National Disability Research Partnership: Learnings and Recommendations

November 2022

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Acknowledgements

Acknowledgement of country

We acknowledge Australia's Aboriginal and Torres Strait Islander community and their rich culture, and pays respect to their Elders past, present and future. We acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First Peoples and as the Traditional Owners and custodians of the land on which we live. We embrace the spirit of reconciliation, working towards the equality of outcomes and ensuring an equal voice.

Historical exclusion of people with disability in research

We acknowledge that people with disability have historically been viewed as subjects (and objects) of tragedy, in need of medical intervention or cure. These ideas about disability still underpin some societal attitudes towards people with disability and have been reflected in research, societal structures and government policies. We must acknowledge who has traditionally been given voice and authority in research, and who has not.

The NDRP is designed to strengthen the authority and authentic involvement of people with disability in research, including as researchers, and to build the capacity of researchers to work in ethical and respectful ways alongside people with disability.

Thank you

We are grateful to the many people who took the time to contribute through surveys, consultations, or by sending us their ideas. We trust this report reflects the collaborative spirit that underpins the National Disability Research Partnership, and all the contributions made to its vision and purpose.

We are grateful to the NDRP Working Party for helping to shape the direction of this project and frame its many complex issues and to Tessa de Vries for her commitment to making this project a success.

The NDRP Establishment Phase was funded by the Department of Social Services through a grant to the Melbourne Disability Institute at the University of Melbourne.

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Other versions of this report including Easy Read and with graphic design can be found at this link: NDRP Report

Executive summary

The vision for the National Disability Research Partnership (NDRP) is to facilitate a collaborative and inclusive disability research program that builds the evidence for developing policy and practice decisions. It will aim to achieve this by funding research that is informed by the NDRP research agenda which has been developed with stakeholders, ensuring all research is done by and with people with disability, building disability research capacity and supporting the uptake of research findings into policy and practice.

A two-year Establishment Phase was tasked with setting up the structure and processes for a longer-term disability research partnership in Australia. This phase was steered by a Working Party made up of advocates, academics and independent advisors, with six of the 13 members being a person with disability. The Establishment Phase ran from June 2020 to June 2022, during which the NDRP Working Party reached out to the disability community for advice and feedback. This report details recommendations for setting up and running a National Disability Research Partnership, based on feedback from a range of stakeholders.

The key sections in this report are:

- The NDRP Guiding Principles
- Governance: who should run the NDRP and how?
- Commitment to research done by and with people with disability
- A preliminary NDRP research agenda
- NDRP research funding
- Building research capacity
- Knowledge translation
- Community of practice
- NDRP communication strategy

The NDRP Working Party is committed to ongoing evolution and will work together with the disability community to refine and improve these recommendations, before the NDRP becomes a fixture of the disability landscape from early 2023.

This report should be read together with the *Recommended NDRP Governance Structure report*; *Preliminary Research Agenda for the National Disability Research Partnership*; and *Building effective system-wide disability research capacity in Australia: What does it look like and how do we get there?*

These reports can all be accessed from this link NDRP Reports

NDRP Timeline

A National Disability Research Partnership has long been a dream/goal for the disability community. Funding from the Australian Government allowed work to start on a two year Establishment Phase in 2020. This report is the outcome of the Establishment Phase and the recommendations will be refined during a Transition Phase before the new NDRP is launched in 2023.

Recommendations

NDRP Principles

- All NDRP activities and decisions should be guided by the NDRP Principles.
- The NDRP Principles should be incorporated into the NDRP’s constitution.

- Once the NDRP is established, its principles should be regularly revised to ensure they remain in step with the ambitions and language preferences of the disability community.

Governance

- Establish the NDRP as a stand-alone, independent not-for-profit organisation, as described in the report *Governance Structure for the NDRP*.

Commitment to inclusive research

- The NDRP should only fund inclusive research that is done by and with people with disability, as reflected in one of NDRP's Principles: collaborative research that recognises, values and centres the knowledge of people with disability in research.
- The NDRP should set high standards for inclusive research and support and promote best practice inclusive research methods.

Research agenda

- The NDRP research agenda should provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.
- The NDRP research agenda should guide the allocation of research funding by the NDRP.
- The NDRP research agenda should complement other disability research initiatives in Australia.

Funding research

- The NDRP should fund research through open funding rounds, guided by the NDRP research agenda.
- The NDRP should facilitate and fund commissioned research through a commissioned research framework (subject to further piloting and refinement).

Building research capacity

- The NDRP should implement a research capacity building strategy that aims to achieve effective, system-wide disability research capacity.

Knowledge translation

- The NDRP should develop a knowledge translation framework that aligns with its purpose and principles.
- Knowledge translation should be a key NDRP activity, making research findings from research facilitated by the NDRP available in accessible, useful, timely and targeted ways.

Community of Practice

- The NDRP should implement an accessible Community of Practice model to bring people together to share learnings, build capacity, promote and support inclusive disability research.

Communication

- All NDRP communications should be accessible, align with the NDRP communication principles and provided in a range of formats.
- The NDRP should continue to develop and improve communication practices by listening, learning from others and adapting.

Reflections

‘My ambition for the NDRP is that research by and with people with disability is the norm; Australian disability research is of high quality and genuinely contributes to transformative change; and the disability research workforce, including disabled researchers, within and outside universities are the best in the world.’

Professor Anne Kavanagh

‘My hope is that the NDRP can unsettle traditional institutionalised ways of doing research ‘on’ or ‘about’ disabled people and instead develop a reflexive, engaged and upskilled research community. We need everyone (including researchers) involved in research actually led by disabled people’.

Ellen Fraser-Barbour

1. Vision and purpose

The vision for the National Disability Research Partnership (NDRP) is to facilitate a collaborative and inclusive disability research program that builds the evidence for developing policy and practice decisions.

It should aim to achieve this by funding research that is informed by a NDRP research agenda which has been developed with stakeholders; ensuring all research is inclusive of people with disability; building disability research capacity; and supporting the uptake of research findings into policy and practice. Sharing knowledge and evidence is key to the impact and success of NDRP.

2. The journey to the NDRP

Australia has seen unprecedented change in disability policy over the last decade, with the introduction of the National Disability Insurance Scheme (NDIS), the National Disability Strategy 2010-2020, and the subsequent Australia’s Disability Strategy 2021-2031[1]. Investment in research funding and capacity to date has not matched policy ambitions. However, the positioning of NDRP as integral to the new Australia’s Disability Strategy 2021-2031 offers the prospect of this now changing. Further, the kind of research partnership that the NDRP aims to achieve is something the disability community has been advocating for many years.

In 2019 researchers, disability advocates, governments and service providers came together to submit a proposal to the Medical Research Future Fund for a National Disability Research Partnership. While this application was unsuccessful, the Australian Government recognised the enormous opportunities presented by disability research funding and invested in the establishment of the NDRP. A grant of $2.5 million was awarded to the Melbourne Disability Institute at the University of Melbourne to lead a two-year Establishment Phase. This phase has been steered by a Working Party made up of advocates, academics and independent advisors, with six of the 13 members being a person with disability. The Establishment Phase ran from June 2020 to June 2022, and was tasked with setting up the structure and processes for a longer-term disability research partnership in Australia.

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[1] Australia’s Disability Strategy 2021-2031. Link here: Disability Strategy

The Working Party reached out to the disability community for advice and feedback on how a National Disability Research Partnership could best be established. The key outputs from the NDRP Establishment Phase were:

- guiding principles
- a future governance structure
- a research agenda
- a plan for developing Australia's disability research capacity
- a commitment to inclusive research
- and a number of research projects funded through an open funding round designed to demonstrate and improve outcomes for people with disability, and also provide practical experience to inform and improve future NDRP processes for commissioning research, building capacity and knowledge translation.

> "It has been a privilege and a pleasure to have been engaged in the development of the NDRP. There were deep seams of experience, knowledge and mutual respect within the working party that provided rich and reflective discussion. It has swelled my hope for the future of research led by people with disability in Australia."
>
> Keran Howe

This report includes a series of recommended ways forward, along with learnings and reflections from the Establishment Phase.

Next steps

In December 2021, the Australian Government announced funding of $12.5 million to fully establish a National Disability Research Partnership over 2022-23 to 2024-25. The Albanese Labor Government has pledged to "build evidence with $15 million for a National Disability Research Partnership"[2].

Between the end of the Establishment Phase and the start of the enduring NDRP, an eight-month Transition Phase from August 2022 to March 2023 will allow the NDRP Working Party to continue its work and ensure the enduring NDRP is ready to start from March 2023. The NDRP is committed to ongoing evolution and will work together with the disability community to refine and improve these recommendations, before the NDRP becomes a fixture of the disability landscape from early 2023. The Australian Government commissioned an independent evaluation to look at what the NDRP Working Party has done to help establish the NDRP which will be released by the Department.

As foreshadowed in the NDRP Governance documents and subject to consideration of the recommendations by Government, during the Transition Phase individuals and organisations may be invited to become members of the NDRP, and members encouraged to nominate for the elected positions on the Board of Directors. The Working Party will advise on the inclusive nomination and voting process to appoint the seven elected Directors of the Board, and will seek nominations for the two government-appointed positions.

The Working Party will also undertake another round of consultation to evolve and refine the recommendations set out in this document. Many stakeholders have only engaged with parts of the

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[2] Better Support for People Living with Disability | Policies | Australian Labor Party (alp.org.au)

NDRP, rather than the whole NDRP. The Working Party has agreed that workshops plus online feedback are the best way to undertake further consultations, and that to do this process justice required more care, time and attention than was available at the end of the Establishment Phase, when all reports had been prepared. The Transition Phase provides an important and timely opportunity to run a thoughtful and inclusive process that engages each of NDRP's stakeholder groups to refine the fundamental recommendations made in this report.

Community Feedback

We are very grateful to everyone who took the time to contribute to our work through surveys, consultations, or by sending us their ideas during the two-year Establishment Phase. All of this has been carefully considered as we have shaped our recommendations. A summary of all the feedback can be found on the NDRP website at this link: Feedback.

3. Working Party

The Working Party was made up of advocates, researchers and independent advisors. The initial members of the Working Party were involved in writing the early funding application to the Medical Research Future Fund. Between June 2020 and September 2020, the Working Party consisted of Anne Kavanagh, Bruce Bonyhady, Jackie Leach Scully, Gwynnyth Llewellyn, Gordon Duff, Helen Dickinson, Keran Howe, Lesley Chenoweth and Elizabeth Kendall. A call for expressions of interest was released in July 2020 for additional members with disability, which led to the appointment of Christina Ryan, Ellen Fraser-Barbour and Scott Avery in September 2020. Ian Watt joined in February 2021. Six of the thirteen members have a disability. You can find out more about the Working Party at this link: [Working Party bios.]()

Any Working Party member who was not employed through a university received an honorarium for their involvement.

- Anne Kavanagh, Co-Director NDRP, University of Melbourne
- Bruce Bonyhady, Co-Director NDRP, University of Melbourne
- Christina Ryan, Independent Advisor
- Ellen Fraser-Barbour, Independent Advisor
- Gordon Duff, Independent Advisor
- Helen Dickinson, University of New South Wales Canberra
- Jackie Leach Scully, University of New South Wales
- Keran Howe, Independent Advisor
- Lesley Chenoweth, Griffith University
- Scott Avery, Independent Advisor
- Elizabeth Kendall, Griffith University
- Ian Watt, Independent Advisor

> "The large presence of disabled people in the room was very valuable. Often the members with disability were consulted first on agenda items before the rest of the Working Party contributed their views. I have never participated in a group which has done this before, over decades of participating in various reference groups, working parties and boards. The Working Party embraced the concerns of the disabled members, even when those concerns were difficult to hear and challenging to implement."
>
> Christina Ryan

4. Recommendations

Based on feedback received through the processes described in this report during the two-year Establishment Phase, the NDRP Working Party has developed draft recommendations for how a fully established NDRP could operate. This document outlines all the recommendations, which will be submitted to the Australian Government for consideration.

NDRP Principles

- All NDRP activities and decisions should be guided by the NDRP Principles.
- The NDRP Principles should be incorporated into the NDRP's constitution.
- Once the NDRP is established, its principles should be regularly revised to ensure they remain in step with the ambitions and language preferences of the disability community.

Governance

- Establish the NDRP as a stand-alone, independent not-for-profit organisation, as described in the report *Governance Structure for the NDRP*.

Commitment to inclusive research

- The NDRP should only fund inclusive research that is done by and with people with disability, as reflected in one of NDRP's Principles: collaborative research that recognises, values and centres the knowledge of people with disability in research.
- The NDRP should set high standards for inclusive research and support and promote best practice inclusive research methods.

Research agenda

- The NDRP research agenda should provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.
- The NDRP research agenda should guide the allocation of research funding by the NDRP.
- The NDRP research agenda should complement other disability research initiatives in Australia.

Funding research

- The NDRP should fund research through open funding rounds, guided by the NDRP research agenda.
- The NDRP should facilitate and fund commissioned research through a commissioned research framework (subject to further piloting and refinement).

Building research capacity

- The NDRP should implement a research capacity building strategy that aims to achieve effective, system-wide disability research capacity.

Knowledge translation

- The NDRP should develop a knowledge translation framework that aligns with its purpose and principles.
- Knowledge translation should be a key NDRP activity, making research findings from research facilitated by the NDRP available in accessible, useful, timely and targeted ways.

Community of Practice

- The NDRP should implement an accessible Community of Practice model to bring people together to share learnings, build capacity, promote and support inclusive disability research.

Communication

- All NDRP communications should be accessible, align with the NDRP communication principles and provided in a range of formats.
- The NDRP should continue to develop and improve communication practices by listening, learning from others and adapting.

Glossary of terms

Words and language are powerful tools. We recognise the diversity of disability and of talking about disability. Language is always evolving and the NDRP Working Party is committed to being respectful, inclusive, and open to change. We use person-first language in this document and refer to people with disability. This is a contested area and some people prefer to use identify-first language.

Below is a glossary of terms that explains the language and terms used throughout this document. More terms can be found at this link: NDRP Glossary.

- **Advocacy organisation**: Advocacy organisation refers to an organisation that unites a group of people to change discriminatory norms, laws and/or policies in order to promote and defend their human rights. There are different types of advocacy. For example, an advocacy organisation may provide individual advocacy, which means standing beside a person to support them in changing discriminatory attitudes or practices that violate their human rights. On the other hand, systemic advocacy promotes policy or practice changes that improve outcomes for many people.

- **Ally:** Someone who aligns with and supports the cause of an individual or group (in this report we mean the cause of people with disability) and uses their privilege to learn from that individual or group and promote their human rights or their cause.

- **Carer**: A person providing unpaid care and support for a person with disability.

- **Disability community:** The term that has been chosen to encompass people with disability, families of people with disability, their carers, allies and support workers.

- **Disabled People's Organisation (DPO):** An organisation owned and run by people with disability. Its board and staff are at least 50% people with disability, plus the CEO (or equivalent) is a person with disability. DPOs have representative status for people with disability.

- **Disability Representative Organisation (DRO):** Membership-based organisations run by or on behalf of a specified group of people with disability.

- **Enduring NDRP**: The long-term organisation that will officially start in early 2023. This comes after the Establishment Phase and the Transition Phase, to become an enduring fixture of the disability landscape in Australia.

- **Establishment Phase:** The two year period from June 2020 to June 2022, for which the Melbourne Disability Institute received funding from the Department of Social Services (DSS). The Establishment Phase has undertaken the groundwork for a longer term partnership and was funded by DSS to deliver five key outcomes: a governance model, a research agenda, a guide to NDRP research, a plan to build research capacity and a pilot funding round.

- **Inclusive research:** Research that is done by and with people with disability. It is research that involves and respects people with disability. It is accessible and easily understood.

- **Knowledge translation**: The creation, synthesis, and dissemination of knowledge (evidence) in a user-friendly and accessible way that is relevant to and meaningful for people who will use the knowledge. Also referred to as research translation, or knowledge exchange.
- **Peak bodies:** A peak body is a non-government organisation whose membership consists of smaller organisations with a shared purpose.
- **People with disability:** The term 'people with disability' has been chosen, rather than 'disabled people', as the most common accepted usage in Australia. However, it is recognised that many people with disability now prefer the term disabled people.
- **Research capability:** An individual person's research knowledge, skills and attitudes or interest. The key difference compared to research capacity is that capability is focused on strengthening an individual's research skills or ability.
- **Research capacity:** The extent to which teams, organisations and disciplines have the ability (research expertise, knowledge and skills) to undertake research activities and disseminate research findings, as well as the organisational culture, funding, infrastructure, time and incentives to do research.
- **Stakeholders:** People who have an interest and want to contribute. For the NDRP these include people with disability; their families, allies and supporters; academics; governments; mainstream and disability services; and other industries.
- **Transition Phase:** Between the end of the Establishment Phase and the start of the enduring NDRP, an eight-month Transition Phase will allow the NDRP to continue its work and ensure the enduring NDRP is ready to start from March 2023.

5. Guiding principles

The Working Party decided that a series of guiding principles was needed to frame the NDRP's goals and ambitions and inform all its decisions and activities. These principles were developed through much thought and consideration over the first year of the Establishment Phase, with advice from several external people on intent and wording. The principles draw on the human rights framework articulated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[3].

The Principles were published on 30 April 2021. The Working Party is committed to continuing to refine and improve the language of these Principles.

Principles preamble

The NDRP should support research that recognises the lifelong experience and contexts in which people are born, grow, live, work, age and die, and the wider set of forces and systems shaping the conditions of their daily life. People with disability come from many different backgrounds and communities and represent the rich diversity of human experiences and perspectives.

Some people with disability face barriers in communicating their goals and aspirations and in making decisions. This may include people with cognitive disability, young children, or others with episodic disability such as mental illness. We acknowledge the role that family, caregivers, allies or supporters may play in supporting decision making and facilitating expression of preference and will.

Many people with disability identify with multiple marginalised groups and may experience intersectional disadvantage because of gender, race, ethnicity, sexual preference, age and location. People with disability who experience intersectional disadvantage have even fewer opportunities to access services, ordinary community activities, decision making, or political and economic life.

