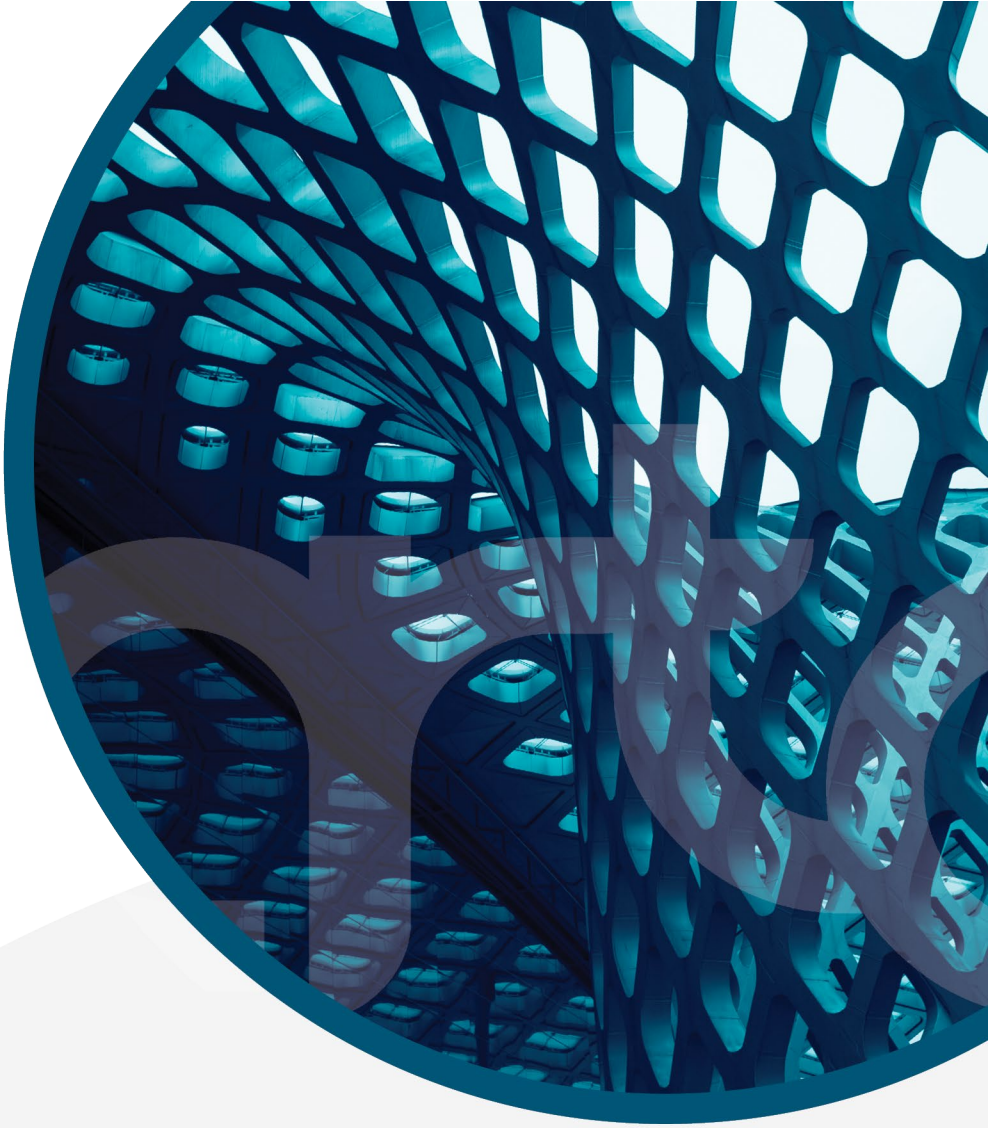

NATIONAL DISABILITY RESEARCH PARTNERSHIP

PROCESS EVALUATION REPORT

DEPARTMENT OF SOCIAL SERVICES

FINAL EVALUATION REPORT

REPORT PERIOD

19 MAY 2022 TO 5 DECEMBER 2022

www.artd.com.au

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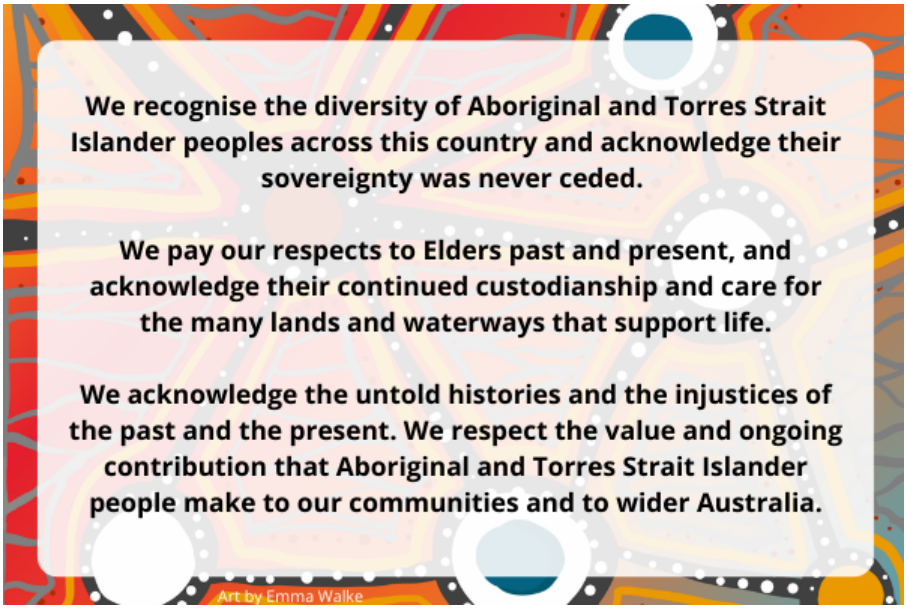

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GLOSSARY

Where possible, these terms have been taken from the NDRP Working Party's glossary.[1]

Term	Definition
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. 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.
APO Disability Research Collection	This collection was developed by the Analysis & Policy Observatory, which is an open access evidence platform. Designed to improve policies and practices, this Collection is for people with disability, their family, caregivers, allies or supporters, disabled people's organisations, policymakers, researchers, advocacy organisations, 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, the Collection supports the work of the National Disability Research Partnership to facilitate a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice. Wherever possible, accessible versions of documents such as plain language summaries, Easy English or audio versions have been included in the Collection.
ARTD	Applied Research Training and Development Pty Ltd, more commonly known as ARTD Consultants.
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, disability support workers and disability service providers.

[1] https://www.ndrp.org.au/glossary.

	It is preferred to 'disability sector', which is often used, because people with disability are not a 'sector'.
Disabled People's Organisation (DPOs)	An organisation owned and run by people with disability. Its board and staff are at least 50% disabled, plus the CEO (or equivalent) is a disabled person. DPOs have representative status of disabled people.
Inclusive research	Research that is done with and by people with disability. It is research that involves and respects people with disability. It is also accessible and easily understood.
NDRP	National Disability Research Partnership. At the time of this report's completion, the NDRP does not yet exist as a separate legal entity. For brevity, throughout this report, 'NDRP' refers to activities undertaken by MDI and/or the NDRP Working Party in the seed funding phase. The final chapter makes recommendations for the future stages of the NDRP.
NDRP Working Party	A Working Party made up of people with disability, advocates, academics and independent advisors.
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' because it is person-first language. However, it is recognised that many people with disability now prefer the term disabled people.
Pilot projects	Pilot projects are collaborative research projects in the NDRP establishment phase. The purpose of pilot projects is to build the evidence base and refine NDRP processes.
Research capability	An individual person's research knowledge, skills and attitudes or interest. The key difference compared to research capacity is that capability is about strengthening an individual's research skills or ability.
Research capacity	Teams, organisations and disciplines having 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.

Research infrastructure	Facilities, resources and services that are used by the research community to conduct research. Research infrastructure includes equipment, libraries, data, computing systems and communication networks.
Seed funding phase	A two-year period from June 2020 to June 2022, for which the Melbourne Disability Institute received funding from the Department of Social Services. This phase covered the groundwork for a longer-term partnership. It included delivery of five key outcomes: a governance model, a research agenda, a practical guide to NDRP research, a plan to build research capacity, and funding of pilot projects. This phase has been referred to as 'establishment phase' in NDRP reports and communications.
Stakeholders	People with disability; their families, allies and supporters; academics; governments; mainstream and disability services; and industry.
Support worker	A person who is paid to provide support or care.

