



National Disability
Research Partnership

Strengthening Research Capacity

The National Disability Research Partnership's plan for
strengthening disability research capacity in Australia



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Executive Summary

About the NDRP

The National Disability Research Partnership (NDRP) funds research led by and with people with disability. Its purpose is to build a national disability research program in Australia that builds evidence for successful policy and practice.

The NDRP will achieve this by:

- funding research that is informed by the NDRP Research Agenda
- making sure research is done by and with people with disability
- strengthening disability research capacity, and
- sharing research findings to improve policy and practice.

NDRP Principles

The NDRP seeks to:



Advance high-quality research that informs disability policy and practice in Australia

- Promote collaborative research across Australia
- Implement the NDRP Research Agenda
- Build an evidence base that informs Australian disability policy and practice



Value the knowledge of people with disability in research

- Respect different sources and forms of knowledge and research
- Support research that gives people with disability real decision-making power
- Support research that involves a wide range of people with disability, including those who are often left out or are not well represented in research
- Make sure people with disability are paid properly for their research work



Strengthen disability research capacity

- Build an active and connected community of disability researchers
- Build career pathways for researchers with disability
- Strengthen Australia's capacity to conduct disability research
- Build capacity in the community to develop and use evidence produced by research



Share research findings widely in useful and accessible ways

- Make information available in accessible and useful ways
- Share what we learn with the disability and wider community
- Use a range of new and traditional ways to share research findings.



Strengthening capacity

One of the ambitions of the NDRP is to strengthen capacity to conduct collaborative, high-quality inclusive disability research. We recognise that there is already capacity in disability research in Australia but that there is a need to substantially improve this, ensure it is disability-inclusive, and focusses on issues of important for people with disability and other stakeholder groups.

This report outlines the NDRP's plan to strengthen capacity for disability research in Australia. It builds on two research reports by UNSW Canberra commissioned by the NDRP Working Party, Disability Research Capacity: [Key Definitions and Frameworks](#) and [Building System-wide Disability Research Capacity in Australia](#).

Acknowledgement

We are grateful to the NDRP Working Party for guiding the establishment of the NDRP, with special thanks to the Research Subcommittee for writing this approach to strengthening capacity: Professor Anne Kavanagh, University of Melbourne; Professor Helen Dickinson, University of New South Wales; Professor Gwynnyth Llewellyn, University of Sydney; Professor Jackie Leach Scully, University of New South Wales; and Professor Elizabeth Kendall, Griffith University. Read more here: [NDRP Working Party](#).

What do we mean by system-wide disability research capacity?

UNSW Canberra's literature review, *Disability Research Capacity: Key Definitions and Frameworks* (Buick, 2021) found confusion in how research capacity and capability are understood, with the terms sometimes used as though they are the same.

The report defined *research capability* as referring to an individuals' research skills and the ability to design research, collect and analyse data and disseminate findings. In contrast, *research capacity* was defined as a system-wide, multilevel concept that includes individuals, groups/ teams, organisations and across organisations. Strengthening research capacity at all levels focusses on enhancing the quality and usefulness of research.



The NDRP uses the term *research capacity* because we recognise that high-quality research requires individual skills as well as investment in research and research infrastructure and supportive environments that facilitate research. This means that the NDRP should focus on individual skills AND institutional factors that enable individuals and groups to conduct high quality research. In addition, research capacity strengthening should focus on academia AND support the disability community (e.g., advocates, services) to participate in, use, and conduct research.

Buick (2021) reported various strategies from the literature that could be used to grow the number and skillsets of individuals such as higher degree and postdoctoral programs that have specific supports in place for students with disability, coaching and mentoring, and secondments and internships. Strategies for building a supportive environment for research might include funding programs, research infrastructure, and mechanisms to enable productive partnerships between academics and the disability community.

The second UNSW report, *Building effective system-wide disability research capacity in Australia* (Buick, West and Dickinson, 2022), was based on a qualitative study, in which participants identified the need to strengthen system-wide research capacity. They recognised that this was a long-term investment that would require changes to the current system as well as a shift in existing mindsets and power relations. This shift in mindsets involves recognition of the importance of inclusive research practice and the centring and valuing of the knowledge of people with disability and their supporters.

The following recommendations come from the NDRP commitment to strengthening system-wide disability research in Australia, grounded in the knowledge gained from the studies undertaken for the two reports and the NDRP Working Party experience with piloting a funding round in 2021.