Principles

Deliver high quality, collaborative research

- Become a world-leading driver of disability research that builds an evidence base
- Advance disability research in Australia by delivering on the National Disability Research Agenda
- Draw on expertise across Australia through collaborative research teams
- Australian policy to be informed by research and evidence

Recognise the knowledge of people with disability in research

- Inclusive research by and with people with disability who hold genuine decision making power
- Genuine, paid for, co-design with people with disability
- Research that addresses the priorities of people with disability
- Research which specifically addresses people with disability who:
    - require support to express their will and preference, and to implement their decisions
    - experience intersectional disadvantage

Value all forms of knowledge

- Recognise and value the knowledge that people with disability contribute to research based on their lived experience
- Respect for different sources and forms of knowledge

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[3] United Nations. "Convention on the Rights of Persons with Disabilities." Treaty Series, vol. 2515, Dec. 2006. Link here: UNCRPD

- Make knowledge accessible to the community in a range of formats

Build research capacity

- Build effective, system-wide disability research capacity
- Create career pathways and targeted support for researchers with disability
- Build capacity of the disability sector to create and use knowledge

> Our principles are ways of working that we think are the most important to reaching our vision. Our principles guide how research should be done, deliver high quality collaborative research, and also to recognise the knowledge of people with disability in research.
>
> Christina Ryan

Recommendations

- All NDRP activities and decisions should be guided by the NDRP Principles.
- The NDRP Principles should be incorporated into the NDRP's constitution.
- Once the NDRP is established, its principles should be regularly revised to ensure they remain in step with the ambitions and language preferences of the disability community.

Next steps

- The NDRP Principles will be reviewed and revised during the Transition Phase, taking into account some of the feedback already received on the order and level of detail for each principle plus additional feedback which is expected during the Transition Phase.

6. Governance: who should run the NDRP and how?

Below is a high level summary of the proposed governance structure for the future NDRP. For a detailed description, please see the accompanying report *Recommended NDRP Governance Structure*.

The recommended governance approach for the NDRP is designed to reflect the NDRP principles and the priorities of stakeholders that were expressed in consultations. Decision making powers will sit with the NDRP members, Board of Directors and partners.

Membership

Membership should be open to any individual or organisation that falls within one or more of the following categories:

- person with disability
- family member, ally or supporter of a person with a disability
- advocate or representative of people with disability, their families and carers
- service provider
- researcher with an interest in disability
- Commonwealth, state or territory government.

The membership fee is expected to be around $100 per year and might be tiered for different sized organisations. All members should be required to demonstrate that they uphold the NDRP principles. Universities and research institutes should also be asked to demonstrate a commitment to building research capacity and to inclusive ethics processes.

Board of Directors

The Board should be skills-based and include up to 12 directors. Of these, seven directors should be elected by members, three should be independent and two appointed Government representatives. The NDRP should recognise the knowledge of people with disability and the value of broad representation. Key skills held by directors should include capacities and experience that help deliver a meaningful, productive and sustainable NDRP and skills in networking, negotiating, conflict resolution and governance.

The following minimum requirements should apply to the Board, noting that at least some of the Directors will need to fall into more than one of these categories:

- At least 50% people with disability (including an independent Chair)
- At least 25% university, community, research institute or academic researchers
- At least 25% family, care giver, supporter or ally of people with disability, or disability service provider
- At least 15% First Nations or people from culturally and linguistically diverse backgrounds.

Committees

The Board should have the following four committees:

- **Audit and risk committee**: Advise the Board on accounting, reporting practices and external and internal audits
- **Governance and nominations committee**: Advise the Board on good governance practices, embedding the NDRP principles, terms of reference and procedures for Board committees
- **Membership and partnership committee**: Seek opportunities at state, national and international level to expand membership and member benefits and build new partnerships

- **Research and development committee**: Advise on research priorities and knowledge translation, develop a collaborative and strategic research program and consider ways to increase uptake of evidence in policy and practice development.

NDRP Independent Advisory Council

NDRP should establish an Independent Advisory Council to provide advice to the board on a range of topics and link to the wider disability community and sector. Membership of the Advisory Council should be broad and include people with disability, their representative organisations, families, carers, friends and supporters of people with disability, peak bodies, disability service providers and researchers.

Recommendations

- Establish the NDRP as a stand-alone, independent not-for-profit organisation, as described in the report *Governance Structure for the NDRP*.

Next steps

- Seek members: set up membership categories and database, develop the application and review processes, and welcome new members.
- Invite members to nominate for the Director positions, and run an inclusive process to appoint the seven elected Directors through nominations and voting.
- Seek nominations from Government for the two government-appointed Director positions.

7. Commitment to inclusive research

The NDRP should only fund inclusive research that is done by and with people with disability. This commitment is reflected in one of NDRP Principles: collaborative research that recognises, values and centres the knowledge of people with disability in research.

'By and with' means a significant shift in the traditional power relationships between the producers and the subjects of research. Inclusive research is led by and/or conducted in collaboration with people with disability, rather than on them; it recognises, values and centres their knowledge; and it ensures they are paid appropriately and supported effectively in their work. We refer to inclusive research, but this type of research has a variety of other names such as co-production, co-design, or co-research.

The engagement of people with disability can take multiple forms, and could be seen as occurring along a continuum encompassing:

- Full engagement of people with disability that are qualified academically, employed as lead researchers or in a research team and contributing to all aspects of the research process
- Full engagement of people with disability as community researchers or citizen scientists who are people with disability involved in research teams who engage in all aspects of the research project. Community researchers and citizen scientists contribute valued lived experience, community cultural knowledge and other ways of 'knowing' to the research process. The focus here is on contributing lived experience, rather than on academic or research qualifications.
- Inclusion of people with disability on advisory groups or reference groups to a research team throughout the research process.
- Inclusion and engagement of people with disability as consultants (usually via a single interview or focus group).

Central to inclusive research is that people with disability have genuine decision-making power at various stages of the research process. They may have more or less involvement at different stages, according to the individual project's methods and goals. The NDRP should encourage and challenge researchers to aim for 'full engagement' and to investigate and develop new ways of working inclusively with people with disability.

Characteristics and principles of inclusive research

There is no single model for inclusive research and, as noted above, no single descriptor as terms such as co-production, codesign and co-research are also used, but there are some key characteristics and principles that underpin research by and with people with disability. Some of these are:

- People with disability have genuine decision-making power;
- Traditional power relations between researchers and participants are challenged;
- The knowledge of people with disability is recognised, valued and centred;
- The research addresses the priorities of people with disability and leads to real life benefits to the disability community.

Guidelines for Co-Production of Research with People with Disability

The Disability Innovation Institute at the University of New South Wales (DIIU) has produced two sets of guidelines for doing research inclusively with people with disability. These guidelines set out key benefits, principles and strategies that underpin their approach to co-producing research with people with disability. The content is drawn from a comprehensive review of the literature, the experience of leading inclusive researchers at UNSW, and input from community partner organisations of people with disability. The NDRP supports these guidelines and encourages researchers to make use of them and of other DIIU guidelines on specialised topics in inclusive research in the same series.

Click here to access the guidelines: Guidelines for Co-Production of Research with People with Disability and Doing Research Inclusively: Co-Production in Action.

What does inclusive research look like in practice?

Given the variety of ways people with disability can be genuinely involved in research, the following case studies provide real examples of how it can be done. These are not intended to be prescriptive, nor are they the best possible methods; the intent is to showcase some of a range of different approaches and demonstrate that inclusive research can be done in many ways.

Case study: Stepping out in the world: the new adulthood for Gen Zs with Down syndrome.

Research team: Associate Professor Rhonda Faragher, Dr Jan Lloyd, Ms Ruth Faragher, Mr Bobby Pate, Rebecca Flanagan, Alana Pettigrew, Mia Johnston and Michael Cox. The University of Melbourne

Project overview

In this project, researchers with Down syndrome gathered data on how young adults with Down syndrome experience their lives.

Expectations for young people with Down syndrome used to be very low: persistent myths and outdated views of the capacities of people with Down syndrome meant that opportunities to attend local schools, gain employment and live independently were rarely possible. This has changed. Now there is a new generation of people with Down syndrome who may experience life in new ways. The group of people born between 1995 and 2012 are referred to as Gen Z.

This project was co-designed with young people with Down syndrome and involved 26 interviews and five focus groups with people with Down syndrome, to understand how they live their lives. All data were collected through interviews and focus groups that were led by trained research assistants with Down syndrome.

> “It’s not about being kind or in any way tokenistic — this employment strategy is absolutely because these individuals are doing work that we simply cannot do without their contribution. We need their expertise and working with this group of people has been just brilliant.”

The outcomes of this research will be shared with the Down syndrome community, the research community, policy makers and professionals who interact with people with Down syndrome. This research will change how people understand the lives of young people with Down syndrome and start to tackle some of the barriers and attitudes that stand in the way of high expectations and better quality of life.

How was this project done by and with people with disability?

This project was one of the nine projects selected for funding through the NDRP’s pilot funding round. We selected this project because:

- The research team had four Chief Investigators, two of whom were young people with Down syndrome.
- It offered an additional four fully paid research assistant roles for individuals with Down syndrome.
- It thought carefully about building capacity and leadership of the research team. The researchers were trained in leading interviews and focus groups, supported by the more senior researchers who had a track record in teaching and working with young people with Down syndrome.
- All of the decisions were shared; the team met weekly to discuss the project and make decisions.
- The outcomes of this project will be shared in different ways to meet the needs of the various groups who will benefit from the information: events and presentations to the Down syndrome community; podcasts, lesson plans and professional development resources for professionals who interact with people with Down syndrome; and open access, peer-reviewed journal articles and conference presentations to the research community.

Reflections from the research team

This project built on previous work that has been undertaken at the University of Queensland. Designing research in collaboration with people with Down syndrome was not new, but employing a team of research assistants was. The team had a focus group discussion about what we valued and what was challenging in being involved in this research.

The research assistants said:

- “Being a research assistant has made me feel brave.”
- “I developed independence.”
- “I liked being paid. I got purple streaks in my hair with my first pay.”
- “I have learnt more about disabilities and more about chromosomes which I found interesting.”
- “I feel included. I work with nice people.”
- “I needed help with field work. I liked travelling.”
- “I want to become more confident. I am learning.”

In the media: ‘We’re awesome legends’: Global focus on UQ’s Down Syndrome research. Listen to the interview here

Giving voice to rural and remote First Nations NDIS participants who are Deaf or Hard of Hearing in the Northern Territory

Research team: Dr Alexandra Devine, Jody Barney, Dr Ashley McAllister, Dr George Disney, Yi Yang, Marie Huska, Dr Damien Howard, James Blyth. The University of Melbourne, Deaf Indigenous Community Consultancy, Phoenix Consultancy, Auslan Consultancy

Project overview

This project aimed to understand how First Nations people who are Deaf or Hard of Hearing living in rural and remote communities access and use NDIS plans. The project first developed and trialed accessible and culturally sensitive research approaches, and then used these approaches to better understand what factors influence access to the NDIS and use of plans.

The lived experiences of First Nations people who are Deaf or Hard of Hearing is not well represented in disability research or policy. Much of the existing NDIS-related research and reporting neglects on the experiences of Deaf participants, let alone the experiences of Deaf participants who also identify as First Nations. These experiences will not be understood unless research approaches are designed that are accessible and culturally appropriate, and community-based research partnerships are built.

This project co-designed and piloted research approaches that were designed to ask First Nations people about their experiences with the NDIS and make sure future research gives voice to First Nations people who are Deaf or Hard of Hearing. The development of research approaches and data collection was led by a Deaf Aboriginal person and involved input from other First Nations people who are Deaf or Hard of Hearing.

How was this project done by and with people with disability?

This project was one of the nine projects selected for funding through the NDRP's pilot funding round. We selected this project because:

- The research team had co-lead investigators: one with and one without disability.
- The project first focused on co-designing research methods to make sure they were inclusive, accessible and culturally sensitive.
- All data collected by people with disability.
- A key focus was making sure the findings from the research were shared with the community. Plain language summaries were developed in different formats, including easy-to-understand print materials, and videos with sign language, captioning and voice-overs.

Reflections from the research team

This project drew on the experiences of researchers with and without the lived experience of being Deaf or Hard of Hearing and belonging to First Nations communities. For the researchers without these lived experiences, it was an extraordinarily steep and transformative learning curve: not only in relation to enhancing our understanding about the diverse life experiences of First Nations people who are Deaf or Hard of Hearing, but also in learning to make all components of our research far more accessible and culturally safe. The project highlighted so many areas where we need more support for and investment in locally-led First Nations ideas and solutions, and we hope that our work contributes to this in the future.

Funding success

This project led to funding being awarded by the NDIS Quality and Safeguards Commission to Deaf Indigenous Community Consultation, in collaboration with Phoenix Consulting and the University of Melbourne, to co-design and develop online training modules. This training will build the capacity of NDIS service providers to provide culturally responsive and safe supports for the First Nations NDIS participants and their families who are Deaf or Hard of Hearing living in rural and remote communities.

Read the media release from Minister Shorten at this link: Disability support boosted by nearly $5M investment

Case study: Experiences of police apprehension for psychosocial disability: a co-designed investigation.

Research team: Rory Randall, Dr Chris Maylea, Fiona Nguyen, Hamilton Kennedy, Professor Stuart Thomas, Associate Professor Robyn Martin, Lucy Bashfield, Simon Katterl, Meena Singh. Royal Melbourne Institute of Technology, Victorian Mental Illness Awareness Council

Project overview

A police callout for psychosocial distress occurs every 12 minutes. More than 6% of all people taken to hospital for psychosocial distress are taken by police, by force. This is ten times higher than for physical health issues. This project aimed to understand the experiences of people who have been apprehended by police under mental health legislation and ask them about preferred alternative crisis responses. This project took a human rights and co-production approach to bring the voices of people with psychosocial disability into the policy discussion and influence policing and other crisis response practices.

The research team was conceived and led by consumer academics; people who experience or are labelled with psychosocial disability and use their experience in research. The consumer academics were supported by researchers with expertise in co-production, mental health and policing, and guided by the 'Been Apprehended Leadership Group' which was made up of people who reflect the diversity of experiences and identities of people who experience or are labelled with psychosocial disability. The Been Apprehended Leadership Group space was designated for only those with psycho-social disability, inviting other team members in for their expertise when needed. The Been Apprehended Leadership Group made all strategic decisions and provided project oversight and governance. This project aimed to go beyond parity and support leadership of people with lived experience.

Findings from this research led to the development of a training resource for guiding police interactions with people experiencing psychosocial distress. Partner organisation Victorian Mental Illness Awareness Council (VMIAC) used the findings from this project to advocate for disabled people's experiences to inform ongoing reforms and hosted the launch of the final report. VMIAC also helped disseminate findings, both technical and plain language, through social and traditional media.

How was this project done by and with people with disability?

This project was one of the nine projects selected for funding through the NDRP's pilot funding round. We selected this project because:

- This project was thought of, designed and led by people with psychosocial disability, including people with experiences of police apprehension. The lived experience project leads were supported researchers without disability.
- This project aimed to challenge traditional power dynamics. It identified and addressed issues of power and control, allowed the time and created the conditions for co-production and genuine collaboration. All decision-making power was relinquished by researchers without disability, and held by researchers with disability and the Been Apprehended Leadership Group.
- The Been Apprehended Leadership Group was supported with the necessary training and various strategies were used to truly support and acknowledge their leadership of the project.

Reflections from the research team

From the Been Apprehended Leadership Group:

- "This project has been pleasant, flexible, respectful, diverse, inclusive and thoughtful I feel like my input is considered and taken seriously."
- "Every co-production process is well orchestrated and takes into account where people are at."

- “I’ve appreciated the time I have been given to reflect and contribute. It has been great to work so closely alongside academics and to see how our ideas are complementary.”
- “I’ve really, really enjoyed my participation. I like the way meetings are run, the project team have done a good job of making people feel included. I especially appreciate the efforts to support our personal needs.”

Reflections from the academics who were involved:

- “This project had true lived experience leadership. I have been involved in a range of projects claiming lived experience leadership, but none have demonstrated the integrity and fidelity this project has. I believe this has meant that those who do not occupy a lived expertise position have been able to learn, reflect and grow in their research perspective and practice. There was a valuing of partnership and mutuality. While there has been recognition of the different stances we all occupy (including the BALG), there has been a partnership approach based on respect and curiosity to explore differences, similarities, expertise and contributions.”
- “I have learned some best practice ideas, methods and processes to take forward into future projects and importantly to consider and implement from the design stages.”
- “The support of the NDRP meant we were able to bring to life ideals of consumer perspective, co-produced research. It was a privilege to be able to set the conditions for authentic mutual collaborative work and see the benefit that brought for the project team, research participants and for the data we produced.”

Case study: "Saying who you are": Identifying best practice to support positive identities for LGBTQ people with intellectual disability.

Research team: Dr Amie O'Shea, Sharon Brennan-Olsen, Cameron Bloomfield, Diana Piantedosi, Caderyn Gaskin, James Lucas, Sarina Avramovic. Partners: Rainbow Rights & Advocacy, Inclusion Melbourne

Project overview

This project came out of a longstanding partnership and working relationship, and many conversations about the underrepresentation of LGBTQ people with intellectual disability in research and advocacy and the need for an evidence base for best practice in supporting LGBTQ people with intellectual disability.

The rights of LGBTQ people with intellectual disability to experience equal and non-discriminatory opportunities for self-expression are well supported by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and echoed in Australia's Disability Strategy.

The project focused on the voices of LGBTQ people with intellectual disability to consider the processes, systems, interventions, supports or frameworks which exist or are desired in people's lives and how they enable or restrict the opportunity to "say who you are". The research methods in this project maximised the opportunity to hear from LGBTQ people with intellectual disability to identify practices and supports. A focus group phase led by Rainbow Rights & Advocacy asked open-ended questions such as 'what helps you to feel good about being LGBTQ?' This resulted in the creation of 22 statements which were organised into four pillars of best practice: *recognition, relationships, place and community*.

A co-designed, modified Delphi method resulted in consensus for the final 17 statements. The Delphi recognised the value of lived experience and recruited a panel made up entirely of LGBTQ people with intellectual disability.

The four elements of best practice and the statements produced through the research are presented in a poster and tea towel to be shared widely with LGBTQ and disability organisations, service providers, policy makers and advocates. Rainbow Rights & Advocacy are preparing a series of posters featuring the statements, for display during their art exhibition in December 2022.

How was this project done by and with people with disability?

This project was one of the nine projects selected for funding through the NDRP's pilot funding round. We selected this project because:

- The project team, made up of LGBTQ people with intellectual disability, service providers and researchers, worked together from the start: conceptualising, designing, implementing and disseminating the research
- Rainbow Rights & Advocacy is a co-initiator and partner organisation: principal investigator Cameron Bloomfield is the spokesperson for Rainbow Rights & Advocacy and identifies as a LGBTQ person with intellectual disability.
- The methods (focus groups and Delphi) were co-designed and all participants in this research (n=24) were LGBTQ people with intellectual disability
- The research team and the Advisory Panel (n=14) were LGBTQ people and/or people with disability
- LGBTQ people with disability were sought for the two research positions identified for this project.
- Advisory Group meetings were chaired by a LGBTQ person with intellectual disability and all discussion was held to cognitive access standards managed collectively by the group.