EXECUTIVE SUMMARY

NATIONAL DISABILITY RESEARCH PARTNERSHIP

The National Disability Research Partnership (NDRP) is intended to help build the evidence base for *Australia's Disability Strategy 2021-2031*, supporting equal opportunities and inclusion of people with disability in all aspects of community life. The Department of Social Services (DSS) provided $2.5 million to the Melbourne Disability Institute (MDI), through the University of Melbourne, to begin establishing the NDRP between June 2020 and June 2022 ("seed funding phase"). MDI set up a Working Party to lead this work.

The Australian Government has committed $15 million for an NDRP to build the evidence base for *Australia's Disability Strategy 2021-31*.

THE EVALUATION

DSS commissioned ARTD Consultants to deliver a process evaluation of the work of MDI and the NDRP Working Party in the seed funding phase, including the process undertaken, and deliverables, as well as recommendations for a monitoring, evaluation and learning framework for the NDRP in future. A process evaluation was identified as appropriate to identify learnings to inform effective and efficient delivery of the NDRP as it moves from the seed funding phase to full establishment.

At the time of this report's completion, the NDRP does not yet exist as a separate legal entity. For brevity, throughout this report, 'NDRP' refers to activities undertaken by MDI and/or the NDRP Working Party in the seed funding phase. The final chapter makes recommendations for the future stages of the NDRP.

The evaluation drew on key NDRP documentation and data (including surveys and social media data), a survey of NDRP stakeholders, and interviews with NDRP members and select external stakeholders. ARTD implemented the methods largely as intended, and has enough data to answer the key evaluation questions.

However, at the time of the evaluation, some NDRP deliverables had not been broadly communicated, and not all respondents were aware of all completed activities. Additionally, the survey had a 9% response rate, and while this is in line with the email open rate for the NDRP mailing list, the findings may not reflect the views of all stakeholders of the NDRP.

KEY FINDINGS

Significant steps have been made in the establishment of the NDRP, an ambitious and complex undertaking. All of the deliverables met requirements as specified in the grant agreement (with final reports provided to Government at the time of publishing this report). Respondents to the evaluation generally thought strong foundations had been laid, particularly to ensure the knowledge of people with disability is valued. However, the

evaluation identified there is not yet broad awareness of the NDRP, and that further steps could be taken to reach and ensure accessibility for people with varying disabilities, increase the likelihood that research funded to influence policy, and support the sustainability of the NDRP in the long-term.

Category	Key Findings
APPROPRIATENESS Application of current NDRP principles in NDRP seed funding activities, projects & practices	• The NDRP principles were well integrated into the design process and activities led by the Working Party, particularly grant funding. • Respondents were most positive about the extent to which the NDRP "recognises the knowledge of people with disability in research", which has been at the core of its operations and activities. • Feedback indicates an additional principle – focus on use and outcomes – could support the intention of the NDRP to drive research that is used by all levels of government, organisations and people with disability to improve the lives of people with disability.
Extent and quality of engagement by people with disability and other stakeholders in the NDRP seed funding activities	• People with disability are engaged at leadership level in the Working Party. People with disability and other stakeholders have also been consulted to inform the NDRP principles, the proposed governance structure and the research agenda. • Clear requirements were set to involve people with disability in the pilot projects, and researchers, including co-researchers, were supported to share learnings, though time constraints affected engagement. • Respondents recognised the strong commitment to the engagement of people with disability, but those without disability rated the engagement of people with disability in the NDRP more highly than respondents with disability. Some respondents suggested more work is required to engage people with intellectual disabilities and people with less common disabilities. • Engagement with stakeholders and NDRP social media data analysis suggest there is not yet broad awareness of the NDRP, reflecting early stages of development, breadth of the disability community, and the challenges of establishing the NDRP during the COVID-19 pandemic.
Extent to which the NDRP seed funding phase has laid a foundation for the genuine involvement of people with disability in research	• Respondents were generally positive about the foundations laid for genuinely engaging people with disability in research through a focus on co-design. • Respondents identified challenges in ensuring engagement of people with various disability types, people experiencing multiple disadvantage and people with disability who are not already engaged. • Respondents identified the importance of broader engagement with the sector, adequate funding for the involvement of people with disability and their representative organisations (including at the proposal stage) and funding for accessible communications.

Category	Key Findings
Foundations for the development of accessible, tailored information that can help people with disability, policy makers and practitioners make evidence-informed decisions	• During the seed funding phase, work was undertaken towards developing a research translation and dissemination framework. • Additionally, pilot projects were required to have a clear and thoughtful research translation strategy. The Analysis and Policy Observatory (APO) disability collection has also been established. • For ensuring accessible communication, the NDRP should establish a program of monitoring of accessibility, linked to sound processes around the design, testing and implementation of communication activities for NDRP information.
EFFECTIVENESS Achievement of NDRP seed funding phase objectives	• MDI/ the Working Party had delivered all of its 6 deliverables for the seed funding phase, in at least a draft form, by the time of this evaluation. • Some deliverables had not yet been communicated at the time of the evaluation, so not all respondents were aware of all completed activities, which impacted their ability to rate appropriateness and effectiveness. • When asked about achievement of the NDRP seed funding phase objectives, respondents with enough knowledge to give a rating were most positive about the design of the governance model being achieved. They were least positive about achievement of the guide to research by and with people with disability.
Outcomes (both intended and unintended) during the seed funding phase	• As expected at this early stage of development, respondents said it was too early to expect significant outcomes. • Besides tangible deliverables, the key outcomes respondents described were the establishment of the fundamental principles and helping bring about a shift in outlook, in terms of ensuring people with disability are at the centre of research.
EFFICIENCY Operational and cost efficiency of implementation of the NDRP in the seed funding phase	• The seed funding phase was delivered within the overall budget of $2.5 million. However, spending on deliverables was higher than anticipated, in particular the delivery of the research agenda as a result of timeline extensions and the complexity of the process. • Respondents indicated the NDRP operated on a lean model, with some Working Party members contributing pro-bono support. Overall, the available data indicate the NDRP was likely under-budgeted relative to the amount of work required to deliver on objectives.
Factors to support operational and cost efficiency in future phases	• Now that recommendations have been made for a governance model for the NDRP, the focus should be on developing the operational structure to ensure efficiency and sustainability. • Respondents suggested focusing on business management, business development and operational support, as well as diversifying funding sources to ensure longer-term sustainability.

Category	Key Findings	
Analysis of evidence and stakeholder feedback identified the following enablers and barriers to success	Enablers: • the Working Party model and members • national scope of activities • collaboration and engagement.	Barriers: • researchers required to provide extra supports • limited communication and awareness of the NDRP • short timelines for delivery • cultural differences between government and academia • COVID-19 pandemic and related impacts on the disability community. Future funding can assist in overcoming some of these barriers, for example, allowing for appropriate investment in remuneration for organisations and individuals engaged as part of research, further investment in accessibility and promotional activities.
Delivery of pilot projects (time and cost-efficiency)	• Due to longer than expected contract negotiations between MDI and successful applicants, funding for the pilot projects was delayed. While the Working Party focused on selecting projects that could be delivered within constrained timelines, the additional time required to ensure genuine co-design and obtain ethics made the short project timeframes difficult. • Budget analysis data show that cost estimates and the reasonableness of costs for projects was a key consideration for the project selection committee, though without strong guidance on what constituted "reasonable" costs for activities. • Evaluation findings support the NDRP's plans to use a mix of short- and longer-term grants through open grant rounds, as well as solicited research projects to achieve efficiency and coverage.	

RECOMMENDATIONS

The evaluation identified some key learnings from the seed funding phase that are presented as recommendations to inform the future delivery of the NDRP, which will be established as an independent entity. An overview is provided below with detailed information about each of these recommendations in Chapter 5 on Learnings and recommendations.



OPERATIONS AND GOVERNANCE

1. Continue to put people with lived experience of disability at the heart of the NDRP, with people with disability at all levels, guiding all activities.
2. Ensure that the governance structure of the NDRP is transparent, independent, and reflective of the stakeholders served.
3. Ensure that appropriate time, operational and financial support is available to deliver NDRP activities.
4. Implement an appropriate organisational structure to support NDRP operations.
5. Diversify funding sources to assure long-term stability of the NDRP.
6. Consider models for appropriate support and remuneration of disability organisations and people with disability.