NDRP actions for strengthening research capacity

Achieving system-wide disability research strengthening will require a multipronged approach. This will include:

Enhanced disability-inclusive research

Increased funding for disability research

Reform ethics frameworks and assessments

Strengthen research knowledge and skills

Reform of university systems, structures and processes

Build sustainable research collaborations

Linkage and analysis of existing datasets

These are outlined in more detail below.

➤ Enhanced disability-inclusive research

The NDRP aims to become a leader in advocating for and promoting disability research in Australia by:

- guiding government and other research agencies to implement inclusive disability policies and practices
- developing best practices in collaborative research by and with people with disability, responding to the priorities of people with disability
- building capacity for individuals with disability and their representative organisations to engage in research.



Given the time taken to train and develop researchers from early career to senior leadership roles, the NDRP is working towards a ten-year vision where most applied disability research is led by people with disability.

The longstanding history of power imbalances in research means there is still a way to go before most disability research is inclusive of people with disability. The involvement of people with disability in research exists on a spectrum, from roles as lead researchers; engagement of co-researchers with expertise based on personal experience of disability; participation of people with disability on advisory or reference groups or as consultants; and people with disability as participants only.

The [Disability Innovation Institute at UNSW \(DIIU\)](#) has produced freely available guides to the rationale behind and processes and practices of conducting inclusive research. Ongoing work at the DIIU is addressing shared governance, ethics, and benchmarking of collaborative, inclusive research. These and other resources will inform the NDRP's collaborative research.

Enhancing disability-inclusive research

Strategy	Responsible agency		
	NDRP	Funding agencies	University Sector
Training the disability and other research communities in how to do disability-inclusive research	✓	✓	✓
Establish internal committees within research funding bodies, such as the NHMRC and ARC, and ensure that people with disability review projects related to disability		✓	✓
Ensure that NHMRC research guidelines incorporate the principles of disability-inclusive research	✓	✓	
Design training modules in universities that cover attitudes to disability, ableism, and guidance on how to conduct disability-inclusive research			✓
Ensure universities have comprehensive Disability Action Plans that specifically support inclusive research practice			✓



Increased funding for disability research

The NDRP is specifically and exclusively focused on research done in partnership with the disability community and by and with people with disability. The NDRP aims to become a leader in best practice disability inclusive research among organisations that fund disability research in Australia.

However, the NDRP is not the sole agency funding or commissioning disability research. There are government agencies such as the National Health and Medical Research Council (NHMRC), government-funded research organisations such as Australia's National Research Organisation for Women's Safety (ANROWS) and Australian Housing and Urban Research Institute (AHURI), and non-government grant funding organisations.



The NDRP will advocate for increased funding from all funding agencies to be allocated to disability research priorities, including substantial investment to implement the NDRP Research Agenda.

While initial funding for the NDRP is entirely from government, the NDRP will seek to grow and diversity its funding sources to increase its impact and to support its independence. The NDRP will be transparent about the relationship between the NDRP and government, and the role of the NDRP in endorsing competitively funded and commissioned research.

Overarching recommendations to improve funding for disability research include:

- research funding that covers the cost of co-design and translation of findings and allows for a longer time frame
- funding to enable advocacy and representative organisations, DPOs and service providers to participate in research
- funding to foster partnerships and networks in disability research
- increased philanthropic investment in disability research.

Increased funding for disability research

Strategy	Responsible agency		
	NDRP	Funding agencies	University Sector
Ensure external funding bodies invest in research that aligns with the Research Agenda	✓	✓	✓
Dedicated ARC and NHMRC funding rounds for disability research projects and programs		✓	
Fellowships for early and mid-career researchers with disability			✓
NHMRC and ARC to develop clear funding criteria for disability research that ensure involvement of people with disability in the research process		✓	

➤ Reform of ethics frameworks and assessments

The approach of human research ethics committees (HRECs) to disability research has been an ongoing concern for disability researchers in Australia. Participants in the qualitative study conducted by Buick, West and Dickinson 2022 noted challenges in getting ethical approval for inclusive disability research for a number of reasons, including unfamiliarity with the methodology and paternalistic attitudes of some HRECs. They saw a key role for the NDRP to improve the capacity of ethics committees and funding bodies to evaluate ethical practice in inclusive disability research.

Recommendations to reform ethics frameworks and assessments include:

- preparing guidance materials for HRECs to assist them in assessing disability research
- training of HRECs to improve understanding of risks and benefits of including people with disability in research
- advocating for NHMRC to develop guidelines for ethical inclusive research and co-production with people with disability along the lines of those developed for research with Aboriginal and Torres Strait Islander peoples and communities. These guidelines should be incorporated into the NHMRC National Statement on Ethical Conduct in Human Research.