The research clearly demonstrates that LGBTQ people with intellectual disability are reliable sources of information about their lives; this message is reinforced by the role of researchers with disability, the exclusive focus on LGBTQ people with intellectual disability as participants, and LGBTQ people and/or people with disability as the support team to enable the research.

Reflections from the research team

- “As an early career researcher, this work was a privilege. We developed a unique series of research outputs which contribute to both the topic and to the wider field of inclusive, collaborative or co-designed research. I suspect it will forever remain one of the highlights of my professional career.” *Amie O’Shea, Chief Investigator and project lead*
- “This is my first ever time of being a Chief Investigator and my job is just my lived experience. I liked in this research teaching people along the way, for example teaching Diana how to work things out in easy English. This gave me a privilege to share my knowledge even to an academic. Not many people with an intellectual disability will ever have the chance to do something like that. Most times when academics write papers about people with disabilities it doesn’t include the people with disabilities. This project has been run with a Chief Investigator who has an intellectual disability. There should be more projects that are run like this. I felt that being involved in this project I was equally respected and not used as a token symbol just because I have an intellectual disability. Everyone respected my barriers, for example I have trouble with typing words in emails and it’s easier for me to pick up the phone and call someone or send a message and ask them to call me and they were all happy to do that. I would love to do it again”. *Cameron Bloomfield, Chief Investigator and Rainbow Rights & Advocacy representative*
- “CI Bloomfield has taught me a different way of listening. I am more deliberate in my communication as a result. CI O’Shea has built strong relationships with the stakeholder groups she collaborates with in her research. Among the many lessons I take from our work together on this project, the imperative for genuine partnerships and co-design approaches have been the most valuable. Additionally, I’ve developed greater skills of knowledge translation. I understand that messaging for a general audience happens in layers. The process of presenting our findings, clarifying the purpose and to whom the work is intended to target, has changed the direction of my own PhD and indeed, my professional career more generally. The results yielded with CI O’Shea’s leadership demonstrate the value of nurturing collaborative (community based) partnerships and the potentialities in embedding true intersectional diversity in research team composition”. *Diana Piantedosi, Associate Research Fellow*

In the media

Click here to read the Conversation article :‘What matters is hope, freedom and saying who you are.’ What LGBTQ+ people with intellectual disabilities want everyone to know”.

Inclusive Research and Ethics

The history of research exploitation of people with disability means that researchers must carefully consider how they work with people with disability. Ethics committees are mindful of the potential for exploitation and often take a protective attitude towards people with disability involved in research, considering them to be a vulnerable group, indeed often questioning whether they should be asked to participate in research. If research processes are aligned with the principles laid out in Article 3 of the UNCRPD, and appropriate supports are in place, both exploitation and paternalism can be avoided.

Obtaining ethical approval is noted as one of the major challenges to engaging in inclusive research. While recognising the right of people with disability to be involved in research, many research ethics committees are nevertheless still unfamiliar with the methods of inclusive research and the distinctive ethical issues they raise.

The NDRP should work with ethics committees, funding bodies, universities, and research institutes to educate ethics committees and advocate for more inclusive practices. The NDRP should work with the Disability Innovation Institute at University of New South Wales during the Transition Phase to support the development of guidelines on inclusive research for ethics committees and will engage with funding bodies and ethics committees to advocate for an individual's right to participate in matters which influence their lives and to do so in a safe, respectful and ethical environment.

Respectful engagement with Disabled People's Organisations

One way that research can be done by and with people with disability is by partnering with Disabled People's Organisations (DPOs), representative organisations or advocacy organisations. We talked to a range of organisations about the challenges involved in research partnerships, and how to overcome these to develop ongoing, respectful engagements. See *Building effective system-wide disability research capacity in Australia* and the Community of Practice report in Appendix G for a detailed description of these discussions.

The NDRP should:

- Acknowledge and provide sufficient resources for the time and effort needed for inclusive research.
- Create pathways for DPOs and advocacy organisations to be involved from the outset of the research process so that shaping research can be disability-led.
- Build capacity for undertaking and engaging with research in DPOs and advocacy organisations.
- Build and maintain relationships with DPOs and the advocacy sector.
- Give DPOs and advocacy organisations advance warning of funding rounds, as they are often inundated with requests when disability-specific funding rounds open. If possible, hold funding rounds at a consistent time each year so organisations know when to expect it.
- Develop a process to connectDPOs and researchers, and helps DPOs identify researchers with expertise in certain areas.
- Tell the stories of people working as co-researchers – to share the benefit and value of this role, but also to raise awareness of the opportunity for involvement.
- Map the DPO, representative and advocacy sector to provide information about organisations' membership, interest areas, capacity for research, regular rhythm of meetings and newsletters. This would assist with early and more effective involvement of people with disabilities, matching organisations and researchers and encouraging collaboration between organisations.

Useful resources

There are many useful resources, in addition to the UNSW Guidelines, that provide guidance and advice on how research can be done by and with people with disability. Some of these resources are listed below.

Participatory and Inclusive Autism Research Practice Guides

Autism Cooperative Research Centre (Autism CRC)

Participatory and Inclusive Autism Research Practice Guides provide researchers with the tools to ensure end-user driven autism research that delivers practical outcomes and resources that benefit the community. These guides, developed by the Autism CRC, outline the benefits of participatory research and provide guidance to enhance the uptake and quality of participatory and inclusive research practices. Click here to access the guides: Participatory and Inclusive Autism Research Practice Guides.

Making research inclusive of people with disabilities

Research for Development Impact Network

The Research for Development Impact Network, Nossal Institute for Global Health, and CBM Australia collaborated together to provide advice and practical steps for practitioners, researchers and policymakers; case studies, checklists, and tools to ensure inclusive practices in the research cycle. Click here to access the resources: Making research inclusive of people with disabilities.

Reflections and learnings

> "Inclusive research is not just about disability research. I look forward to the day when all research that impacts Australian people includes the views of, and evidence about, Australians with disability."
>
> Keran Howe

> "The emphasis on inclusion being an underpinning of disability research has become a core principle of the NDRP. We hope that it changes the landscape of who does research about disability over the decades to come. That the work is designed, driven, and used by disabled people so that we move from being the objects of research to becoming the owners of research, including its practical uses in improving equality for disabled people"
>
> Christina Ryan

Researchers on the nine projects funded by the NDRP in its pilot funding round were invited to share their reflections and learnings in their final reports. The following are some of the key reflections from research teams, in their own words.

- Research participants regularly gave feedback on the importance of being able to speak about the experiences they had had and how comfortable they had felt by having researchers with lived experience interview them.

- The project would not have been possible without taking an inclusive and co-designed approach. We were completely reliant on the Co-Lead Investigator's lived experience and connections with communities to engage in yarning with the project participants.
- Overall, two-way capacity building of bi-cultural understanding and inclusive research of the team was strengthened through the inclusive nature of the project.
- Authentic inclusion of researchers with intellectual disability benefited from having one project member dedicated to guiding and facilitating their inclusion in all aspects of a project.
- One of the primary benefits of being inclusive was the inside knowledge and vested interests of the co-researchers. Another benefit was the co-researcher's personal and professional development. In the words of one co-researcher:
  "I found that working with others on the team has been great because everyone has been very nice and supportive of one another. I have learnt new skills/knowledge during the project such as creating reports on our findings, doing focus group presentations, 1:1 interviews…"
- It must be acknowledged that employing people with intellectual disabilities requires considerable support. Our university has moved to automated processes for most administrative systems such as HR. Onboarding information and processes were not accessible. Individuals were required to access emails and enter hours for pay on systems that were password protected. This made assisting staff time-consuming and challenging.
- Working with disability organisations from the outset made research translation a consideration throughout the study and ensures outcomes will be of use to the community. The partnership with disability organisations also enhanced the inclusive nature of the project.
- The research was designed on a premise of intersectional inclusion – it would not have been possible to do this work without it. This meant explicitly creating a culturally appropriate and safe space that embraced all genders and sexualities, as well as all levels of cognitive and other forms of ability. The former was a learning opportunity for the people without intellectual disability, who are rarely asked to share their personal selves in the same way that people with intellectual disability routinely are.
- Resources were allocated to supporting Peer Researchers (LGBTQ people with intellectual disability involved on the research team) and participants (LGBTQ people with intellectual disability who participated in the research). This included providing phone call reminders of appointments, support navigating online spaces, creating easy English meeting agendas, advocacy or advice within university systems and more.

Recommendations

- The NDRP should only fund inclusive research that is done by and with people with disability, as reflected in one of NDRP Principles: collaborative research that recognises, values and centres the knowledge of people with disability in research.
- The NDRP should set high standards for inclusive research and support and promote best practice inclusive research methods.

Next steps

- **Work with UNSW Disability Innovation Institute to support the development of guidelines for ethics committees on disability inclusive research.**

- **Work with peak bodies, DPOs and advocacy organisations to map the skills and interests of the advocacy sector.**

8. Research agenda

See accompanying report: *Preliminary Research Agenda for the National Disability Research Partnership for more information.* This report includes the process, context, preliminary agenda and next steps for the NDRP research agenda, which is intended to guide the allocation of research funding by the NDRP over a ten-year time period.

The NDRP research agenda is designed to advance the capacity for Australia to meet its obligations as a signatory to the United Nations Convention of the Rights of Persons with Disability (UNCPRD), and to align with and advance the NDRP Principles. The research agenda builds on decades of disability research and policy work that provide the foundation for this agenda, and seeks to support government initiatives such as Australia's Disability Strategy and the First Nations Disability Sector Strengthening Plan.

A preliminary research agenda was developed over a two-year period through a multi-step process. First, the NDRP Working Party appointed a consortium led by the University of Sydney to undertake a three-phase process to map Australian disability research, survey consult with stakeholders and initiate a process to synthesise and refine findings. The large consortium included academics from across Australia and non-governmental organisations, including Disabled People's and Representative Organisations. A sub-committee of the Working Party drew on the Consortium's findings and mapped these to the outcome areas and policy priorities of Australia's Disability Strategy.

The preliminary research agenda presented in this report will be expanded and refined in consultation with stakeholders. Subsequently the NDRP Working Party will produce a fit-for-purpose NDRP research agenda which will be made publicly available once the new NDRP entity is established.

It is anticipated that the completed NDRP research agenda will aim to encourage research focused on policy and practice design. It will be inclusive, driven by the NDRP principle of research by and with people with disability. It will emphasise that research should contribute to the evidence base to inform future systems reform, policies and programs. It will provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.

Recommendations

- The NDRP research agenda should provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.
- The NDRP research agenda should guide the allocation of research funding by the NDRP.
- The NDRP research agenda should complement other disability research initiatives in Australia.

Next steps

- **Expand and refine the Preliminary Research Agenda in consultation with stakeholders to produce a fit-for-purpose NDRP research agenda during the Transition Phase.**

9. Funding research

The NDRP should facilitate research in one of two ways: through **open funding rounds** designed to address the priorities in the NDRP research agenda, or through research that is **directly commissioned** and funded by a stakeholder. A large portion of the NDRP's funding will be used to support research through the open funding rounds.

The NDRP should work with the Australian Research Council, the National Health and Medical Research Council and other funding bodies such as Australia's National Research Organisation for Women's Safety Limited (ANROWS) and Australian Housing and Urban Research Institute (AHURI) to influence the focus of their funding rounds. This section describes the ways in which research that falls under the NDRP should be funded.

Open funding rounds

1. Focus of funding round determined from research agenda
2. Call for proposals developed and advertised widely
3. Proposals reviewed against selection criteria and NDRP Principles
4. Research projects undertaken
5. New knowledge shared

Directly commissioned research

1. Organisation wishing to commission research approaches the NDRP.
2. Four key conditions must be agreed to prior to NDRP involvement
3. Phase 1: The NDRP works with commissioner to understand the issue in question and frame the research question
4. Phase 2: Research projects undertaken
5. Phase 3: New knowledge shared

9.1. Open Funding Rounds

The NDRP should run regular open funding rounds to address the priorities set out in the NDRP research agenda. Research must be done by and with people with disability, align with the NDRP Guiding Principles, and address the specific focus of the funding round. Applications should be accepted from any incorporated association in Australia.

Applicants should be invited to submit proposals for research projects that address the priorities for that funding round. Projects may be short, medium or long term. The timeline restrictions that applied to the 2020 pilot funding round will not apply to future funding rounds. Selected projects will ideally provide a combination of quick solutions and longer, strategic approaches to solving long-term problems.

The funding rounds should be advertised well ahead of time and circulated widely through the NDRP newsletter, social media channels, peak bodies and grant advertising platforms. Promotion of the funding round should target the disability community.

The pilot funding round held during the NDRP Establishment Phase received 123 applications and was able to award $1 million. Of the 123 applications, nine were selected for funding. The process, learnings, template documents and conflict of interest management strategy are all detailed in the appendices of this report:

- Appendix A: Pilot Funding Round Process and Learnings
- Appendix B: Call for proposals template
- Appendix C: Frequently asked questions
- Appendix D: Conflict of interest
- Appendix E: Post-funding round survey results
- Appendix F: Applying NDRP principles to making decisions about funding applications

Unresolved challenges

All the learnings from the pilot funding round are set out in Appendix A. The following challenges remain unresolved and should be addressed before the next funding round:

- Better definition of 'involvement of people with disability' and clearer standards against which to screen this. Consider the continuum of involvement and be clearer about the requirement for full engagement.
- Consider weighting of selection criteria. The decision to weight all criteria equally caused some difficulty in the review process.
- Have a tie-breaker process for deciding which proposal to prioritise when two or more are rated the same. A key issue will be whether research quality trumps inclusivity, or vice versa.
- Find an acceptable compromise when an excellent project on an important topic is proposed but there is no person with disability available to be a researcher or project lead; inflexibility here could lead to a situation where a small number of potential researchers are overloaded, or valuable research goes unfunded. What is the compromise over the next few years while capacity is built up?
- Find a process that best involves stakeholders such as policy makers, service providers or advocacy organisations in the review process.

Characteristics of a good application

One of the learnings from the pilot funding round was the need to detail the characteristics of a good application. An initial version of this is included in Appendix A and should continue to be refined over the course of the NDRP.

9.2. Commissioned Research

In some circumstances the NDRP may be asked by government departments or other stakeholders to address a particular issue, that may fall outside the priorities of the open funding rounds. In this case the NDRP should have a separate process through which it can bring together people with disability, researchers and other stakeholders as needed for collaborative research on the issue in question. This type of research is referred to as commissioned research throughout this document.

Proposed process

Over time, the NDRP will trial and evolve its processes for research that is directly commissioned by stakeholders. The following process is proposed as a starting point and closely resembles the Australian and

New Zealand School of Government (ANZSOG) approach to commissioned research. The ANZSOG process has been developed and refined over many months, and ANZSOG has experience with this process that the NDRP can learn from. Their model offers a good example for the NDRP to follow. ANZSOG has shared their learnings and given their permission for the NDRP to consider using and adapting their process.

This is a suggested way forward, not yet piloted in the context of the NDRP, and requires further thought and refinement.

Conditions

To ensure all research facilitated by the NDRP is in line with the NDRP vision and principles, the stakeholder who is funding the research should be required to agree to four conditions:

1. The research will be done in accordance with NDRP Principles
2. The funder acknowledges that genuine inclusive research takes time. The funder will have to negotiate and agree the timeline with the NDRP.
3. The funder must commit to working with the NDRP on shaping the research question so that it can best address the issue and avoids duplication.
4. The funder must agree to research outputs being made publicly available through academic publications, mainstream media and in a range of accessible formats (see knowledge translation strategy).

It is not anticipated that all disability research in Australia will be commissioned through the NDRP. In many cases the funder would engage directly with the researchers as happens currently, and commission them without the NDRP being involved. In instances where the NDRP is approached to undertake commissioned research, the NDRP will need to decide if the research meets the conditions, what role NDRP will play, and whether the projects need to have specific policy or practice purposes.

Phases

Commissioned research could involve three phases: framing research questions, doing the research, and knowledge translation.

Phase 1: Framing Research Questions

Framing the research questions in a way that sets the project up for success is critical. Projects should provide useful answers, not just to the stakeholder who is funding the research, but also to people with disability and where appropriate their families, allies and supporters.

In this phase, the NDRP Research and Development Committee and people with disability should work with the funder to gain a good understanding of the issue they want to address and to frame the research questions. This phase may include a rapid review of evidence and in-depth discussions with the commissioner and other stakeholder, and will result in research questions, a ballpark budget and an indicative timeline for the research project.

Phase 1 could be led by the NDRP and funded by the stakeholder who is commissioning the research, or it could be led by an external research team, jointly identified by the NDRP and the funder, as part of a small funded project. It is a low-cost way to determine how much and what kind of research is needed to address the issue in question, and to ensure the research questions are framed in the optimal way.

Possible timeline: 6-8 weeks, noting some proposed research may require more time to frame the research questions depending on the complexity of the issues to be examined.

The outputs from this phase would be (1) research questions, and (2) approximate budget and indicative timeline.

Phase 2: Research Project

The scope and focus of the research project decided on in Phase 1 could then be written by the NDRP into an open or targeted request for proposals. The NDRP will also facilitate the application process, releasing the documents, answering questions and accepting applications. One possible way to do this is through a panel of trusted inclusive disability researchers, refreshed every year to make sure it is open to new researchers. Alternatively, the external research team identified in Phase 1 could be invited to submit a full research proposal.

Researchers submitting proposals would need to address selection criteria that detail how the research will be done in accordance with the NDRP Principles.

Once the successful team has been selected, they will undertake research to answer the research questions determined in Phase 1. During this phase, the funder may be involved in regular meetings and will receive interim updates on research findings. The NDRP will need to decide on its role: is it the facilitator of the relationship between the funder and the researcher, and the funder takes responsibility for managing the research implementation and delivery? Or does the NDRP take a more active brokering role and take responsibility for ensuring quality and timely delivery?

Contracts for this phase would depend on the answer to the above questions but could be between the NDRP and the researcher or between the funder and the researcher. Any new intellectual property created through this project should be owned by the funder, with royalty free licenses to both the NDRP and the researchers.

Timeline: would vary according to complexity of project and must allow sufficient time for inclusive research.

Phase 3: Knowledge Translation

Phase 3 would focus on ensuring the funder understands and can use the knowledge produced through the research. This could involve the analysis of research data and discussion about how the findings can best be shared. For example as reports, fact sheets, infographics, videos, etc. It could also involve discussions about what policy or practice changes might occur.

Recommendations

- The NDRP should fund research through open funding rounds, guided by the NDRP research agenda.
- The NDRP should facilitate and fund commissioned research through a commissioned research framework (subject to further piloting and refinement).