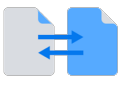
NDRP PRINCIPLES

7. Further clarify key terms, such as “high quality” and “value all forms of knowledge” to enhance shared understanding of the NDRP principles and the ability of future evaluations to assess the extent to which the principles are being applied.
8. Strengthen descriptions of the NDRP principles to broaden their adaptability to inform all decision making within the NDRP.



STAKEHOLDER ENGAGEMENT

9. Invest in marketing and communication of the NDRP to build reach, awareness and engagement, especially in the disability community.
10. Increase NDRP engagement with the Australian Government, and state and territory governments.
11. Continue to address intersectionality of disability with other aspects of identity subject to discrimination and marginalisation, and the impact of this on research access, policy making and translation to practice.



RESEARCH TRANSLATION AND MOBILISATION

12. Consider an additional NDRP principle about focusing on research use and outcomes for people with disability.
13. Further consider appropriate roles for the NDRP in knowledge mobilisation, recognising that knowledge flows in both directions between researchers and end users.

14. Build NDRP investment in activities that support research translation.

MONITORING, EVALUATION AND LEARNING

15. Ensure the NDRP monitoring, evaluation and learning (MEL) framework includes a focus on collaboration and partnerships, informed by frameworks for the evaluation of collaboration-focused activities.
16. Extend the NDRP MEL framework to incorporate board/ governance performance.
17. The NDRP MEL framework should assess the appropriateness of the NDRP principles, the extent they are adhered to, and how this affects outcomes.
18. Ensure that reporting requirements for NDRP research projects enable and support monitoring, evaluation and learning.
19. The NDRP MEL framework should draw on implementation science to support and measure capacity building and research translation outcomes among stakeholders

1. EVALUATION OF THE NDRP

1.1 NATIONAL DISABILITY RESEARCH PARTNERSHIP

1.1.1 THE NEED FOR A NATIONAL DISABILITY RESEARCH PARTNERSHIP

A 2014 audit of disability research in Australia[2] concluded that disability research was often small scale, fragmented, poorly integrated into policy and practice and not fit for purpose. It identified a need to rapidly scale up research capacity to ensure that disability policy could be founded on a robust and established evidence base.

Additionally, people with disability have been the subject of research rather than having a key role in shaping research that affects their lives. The disability community has been advocating for a partnership in disability research for years.[3]

1.1.2 NATIONAL DISABILITY RESEARCH PARTNERSHIP

Australia's Disability Strategy 2021-2031 includes a commitment to the development of an evidence base and translation of research to policy, enabling people with disability to participate fully in society. A key part of this commitment is the creation of an organisation to facilitate a collaborative, translational research program through partnerships between academics, people with disability, their families and carers, peak advocacy and consumer groups, all levels of government and service providers.

Between June 2020 to June 2022, the Department of Social Services (DSS) provided seed funding of $2.5 million to the Melbourne Disability Institute (MDI), through the University of Melbourne, to begin establishing the National Disability Research Partnership (NDRP) ("seed funding phase").

WORKING PARTY

To support the establishment of the NDRP, the MDI set up a Working Party comprising 13 people, including people with disability, university researchers and independent advisors.

STAKEHOLDERS

The NDRP occupies a unique position in the disability landscape. At the centre is its focus on research addressing priorities for people with disability, and their support networks. Research is expected to be developed through partnerships between people with disability, university and research/ policy institutes, disabled people's organisations, service sector and advocacy bodies. Decision-makers in the Australian Government and state and territory governments

[2] Llewellyn, G. (2014). Report of audit of disability research in Australia. https://apo.org.au/node/312552.
[3] National Disability Research Partnership (2022). Learnings and Recommendations report. https://www.ndrp.org.au/recommendations

are also key stakeholders to inform and use research in a range of policies affecting people with disability.

DELIVERABLES OF THE SEED FUNDING PHASE

The NDRP seed funding phase involved the development of five core deliverables by MDI and the NDRP Working Party. These are:



- deliver a national disability research agenda



- design a governance model to support the long-term NDRP



- map and develop research capacity in Australia



- write a practical guide to NDRP research



- fund a series of pilot projects to build the evidence base and refine NDRP processes.

At the end of the seed funding phase, the NDRP Working Party provided a set of recommendations for the full establishment of the NDRP.

ONGOING FUNDING

The Australian Government has committed $15 million over 2022-23 to 2024-25 for an NDRP to build the evidence base for *Australia's Disability Strategy 2021-31*.

DSS will use the NDRP Working Party's recommendations to inform the establishment of a legal NDRP entity and its governance arrangements. This work and the implementation of the NDRP will be done in close consultation with the NDRP Working Party.

1.1.3 RELATED WORK ON A NATIONAL DISABILITY DATA ASSET

As part of *Australia's Disability Research Strategy 2021-2031*, the Australian Government has also invested in a National Disability Data Asset (NDDA) in partnership with state and territory governments. The aim is to develop a cross-jurisdictional national disability data set that can provide better understanding of how people with disability are supported through services, payments and programs across multiple service systems. The NDDA project has recently moved to the establishment phase and the NDDA and NDRP are currently linked

through DSS and collaboration with the NDRP Working Party. The NDDA is expected to provide new data infrastructure to support the realisation of the NDRP research agenda.[4]

1.2 THE EVALUATION

1.2.1 PURPOSE AND SCOPE

To inform the full establishment of the NDRP and to support future funding of the NDRP to be delivered effectively and efficiently, DSS commissioned ARTD to deliver a process evaluation of the NDRP seed funding phase. This included making recommendations for ongoing monitoring and evaluation of the NDRP.

At the time of this report's completion, the NDRP does not yet exist as a separate legal entity. For brevity, throughout this report, 'NDRP' refers to activities undertaken by MDI and/or the NDRP Working Party in the seed funding phase. The final chapter makes recommendations for the future stages of the NDRP.

1.2.2 KEY EVALUATION QUESTIONS

The evaluation was tasked with answering the questions listed below.

Appropriateness

1. To what extent have the current NDRP principles been applied in NDRP seed funding activities, projects and practices?
2. To what extent is the work under the NDRP seed funding phase laying a foundation for the genuine involvement of people with disability in research?
3. What is the extent and quality of engagement by people with disability and other stakeholders in the NDRP seed funding activities?
4. To what extent has the NDRP laid the foundation for the development of accessible, tailored information that can help people with disability, policy makers and practitioners make evidence-informed decisions?

Effectiveness

5. To what extent have the NDRP seed funding objectives been achieved?
6. What outcomes, both intended and unintended, were observed during the seed funding phase?

Efficiency

7. Has the NDRP been operationally and cost efficiently implemented during the seed funding phase?
8. What factors need to be considered in order to support operational and cost efficiency in future phases?
9. What were the enablers and barriers to success during the seed funding phase?

[4] National Disability Research Partnership (2022). Preliminary Research Agenda. https://www.ndrp.org.au/researchagenda.

10. How might the pilot projects have been delivered more efficiently (time and cost-efficiency)?

Learnings and recommendations

11. What can be learned from the seed funding phase that can inform future delivery of the NDRP?

1.2.3 METHODS

The evaluation draws on key NDRP documentation and data and feedback from NDRP stakeholders. See Table 1 below for an overview and Appendix 3 for a table mapping methods against evaluation questions.