Strengthen research knowledge and skills for disability research within and outside of academia



The NDRP will work to strengthen capacity of people with disability to do research, of DPOs and DROs to undertake, understand and disseminate research, and of funding agencies and organisations to fund disability research that aligns with the NDRP approach of research by and with people with disability.

The NDRP will advocate with the university, government and disability sectors to increase knowledge and skills within and outside of academia.

Strategies that the NDRP could advocate for include:

- secondments, internships and student placements across different parts of the disability research environments (e.g., students within DPOs, advocates co-located with academics)
- cross-university mentoring program for researchers with disability
- professional development for advocates and service providers on disability research including interpreting research, data, ethics, and study design
- training government officials and academics in writing in plain English and Easy Read.

➤ Reform of university systems, structures and processes

Current university systems and processes are a major barrier to conducting disability research and for development of people with disability as researchers. For example, there is a lack of people with disability in leadership roles in universities.

Specifically, the NDRP could consider advocating for a Charter that university members sign up to that advances their capacity in disability research and supports people with disability to enter and remain in academia.



Reform of university systems, structures and processes

Strategy	Responsible agency		
	NDRP	Funding agencies	University Sector
Appoint a Pro or Deputy Vice Chancellor for Disability and appoint people with disability to leadership roles			✓
Address power imbalances, ableism, and attitudinal barriers to people with disability participating in university life			✓
Provide greater accessibility and dedicated funding for accessibility (e.g., physical, IT)			✓
Affirmative action quotas to increase the pool of students and staff with disability			✓
PhD scholarship and early-career fellowships for researchers with disability			✓
Develop interdisciplinary curricula that exposes all students to disability-related issues			✓
Create non-traditional pathways that enable people with disability to enter and remain in academia			✓
Build psychological safety for students and staff with disability			✓



Build sustainable research collaborations

Long-term research partnerships across the disability community, universities, DPOs, services and government rather than one-off projects are needed to strengthen capacity. Although there is evidence of existing partnerships, there is a critical need for expansion. An important observation from the Buick, West and Dickinson 2022 report was the importance of ‘boundary spanning’, such as academics acting as advocates, and advocates engaging in and using research. Skills to enable this capacity can be built through providing opportunities for networking and sharing knowledge through communities of practice.

The NDRP is committed to working in partnership with the disability community, respecting experience and expertise from different sources and forms of knowledge.

A national disability research partnership entity appears to be unique to Australia. The NDRP will learn how to best achieve productive research partnerships with the disability community as experience builds over time.

Strategies for the NDRP to consider include:

- funding for advocacy organisations, DPOs and service providers to develop and participate in research partnerships including time for reflecting and learning
- database that captures the expertise of academics that can be used to connect advocates with academics in mutual areas of research interest
- facilitate a Community of Practice that brings together academics, advocacy organisations, and service providers in areas of interest
- facilitate seminars/webinars that bring academics, advocacy organisations, and services together in areas of interest
- encourage universities to address prohibitive cost barriers to academics working with advocacy organisations, such as permitting in-kind contributions from academics and waiving or reducing the multipliers applied to research funding.



Improve the linkage and analysis of existing datasets

Government participants recognised the importance of linked data, available to approved users, as important to building evidence. The National Disability Data Asset is an \$68 million investment to build this research infrastructure. Non-government participants noted the lack of skills analysing such complex data and concerns that this could mean that government analysts are the main users of the NDDA or related linked datasets. Interviewees also noted the importance of strengthening data literacy across the sector and developing collaborative ways of working that mean analyses using the NDDA answer questions that are important to people with disability.

Strategies for the NDRP to consider include:

- strengthen data literacy across the disability sector enhancing capacity to generate questions, interpret findings, and contextualise findings in the everyday experiences of people with disability
- identify and fund ways to build analytical capacity of complex linked data
- data dashboard that can be interrogated to enable advocates and services to ask questions of the data
- inclusion of NDRP Board or committees on NDDA Advisory Council and subcommittees to enable cross-fertilisation.



Concluding remarks

The Capacity Strengthening workplan provides a template for the NDRP Board and Secretariat to strengthen disability research capacity in Australia. Following the workplan at set up will enable the NDRP to deliver on key activities in the first two years, begin to enhance research capacity, and leverage sustainable funding into the future.