Next steps

- The NDRP should trial and evolve its process for research that is directly commissioned by stakeholders. This model is proposed as a starting point and should be refined through consultation during the Transition Phase to reach a clear, effective process that is in line with the NDRP principles and can be implemented once the Enduring NDRP is established.

10. Building Research Capacity

The NDRP commissioned a research project to look at ways to develop disability research capacity in Australia. The full project report can be read in the accompanying report: *Building effective system-wide disability research capacity in Australia: What does it look like and how do we get there?*

In order to develop disability research capacity, it is important that there is a shared understanding of what effective research capacity looks like. This project engaged a range of stakeholders (43 in total) to identify what effective Australian disability research capacity could look like and the potential mechanisms for generating change and forward advancement.

Most participants agreed there is still significant work to do if Australia is to achieve effective, system-wide disability research capacity. Moreover, most agreed that this will not involve 'quick fixes' but significant changes to practical elements of the system, as well as changes to existing mindsets and power relations. The schedule and direction of reform will need to be a carefully thought-through program of change, which will likely take at least 10 years to realise.

Data suggest that this program of change and the realisation of system-wide disability research capacity requires the following:

- **Disability inclusive research** - a recurring theme in our study was that quality disability research needs to engage people with disability and the disability community throughout the research process. Research needs to be designed in a way that is disability inclusive, with engagement and inclusion embedded as the norm in conducting disability research. This is required to address the numerous challenges and barriers identified by our participants (identified in this report), as well as to demonstrate the value placed on the lived experience knowledge of people with disability.
- **The establishment of a disability research agenda** - there is a need for a clear and shared disability research agenda that is co-developed with the disability community to focus on identified areas of need. This agenda would identify priority areas for investment and funding, establish programs of work to deliver on priorities, and support the establishment of relationships and partnerships focused on delivering these programs of work.
- **Funding disability research** - a key enabler for effective system-wide disability research capacity is a range of funding mechanisms to support a broader scope of research than is currently the case across a range of disciplines. This funding needs to align with the research agenda and support inclusive disability research.
- **Reform of ethics frameworks and assessments** - system-wide disability research capacity requires appropriate ethical frameworks and assessment processes. This is most likely to involve revisions of the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research, with suggestions that the NHMRC could establish guidelines on ethical conduct in research with people with disability, similar to the approach adopted for Indigenous research.
- **Developing research knowledge and skills** - system-wide disability research capacity requires a range of development opportunities to enable a more structured and planned approach to developing research knowledge and skills across the disability field. This includes but is not limited to secondments, internships, mentoring and student placements.
- **Changes to university systems, structures and processes** - facilitating system-wide disability research capacity in Australia requires changes to university structures and processes to address the

challenges raised by stakeholders, including ableism and discriminatory mindsets, accessibility issues, precarious employment, and performance expectations.

- **Longer-term partnerships** - system-wide disability research capacity requires longer-term partnerships across the disability field. These partnerships must ensure engagement of people with disability in all aspects of the research process, including research design, applying for and securing research funding, and knowledge translation.
- **More formal mechanisms to enable networking and information sharing –** system-wide disability research capacity requires people from across the disability field to engage in a more meaningful and deliberate way; for example, through conferences, particularly those that are inclusive of people with disability, and through communities of practice.
- **Improved knowledge translation** – system-wide disability research capacity needs effective knowledge translation, with research findings communicated well, in an accessible manner and in a variety of forms.
- **A database or clearinghouse of existing and current research** - system-wide disability research capacity requires a curated database that stores translated research. This may involve better utilisation of the 'disability research collection' in the Analysis and Policy Observatory (APO) database (see APO, 2022a), a well-established digital repository and open access information platform.
- **Linking and using existing datasets –** system-wide disability research capacity also requires mechanisms to access, link and share de-identified data. A mechanism under development, the National Disability Data Asset (NDDA), was discussed as one example of this.

Building research capacity across all stakeholders involved in disability research will require resources to develop both individual research capacity and wider system change. It will require improved partnerships and information sharing between stakeholders, additional resources, and valuing multiple sources of knowledge and skills. It will also require power sharing and, in some cases, relinquishing power. The full capacity building report outlines several steps that may be taken to achieve this.

Most of all, building effective system-wide disability research capacity in Australia will require changes in mindsets. Mindsets need to be developed that understand the value derived from inclusive disability research and co-design, thereby improving the relevance of disability research to both disability and mainstream communities and improving the quality of research itself. The change in mindsets would involve centering and valuing the knowledge that people with disability contribute to the field based on their lived experience. It would also involve a willingness to readily engage in the rigor and ethics of inclusive disability research, with the view that authentic co-designed and inclusive disability research *can* be undertaken when there is genuine commitment and sufficient resources to make it happen. The change also requires acknowledging the ownership and sovereignty of disability research by the disability community. Finally, the change in mindsets is necessary to provide opportunities so that more people with disability can become sector leaders and high-level researchers, and direct and lead programs of disability research – as the saying goes, 'nothing about us without us'.

Recommendations

- The NDRP should implement a research capacity building strategy that aims to achieve effective, system-wide disability research capacity.

Next steps

- **Based on the recommendations in this report, develop a plan to develop disability research capacity in consultation with stakeholders during the Transition Phase.**

11. Knowledge Translation

This knowledge translation strategy is a first draft, taking into account the clear message from all stakeholders that the NDRP should play an active role in making sure research findings are known, provide useful answers, and can influence change. This draft strategy will be refined during the Transition Phase.

One of the issues the NDRP plans to address is the gap between what is known, and what is actually done. This is sometimes referred to as the 'knowledge to action gap' and occurs when there is high quality evidence available, but it has not been taken up by practice or policy making. This gap has been raised by many stakeholders as a major barrier to having good, evidence-based policies and practices in Australia. Often there is also a gap between the evidence that is currently available, and information drawn from this evidence that is needed to inform policy and practice decisions.

Some of the reasons the knowledge to action gap exists are:

- Research findings are often published in academic journals, with lots of jargon and complicated language. These articles are often behind paywalls and cannot be accessed by the general public; and even if they are freely available, the message is not tailored to the disability community (who are usually the ones using this knowledge).
- Findings are not made available in accessible formats such as plain language summaries, fact sheets, Easy Read summaries, podcasts, or targeted pieces like policy briefs or practice guides.
- Funding is usually to do research. There is much less funding available to focus on sharing the findings and talking to people who might be able to use the research.

The NDRP is committed to supporting high quality, inclusive research ***and*** to making the findings from that research available in useful, timely and targeted ways. This will ensure a range of stakeholders can use the information to change or create policies or practice, or to make more informed decisions. The NDRP also plans to work in partnership with stakeholders who use research findings, ensuring that research findings are known, provide useful answers, and can influence change. We call this knowledge translation or research translation. Although developing a knowledge translation strategy was not one of the deliverables of the two-year Establishment Phase, the Working Party quickly realised this is an important part of disability research that NDRP should address.

Key principles

As with all our other work, a set of key principles should guide all NDRP knowledge translation activities. These are:

- **Facilitate research:** The NDRP provides funding, connecting people and organisations, and supporting knowledge dissemination and translation.
- **Build capacity:** The NDRP will aim to build capacity in both conducting research and knowledge translation, so that research teams further develop their skills. The NDRP will also build the capacity

of people who use research to evaluate the quality of research findings and use evidence in their policy-making or practice decisions.
- **Partnership:** The NDRP will support researchers to form early partnerships with stakeholders to make sure the end products are fit for purpose. The NDRP will also work in partnership with research teams, using its network to bring people together, facilitate conversations and make knowledge broadly available.
- **From the outset**: The NDRP will require researchers to consider knowledge translation and impact from the outset of any research project.
- **Publicly available**: All research that is funded or facilitated by the NDRP, either through open funding rounds or directly commissioned by stakeholders, will have publicly available and accessible outputs that are designed with end-users in mind.

NDRP’s role in knowledge translation

The NDRP will support knowledge translation for projects that it funds. It could do this in the following ways:

1. Set expectations

As part of its funding application process, the NDRP will expect researchers to think about what will be produced as a result of their projects and how this might effect change. Researchers will be expected to develop an understanding of who might be able to use the findings from their research (end-users) and tailor their approach accordingly. NDRP may have to assist in this process, especially in its early years, as part of strengthening connections between researchers and stakeholders. End-users will most likely be people with disability, their families, allies and supporters, policy makers, service providers or other groups. Thinking this through from the beginning should be a key criterion in applying for funding. The project budget should include enough funds to support effective communication of findings and knowledge translation activities.

The NDRP should expect a range of outputs from each project, tailored to meet the needs of the people who might use the knowledge. Examples of project outputs include:

- Engaging, concise plain language summaries of the key messages
- Visual summaries such as infographics, fact sheets or videos
- Audio options such as a podcast
- Easy English or Easy Read summaries
- Policy briefs, media articles, practice guides
- Journal articles (the NDRP expects articles to be published in open access journals).

2. Build capacity

In line with the NDRP’s commitment to building capacity in the disability research community and the broader disability sector, the NDRP could establish processes and structures to build capacity for knowledge translation.

- Design and deliver tailored workshops. The NDRP could partner with organisations such as the Centre for Accessibility to provide training in conceptualising and producing quality accessible research outputs. These workshops could aim to develop skills and confidence in thinking through who will use research findings, and how to package up the information in the most suitable way.
- Resource hub: The NDRP could develop and maintain an accessible translation resource hub on its website. This hub will share advice, guidance, and good examples to draw from. It could also share

information about organisations that can provide specialist support, for example in creating Easy English or Easy Read summaries.

3. Support collaboration

Good knowledge translation involves effective collaborations between researchers and people who might use research. The NDRP should expect and facilitate research collaborations: this could also be a key criterion in applying for funding. Research teams should work with people who might use the knowledge produced; for example, advocates, policy-makers or service providers. The NDRP should expect researchers to form these relationships and have conversations early about the area being addressed, how research findings can be used, and what format they should be produced in.

4. Share findings

The NDRP should actively share research findings through its network and through the APO Disability Research Collection. The APO Disability Research Collection is a repository of publicly available disability research reports. Information on the APO platform is usually sourced from a wide range of organisations such as governments, agencies, regulators, research institutes, non-for-profits and think tanks. During the Establishment Phase, the NDRP released a monthly e-newsletter with the latest resources.

The NDRP should continue to fund the APO to provide the infrastructure to house and share resources through the Disability Research Collection. One of the reflections from the Establishment Phase is to consider ways to improve the curation of the Collection. A limitation of the Disability Research Collection is that it is a repository of reports that can be searched by key words and broad themes, but it is not organised in any particular way. The NDRP could improve the usefulness of the Collection through careful curation and editorials describing featured reports. Regular editorials could share an analysis of the current state of knowledge on the topic of curated collections within the APO Disability Research Collection.

The NDRP should also support interactive ways to make knowledge available, through a podcast or webinar series that explores specific topics from a range of perspectives. High quality podcasts can be an effective way to reach a wide audience and can be a powerful tool for making research available to the public. Webinar series can also engage a broader audience in discussions about research findings; we consider the Child Family Community Australia (CFCA) model a useful model. More information can be found at this link: CFCA webinar series.

5. Spark conversation

The NDRP could host regular conversations or ‘public dialogues’ that explore evidence and research findings on particular topics from different perspectives. These conversations could bring people who do the research with those who might use the research together, to reach a deeper understanding of how the evidence can help inform change.

An example of how this could be done can be found at this link: Economic and Social Research Council Public Dialogues.

The NDRP could also facilitate direct conversations between researchers and end-users of the research in cases where these conversations might fast-track the uptake of the knowledge created.

Leverage NDRP networks

The NDRP will be in the unique position of having a bird's eye view of policy and practice-relevant disability research and having extensive networks in Australia and internationally. The NDRP should build and leverage its domestic networks so that it can make connections between people who produce research and people who use research, and make introductions that add value for each stakeholder. The NDRP should also build and leverage its international networks to be fully cognisant of research and policy initiatives in the disability field which may have relevance and be suited to the Australian context. This brings two-way benefits which ultimately advantage people with disability in Australia. The broader the NDRP network, the more widely outputs can be shared.

APO Disability Research Collection

Designed to improve policies and practices, the Disability Research Collection is for people with disability, their families, caregivers, allies or supporters, disabled people's organisations, advocacy and representative organisations, policymakers, researchers, service providers and practitioners. The Collection aims to share evidence and knowledge on a range of topics to help advance the rights of people with disability.

Established in November 2020 by the National Disability Research Partnership together with the Analysis and Policy Observatory, the Collection supports the work of the NDRP. Wherever possible, accessible versions of documents such as plain language summaries, Easy Read or audio versions have been included in the Collection. Specific Topics in Focus provide further insights to content in this Collection.

See the Collection at this link: APO Disability Research Collection.

The Disability Research Collection now houses over 800 resources, has received over 5,500 front page views and all resources in the collection have received over 120,000 views. Five e-newsletters containing the latest resources were sent to the NDRP mailing list. Three new Topics in Focus were established: one funded by government and two funded by the Summer Foundation.

Limitations

It should be noted that the NDRP's role is not to become *the* clearinghouse for all disability research. The APO Disability Research Collection will provide the infrastructure for a curated database containing open access reports and publications. The NDRP should work with the APO to improve curation and knowledge sharing.

A limitation of the Disability Research Collection, as noted above, is that it is a repository of reports that can be searched by key words and broad themes, but is not organised in any particular way. The NDRP could improve the usefulness of the Collection through careful curation and editorials.

Good models to draw from

The What Works Network (UK): The What Works Network uses evidence to improve the design and delivery of public services. This initiative aims to improve the way governments and other public sector organisations create, share and use (or 'generate, translate and adopt') high quality evidence in decision-making. It supports more effective and efficient services across the public sector at national and local levels. The network is made up of nine independent What Works Centres, three affiliate members and one associate member. Together these centres cover policy areas that account for more than £250 billion of public spending. Link to the website here: What Works Network

A particular example is the Teaching and Learning Toolkits, which are designed to support teachers and school leaders who are making decisions about how to improve learning outcomes. Link to the Toolkit here: Teaching and Learning Toolkit

Research in Practice (UK) works with organisations to enable them to access, understand and apply evidence in their work with children and families, young people and adults. Research in Practice brings together academic research, practice expertise and the experiences of people accessing services. They then apply this knowledge to develop a range of resources and learning opportunities, as well as delivering tailored services, expertise and training. It offers membership that gives people access to resources and training opportunities, and provides expert knowledge, advice and training to support improvement for organisations. Link to their website here: Research in Practice website.

Sharing learnings

Another way of translating knowledge is between the NDRP itself and other research programs. The NDRP Working Party is grateful to other research programs who have shared their learnings and supported the NDRP establishment journey. The generosity of organisations such as the Australian Housing and Urban Research Institute (AHURI), Australia's National Research Organisation for Women's Safety (ANROWS), Australian Research Alliance for Children and Youth (ARACY), Sax Institute, Australian & New Zealand School of Government (ANZSOG), the Autism Cooperative Research Centre, Centre of Excellence in Bio-security Risk Analysis (CEBRA), and the Lowitja Institute have helped the Working Party refine ideas, understand shared challenges, and avoid common pitfalls. A suggested way forward might be to establish a Community of Practice where key people from similar research programs could come together and share learnings. The NDRP should also aim to build relationships with funding bodies such as the National Health & Medical Research Council and the Australian Research Council.

Recommendations

- The NDRP should develop a knowledge translation framework that aligns with its purpose and principles.
- Knowledge translation should be a key NDRP activity, making research findings from research facilitated by the NDRP available in useful, timely and targeted ways.

Next steps

- Further develop and refine this draft knowledge translation during the Transition Phase to incorporate knowledge translation models and frameworks that align with the NDRP's purpose and context.
- Continue to fund the APO Disability Research Collection to provide the infrastructure to house and share resources, and work with the APO to improve curation and knowledge sharing.
- Actively grow the NDRP network and increase its reach.

12. Community of Practice

After the pilot open funding round held in June 2021, researchers from the nine projects which were selected came together to form the NDRP Community of Practice, from October 2021 to June 2022. Below is a brief summary of the topics, learnings and recommendations. The full report on the Community of Practice is included at Appendix G.

Purpose

The purpose of the Community of Practice was to: share learnings about disability research done by and with people with disability; refine the NDRP processes for supporting inclusive and collaborative disability research; and to explore whether a Community of Practice is an effective means of learning and building capacity for inclusive research. It explored questions such as how best to undertake inclusive research, and what needs to be in place for effective research partnerships with people with disability, Disabled People's Organisations, representative organisations and advocacy organisations.

The Community of Practice was co-convened by Keran Howe and Lesley Chenoweth and attended by two researchers from each project. Cath McNamara was invited to be an independent observer, to reflect on the inclusivity of the process and to summarise key messages.

Topics

The topics discussed in the eight sessions were:

- Introduction to the NDRP and Community of Practice, how best to work together, what members would like to contribute and gain.
- Research Ethics Committees – what do Research Ethics Committees want, what are they looking for? Presentation by Jackie Leach Scully, Director of the Disability Innovation Institute, University of New South Wales.
- Effective partnerships between DPOs, advocacy and representative organisations and researchers.
- Research led by people with disability and done in partnership with government – challenges and how to overcome these.
- Improving the NDRP research translation approach.
- Review of funded projects' experience of the NDRP research program.
- Sharing project findings.

Our learnings

The Community of Practice was seen as valuable and should be continued in the future NDRP. There may be an opportunity to increase its effectiveness by broadening it to include people from different disciplines, so as to combine the expertise of researchers with different ways of thinking. Community of Practice members felt that it had provided a novel experience of sharing and learning rather than competing. This had shifted their way of thinking. Future Communities of Practice could be formed around a range of topics: for example around funding rounds, as this one was, or around particular areas of interest such as knowledge translation, intersectional research, or specific research areas.

Key learnings include:

- Foundation principles need to be in place before the research starts. Appropriate language must be used when talking about inclusive research; ensure projects engage diverse voices advising on how to establish the research; and acknowledge the value of co-designing research with people with lived experience as well as researchers and government.
- Funding contracts should stipulate the involvement of people with disability in the development of research.
- The NDRP could build capacity of research teams to develop accessible outputs, and provide resources for accessible research translation.
- The requirement for inclusive research has been useful in shifting thinking in some universities where inclusive research has been less developed. Researchers have been able to use the NDRP requirements to lobby for change, and show that employment of researchers with disabilities is not tokenistic by demonstrating their ability to do work that researchers without disabilities cannot do—for example, by collecting richer data because many people with disability feel more comfortable and safer talking to another person with disability.
- Online activities have made things more inclusive for a lot of people with disability. COVID has forced researchers to adapt and has shown that it is possible, and even easier, to work online with people with disability. The Community of Practice members found Zoom easier to use than Teams; Zoom allows easier 'pinning' of Auslan interpreters, for example, and an easier way to view every participant in the meeting. However, automatic captioning is currently easier to access in Teams.
- The NDRP can assist DPOs, representative organisations and advocacy organisations to engage in research. The NDRP can fund a mapping exercise of expertise in the DPO and advocacy sector, support relationships to enable information exchange and collaboration, and build capacity.