TABLE 1. DESCRIPTION OF DATA SOURCES

Data source	Description	Sample	Sample limitations	Timing
NDRP Documents provided by MDI/ NDRP Working Party	Cataloguing, summary and analysis against key evaluation questions.	94 documents covering: • planning • Working Party minutes • documents for the pilot projects funding round.	n/a	Documents cover seed funding period; updated documents provided as they became available during the evaluation.
Cost data	Budget and expenditure data covering the seed funding period.	n/a	n/a	Covers the full seed funding phase. Updated data provided 28/9/2022.
Social and web media	Analysis of reach and engagement for NDRP social media and web media.	Data covers: • website views • blog posts • email campaigns • Twitter • APO collection.	n/a	Supplied to ARTD by the NDRP on 14/8/2022
Survey	An online survey collecting qualitative and quantitative data developed by ARTD, hosted on Qualtrics and distributed to NDRP stakeholders.	The survey was sent to a total of 1015 stakeholders on the NDRP mailing list and received 91 responses. This is a 9% response rate.	This is a reasonable response rate as it is in line with the open rate of NDRP communications.	28/7/2022 to 31/8/2022.
Internal interviews	45-minute interviews held by phone or an online meeting.	38 interviews were conducted with 40 internal stakeholders (since some interviews had multiple stakeholders):	23 internal stakeholders were contacted but chose not to be interviewed: • 6 from government	5/8/2022 to 5/9/2022

Data source	Description	Sample	Sample limitations	Timing
		• 15 Working Party members • 7 from government (DSS, NDIA, state governments) • 18 academics including pilot project chief investigators and researchers with disability, agenda setting and capacity building project teams.	• 17 academics Only one state government was represented in the stakeholders interviewed.	
External interviews	45-minute interviews by phone or an online meeting platform.	12 interviews conducted with 14 external stakeholders.	Many said they were not well-informed enough about the NDRP to confidently assess its activities – some did not give numerical ratings; some did. 15 internal stakeholders were contacted but chose not to be interviewed: 4 from peak bodies or support services 9 from DPOs (Disabled Persons' Organisations) 2 from research and policy institutes.	5/8/2022 to 12/9/2022

1.2.4 ETHICS

Given the focus of this project on identifying process improvements and the type of data collected had minimal risk of surfacing trauma, the evaluation did not require external ethical approval. However, we conducted an internal ethical review consistent with NHMRC (National Health and Medical Research Council) Guidelines,[5] to identify and address any potential risks.

Respondents were informed that participation was voluntary and provided informed consent. To protect respondents' privacy, names and identifying information were removed or changed when using quotes.

1.2.5 STRENGTHS AND LIMITATIONS

ARTD was able to implement the evaluation methods largely as intended and had sufficient data to answer the key evaluation questions. However, at the time of the evaluation, some of the NDRP deliverables were still in progress and had not yet been more broadly communicated, which affected respondents' understanding and ability to rate and comment on the appropriateness and effectiveness of the seed funding phase. Additionally, the survey had a 9% response rate, and while this is in line with the open rate for the NDRP mailing list, the findings may not reflect the views of all stakeholders.

[5] The *National Statement on Ethical Conduct in Human Research* (2007, updated 2018). https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018.

2. FINDINGS: APPROPRIATENESS

2.1 TO WHAT EXTENT HAVE THE CURRENT NDRP PRINCIPLES BEEN APPLIED IN NDRP SEED FUNDING PHASE ACTIVITIES, PROJECTS AND PRACTICES?

2.1.1 DEVELOPMENT OF THE NDRP PRINCIPLES

The NDRP Working Party – with input from several external stakeholders – developed four principles to guide the operation and activities of the NDRP:

- deliver high quality, collaborative research
- recognise the knowledge of people with disability in research
- value all forms of knowledge
- build research capacity (See Appendix 2 for a full description of each principle).

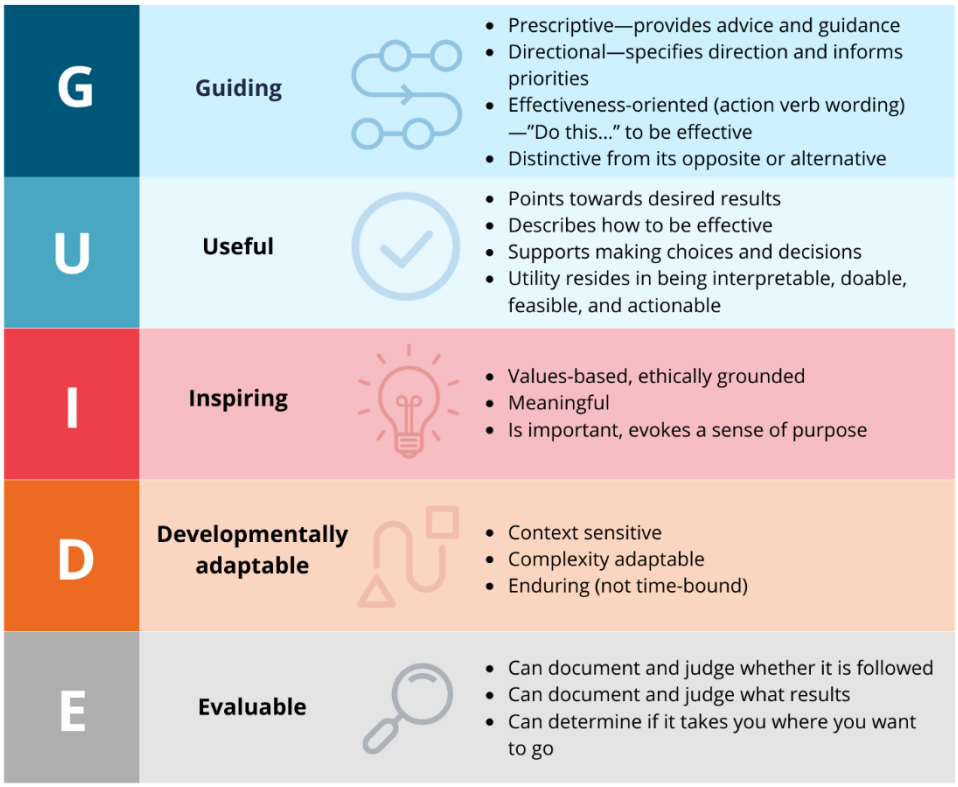
The Working Party sought feedback on, and made refinements to, the principles during the seed funding phase. The Working Party also expects that the principles will be further refined, consistent with the iterative development of the NDRP.

Feedback on the principles from consultation conducted by the NDRP Working Party in the second half of 2021 was predominantly positive. There were only a few suggested changes to the principles, including integrating capacity building in evaluation into the principles; highlighting that lived experience should be valued at all stages of processes; and including that people with disability need to see the outcomes of their research participation. Some also suggested that "recognise the knowledge of people with disability in research" should be re-designated as the first principle.

2.1.2 APPROPRIATENESS OF THE NDRP PRINCIPLES

Evaluation theorist Michael Quinn Patton sets out five criteria for assessing the effectiveness of initiatives guided by principles (Figure 1).

FIGURE 1. ASSESSING THE EFFECTIVENESS OF PRINCIPLES



Source: Patton, M.Q. (2017). Principles Focussed Evaluation. Guildford University Press, New York.

Using these criteria, the evaluation team assessed the NDRP principles:

- **Guiding:** the principles are directive; they say "do this".
- **Useful:** the principles point to the desired end goals of the NDRP and make clear the NDRP's priorities, in particular recognising the knowledge of people with disability. However, an additional principle focused on use and outcomes for people with disability could further support the intent of the NDRP to drive research that is used by government, organisations and people with disability to make a positive difference to the lives of people with disability.
- **Inspiring:** they are values based. The principles reflect the human rights framework embedded within the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) and the preamble to the principles recognises the diversity of people with disability, intersectional disadvantage, and the role of families and carers.
- **Developmentally adaptable:** the descriptions of the principles tend to focus more on activities than the structures and operations of the NDRP. Broadening the descriptions could make them more adaptable to guide decision-making and action at all levels of the NDRP.
- **Evaluable**: interviewees disagreed about or were confused by key terms, such as "high quality" and "value all forms of knowledge", suggesting these could be further clarified to enhance shared understanding of the principles and strengthen the ability of future evaluations to assess the extent to which the principles are being applied, as evaluation is core to the NDRP.

2.1.3 INTEGRATION OF THE PRINCIPLES INTO NDRP OPERATIONS AND ACTIVITIES

The principles have been well integrated into the design process and activities led by the Working Party. The NDRP principles were shared on the NDRP website and used in public facing activities, such as the request for pilot proposals.

The governance structure for the seed funding phase and the proposed NDRP governance structure reflect the principle of recognising the knowledge of people with disability in research. There were key members with disability in the Working Party and the Working Party proposed that people with disability will make up 50% of board members of a future NDRP, thereby valuing their knowledge and ensuring they have governing power.

