilities to assist policymakers in creating inclusive systems and processes. Resources are also available on accessible information, inclusive meetings and inclusive consultations on the Towards Inclusive Practice website.	Download the guide Towards Inclusive Practice
First Peoples Disability Network (FPDN)	A national organisation led by and for Australia's First Peoples with disabilities, offering resources and training.	Visit FPDN
People With Disability Australia (PWDA)	Information on PWDA's services helping organisations improve how they include people with disability in their research and events.	Learn about the services
Children and Young People with Disability Australia (CYDA)	Resources, made or co-designed by young people with disability, to help parents, caregivers and educators.	Visit CYDA
National Ethnic Disability Alliance (NEDA)	NEDA believes: People from non-English Speaking backgrounds (NESB) with disability, their families and carers are experts in knowing how they want to receive services and supports.	Visit NEDA
Australian Federation of Disability Organisations (AFDO)	Connect with Me Guide & Toolkit for organisations working & co-designing with people with disability.	Visit AFDO
Disability Advocacy Network Australia (DANA)	National representative body for a network of independent disability advocacy organisations in Australia. They also host the National Centre for Disability Advocacy.	Reports

Area	Description	Link
Advocacy for Inclusion	Self-advocacy kit: This kit can be used by a person reading it on their own, in a group where ideas can be discussed, or in a workshop.	The kit
Physical Disability Australia	PDA takes every opportunity that resources allow to provide formal submissions and consultations to the Government and NDIS.	Submissions and campaigns
Autism Alliance National	To strengthen our influence in legislation, policy and community attitudes we bring together perspectives from various disability representative organisations.	Position statements
Community Mental Health Australia	The coalition of peak community mental health organisations from States and Territories, established to promote the importance and benefits of community mental health and recovery services across Australia.	Resources
Deaf Australia	Deaf Australia's Accessibility & Inclusion Toolkit	Toolkit
Blind Citizens Australia	Policy and advocacy hub	Hub
QLD	Queenslanders with Disability Network (QDN) outlines principles for co-designing with people with disability, emphasising authentic voice, respect, rights, resilience, and collective action.	Access the Principles
WA	Example of co-design of a local community disability advocacy model	Information
TAS	Disability Voices Tasmania project work	Current projects
NSW	Disability Advocacy New South Wales resources Family Advocacy supports people with disability and their families to promote and defend the rights and interests of people with developmental disability.	Resources Inclusion Collection
VIC	Women with Disabilities Victoria's guide promotes principled consultation and co-design with women with disabilities. It outlines a set of eight practices that enable ethical, effective work.	Download the Ask experts Guide

Area	Description	Link
	In this guide, the word refers to women with disabilities who are advocating for gender and disability equality.	Download We are the experts Guide
NT	Inclusion NT works to build a community in the Northern Territory that is inclusive of people with intellectual disability and provides opportunities for leadership.	Link
ACT	ACT Down Syndrome & Intellectual Disability (DSID) leads the way in building an inclusive community for people for people with intellectual disability.	Link
SA	Purple Orange's example introduces co-design principles and practices, aiming to involve people with disability in decision-making processes. SACID and Speak Out Advocacy co-designing improved pathways for people with intellectual disability to be leaders in organisations and communities	Download Guide Read more