On reflection, learnings for the structure and running of a Community of Practice include:

- Aim to keep meetings to one hour long.
- Keep the group size relatively small (e.g 8-10 participants) to enable everyone to participate actively.
- Engage in regular and ongoing discussion about how to make the sessions most accessible and inclusive.
- Think about the best ways to keep people engaged. Chief investigators were most vocal in the majority of sessions. Consider whether a parallel process might support other people who don't fully engage.
- Careful planning is crucial. Planning ahead, preparing a briefing prior to each session and having two experienced facilitators facilitating the session will lead to a smoother process.
- Be flexible and take advice from the members of the Community of Practice about what topics to pursue in later sessions.
- Actively seek out useful resources from each member and share these with all members. Consider storing useful resources at a central point.
- Actively seek ways to create a network of researchers interested in inclusive research to learn from each other.
- Consider ways to broaden membership of the Community of Practice.

Accessibility

Careful thought is required to ensure that the Community of Practice processes are accessible to all and pitched appropriately for the group. The question of who is responsible for ensuring this access remained an unresolved challenge. Some Community of Practice members thought the NDRP should be responsible for making materials available in all required formats, some thought a lead person with disability could be assigned to support the process, and others thought it should be the research team's responsibility given they know the support required. The following quotes illustrate this debate:

"Additional time was needed to brief and debrief with the Co-Researchers before and after the CoP meetings, so this would need to be factored into future CoP/ funding conditions. Perhaps there could be a 'lead' Co-Researcher supplied by the NDRP who could also support this process before and after the meetings to ensure meaningful and accessible contributions."

"Accessible documents available before meetings is only one strategy, and probably the responsibility of the researcher from the individual's team. That is because they are likely to know the support required. For example, [one of our team] finds Easy Read documents with pictures to be insulting, though he does require plain language support. For this reason, it is not practical for the hosts of the COP to prepare these documents for all. Time is required, though, for local teams to do this."

Recommendations

1. The NDRP should implement an accessible Community of Practice model to bring people together to share learnings, build capacity, and promote and support inclusive disability research.

13. NDRP Communication Strategy

The NDRP will use communication to inform stakeholders, influence change and invite feedback and should ensure everyone has the same access and opportunity to read documents, provide feedback, use websites, attend events, and more. This section outlines a recommended communications strategy for the future NDRP and aligns closely with Section 11: Knowledge Translation.

Communication Principles

In addition to the NDRP Guiding Principles, the following communication principles should guide all its communication:

- Respectful use of language. The NDRP will aim to align with the disability community's language preferences and acknowledges that this may change and evolve over time.
- Clear, concise communication that is based on plain language as a minimum and is adapted in various formats for different communication needs.
- Willingness to listen, learn and adapt to feedback on accessibility.
- Prioritisation of the voices of people with disability. It is critical not to conflate the experiences of people with disability with the experiences of their family members, carers or supporters.
- Measured and respectful sharing of research findings and stories, without sensationalising or devaluing previous research.

Minimum standards

The NDRP should make sure its communication and research findings are accessible to a range of audiences. The following minimum accessibility standards should be applied to the NDRP's communications:

- All written communication (documents, blogs, newsletters) will be in sans serif fonts, with accessible formatting, and will be written in plain language as a minimum. All documents will be accessible to screen readers and should include an accessibility statement that invites feedback and offers support.
- All written documents will be optimised for screen readers and made available in Word and PDF formats.
- All video and audio media will include a transcript and captions, and Auslan as needed.
- All public documents (such as major reports) will be accompanied by an Easy Read summary, an infographic or fact sheet, and an audio version.
- The NDRP digital web presence will be universally accessible – complying with the Web Content Accessibility Guidelines (WCAG) version 2.1 at a minimum.
- All meetings will provide the required accessibility support for attendees, including captions, Auslan interpretation or other supports needed.
- All public events or webinars will consider accessibility as a priority. All public events or webinars will be live captioned as a minimum, and will provide Auslan interpreters, a hearing loop, Easy English interpretations and other supports as required.

Communication Strategies

- Having effective strategies for communicating with a range of audiences is vital to the NDRP's success. This should be a key consideration for the Board and should be budgeted for accordingly.

- Different formats will be provided for different communication needs as required. This will require ongoing effort from the NDRP to understand its audiences and their communication needs, and consider ways to provide information that is easy to understand. Intersectional needs should also be considered in relation to language access, including but not limited to First Nations peoples, people from culturally and linguistically diverse backgrounds, people who do not have access to smart phones or computers, people in remote or rural areas, and more.
- The NDRP should make use of a range of communication pathways, including but not limited to:
    - Monthly newsletters
    - Blog posts on website
    - Social media including Twitter, Facebook, LinkedIn, etc.
    - Website
    - Events and webinars
    - Podcast series
- The NDRP could facilitate discussions that bring people together to talk about the best ways to communicate with people with disability and the broader disability community, and build relationships with external stakeholders and organisations that are developing good communication resources.

Recommendations

- All NDRP communications should be accessible, align with the NDRP communication principles and provided in a range of formats.
- The NDRP should continue to develop and improve communication practices by listening, learnings from others and adapting.

What’s next

The NDRP Working Party engaged a broad range of stakeholders during the Establishment Phase, seeking feedback on many of its deliverables to help shape recommendations. The Working Party notes that many stakeholders have engaged with discrete parts of the NDRP, but only a handful of disability representative organisations have had the opportunity to engage with the ‘whole’ NDRP and the interaction between all the elements.

The NDRP Working Party is committed to ongoing evolution and will work together with the disability community through a collaborative process to refine and improve these recommendations, before the NDRP becomes a fixture of the disability landscape from early 2023.

Each section of this report outlined the next steps needed to transition to a fully established NDRP. These are:

NDRP Principles

- All NDRP activities and decisions should be guided by the NDRP Principles
- The principles will be reviewed and revised during the Transition Phase, taking into account some of the feedback already received on the order and level of detail for each principle plus additional feedback which is expected during the Transition Phase.

Governance

- Establish the NDRP as a stand-alone, independent organisation.
- Seek members: set up membership categories and database, develop the application and review processes, and welcome new members.
- Invite members to nominate for the Director positions, and run an inclusive process to appoint the seven elected Directors through nominations and voting.
- Seek nominations from government for the two government-appointed Director positions.

Guide to inclusive research

- Work with UNSW Disability Innovation Institute to support the development of guidelines for ethics committees on disability inclusive research.
- Work with peak bodies, DPOs and advocacy organisations to map the skills and interests of the advocacy sector.

Research agenda

- Expand and refine the Preliminary Research Agenda in consultation with stakeholders to produce a fit-for-purpose NDRP research agenda during the Transition Phase.

Approach to commissioned research

- Refine the proposed commissioned research model through consultation during the Transition Phase, so that it can be piloted when the enduring NDRP is established.

Disability research capacity

- Create a plan to develop disability research capacity in consultation with stakeholders, based on the recommendations in Building effective system-wide disability research capacity in Australia: What does it look like and how do we get there?

Knowledge translation

- Further develop and refine the draft knowledge translation during the Transition Phase to incorporate knowledge translation models and frameworks that align with the NDRP's purpose and context.
- Continue to fund the APO Disability Research Collection to provide the infrastructure to house and share resources.
- Actively grow the NDRP network to increase reach.

Community of practice

- The online Community of Practice will continue for a few months, to focus on knowledge translation of the nine projects funded in the 2021 pilot funding round.
- Map the expertise and interest areas of DPOs, representative organisations and advocacy organisations.

After these activities have occurred, we will share an updated version of this report, which will guide the Enduring National Disability Research Partnership.

> 'The NDRP has the potential to position Australia as global leaders in inclusive disability research.'
>
> Bruce Bonyhady

Thank you

The members of the NDRP Working Party are humbled by the enormous opportunity that we have had over the past two and a half years to play our part in shaping the future of disability research in Australia. Our role would not have been possible without the deep engagement and collaboration of the disability community, and we are grateful to everyone who shared their ideas and views with us.

The next steps of this journey will require even greater collaboration. We look forward to working with all NDRP stakeholders as the NDRP transitions to a permanent and fully operational organisation with its own independent Board in early 2023.

Evidence-based and inclusive disability policy and practice are now within the grasp of the disability community.

Appendix A: Pilot Funding Round Process and Learnings

Process

This section outlines the process used to review proposals received through the first open NDRP Research Funding Round.

Stage 1: Declaring conflict of interest

As proposals were received, the NDRP Coordinator added them to a master list which contained the project title, Chief Investigator name, all other investigator names and lead organisation. This list was circulated to all reviewers who declared any conflicts of interest, in line with NHMRC Guidelines.

Where there was too much declared conflict of interest (ie fewer than three reviewers with no conflict), external reviewers were invited to score proposals during the shortlisting phase.

Projects focusing on Aboriginal and Torres Strait Islander research were assessed by external reviewers with specific research expertise and lived experience in relation to Indigenous populations, in addition to the review panel.

See *Appendix A: NHMRC Guidance for Declaring and Assessing Disclosures of Interest*.

Stage 2: Screening

A screening process was proposed to ensure only research done by and with people with disability progressed to the next phase. However, after trialing this it was considered too difficult to make a clear and fair judgement on this and would likely not have screened out many projects. All proposals therefore progressed to the shortlisting phase.

See Learnings section for further reflections.

Stage 3: Shortlisting

Number of proposals received: 123.

Proposals were allocated to one of three review committees, taking into account the tabled Conflicts of Interest. Each committee received one third of the proposals to review against all five selection criteria with ‘yes’, ‘no’ or ‘maybe’. See below indicators for each criterion. The five key selection criteria were all weighted equally and reviewers were not required to score areas where they did not feel confident in (e.g. methods, track record).

Completed review spreadsheets were sent to the NDRP Coordinator for collation. The number of yes, no and maybe scores was calculated: the proposals were then ranked according to the most ‘yes’ scores. Each review panel met to discuss this ranking and decide which proposals should progress to the selection phase. Members of the review panels were given the opportunity to speak to projects they scored very highly and for which other reviewers had lower scores.

The initial plan was for each panel to progress a number of proposals to the selection phase, and for all nine reviewers to read and rank the shortlisted proposals, and for government to have an opportunity to comment. This plan was changed after realising (1) there was far too much conflict of interest for this to work equitably and (2) the timeline was too short to allow this. In part these challenges reflected the very large number of proposals and their high quality.

The revised plan was for each review panel to select their top three projects, and to fund these. Government representatives were invited to comment on the policy relevance of shortlisted proposals and to provide feedback to applicants on how this can be improved.

The shortlisting panels consisted of:

- Professor Anne Kavanagh (Chair), Professor Helen Dickinson, Ms Keran Howe
- Professor Gwynnyth Llewellyn (Chair), Ms Ellen Fraser-Barbour, Professor Jackie Leach Scully,
- Professor Lesley Chenoweth (Chair), Professor Elizabeth Kendall, Ms Christina Ryan

Each panel was deliberately structured to include two academics and at least one person with disability (some panel members were academics with disability), to reflect the principles of NDRP. Any reviewers who were not paid by a university, were paid for their time.

Stage 4: Selection

The aim of the selection process was to agree on which projects should be funded: ideally a range of **projects (across several of the eight themes, as much as possible) that are collaborative, inclusive and have high quality research methods. Ideally the outcomes will address an area of importance to people with disability, be policy-relevant and meaningful.** The plan was changed – see above.

Stage 5: Communicating outcomes

All chief investigators received a letter notifying them of the outcome. Specific feedback was given to 16 research teams who requested it.

Learnings and recommendations

Application process

- Clearer communication regarding overheads for universities
- Clearer communication about GST in budgets
- Provide a simple template for completion and provide accessibility tips (e.g. tag images)
- Clearer request to submit only ONE document with consistent naming e.g. SURNAME_NDRP Application
- Longer timeframe for application and review; noting the necessity of short timeframes in this pilot round to ensure projects are completed during NDRP Establishment Phase.
- Many DPOs have raised the influx of partnership requests when funding rounds are open; consider the best way to support development of good working relationships. Consider asking for letters of support from partner organisations.
- Clearer guidelines about disability vs health condition: use WHO or UNCRPD definition of disabilities?
- Broader advertising: this advertising was done by Twitter, Grants Hub and NDRP Newsletter.
- Received more applicants than anticipated which put additional pressure on an already short timeline. Consider more targeted funding rounds in future.

Selection criteria

- Consider weighting of selection criteria. The decision to weight all criteria equally caused a bit of difficulty in the review process.
- Consider a process which will support innovative ideas and research; consider how this aligns with the UNCRPD.
- Have a process for deciding when to fund one proposal over another when they are rated the same. A key issue will be whether research quality trumps inclusion of people with disability, or vice versa.
- Add in an explicit criterion for policy or practice relevance.
- The criterion of building research capacity of people with disability was very rarely addressed; suggest more focus on this in future rounds.

Assessment criteria

- Refine framework by which people demonstrate their project is addressing an area of importance to people with disability. This was subjective and could be clearer in future.
- Better definition of 'involvement of people with disability' and clearer standards against which to screen this..
- Find an acceptable compromise for excellent projects on an important topic where there is no person with disability available to be a researcher or project lead. There might be issues of sheer availability, time, capacity, and we risk ending up with a situation where a small number of potential researchers are overloaded. In an ideal situation of course that wouldn't happen but the ideal doesn't exist yet, so what is our compromise over the next few years while capacity is built up?
- Refine "decision-making power" and provide examples, or find a different way to conceptualise this, as this was difficult to explain and difficult to assess.
- Refine what a genuine working relationship really involves and ask for evidence that this has been done.
- Develop guidance on payment rates for people with disability. There were divergent views ranging from $50 per hour participant rate to amounts double or triple this.
- Clearer request for proof of track record and clearer way to assess this.
- On budget items: simplify to ask if project offers value for money, and assess only once projects have been shortlisted.

Declaring and managing conflict of interest

- The declaring of COI by reviewers worked relatively well, however there were still quite a lot of conflicts.
- To manage conflicts, projects were allocated to panels with the least conflict. In the case of a few applications, two members of panel 3 had no conflicts but the third member did. These applications were allocated to panel three and the third member who had conflicts was not asked to review these – we asked reviewers from different panels who did not have a conflict to score these particular applications instead. This did not work very well when it came to that panel discussing and shortlisting their applications. A better process is needed in future, and a larger pool of reviewers.

Review process: screening

- A good screening process is vital to ensure only compliant applications proceed to the shortlisting phase.

- This did not work in the piloted process and needs to be improved for future rounds.
- Be clearer from the outset which criterion applications will be screened against, and choose a criterion that can easily be assessed for clear and transparent ‘in’ or ‘out’ judgements. The criterion selected for this pilot round had too many variables and too little inter-rater reliability.

Review process: shortlisting and selection

- The review panels in this round consisted of academics and people with disability. It was decided not to seek additional content experts given the broad range of themes and random allocation of applications to panels. Indigenous proposals were reviewed externally; in future rounds NDRP could consider coordinating a panel of Indigenous people with research expertise and/or lived experience of disability.
- Number of review panels should reflect the number of applications to create a manageable workload. Note increased variability and possible need for pre-training or discussion about assessing against criteria.
- Design a better process to enable input from disability advocates and policy makers.
- Design a process to enable comparison of community-based research with academic research
- Consider investing in areas of emerging research vs areas where a substantial amount of work is already happening.

Research capacity

- All of the selected projects were led by researchers who have established relationships with DPOs and community organisations
- There was a reasonable mix of career stage though many were senior researchers; one early career researcher and two mid-career researchers.
- We received very few quantitative projects, ethics-focused projects or projects from science and engineering. Consider if this is due to the selection criteria or a lack of capacity in those areas. A better process is needed to support broader disciplines.
- Track record and ability to work together responses varied enormously: some provided references, some provided links, some provided nothing. Note absence of references often associated with community-led research: need process to assess this and judge capacity.
- Design a process to support community-led research and early career researchers, especially those with disability.
- This round had a few excellent ideas which did not have strong methods. NDRP has an opportunity to support those few excellent ideas but not at the expense of poor method, because poor method is unlikely to provide insights/answers to the questions being asked. NDRP could consider different processes for different groups, e.g. an ideas innovation/support hub; early career researcher opportunities whether this be individuals or organisations engaging in research; a funding round such as the one we have had where the highest quality proposals on all criteria are funded. NB: ensure this doesn’t create a divide between academia vs community-led research.
- Suggest a process for connecting researchers with community organisations.

Characteristics of a good application

One of the learnings from the pilot funding round was to detail the characteristics of a good application. An initial version of this is included here and will continue to be refined over the course of the NDRP.

Selection criteria	Characteristics of a good application
Address research priority	The project addresses the priority that is the focus of the NDRP funding round. The project is likely to deliver outcomes that will help advance knowledge on the topic in question.
Research done by and with people with disability	**Leadership**: A clear plan that explicitly describes roles and responsibilities of the research team, including people with disability in leadership roles.
	Decision-making power: A clear process for how decisions will be made; people with disability hold decision-making power. If the project involves an advisory or reference group, the proposal must explain how they will be genuinely engaged in making decisions about project directions.
	Involvement: A clear description of how people with disability are involved in the conception, execution and dissemination of the research. Roles and processes are described for each stage of the process. There is acknowledgment and recognition of the value people with disability can bring to each stage.
High quality research	**Quality**: High quality research that is rigorous, transparent and reproducible. Refer to NHMRC Research Quality at this link: Research Quality
	Method: The research methods are clearly explained, and can feasibly produce an answer to the proposed research question.
	Achievable: The proposal outlines a realistic, achievable timeline. If there are multiple steps, a good management plan is included. Sufficient time has been allowed for co-produced research, ethics applications, data collection, etc.
Build research capacity	**People with disability**: The proposal has a clear intention and plan for building capacity of people with disability. The proposal includes appropriate support and mentoring, and careful thought is given to potential career pathways.
	Early career researchers: The proposal includes roles and career development opportunities for early career researchers.
Track record and demonstrated capacity	**Track record**: The project team as a whole has the right research skills, experience and ability to deliver each part of the project.
	Ability to work together: The proposal includes strategies that will enable productive collaboration, and ideally some kind of evidence that the team can work together effectively.
	Experience in inclusive research: There is evidence that at least one person on the research team has demonstrated experience in doing disability research by and with people with disability.
Knowledge translation	**Dissemination**: The proposal includes a clear and thoughtful approach to making findings widely accessible. The proposal should outline how it will seek to identify the academic and non-academic audiences for the findings, and how they can be made available in the most suitable way. It should include accessible methods such as podcasts, videos,

	infographics, easy read summaries, etc, as well as traditional methods such as publications and presentations.
	Translation: The proposal should outline a clear research translation strategy: what is the impact from this research on policy or practice? How will the project develop outputs that will be relevant and useful for policy and/or decision making.
Budget	**Reasonable**: The budget is reasonable for the project proposed.
	Payment of people with disability: People with disability are paid appropriately.
	Dissemination and translation: The budget includes fair and reasonable funding for accessible research dissemination and translation.
	Academic salaries: There is justification for supporting academic researchers who receive their salaries from a university; noting that academics on research contracts paid for by external grants are eligible to apply for salary.