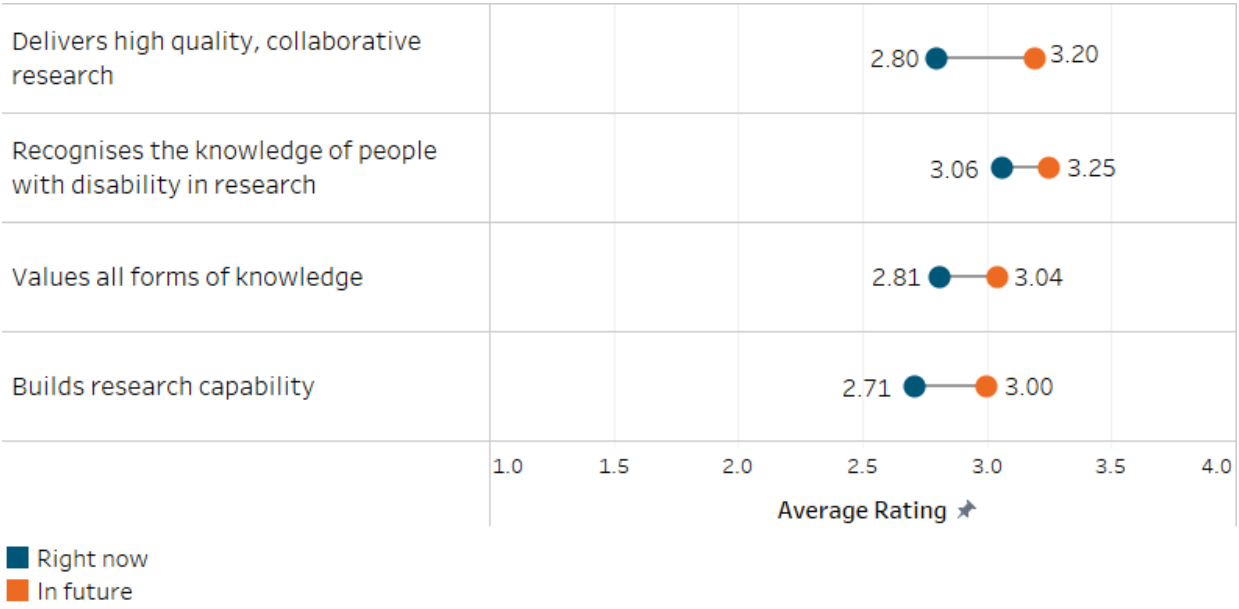
In the pilot project funding round, the NDRP principles informed project selection criteria. Projects had to demonstrate research capability, in line with the principle of delivering high quality research.[6] Projects also had to be conceptualised, executed and disseminated by and with people with disability, in line with the principles of collaborative research and recognition of people with disabilities' knowledge in research, and building research capacity. Budget criteria specified the appropriate payment of people with disability, which reflects the principle of recognising the knowledge of people with disability in research. Criteria aligned with the principles were also used as a guiding template for project reports in which project teams demonstrated a commitment to and realisation of NDRP principles. Examples of this include project teams describing the genuine inclusion of team members with disability, the collaboration between team members with and without disability and the professional development of researchers with and without disability during the project lifecycle.

2.1.4 PERCEPTIONS OF THE ACHIEVEMENT OF THE PRINCIPLES

Respondents to the survey and interviews were asked to assess on a scale of 1-4 (where 1 meant not at all and 4 meant completely) the extent to which the NDRP principles are currently being achieved and the extent to which they expect the principles will be achieved in future (Figure 2). Respondents were most positive about the NDRP "recognising the knowledge of people with disability in research", reflecting the efforts to ensure that this is the core of the NDRP. Across all of the principles, they were more optimistic about future than current delivery of the principles, given the early stage of the NDRP.

[6] National Disability Research Partnership (2021). Request for Proposals. NDRP Research Funding Round. https://www.ndrp.org.au/funding-round.

FIGURE 2. PERCEPTION OF ACHIEVEMENT OF NDRP PRINCIPLES CURRENTLY AND LIKELIHOOD IN FUTURE



Respondents: Delivers high quality, collaborative research right now (124), in future (123). Recognises the knowledge of people with disability in research right now (124), in future (122). Values all forms of knowledge right now (122), in future (121). Builds research capacity right now (123), in future (119).

Respondents to the survey and interviews were categorised into groups to identify any differences between stakeholder groups. Respondents could fit into more than one category, and the category 'not any of the above' refers to those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

People with disability were less positive than other respondents the NDRP principles are currently being achieved or will be in future (Figure 3).

FIGURE 3. PERCEPTION OF ACHIEVEMENT OF NDRP PRINCIPLES CURRENTLY AND LIKELIHOOD IN FUTURE BY DISABILITY STATUS

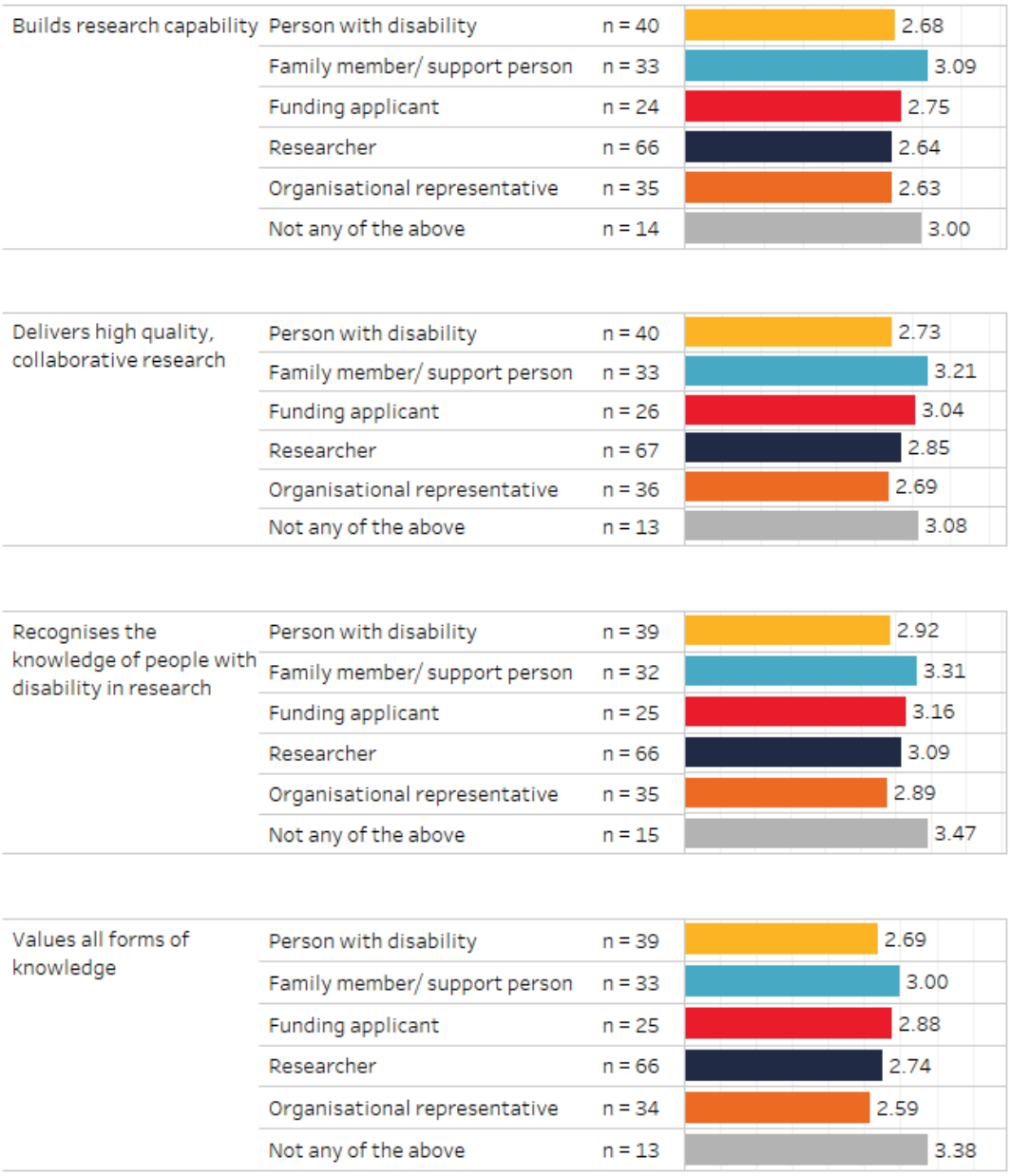


Number of respondents to each question: (person with disability , person without disability)
Delivers high quality, collaborative research right now (40, 84), in future (38, 85).
Recognises the knowledge of people with disability in research right now (38, 85), in future (39, 84).
Values all forms of knowledge right now (39, 82) in future (39,83).
Builds research capacity right now (38,81) in future (38,81).