Appendix B: Call for proposals template

Project title: National Disability Research Partnership Funding Round

Brief summary: Inviting proposals for disability research projects done by and with people with disability.

Proposals due: 2 July 2021

Contact officer: Please note that all communication about this call for proposals, and the final application should be submitted to: Tessa de Vries, NDRP Coordinator, info@ndrp.org.au

NDRP prefers email communication where possible for record keeping. Phone calls are accepted: call 03 8344 2813.

Summary

The NDRP 2021 Research Funding Round is designed to fund disability research that will deliver new findings, and test and refine the NDRP processes. Research must be done by and with people with disability, align with the NDRP Guiding Principles and address an area of demonstrated importance to people with disability. Applications are accepted from any incorporated association in Australia. Collaborations are encouraged and research proposals are invited for projects addressing one or more of eight key themes. Project budgets may be anywhere up to $150,000 inclusive of GST and must be achievable within a ten-month timeframe. The total funding pool available is $1 million.

About the National Disability Research Partnership

The National Disability Research Partnership (NDRP) will drive a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice.

The Commonwealth government has provided seed funding to establish the NDRP. A two-year Establishment Phase is being guided by a Working Party and has five core deliverables:

- Deliver a national disability research agenda
- Design a governance model to support the long term NDRP
- Map and develop disability research capacity
- Write a practical guide to NDRP research
- Pilot a research funding round to build the evidence base and to demonstrate and refine NDRP processes

Further information about NDRP is available at this link: NDRP website.

Guiding Principles

All NDRP activities will be underpinned by the NDRP Guiding Principles. These principles draw on the human rights framework articulated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the National Disability Strategy. We encourage all applicants to read more about these principles at this link: NDRP Principles.

The principles are:

- Deliver high quality, collaborative research
- Recognise the knowledge of people with disability in research
- Value all forms of knowledge
- Build research capability

Research projects funded through this round are expected to align with the NDRP Guiding Principles, the UNCRPD and the National Disability Strategy.

Terminology

Words and language are powerful tools. We recognise the diversity of disability and the different ways of talking about disability. Language is always evolving and the NDRP Working Party is committed to being respectful, inclusive, and open to change. A glossary of terms that explains the language and terms used throughout this document can be found at this link: NDRP Glossary.

About the NDRP Research Funding Round

Purpose

The purpose of this research funding round is two-fold:

1. **To build evidence for successful innovation in disability policy and practice**
   This funding round aims to extend disability research in Australia. Research projects must be able to deliver outcomes within ten months and make any new knowledge accessible to the disability community. Projects may include scoping studies, surveys, secondary data analysis, case studies or qualitative text data.

2. **To test and refine NDRP processes, approach and ability to deliver on the vision.**
   This research funding round is a key deliverable of the NDRP Establishment Phase. In the Establishment Phase, the NDRP Working Party is developing and refining processes that will best support a sustainable collaborative research partnership in Australia. The NDRP Working Party will work with the successful research teams to learn and improve processes. This will also inform the development of a Practical Guide to NDRP Research.

Research themes

Despite advances in some areas of disability research and increasing quality and quantity of data available, eight themes are consistently raised as priorities in disability research agendas and strategies. This round of NDRP Research Funding invites proposals for high quality, collaborative research that addresses topics of importance to people with disability within one or more of these themes:

- Aboriginal or Torres Strait Islander people with disability
- Women with disability
- Children and young people with disability
- People with disability in rural and remote areas
- People with disability from culturally and linguistically diverse backgrounds
- Lesbian, gay, bisexual, transgender and intersex (LGBTI) people with disability
- People with disability who require support to express their will and preference, and to implement their decisions
- People with disability who experience other intersectional disadvantage.

Proposals must demonstrate that the project is addressing an area of importance to people with disability.

Outcome

Funded projects are expected to deliver new evidence related to Australians with disability. Researchers will be asked to think carefully about making findings easily accessible to the community. The NDRP

Secretariat will support researchers with accessible research translation, but project teams are encouraged to think about accessible communication and build it into their projects from the beginning.

Projects might include:

- Scoping studies: exploratory projects that map literature available on a topic and identify key concepts, theories, evidence sources and research gaps.
- Secondary data analysis: projects that analyse existing data i.e. data previously collected in research projects, administrative data including linked data, national surveys, etc.
- Qualitative text data collected through interviews, focus groups, publicly available data such as social media.
- Case studies.
- Surveys.

Projects may build on or extend current research projects. New data collection will only be considered if a compelling case can be made for the feasibility of the project within the timeline, including obtaining ethics approval, recruitment, field work and data analysis.

Researchers will be asked to submit a progress report and a final report.

Ethical standards and guidelines

Any research project funded by NDRP that involves human participants must be reviewed and approved by Human Research Ethics Committees (HRECs) to ensure they are ethically acceptable. See a list of HRECs approved by the National Health and Medical Research Council at this link: Human Research Ethics Committees.

Project timeline

These projects are part of the establishment phase of the NDRP, which runs until the end of June 2022. Because of this, the projects need to be completed by the end of May 2022 to allow time to share findings and incorporate final learnings to the recommendations for a longer-term NDRP.

Allowing time to develop proposals, a robust review process and finalise contracts, the projects are likely to start in August 2021. This leaves ten (10) months for the research project timeline. The NDRP will be looking for projects that can feasibly be delivered in this timeline. The NDRP Working Party acknowledges the time needed to engage with the disability community and does not wish to minimise this.

- Projects commence: August 2021. First funding payment made (40%).
- Progress report: November 2021. This report will provide an update on research progress and detail the involvement of people with disability. It will also share reflections on the NDRP processes to this point. Second milestone payment made (40%).
- Final report: 30 May 2022. This report will document the research process and findings, and include reflection on the NDRP principles and processes as mentioned in Purpose 2 in Section 3.1 of this document. The report will also describe how research findings are being made widely available in accessible formats. Final payment made (20%).

Eligibility

Applications are invited from any incorporated Australian organisation. The NDRP encourages collaborations that draw on expertise from across Australia.

Note on funding: equitable funding and accessibility accommodations must be built into the project budget for collaborations with Disabled People Organisations, representative organisations, advocacy organisations or peak bodies.

Selection criteria

Project proposals will be assessed against the following criteria:

1. **Research that addresses the priorities of people with disability**. The proposed project must address an area of demonstrated importance to people with disability, fall within one of the eight themes listed in section 3.2, and align with the UNCRPD and the National Disability Strategy.
2. **Research by and with people with disability**: Reviewers will look for projects that are led by and/or conducted with people with disability who have decision-making power. People with disability must be paid and supported appropriately. The NDRP expects genuine working relationships. The research proposal must clearly describe how people with disability are involved in the conception, execution and dissemination of the research, how decisions will be shared and acknowledging the diversity of people with disability.
3. **High quality research.** The proposed method should be appropriate for answering the proposed research question, and feasible in the time and with the resources available**.**
4. **Knowledge that is accessible to the community**: The project proposal must outline a clear and thoughtful research translation approach to making findings widely accessible.
5. **Capacity to undertake research** in an area of demonstrated importance to the disability community. The proposal should outline the team's capacity to do the proposed research, including track record, proven ability to work together, and demonstrated experience in doing disability research by and with people with disability. The proposal must also demonstrate that it is achievable in the timeline available and within the budget proposed. Projects that build research capacity of people with disability will be highly regarded.

Assessment

The NDRP Working Party will convene assessment panels consisting of peer assessors including people with disability and researchers. Proposals will be assessed against the five selection criteria listed in section 3.7.

The NDRP Working Party conflict of interest policy can be found on the NDRP website at this link: Conflict of Interest. Any Working Party members who intend to submit a project proposal have declared a conflict of interest and have not heard, read or otherwise learned of any detail of the funding round. Working Party members who are directly involved in shaping this funding round will not be involved in any funding proposals, in any capacity. They will also not discuss any part of this funding round nor give general or specific advice to anybody. This exclusion applies only to the NDRP Working Party. Colleagues or direct reports of Working Party members may submit funding proposals without the involvement or support of the Working Party member.

Funding

Projects can apply for funding up to $150,000 (excluding GST). A total funding pool of $1 million is available for this round. This funding round aims to fund a range of projects with a balance between small, medium and larger projects.

The NDRP Working Party reserves the right to recommend funding levels which may be less than those requested in the proposal.

This funding is eligible as category 1 research income. See frequently asked questions for more information.

Costs the funding can be used for are stipulated in the Head Agreement with the Commonwealth Department of Social Services (attached at Appendix B) and reflected in the research project funding. These are:

- Operating and administration expenses **directly related to the delivery** of the project, such as:
    - staff salaries (including for the lead researcher*) and salary on-costs (leave loading, superannuation, workers compensation etc), which can be directly attributed to the provision of the project
    - telephones
    - rent and outgoings
    - computer/IT/website/software
    - insurance
    - utilities
    - postage
    - stationery and printing
    - travel/accommodation costs directly related to the research project. Please note travel costs will be reimbursed on receipt of invoices/receipts
    - assets that can be reasonably attributed to meeting agreement deliverables
    - screening processes for paid, unpaid and sub-contracted staff (such as working with children check)
- Appropriate and sufficient payment to advocacy organisations and people with disability who are involved in the project.
- Accessibility: captioning, support (including support workers if required), or any other costs related to removing access barriers.
- Inclusive and accessible stakeholder engagement processes.

*where lead researchers are paid **directly** by an organisation such as University or research institute to conduct research as part of their employment, their salary cost should be included as in-kind. Lead researchers in these organisations who are employed on external contracts are eligible to apply for funding for their salaries.

Collaboration with NDRP Working Party

Projects that are selected and funded in this round will be supported by a subset of the NDRP Working Party. The NDRP Working Party will regularly check in with project teams to lend support and ask for reflections on the processes being piloted. The NDRP Working Party will convene a community of practice made up of team members of funded projects to help build a connected disability research ecosystem and share learnings.

This community of practice will be asked for reflection and improvement on various parts of the NDRP processes, including working towards best practice accessible research dissemination.

About this call for proposals

By submitting a proposal for an NDRP research project, you agree to be bound by the terms and conditions set out in Appendix A.

Submission timeline

Stage	Date and Time
Clarification period: questions accepted	until 5pm Thursday 1 July
Proposals due	5pm AEDT Friday 2 July 2021

Review of proposals	2 - 23 July 2021
Award notification and commence contracting	24 July 2021
Projects commence on signing of contract	August 2021

Submission process

Submissions are only accepted via email. Applicants are asked to submit an accessible document containing their proposal with the following sections:

1. Project title

2. Project team: lead investigator, organisation (including ABN or ACN) and collaborating organisations. Please provide letters of support from collaborating organisations that outline their involvement.

3. Brief project summary. 200 words

4. Statement outlining how this addresses the priorities of people with disability. 300-500 words addressing Selection Criteria 1.

5. Statement outlining how this research will be done by and with people with disability. 500-800 words addressing Selection Criteria 2.

6. Research methods: a description of the aims, research questions, methods, conceptual or theoretical approaches (if relevant), data collection approach, analyses. 500-800 words addressing Selection Criteria 3.

7. Research translation: outline how findings from this project will be made widely accessible. 300-500 words addressing Selection Criteria 4.

8. Capacity to undertake research and feasibility: outline the team's capacity to do the proposed research, including track record, proven ability to work together, and demonstrated experience in doing disability research by and with people with disability. Also include a timeline and feasibility of achieving the research in the time available. If data is being collected this section should also outline how ethics approval will be obtained. 500-800 words addressing Selection Criteria 5.

9. Budget. A budget (excluding GST) must list the costs involved with delivering the project, including but not limited to:
    - staff costs: salaries and salary-related on costs
    - project costs: meetings, focus groups, interviews, data access, participant payments
    - partner payments
    - accessibility including captioning, support or other adjustments
    - travel
    - materials, resource development or printing
    - communication or research translation costs
    - the value of any in-kind contributions.

10. Brief bios (~200 words) for each team member which also outlines their role on the project.

Terms & conditions of this Request for Proposal

Successful suppliers must comply with terms and conditions outlined in Appendix A and those stipulated by the Department of Social Services (DSS):

- DSS Departmental Policies*;
- the relevant Guidelines*;
- the Data Exchange Protocols*; and
- any other service compliance requirements applicable for the Activities you are funded to deliver.

*Any or all of these may be amended by DSS from time to time. If DSS amend these they will notify us and we will notify you in writing at least one month prior to the changes coming into effect. The latest version can be found on the DSS website www.dss.gov.au. You must ensure that cultural and linguistic diversity is not a barrier for people targeted by this Activity, by providing access to language services where appropriate.

Appendix C: Funding round frequently asked questions

Q: Does "incorporated Australian organisation" mean only not-for-profit organisations, or does this include proprietary limited businesses?
A: What we mean by 'any incorporated organisation' is any organisation who has an ABN or ACN.

Q: Can you please advise if there is any restriction on the number of applications that a researcher can be listed on (as either a principle investigator or co-investigator) during this funding round?
A: You can be chief investigator one only one project, but there is no limit to how many you can be co-investigator or partner on, given we are encouraging collaborations.

Q: Is buying out teaching time for salaried academics an eligible budget item?
In exceptional circumstances we will provide funds to cover teaching up to a maximum of $10,000 across the entire project. The application should provide a breakdown of how the funds requested will be used. Applicants requesting funds for teaching relief must submit a 300-word justification about why the funding is essential to complete the project and submit a letter of approval from their Head of Department. The NDRP will also ask for evidence at the end of the project that the funds were spent on teaching relief. The NDRP will make a final decision as to whether the request for teaching relief is supported.

Q: Is this category 1 funding? What does this mean for university overheads in budgets?
Yes, funding through NDRP funding rounds is Category 1: Australian Competitive Grant Research Income under the Higher Education Research Data Collection (HERDC) classification. This means that eligible Australian higher education providers receive research block grants for research and research training. Many universities have internal policies that provide guidance on how to budget for Category 1 research funds; this often excludes or minimises the overheads that can be charged.

Q: Ten months seems short for good quality co-design with people with disability or collaborations with DPOs. Is there a reason for this time limitation?
A: Yes, the reason the projects have to be finished by May 2022 is because the NDRP Establishment Phase ends 30 June 2022. By June we will need to have finished all our projects, shared the findings and built any final learnings into our Guide to NDRP Research document. Unfortunately we've done everything we can to extend the timeline for research projects. The longer-term NDRP, if it is successful, will not have the same time restrictions.

Q: Can you please clarify what is meant by research that is done 'by and with people with disability' in the case of research that is focussed on issues most relevant to people with severe or profound intellectual disability can this phrase be taken to include parents or significant others?
A: As outlined in the NDRP Guiding Principles, we acknowledge that some people with disability face barriers in communicating their goals and aspirations and making decisions. This may include people with cognitive disability, young children, or others with episodic disability such as mental illness. In these circumstances the NDRP acknowledges the role that family, caregivers, allies or supporters may play in supporting decision making and facilitating expression of preference and will. So if family members are supporting the decision making, expression and communication of people with disability then they may be considered as by and with people with disability.

Q: Can we apply for a grant for an overseas project?

A: No. The National Disability Research Partnership (at least the Establishment Phase we are currently in) is funded by the Commonwealth Department of Social Services and the intent is for it to benefit Australians with disability.

Appendix D: NHMRC Guidance for Declaring and Assessing Disclosures of Interest

In reviewing the applications for funding in the NDRP Pilot Funding Round, the NDRP Working Party decided to adopt the NHMRC Conflict of Interest Policy to identify and manage conflicts of interest. This policy can be be found at this link: NHMRC Peer Review Guidelines

Conflicts of interest are frequently regarded as a positive indicator that peer reviewers are recognised leaders who:

- have expert advice or skills
- have been given professional opportunities
- have received government funding, and
- are supported by the companies working to raise the standard of individual and public health throughout Australia.

Interests may fall into the broad domains of:

- Involvement with the application under review
- Collaborations
- Working relationships
- Teaching or supervisory relationships
- Professional relationships and associations
- Financial relationships or interests
- Social relationships or associations
- Other relevant interests or relationships

A disclosure of interest does not mean that a peer reviewer has engaged in an inappropriate activity. It is a collaboration or relationship which may, or could be perceived to, impact impartial peer review and thus needs to be disclosed and transparently managed (where necessary) to safeguard the integrity of the peer review process. It is the peer reviewer's responsibility to disclose all interests. Failure to do so without a reasonable excuse may result in the peer reviewer being removed from the peer review process.

In determining if an interest is a conflict, peer reviewers should give consideration to the following values that underpin the robust nature of peer review:

- Excellence through expert peer review: The benefits of peer reviewers' expert advice need to be balanced with the risk of real and or perceived interests affecting an impartial review.
- Significance: Not all interests are equal. The type of interest needs to be considered in terms of its significance and time when it occurred.
- Integrity through disclosure: Peer review rests on the integrity of peer reviewers to disclose any interests and contribute to transparently managing any real or perceived conflicts in a rigorous way. The peer review system cannot be effective without trusting peer reviewers' integrity.

In determining if an interest is a ‘High’, ‘Low’, or ‘No’ Conflict of Interest, the responsibility is on the peer reviewer to consider the specific circumstances of the situation. This includes:

- the significance of the interest
- its impact on the impartiality of the reviewer, and
- maintaining the integrity of the peer review process.

Once a peer reviewer discloses an interest they can provide a brief explanation of the interest in to enable a judgement of its significance. Wherever possible, peer reviewers are encouraged to provide sufficient detail in the explanation such as the date (month and year) of collaborations. Disclosures of interest are to be documented for conflicts of interest with both CIs and AIs.

The written declaration of interest is retained for auditing purposes. The details below provide general examples and are not to be regarded as a prescriptive checklist.

HIGH Conflict of Interest

Situation		Example
Associated with Application and/or Chief Investigator (CI)	✓	Peer reviewer is a CI or AI on the application under review.
	✓	Peer reviewer has had discussions/significant input into the study design or research proposal of this application.
Collaborations	✓	Peer reviewer has collaborated, in a significant way, on publications within the last three calendar years (co-authorship), or on pending current-round applications, existing NHMRC grants or other grants.
	✓	There is an in/direct association/collaboration between the peer reviewer and a member of the CI team, such that the peer reviewer may have, or may be perceived to have, a vested interest in this research.
Working relationships	✓	Peer reviewer has the same employer, is part of the same organisation, or is negotiating for employment at the applicant’s institution, including: • in the same research field at an independent Medical Research Institute • in the same Department or School of a university • in the same Department of a hospital.
	✓	Peer reviewer is in a position of influence within an organisation, or has a pecuniary interest, e.g. Dean of Faculty or School/Institute Directors.
	✓	Peer reviewer would benefit if the proposal was successful as an associate on the same scientific advisory committee, review board, exam board, trial committee, Data and Safety Monitoring Board etc. for example, a board of the hospital in which the research would be conducted.

Professional relationships and interests	✓	Peer reviewer's organisation is affiliated or associated with organisations that may have, or may be perceived to have, vested interest in the research. For example, a pharmaceutical company, which has provided drugs for testing and therefore has a vested interest in the outcome.
Social relationship and / or interests	✓	The peer reviewer has a known personal/social/perceived relationship with a CI on the application.
Teaching or supervisory relationship	✓	Peer reviewer has taught or supervised the applicant for either undergraduate or postgraduate studies, co-supervised a CI, within the last three years.
Direct financial interest in the application	✓	Peer reviewer has the potential for financial gains if the application is successful, such as, benefits from: payments from resulting patents, supply of goods and services, access to facilities, and provision of cells/animals as part of the collaboration.
	✓	Peer reviewer receives research funding or other support from a company and the research proposal may involve collaboration/association with that company.
Other interests or situations	✓	Peer reviewer has had an ongoing scientific disagreement and/or dispute with the applicant/s. This may still be ruled as a high CoI if the events in question occurred beyond the last three years.
	✓	The peer reviewer feels that there are other interests or situations not covered above that could influence/or be perceived to influence, the peer review process.

LOW Conflict of Interest

Situation		Example
Collaborations	✓	Peer reviewer and a CI on the application have collaborated more than three years ago.
	✓	Within the last three years the peer reviewer has published with the CI as part of a multi-author collaborative team (i.e. ≥10 authors) where the peer reviewer did not interact or collaborate with the CI directly.
	✓	A co-worker is planning future collaborations with a CI.
	✓	Peer reviewer and a named AI on the application are actively collaborating or have previously collaborated within the last three years.
	✓	Without financial gain or exchange, a peer reviewer and a contributor of the research team have shared cells/animals/reagents/specialist expertise (biostatistician) etc. but have no other connection to each other.

	✓	Collaboration between a peer reviewer's colleague/research group and a CI, where the peer reviewer did not participate or have a perceived interest in the collaboration.
	✓	Peer reviewer is considering/planning/or has planned a future collaboration with a CI on the application but has no current collaborations or joint applications.
Working relationships	✓	Peer reviewer has the same employer, is part of the same organisation or is negotiating employment at the applicant's institution.
	✓	Peer reviewer and a CI work: ● at the same institution and do not know each other ● in the same Faculty or College of a university but in different Schools or Departments and do not know each other ● in the same organisation, but the peer reviewer or applicant holds an honorary appointment.
	✓	Peer reviewer and a CI work for two organisations that are affiliated but there is no direct association/collaboration.
	✓	Peer reviewer and a CI are on the same scientific advisory committee, review board, exam board, trial committee, Data and Safety Monitoring Board etc., but otherwise have no association that would constitute a High decision.
Professional relationships and interests	✓	Peer reviewer's organisation is affiliated with the CI's organisation.
	✓	Where two organisations are affiliated but there is no direct association/collaboration between the CI and peer reviewer and there is no other link that would constitute a 'High' decision.
	✓	When the peer reviewer's institution has an indirect affiliation/association with the organisation(s) that may have, or may be perceived to have, a vested interest in this research.
Social relationship and / or interests	✓	Peer reviewer's partner or an immediate family member has a known personal/social (non-work)/perceived relationship with a CI on the application, but the peer reviewer themselves does not have any link with the CI that would be perceived or constitute a 'High' decision.
Teaching or supervisory relationship	✓	Peer reviewer taught or supervised the applicant for either undergraduate or postgraduate studies, or co-supervised a CI, or the peer reviewer's research was supervised by a CI, more than three years ago.
Financial interest in the application	✓	Peer reviewer has an associated patent pending; supplied goods and services, improved access to facilities, or provided cells/animals etc. to a named CI for either undergraduate or postgraduate studies.
	✓	Peer reviewer has intellectual property that is being commercialised by an affiliated institution. Peer reviewer has previously provided and/or received cells/animals to/from a CI on the application, but has no other financial interests directly relating to this application that would constitute a 'High' decision.

	✓	Peer reviewer receives research funding or other support from a company, and the research proposal may impact upon the company.
Other interests or situations	✓	Peer reviewer may be, or may be perceived to be biased in their review of the application. For example, peer reviewer is a lobbyist on an issue related to the application.

Appendix E: Post-funding round survey results

NDRP Research Funding Round - survey

July 22nd 2021, 12:24 am MDT

Q1 - Where did you hear about the NDRP Research Funding Round?

#	Answer	%	Count
1	NDRP Newsletter	17.72%	14
2	Twitter	5.06%	4
3	Grants hub	10.13%	8
4	Word of mouth	50.63%	40
5	Other	16.46%	13
	Total	100%	79

If Other :

- Partner organisation
- Email from a colleague
- University
- Fellow researcher
- Google search
- University research office
- researcher colleague
- Research group
- Google search
- Social Media
- College newsletter

Q2 - Was the call for proposals clear enough? Could anything be improved?

#	Answer	%	Count
1	Yes, very clear	81.33%	61
2	No, some things could be improved:	18.67%	14
	Total	100%	75

Q2 No, some things could be improved:

No, some things could be improved: - Text
We only heard by word of mouth. Wider promotion would assist.
Guidelines and areas to include or consider could all be in one document. Somewhere in the attached doc and other information on website
The FAQs were a little misleading. Particularly the one about researchers on soft money.
I was unsure of organisational eligibility based on how it was worded. The order of information on the application made some of the explanations a bit difficult to order logically - perhaps think about that. I liked the length of the application and the items sought.
Minor points: (1) Clarity around the level of involvement/participation of people with disability in the proposed projects; (2) whether research with family, supporters or carers of people with disability would be considered; (3) Expected project deliverables
it would be helpful to have examples of the kinds of projects that you are particularly interested in funding, or more elaborate descriptions of certain things, like what NDRP seems an appropriate per centage or amount for partner payments
Guidelines were confusing
The funding round details and call for proposals were a little hard to find on the website, perhaps these could be more prominent?
One area that could be enhanced would be additional detail s around eligibile and ineligible expenditure for the call
Nature of in-kind support information required; detail regarding partner organisations and individuals
Perhaps putting requirements (sections and word counts) earlier in the call for proposals could make it more clear? Otherwise, the document was clear and thorough and simple to follow.
Please know that most sections were very clear, however a link to the Glossary in your website may also be beneficial

Q3 - Do you have any feedback for the NDRP that might inform any future funding rounds?

The timeframes for completion were very tight, but I understand why

It's just great that you are offering these opportunities. We liked the alignment with the UNCRDP and the National Disability Strategy.

Great to have the option to ask questions and receive answers in a timely manner. Also good to know how any applications you received - great to read that on your website, thank you. Also great timelines for providing a response to the application. Maybe combine the questions you received into the FAQ for the next round. More funding to fund more projects would be great:)

I found the process to be very straight forward - thank you

No. Process was very clear.

Good outline and very responsive with questions

Great system, everything nice and clear and easy to submit. Well defined criteria, all our questions answered very quickly. Thank you!

Some information on the research infrastructure levy and whether it was needed would be helpful.

I know particular time pressures are evident now, but to really do great work, more time is needed to deliver projects. integrated knowledge translation approaches should allow people to deliver outputs/outcomes along the way

A template might make writing the proposal easier.

create a list of disability rights researchers in academia. I have creaed a draft list, but keeping it current is a challenge. create this list to enspire students and to ehlp policy makers find people. oh, and for great initiatives like your's to reach out to them.

I understand the pressures in this round but configuring a project for ten months over the Christmas break does not seem like the best way to establish a research program

A wonderful opportunity to encourage collaboration between so many sectors. Thank you.

Longer period of time between call and submission closing date.

Level of detail required for the budget could be helpful.

I thought the process was simple and the information you provided clear

broader themes

Having a separate stand alone proposal application form either in word format or online would have been helpful

email submission always leaves things up to be a bit subjective - submitting within a survey, application hub, or other platform might be easier. otherwise, was easy and all good!

I thought the application was accessible. It was nice to be able to submit a word document and not have to wrangle partner's CVs or fill out a complex online application system. I think there could be a note added about the use of figures and references, but otherwise I thought it was very clear.

It was clearly set out and queries we’re answered quickly. Tight timeframe for projects is tricky but you did a good job acknowledging this limitation in the application document.

I felt like the criteria and information was clear. The FAQs were very helpful.

Perhaps in budget section have a note for any in kind contributions/ & maybe allow for any attachments or web links to be added to the submission within reason

Need projects to run longer than 10 months

I think it needed to be promoted better. I work in the Disability space, I did not see it promoted in the usual newsletters, heard about it from a colleague.

I'm excited to see this program develop, I love the disability justice emphasis of this call, and hope there is scope for disabled researchers like myself to submit projects in the future calls. thank you for being open to feedback and transparent about the process.

No, Tessa was lovely and extremely helpful.

Budget template would be useful.

The application was straight-forward and not too onerous, striking the right balance between level of detail and length. Thus it did not take as long and was not as overly complex as other Cat1 grants. Thank you!

No, I thought all questions were relevant. It is obviously hard going through the process of getting full commitments to research projects from partners when the future funding is unknown - just something to be mindful of.

A lovely, uncomplicated and concise EOI. A small suggestion - could cross sector research alliances be promoted more in the grant's structure? That is, groups from 'outside' established disabilities research who seek to use the grant to build relationships?

10 months is a very short time to do meaningful codesign with people with cognitive disability.

The active involvement of persons with disability is laudable and understandable but risks tokenistic efforts.

Clearer guidelines

Yes, the FAQ and the info on the PDF didn't always align. For example the FAQ indicated that if you wanted teaching buy-out you needed a 300w justification and your supervisor to sign approval, that wasn't on the PDF grant guidelines and is obviously important. When I searched I couldn't find anything on the PDF and hadn''t seen the FAQs. So didn't provide this. Other than replicating all the essential requirement info in one place it was quite easy. It was good being able to submit and not rely on the instritute research office to submit.

I think just sending it in word is problematic and probably both word and pdf should be submitted. Also, some of the sections were redudant so the Indicatiors could have been clearer.

It was wonderful that the process was simple following a set criteria with the simplicity of a word document. Great contact details provided

It was great that you were taking questions right up until the day before. Thank you.

I needed to check the submission email address. Perhaps create a dedicated 'grant submission' email address. I am not sure this is possible, but you could indicate that language could be tailored to the targeted group e.g. person first or identity first language depending on the group

Suggest providing a Word or pdf template for research proposals.

The call for applications was actually about groups not research topics.

The list of questions and answers at https://www.ndrp.org.au/funding-round was very helpful as it clarified our pre-submission discussion regarding inclusion of episodic disabilities. Overall a very exciting and positive step, thank you for the opportunity to be a part of the process

An online system to submit grants (e.g. SmartyGrants) might ease administrative work for NDRP. In saying this, the current system was seamless/convenient for applicants.

The focus on co-production is good but not strong enough. The need for people with disability to be project leaders should be made clear throughout the call for proposals.

I think the Themes are not really themes? they are more groups of people for/ with whom research needs to be done; i.e. a theme may be intersectionality, or mental health, etc., but children with disability is less of a theme and more of a target group?

The criteria were very narrow and intersectionality is a contested concept that might have put some people off applying for a grant

Very happy with the process, perhaps a template (basic one) for the submission would be helpful.

The process was great, in the future it would be good to have a clearer understand form NDRP about what information and outcomes they are expecting to result from the grants on offer - i.e. what does good look like for NDRP, we suspect that this will be done for this round based on the outcome of the grant application. i.e if unsuccessful we will be provided with feedback.

It was a really straightforward application process, with slightly more time, we may have submitted an improved proposal. Similarly, a 12 month research phase would provide some wriggle room compared to a ten-month turn around. Nonetheless, we would be really excited to implement our proposed research if successful.

It might be fairer to use blind review, rather than named applicants. Also to prioritise disabled PI's.

Some sections were too heavily weighted wordcount wise - greater words for actual research protocol/methodology may be helpful.

Would like to have more time to put an application together for this funding given its nature (i.e. involvement of people with disability). It would be good to have an ECR category.

I thought it was a really easy to understand process, the questions were clear and allowed one to write a grant that was hopefully in line with the aims of the NDRP scheme

Appendix F: Applying NDRP principles to making decisions about funding applications

Criterion 1: Research by and with people with disability	
a. Projects are led by and/or conducted with people with disability	Look for clear evidence of leadership: People with disability are listed on the project team as researchers (chief or other investigator) or project leads/co-leads. Advisory or reference groups are also acceptable but they must be involved throughout the project. Yes = involvement explicitly described, appropriate and genuine Maybe = addressed but vague : e.g., advisory group but not clear how they will be involved in all stages. No = no evidence of genuine involvement of people with disability,
b. clearly describe how decisions will be shared	Decision-making process clearly described. Evidence that decision-making power is shared and that there are genuine relationships. Yes = clear process for sharing decision making Maybe = decision-making process acknowledged but not clear how decision-making processes are shared No = no decision-making process considered, or people with disability involved but clearly do not hold decision making power
c. clearly describe how people with disability are involved in the conception, execution and dissemination of the research.	Roles and process clearly described for each stage of the project. Clear evidence that people are involved in this project throughout. Yes = clear roles, process and genuine involvement in all parts of the proposed research project. Maybe = involvement seems genuinely well intended but the methods can be improved. No = not clear or genuine involvement of people with disability
d. have people with disability who are paid and supported appropriately.	This is a critical criterion but will be reviewed and discussed after projects have been shortlisted (not in shortlisting phase) See budget review note below.
Criterion 2: High quality research.	
a. appropriate for answering the proposed research question	Research method outlined clearly, and can feasibly produce an answer to the proposed research question Yes = method clearly described and appropriate Maybe = method okay but could be improved No = method not clearly described and not appropriate for answering the question
b. feasible in the time	Look for a realistic, achievable timeline. Are there multiple steps which may be difficult to achieve? If approval by a research ethics committee is required, has there been enough time allocated for this to happen? Yes = realistic and achievable timeline Maybe = possibility that project can't be achieved in this timeline or critical steps that haven't been allowed for No = not achievable
Criterion 3: Build research capacity	

a. build research capacity of people with disability	Clear intention and plan for building capacity of people with disability (noting limitations of what can be feasibly done in ten months Yes = proposed project has clear strategy for building capacity Maybe = has potential but not explicitly addressed No = no intention or plan for building capacity
Criterion 4: Capacity to undertake research in an area of demonstrated importance to the disability community	
a. Track record	The team as a whole should have the right skillset to deliver each part of the project. Note the intention of this is not to disadvantage early career researchers or non-academic teams however it is important that team has the expertise to do the research (e.g., focus groups, qualitative and/or quantitative data methods and analyses described),. Yes = team composition has the right skillsets for each part of the project Maybe = not clearly described or have 'most' but not all required skills No = lacking capacity to deliver critical parts of the project
b. proven ability to work together.	Look for evidence of the team either having worked together before OR having strategies to enable productive collaboration. We don't want to disadvantage new collaborations Yes = team has successfully worked together in the past or they have outlined collaboration strategies that will ensure the new collaboration is successful Maybe = has potential but not explicitly addressed No = new collaboration, no strategy described
c. demonstrated experience in doing disability research by and with people with disability	Evidence that at least one of the research team has the capacity to do this. NB we will not exclude people who have never done this before but they need to be very clear how it will be done. Yes = the research team has experience and capacity to do research by and with people with disability Maybe = has potential but not explicitly addressed No = no experience and no plan; unlikely to succeed.
Criterion 5: Knowledge that is accessible to the community	
a. outline a clear and thoughtful research translation approach to making findings widely accessible.	Look for a clear strategy to make sure the findings are made available to a wide range of academic and non-academic audiences; thinking outside of publications and presentations. E.g., podcasts, videos, easy read summaries, infographics, public webinars or news articles Yes = evidence of thorough consideration of accessible research translation in multiple formats appropriate for their audience Maybe = have given it genuine thought but lacking specificity or creativity (we can work with them) No = only focusing on traditional avenues of dissemination
Criterion 6: Budget	
a. Is the budget reasonable?	Is the budget reasonable for the project proposed? Are there parts of the budget that are not well justified or where costs are too high? Yes = budget reasonable and presents good value for money

	Maybe = budget seems high or low and may need amending, but still presents good value for money No = budget not reasonable for the proposed project
b. Are people with disability paid appropriately?	Explicit details about how people with disability will be paid. Are people with disability being paid fairly for their expertise or is it tokenism? If no payment to people with disability, is there justification for that (e.g., in-kind support from CEO or DPO that has been agreed upon and/or DPO is lead organisation) Yes = clear details about fair payment to people with disability Maybe = fair payments implied but not described, or could easily be amended for improvement No = no clear details about payment, or payment token.
c. Are translation strategies appropriately funded?	Budget has fair and reasonable funding for accessible research translation Yes = fair and reasonable funding Maybe = included but likely underfunded No = not included in budget
d. If there is teaching relief requested, is it justified?	In exceptional circumstances we will provide funds to cover teaching up to a maximum of $10,000 across the entire project. The application should provide a breakdown of how the funds requested will be used. Applicants requesting funds for teaching relief must submit a 300-word justification about why the funding is essential to complete the project and submit a letter of approval from their Head of Department. Yes = justified and essential No = not justified and not essential
e. Academic salaries (if applicable)	Is there justification for supporting salaries of academic researchers who receive their salaries from the University noting that academic on research contracts paid for by external grants are eligible to apply for salary? Yes = justified and essential No = not justified and not essential

Appendix G: Community of Practice Report

After the pilot open funding round held in June 2021, researchers from the nine projects which were selected came together to form the NDRP Community of Practice, from October 2021 to June 2022. Below is the full report on the Community of Practice.