Respondents from the 'not any of the above' group, which were those most closely involved with NDRP activities, were, overall, more positive that the principles have been achieved. These respondents tended to be better informed in terms of work undertaken by MDI and the NDRP Working Party. (Figure 4, Figure 5).

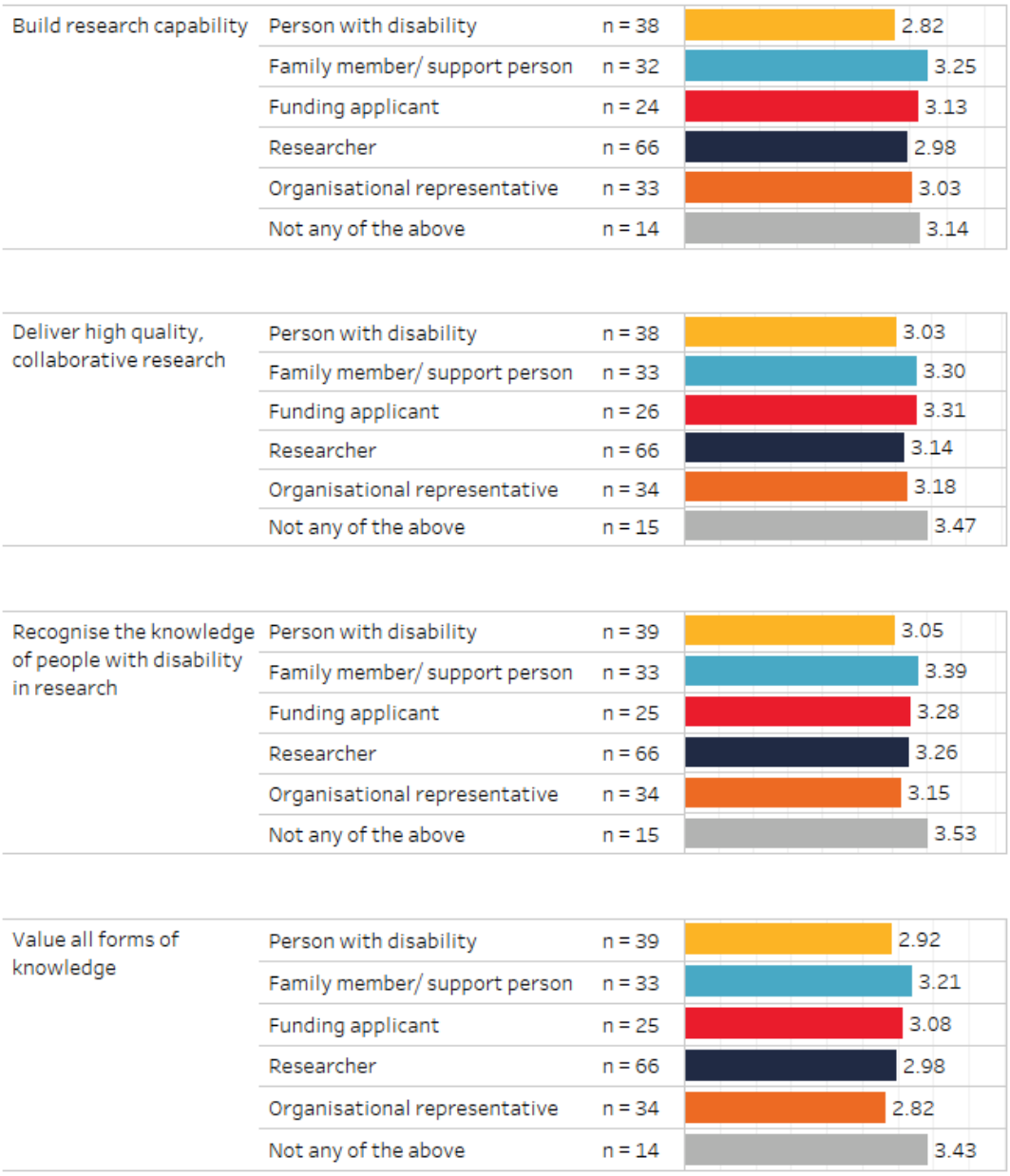
Several organisational representatives said that they had not received enough information from the NDRP to assess how well it has achieved its principles. This might be a general explanation for the lower ratings provided by this group because some respondents provided this reason for rating the NDRP as not fully achieving some principles.

FIGURE 4. EXTENT OF AGREEMENT THAT NDRP PRINCIPLES HAVE BEEN ACHIEVED AT PRESENT BY RESPONDENT GROUP



Note: Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

FIGURE 5. EXTENT OF AGREEMENT THAT NDRP PRINCIPLES WILL BE ACHIEVED IN FUTURE BY RESPONDENT GROUP



Note: Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

DELIVERS HIGH QUALITY, COLLABORATIVE RESEARCH

Respondents perceived the biggest gap between current and future achievement of the principle of delivering high quality, collaborative research. In interviews, most respondents indicated the potential to achieve this principle. While the Community of Practice had helped achieve this principle to date, respondents noted that the small number of projects funded in the seed funding phase limited the extent to which the principle had been achieved.

> *The pilot projects which they funded were certainly designed to be inclusive and to be codesigned and that was great to see that. And they had a community of practice – a forum that the project leads came to and that was a really useful exercise. [Researcher]*

> *Because we have the community of practice, that was bringing together researchers with diverse experiences, people with and without disabilities. You could clearly see that across the projects there's been a lot of focus on ensuring that all processes were inclusive and combined. [Researcher]*

The most common explanations for why respondents thought the NDRP would achieve this principle in the future were the requirement for funded projects to include people with disability and the Community of Practice.

There were some differences of view among different respondent groups about what counts as 'high quality' research. For example, researchers prioritised academic rigour, while some government respondents suggested that there could be more focus on ensuring NDRP funded research is policy relevant and delivered in time to inform policy. One government respondent suggested a focus on research being policy relevant should be given equal weight to other criteria for funded projects. Government respondents were not all confident that the issue of ensuring NDRP research is policy relevant would be overcome in future. However, one Working Party member pointed out that the recommended future funding requirements ensure that the research is answering a question that is relevant to people with disability, which should mean that it is useful to government improving outcomes that are meaningful to people with disability.

Some respondents noted that the NDRP's ability to deliver high quality, collaborative research is dependent on adequate funding rather than internal factors.

RECOGNISES THE KNOWLEDGE OF PEOPLE WITH DISABILITY IN RESEARCH

Of the four principles, respondents were most positive about the current and future achievement of recognising the knowledge of people with disability in research, but the difference was most apparent in the assessment of current achievement. Many respondents explained this was because of how people with disability had been involved in the pilot projects.

Many respondents described the groundwork completed to recognise the knowledge of people with disability, such as having the right people involved, requiring pilot projects to recognise the knowledge of people with disability, and consulting with people with disability. Most thought that this would allow the NDRP to recognise the knowledge of people with disability in research more fully in the future.

> *I have been impressed with NDRP's approach to consumer contributions as co-researchers, building a community of practice amongst the researchers and ensuring information is accessible to multiple audiences so that is the reason why I have rated them so highly. [Chief Investigator]*

> *That whole piece of "no research about us without us" type discourse – I think the really important thing that's come through from it, is that they've tried to get the whole*

> *disability research field to really embrace that, and push it, and explain why you need to have lived experience of people with disability, to be part and parcel of driving the research. So there's really the absolute need of that support; to have this national initiative to coordinate all this. [Sector Representative]*

However, some respondents claimed that co-design was impeded by traditional academic attitudes, suggesting researchers in general tend towards traditional ways of doing research, and may be resistant to change to enable people with disability to lead research. While the pilot project selection focused on research projects for completion in the short timeframes available, some respondents referenced short timeframes for funding applications and projects limiting the ability of people with intellectual disabilities to engage. These respondents acknowledge that this will be addressed when the NDRP can fund longer-term projects.