Purpose

The purpose of the Community of Practice was to: share learnings about disability research done by and with people with disability; refine the NDRP processes for supporting inclusive and collaborative disability research; and to explore whether a Community of Practice is an effective means of learning and building capacity for inclusive research. It explored questions such as how best to undertake inclusive research, and what needs to be in place for effective research partnerships with people with disability, Disabled People's Organisations, representative organisations and advocacy organisations.

The Community of Practice was co-convened by Keran Howe and Lesley Chenoweth and attended by two researchers from each project. Cath McNamara was invited to be an independent observer, to reflect on the inclusivity of the process and to summarise key messages.

Topics

The topics discussed in the eight sessions were:

- Introduction to the NDRP and Community of Practice, how best to work together, what members would like to contribute and gain.
- Research Ethics Committees – what do Research Ethics Committees want, what are they looking for? Presentation by Jackie Leach Scully, Director of the Disability Innovation Institute, University of New South Wales.
- Effective partnerships between DPOs, advocacy and representative organisations and researchers.
- Research led by people with disability and done in partnership with government – challenges and how to overcome these.
- Improving the NDRP research translation approach.
- Review of funded projects' experience of the NDRP research program.
- Sharing project findings.

Consistent themes

The following themes were raised in the Community of Practice sessions.

Value of being part of a community

Members of the Community of Practice reflected on the value of being part of a community on several occasions, and how much they valued the opportunity to share experiences and exchanging learning. Members expressed a desire for community in the traditional sense where they could feel a part of something larger.

> *"The meetings were a welcoming and safe space to discuss and share issues arising from our projects, the grant scheme or disability research more broadly. It was a particularly good forum for researchers to share their experiences/ tips/issues. Any concerns aired were taken seriously by the NDRP".*

> *"It's been an unusually joyful experience, seeing the collegiality and honesty when we*

> *researchers are usually put up to compete with each other and keep things secret so no one can 'steal' them. Also as someone probably the most junior in the lead researcher category I've enjoyed the chance to meet people like Lesley who I've looked up to for a long time."*

The demands of the short project timeline made attendance at the Community of Practice sessions challenging for some.

> *"It was difficult to engage as fully with the CoP as we would have liked whilst meeting all the demands of project timelines and the rest of working life. Sometimes even finding the time for the meetings was difficult and doing any preparation beforehand just not possible."*

Despite the efforts of the facilitators and Independent Observer to ensure the process and discussions were accessible and inclusive, feedback was that some of the researchers with disability were not always engaged because the language used or information provided was not pitched appropriately. This needs to be carefully thought through for any future Community of Practice.

> *"It can be a little hard to follow on what subjects that they are talking about and some long words and acronyms mean."*
>
> *"The online format created some difficulties for including people with disability as members of the CoP. Augmentative and alternative communication etiquette requires that other people do not speak while the person is composing their message and this was not always followed.*

One researcher suggested this might be the responsibility of each research project lead who are best placed to know the needs of each co-researcher.

The research process

The Community of Practice discussed the barriers to good inclusive research. Many of these were also mentioned by other stakeholders in broader consultations led by the NDRP Working Party: the need for an overarching research agenda, building research capacity, understanding research stakeholders needs and more effective research translation. Members of the Community of Practice also talked about the need to allow for different levels of inclusiveness and to keep the door open for new ways of approaching research.

- **Inclusive research:** Members of the Community of Practice were strongly committed to inclusive research, for two main reasons: to uphold a human rights approach and address a tradition of exclusion, and because they felt that engaging people with disability at all points in the research development, implementation and translation improved the quality of the evidence collected. Inclusive research should make sure people's intersectional identities are acknowledged. People with disability have other identities; for example they may be First Nations peoples, they may be women, they may be from a different cultural background. To genuinely engage people with disability in research, trust and understanding must be built based on language and communication appropriate to the context and the group or community. Research funding is often inadequate to allow the time and adaptations needed to support genuine inclusive research.
- **Research agenda**: the Community of Practice often discussed the importance of an overarching research agenda that can guide disability research, and addresses areas that are important to the disability community.

- **Data**: there was general frustration with getting access to data at both state government and Commonwealth government levels. One member commented *"we've jumped through all the different hoops multiple times and the hoops just keep changing."*
- **Ethics**: Obtaining ethical approval is noted as one of the major challenges to engaging in inclusive research. While recognising the right of people with disability to be involved in research, many research ethics committees are nevertheless still unfamiliar with the methods of inclusive research and the distinctive ethical issues they raise. One member commented "*We found the presentation by Prof Jackie Leach Scully on ethical considerations to be very useful as we encounter push back from HRECs in considering applications involving people with disability as co-researchers."* The NDRP acknowledges this challenge and is committed to working with ethics committees, funding bodies, universities, and research institutes to educate ethics committees and advocate for more inclusive practices.
- **University processes**: many members had to work with their universities to make sure processes such as onboarding and submitting timesheets were accessible. One member commented *"Authentic inclusion of researchers with intellectual disability [benefits from having] at least one project member dedicated to guiding and facilitating their inclusion in all aspects of a project."*

Building capacity

All members of the Community of Practice were invited to take part in the research project "Building effective system-wide disability research capacity in Australia: What does it look like and how do we get there?" In addition to being interviewed for that project, capacity building was discussed in the Community of Practice. Some of the suggestions were:

- Create new career pathways for researchers with disability
- Share the stories of researchers with disability widely so other people with disability know it is a possible option.
- Collaborate with new partners and new disciplines - build the capacity of disability researchers by working with people outside our discipline, thereby enhancing the scope of our work and their capacity as they work in their own area.
- Think about identifying existing capacity and building new capacity in Disabled People's Organisations, representative organisations and advocacy organisations.

One member commented:

"there was a missed opportunity for co-researchers with disability to engage with the community of practice. The CoP missed an opportunity to build capacity and learning, and upskilling of co-researchers for future inclusive research. In particular, there is potential to broaden the scope of the CoP and ensure different members of the research team attend to discuss specific themes – particularly around inclusive research practice. For example, managing/budgeting/designing inclusive research, recruiting hard to reach research participants, training and supporting community researchers (and being trained and supported by community researchers), analysing data all together, and identifying the most effective dissemination channels."

Effective research partnerships

The Community of Practice discussed ways to engage with people who do not usually get the opportunity to participate in research, and ways for them have a real voice. Adequate time needs to be allowed for this process. Researchers with disability were interested in networking opportunities and wanted to learn more about Disabled People's Organisations, representative organisations and advocacy organisations.

Session three focused on how researchers can effectively engage with DPOs, representative organisations and advocacy organisations.

Challenges

- DPOs and advocacy organisations often have no funding or capacity for research. If they are to be effectively involved in research, their involvement must properly resourced.
- DPOs are often involved later in the research process after the research questions and plan are formulated. This means that the questions the disability community want answered are not addressed, there is no capacity building for an organisation and its members, and it is difficult to involve people with disability effectively.
- Pressures for government agencies and commissioning of research: Research topics and timelines are influenced by requests or interest from stakeholders such as policy makers or the National Disability Insurance Agency. Many of the allocations of funding for research purposes come at the end of a budget year when money needs to be allocated quickly, therefore time frames are tight which impacts on the quality of what can be achieved.

Solutions that NDRP can implement

- Acknowledge and provide sufficient resources for the time and effort needed to provide full accessibility and support for people with disability to be involved with research (a number of DPOs provide guidelines / resources about what is needed).
- Create pathways for DPOs and advocacy organisations to be involved at the beginning of the research process so that shaping research can be disability-led.
- Dedicate funds to building capacity for research in DPOs and advocacy organisations.
- Build and maintain relationships with DPOs and the advocacy sector.
- Give DPOs and advocacy organisations advance warning of funding rounds, as they are often inundated with requests when disability-relevant funding rounds open.
- The NDRP can assist DPOs, representative organisations and advocacy organisations to engage in research. The NDRP can fund a mapping exercise of expertise in the DPO and advocacy sector, support relationships to enable information exchange and collaboration, and build capacity.
- Tell the stories of people working in research as co-researchers – to share the benefit and value of this, but also to raise awareness of the opportunity for involvement.
- Directly commission DPOs to do research rather than funding big consultancy firms to glean the information from DPOs and advocacy organisations.

Knowledge translation

The Community of Practice helped shape the NDRP's approach to knowledge translation. Their key points were:

- Planning for research translation needs to be built in from the beginning
- Foreground knowledge of experts by experience
- Use different ways of producing and providing information
- Research translation should be a criterion for grant applications, with sufficient time allowed to do this phase
- Accessible Research translation is a specialist skill and funding should be allocated to employ translation specialists or build capacity for this skillset.

Our learnings

The Community of Practice was seen as valuable and should be continued in the future NDRP. There may be an opportunity to increase its effectiveness by broadening it to include people from different disciplines, so as to combine the expertise of researchers with different ways of thinking. Community of Practice members felt that it had provided a novel experience of sharing and learning rather than competing. This had shifted their way of thinking. Future Communities of Practice could be formed around a range of topics: for example around funding rounds, as this one was, or around particular areas of interest such as knowledge translation, intersectional research, or specific research areas.

Key learnings include:

- Foundation principles need to be in place before the research starts. Appropriate language must be used when talking about inclusive research; ensure projects engage diverse voices advising on how to establish the research; and acknowledge the value of co-designing research with people with lived experience as well as researchers and government.
- Funding contracts should stipulate the involvement of people with disability in the development of research.
- The NDRP could build capacity of research teams to develop accessible outputs, and provide resources for accessible research translation.
- The NDRP's requirement for inclusive research has been useful in shifting thinking in some universities where inclusive research has been less developed. Researchers have been able to use the NDRP requirements to lobby for change, and show that employment of researchers with disabilities is not tokenistic by demonstrating their ability to do work that researchers without disabilities cannot do—for example, by collecting richer data because many people with disability feel more comfortable and safer talking to another person with disability.
- Online activities have made things more inclusive for a lot of people with disability. COVID has forced researchers to adapt and has shown that it is possible, and even easier, to work online with people with disability. The Community of Practice members found Zoom easier to use than Teams; Zoom allows easier 'pinning' of Auslan interpreters, for example, and an easier way to view every participant in the meeting. However, automatic captioning is currently easier to access in Teams.
- The NDRP can assist DPOs, representative organisations and advocacy organisations to engage in research. The NDRP can fund a mapping exercise of expertise in the DPO and advocacy sector, support relationships to enable information exchange and collaboration, and build capacity.

Learnings for the structure and running of a Community of Practice include:

- Aim to keep meetings to one hour long.
- Keep the group size relatively small (e.g 8-10 participants) to enable everyone to participate actively.
- Engage in regular and ongoing discussion about how to make the sessions most accessible and inclusive.
- Think about the best ways to keep people engaged. Chief investigators were most vocal in the majority of sessions. Consider whether a parallel process might support other people who don't fully engage.
- Careful planning is crucial. Planning ahead, preparing a briefing prior to each session and having two experienced facilitators facilitating the session will lead to a smoother process.
- Be flexible and take advice from the members of the Community of Practice about what topics to pursue in later sessions.

- Actively seek out useful resources from each member and share these with all members. Consider storing useful resources at a central point.
- Actively seek ways to create a network of researchers interested in inclusive research to learn from each other.

Accessibility

Careful thought is required to ensure that the Community of Practice processes are accessible to all and pitched appropriately for the group. The question of who is responsible for ensuring this access remained an unresolved challenge. Some Community of Practice members thought the NDRP should be responsible for making materials available in all required formats, some thought a lead person with disability could be assigned to support the process, and others thought it should be the research team's responsibility given they know the support required. The following quotes illustrate this debate:

"Additional time was needed to brief and debrief with the Co-Researchers before and after the CoP meetings, so this would need to be factored into future CoP/ funding conditions. Perhaps there could be a 'lead' Co-Researcher supplied by NDRP who could also support this process before and after the meetings to ensure meaningful and accessible contributions."

"Accessible documents available before meetings is only one strategy, and probably the responsibility of the researcher from the individual's team. That is because they are likely to know the support required. For example, [one of our team] finds Easy Read documents with pictures to be insulting, though he does require plain language support. For this reason, it is not practical for the hosts of the COP to prepare these documents for all. Time is required, though, for local teams to do this."

Key reflections

1. Continue an online Community of Practice but broaden the membership base to include other disciplines and potential research partners interested in undertaking inclusive research.
2. Make sure the process is accessible to all: discuss accessibility and inclusivity regularly.
3. Make sure that inclusive research remains part of NDRP foundational principles and funding criteria.
4. Make sure that knowledge translation is part of funding allocations. Create a 'resource hub' with links to best practice examples.
5. Map the expertise and interest areas of DPOs, representative organisations and advocacy organisations. Support relationships in the sector to enable information sharing and collaboration.
6. Advocate for disability-focused funding rounds run by the Australian Research Council and the National Health and Medical Research Council.
7. Consider the NDRP's role in resourcing DPOs and advocacy organisations to participate in research.

Feedback on the Community of Practice

Project A:

The NDRP Community of Practice has been an invaluable part of the process. It was so useful to remain engaged with the other project teams throughout the project to reflect on how projects were unfolding, share resources and solutions. It would also be great to come together and share project findings as we are really keen to learn from the experiences and outcomes across the different projects. Incorporating the Community of Practice into future NDRP research funding would be really beneficial, although would need to think through how to keep busy project teams without NDRP funding sustainably engaged and benefitting from the network.

Project B

We found the Community of Practice (CoP) meetings engendered a sense of community, connection and support. Subsequently, we did not feel like we were conducting our project in isolation, as is the case with most grant schemes. It was encouraging to feel part of something larger than just our own projects. The meetings were a welcoming and safe space to discuss and share issues arising from our projects, the grant scheme or disability research more broadly. It was a particularly good forum for researchers to share their experiences/ tips/issues. Any concerns aired were taken seriously by the NDRP.

However, it was difficult to engage as fully with the CoP as we would have liked whilst meeting all the demands of project timelines and the rest of working life. Sometimes even finding the time for the meetings was difficult and doing any preparation beforehand just not possible.

Additional time was also needed to brief and debrief with the Co-Researchers before and after the CoP meetings, so this would need to be factored into future CoP/ funding conditions. Perhaps there could be a ‘lead’ Co-Researcher supplied by NDRP who could also support this process before and after the meetings to ensure meaningful and accessible contributions.

We wonder if it may be more appropriate to have a CoP follow-on to learn from this first tranche of funded projects. Continuing CoP meetings for a few months after the end of May, might enable Co-Researchers to present some of the findings from each project to the whole group, as this was not possible during the short timeframe we had.

We also felt perhaps the CoP could be more accessible and inclusive to Co-Researchers, as they spoke very little in CoP meetings. As the Co-Researcher on our project designated to attend the CoP meetings said: *“It can be a little hard to follow on what subjects that they are talking about and some long words and acronyms mean.”*

Project C

The Community of Practice was a supportive and well facilitated space. It was quite unique for me, as an early career researcher, to connect with colleagues in this way. The events were well organised and collaborative, and the discussion was respectful. I would have liked initially hearing a 5-minute presentation from each project to understand their aims and methods, and this might have helped to connect with particular areas or challenges as they came up. Maybe future CoPs could include a quick update on project progress (encouraging honesty by having some distance from ‘official’ NDRP given their role as funders). I felt that NDRP taking the lead in promoting a respectful and inclusive environment set the tone for the research projects and modelled how inclusion and reflection can look in practice. Facilitating Communities of Practice within future grant rounds would allow others this opportunity, and/or specialist sub-groups who could support each other and researchers from other areas (for example, a specialist group focusing on intellectual disability, which could then also support researchers from other areas of disability with understanding the issues related to intellectual disability. OR a group on intersectional research where working across Indigenous/LGBTQ/CALD and disability issues could be examined in more depth.

Project D

The Community of Practice (CoP) was very useful for connecting with other grant recipients and discussing a range of issues common across the projects. The Project Lead and Project Manager took part in the CoP meetings. The co-convenors, Keran Howe and Lesley Chenoweth did an excellent job facilitating the discussion and ensuring everyone was encouraged to contribute. We found the presentation by Prof Jackie Leach Scully on ethical considerations to be very useful as we encounter push back from HRECs in considering applications involving people with disability as co-researchers.

The online format created some difficulties for including people with disability as members of the CoP and we noted that one member who used a speech generating device dropped off from attending. We don’t know why that occurred, but it could be due to difficulty engaging in this online forum. We felt that time was often not given for this person to compose what they wanted to say. Augmentative and alternative communication etiquette requires that other people do not speak while the person is composing their message and this was not always followed.

Project E

The Community of Practice (CoP) was a useful and productive mechanism to facilitate the sharing of good practice between research teams. The CoP was expertly facilitated by the chairs following defined agendas and were inclusive of attendees.

Participation of the project team in the Community of Practice was limited to two people and attended by the lead investigator and research manager who provided feedback to other members of the team. At conception, the research team asked whether project partners and in particular community researchers could be supported to attend as this was not something resourced within the project. [The NDRP provided additional resources to support their involvement.]

The CoP meetings were relevant to the project members who attended as it often focused on project governance issues including contracting, ethics, research design, among other things. However, the research team also felt that there was a missed opportunity for co-researchers with disability to engage with the community of practice. The CoP missed an opportunity to build capacity and learning, and upskilling of co-researchers for future inclusive research. Working with skilled co-researchers provides value for money for future NDRP funded project. In particular, there is potential to broaden the scope of the CoP and ensure different members of the research team attend to discuss specific themes – particularly around inclusive research practice. For example, managing/budgeting/designing inclusive research, recruiting hard to reach research participants, training and supporting community researchers (and being trained and supported by community researchers), analysing data all together, and identifying the most effective dissemination channels. To ensure CoP meetings are accessible, content needs to be shared in advance of the meetings in accessible forms.

Project F

This was an innovative aspect of the grant scheme and one we appreciated a great deal. The opportunity to engage with other researchers working in the same field was invaluable. It was an important forum to share ideas and issues around inclusive research. Hearing more about what other projects were doing would also have been helpful.

Supporting the researchers with intellectual disability to participate is an area to develop. Accessible documents available before meetings is only one strategy, and probably the responsibility of the researcher from the individual’s team. That is because they are likely to know the support required. For example, [one of our team] finds Easy Read documents with pictures to be insulting, though he does require plain language support. For this reason, it is not practical for the hosts of the COP to prepare these documents for all. Time is required, though, for local teams to do this. Pausing and allowing rephrasing by support staff during meetings was an effective strategy used in the COP to assist participants to follow and contribute to research discussions.

The COP is a valuable addition to disability research in Australia, allowing researchers to collaborate, share information and hear of other challenges and successes. While each of us will read the published papers, the COP gives a forum to discuss the day-to-day work of researchers that never gets included in manuscripts. The opportunity to learn from each other is vital and valued.