> *I think the NDRP needs to tighten up the process a bit to make sure the projects they are funding are genuinely led by people with disabilities. [Chief Investigator]*

> *There's very much an emphasis on co-design and inclusion… but the timelines were restrictive… we only had funding for a certain number of hours a week for the co-researchers and the research assistants… if you're going to support people with disability in the process of research, you need to really find the accessibility needs and the budgets need to reflect that and the timing needs to reflect that. I think the turnaround of nine months is not long enough to really do co-design. [Researcher]*

VALUES ALL FORMS OF KNOWLEDGE

Respondents were broadly positive about the achievement of the principle of valuing all forms of knowledge, saying that during the seed funding phase the knowledge of people with lived experience had been valued. However, they rated future achievement of this principle the second lowest among the principles.

This is an ambitious principle as it requires a shift in thinking about what constitutes knowledge. Researchers and NDRP Working Party members noted this requires going beyond traditional academic perspectives, which focus on scientific findings and journal articles, compared to alternate visual methods of communication.

While one Working Party member said the research structures set up in the seed funding phase value all forms of knowledge, another suggested improvements could be made in valuing Indigenous community knowledge and in conducting and presenting research in a way that is more accessible to all people with disability. Another Working Party member identified that valuing the knowledge of advocacy organisations is important, since it hasn't traditionally found space for expression in academia.

> *'The Working Party tended to focus on traditional forms of knowledge. So there's room and scope to look at alternative forms of knowledge that might not be classical or traditional…. Also in terms of Indigenous knowledge, there's an overlap there.' [NDRP Working Party]*

One Government respondent suggested that to date the research funded had not been quantitative enough. They raised the need for better integration with use of the National Disability Data Asset once this is established. On the other hand, a Working Party member emphasised the importance of recognising the value in doing in-depth qualitative research with small groups.

This reflects a diversity of views around which forms of knowledge need to be valued more by the NDRP.

There were also some respondents who said that they did not know what valuing all forms of knowledge would entail, and so declined to give a rating.

BUILDS RESEARCH CAPACITY

Respondents generally thought research capacity had been built in the seed funding phase and the NDRP will continue to do so in the future, but they rated both current and future achievement of this principle lower than the other principles.

Respondents noted the Community of Practice and focus on including people with disability in research had supported capacity building. However, capacity building takes time and some thought not as much work had been done on this principle as others in the seed funding phase. Some respondents specifically suggested achievement of this principle will require additional funding, and longer timelines than the pilot projects had.

> *If we want to build research capacity among people with lived experience, projects need to be funded in a different way. And the timelines for projects need to be different, and the demands placed on people with lived experience need to be acknowledged. Trying to set up a community of practice at the same time as doing a project with limited time span doesn't work. And I don't think it acknowledges the burden placed. [Researcher]*

> *In order to build research capability, you would need firstly a capability framework, identify where the gaps are and target the projects towards those capabilities. I haven't seen the demonstration projects targeted in that lens. [Government respondent]*

Some respondents said that collaboration from universities would be required to build capacity, but this is not within the NDRP's control. Some thought the NDRP could do a better job building capacity among people with intellectual disability and advocacy organisations.

One Working Party member said that the NDRP would be able to build capacity best by supporting others to build capacity.

> *It feels like we should be building everyone's capacity to build capacity, rather than being the place to build capacity… everybody should be participating in the capacity building work. [NDRP Working Party]*

2.2 WHAT IS THE EXTENT AND QUALITY OF ENGAGEMENT OF PEOPLE WITH DISABILITY AND OTHER STAKEHOLDERS IN THE NDRP SEED FUNDING PHASE ACTIVITIES?

2.2.1 ENGAGEMENT ACTIVITIES UNDERTAKEN

NDRP GOVERNANCE

Several of the initial members of the NDRP Working Party had lived experience of disability. In October 2020, three additional members with disability were appointed to increase the representation of people with disability. However, the recruitment process for these additional members created some confusion as some disabled peoples' organisations assumed there had not initially been members of the Working Party with lived experience.

The NDRP Working Party engaged with disabled peoples' organisations, advocacy organisations and peak bodies through consultations and surveys about the proposed governance model for the NDRP. While there was engagement with a broad range of organisations, it is not clear how people with disability were directly involved and the extent to which people with varying disabilities and people from diverse backgrounds were engaged. NDRP documentation provided by MDI and the Working Party did not contain information about the number of people with disability involved in consultations or demographics and the survey conducted by the NDRP Working Party had only one response from a person with disability. However, as survey participants could only select one response option, it is possible that more people with disability participated than represented in the categories, as people who identified with multiple response options may have chosen another category.

DISABILITY RESEARCH AGENDA

The development of the disability research agenda was led by a consortium of academics, people with lived experience of disability, carers and members of non-government organisations, including disabled people's organisations.[7] The consortium surveyed and consulted with people with disability, their representative organisations, researchers, families and supporters, service providers, all levels of government and other stakeholders to identify key issues for disability research – engaging nearly 1000 respondents (Figure 6).

[7] Smith-Merry, J., O'Donovan, M.-A., Dew, A. et al. (2022). The Future of Disability Research in Australia: Protocol for a Multiphase Agenda-Setting Study. *JMIR Res Protoc*, 11(1). See https://apo.org.au/node/319356 for open access.

FIGURE 6. NDRP RESEARCH AGENDA CONSORTIUM CONSULTATION DEMOGRAPHIC INFORMATION



However, there were some limitations to the quality and extent of engagement. COVID-19 had a significant impact on the capacity of the consortium to hold stakeholder consultations. Most consultation participants were from the eastern states of Australia and it is not clear how well views from people living in non-urban settings were captured. Further, despite targeted consultation, more input from Indigenous people is required and it is not evident how well culturally and linguistically diverse people and other minority groups were represented. Because the consultation survey asked people to prioritise areas of research, if respondents did not consider the needs and interests of smaller groups, areas of interest to them may not have received a high rating.

PILOT PROJECTS FUNDING ROUND

The genuine involvement of people with lived experience was a key selection and reporting criteria for pilot projects. While the NDRP Working Party identified that a clear definition of genuine involvement and a consistent way to assess this were missing, people with lived experience of disability were involved in all pilot projects. People with disability were most commonly involved as co-researchers (in five projects), and in other cases through a reference group or expert advisory group or as lead researchers with lived experience. While many project teams reported on the involvement of people with disability in detail – which included involvement of co-researchers in preparation of participant information material and interview guides, co-facilitation of interviews, data analysis, project management, as members in advisory committees, and as accessibility advisors – some provided less information. Some researchers noted short timeframes presented a barrier to the genuine involvement of people with lived experience in their projects. Very few project teams included feedback from their team members with lived experience in their project reports

and only one project team included direct reflections from their two co-researchers with disability, noting that the standard report template did not provide a designated space for comments from researchers with disability. The Working Party took feedback about this on board, and in their final report on the seed funding phase, they specifically sought out quotes from researchers with disability to present in case studies.

When feedback from researchers with disability was provided, this was mostly positive – they felt included and respected, enjoyed helping the team and learned new skills. However, some reference group members wanted more direct engagement with the research team.

COMMUNITY OF PRACTICE

The Community of Practice meetings provided an opportunity for engagement of project researchers and co-researchers with lived experience of disability. These were held monthly for two members from each pilot project team (at least one with lived experience). The purpose of the meetings was to share learnings about inclusive research, develop an accessible research translation strategy, and refine NDRP processes for supporting inclusive research. Feedback from research teams about the Community of Practice was highly positive and many wanted it to continue past the life of their project. However, some researchers raised that the meetings were not always accessible, for example for people with intellectual disability or for researchers with diverse communication needs. One co-researcher with lived experience raised that it was not always easy to follow the meetings due to difficult words or acronyms, while another researcher reported that their team member with lived experience said the meeting sometimes 'went over their head' or they felt 'put on the spot' when asked a question. Some researchers raised that the voices of researchers without lived experience were dominant during Community of Practice meetings and suggested having an additional space for researchers with lived experience to connect and share their experiences. This echoes the calls of lived experience members from one research team who wanted more exchange with co-researchers from other teams.

OTHER ACTIVITIES

NDRP documentation provided by MDI/ the NDRP Working Party contained limited information about the extent and quality of engagement by people with disability in other activities, including research guide development and capability mapping and building activities.

To ensure stakeholder involvement in their final report and recommendations, the Working Party had intended to arrange workshops with representation from multiple stakeholder groups, but this engagement was postponed to the next phase of the NDRP due to time constraints.

ENGAGEMENT WITH NDRP COMMUNICATIONS

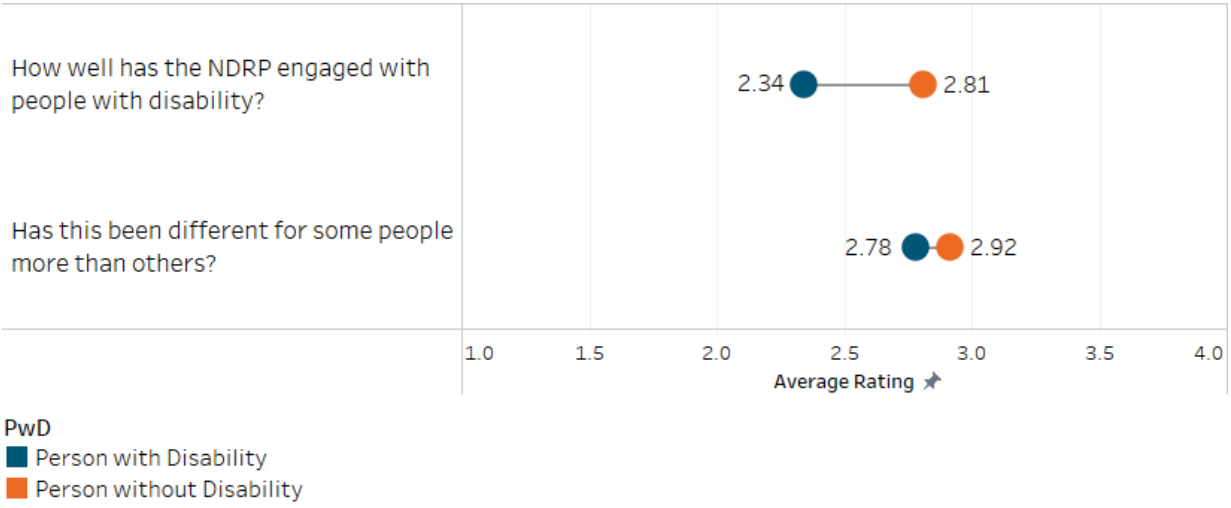
While email read and click rates are good, the reach of the NDRP's mailing list is only 1,000 people, which is low given the size of the community. NDRP social media engagement has been limited to date, with only 361 Twitter followers, 66 likes on Facebook, and low post

rates. NDRP website views have remained static after the grant round period and only two blog posts saw more than 15 hits.

2.2.2 PERCEPTIONS OF THE ENGAGEMENT OF PEOPLE WITH DISABILITY AND OTHER STAKEHOLDERS

Respondents with disability rated the engagement with people with disability in the NDRP seed funding phase lower than those without disability (Figure 7). Respondents generally thought engagement was different for some people with disability, reflecting the significant challenge of engaging the diverse disability community.

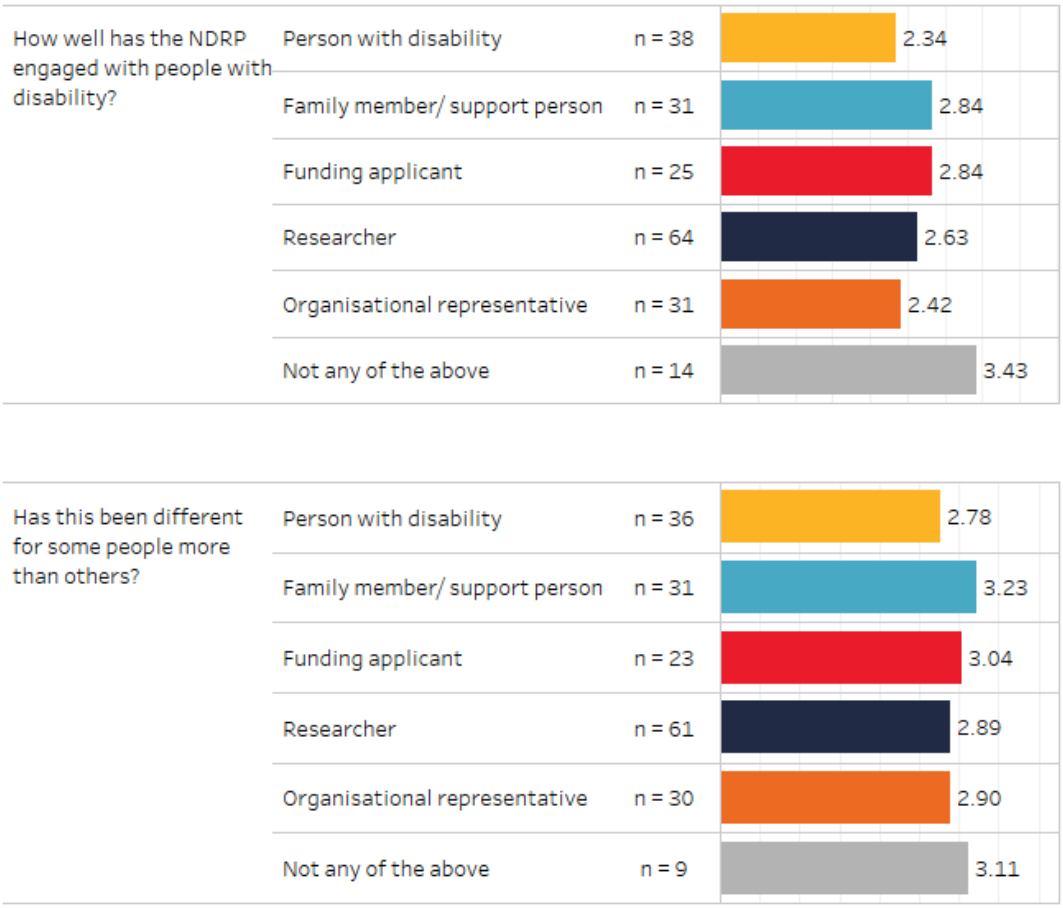
FIGURE 7. RATINGS FOR ENGAGEMENT WITH PEOPLE WITH DISABILITY BY DISABILITY STATUS



Number of respondents: (person with disability, person without disability)
"How well has the NDRP engaged with people with disability?" (38, 80); "Has this been different for some more than others?" (36, 72).

Similar to their assessment of the achievement of the NDRP principles, those who were more directly involved with NDRP activities ('Not any of the above') were more positive about the engagement that had taken place, given their awareness of activities completed (Figure 8).

FIGURE 8. RATINGS FOR ENGAGEMENT WITH PEOPLE WITH DISABILITY BY RESPONDENT GROUP



Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

Respondents recognised the clear commitment to the engagement of people with disability, but some questioned the extent of reach achieved in the seed funding phase, noting that more work would be needed to ensure diverse voices are included.

Some respondents suggested that to date there has been good engagement with people who are already involved in research and organisations with which the NDRP Working Party had an established relationship. However, these and other respondents felt that people with disability outside academic research need to be engaged to make the NDRP and its research known to the broader disability community. For example, one respondent commented that disability leaders who are researchers have generally been engaged, rather than other disability leaders. Another said people with disability who are not already accessing disability services have not yet been adequately engaged.

> *I think the people for whom their ways of engaging suit their needs, they've done it really well, but we have to figure out what do we do for those people who are not going to engage for various reasons. [Researcher]*

> *But in terms of breadth, I genuinely don't know whether they did disability specific engagement. Did they talk to Cerebral Palsy Alliance? The Stroke Foundation? Have a*

> *conversation with the Butterfly Foundation?... I don't know whether they did that length and breadth. [Sector Representative]*

Some respondents felt that the NDRP had not adequately engaged with people with certain types of disabilities, especially people with intellectual disabilities, people with less common disabilities and people who use alternative or augmented forms of communication. Some suggested that this was because they weren't adequately tailoring their outreach strategies for a diverse range of stakeholders.

> *There are many types of disabilities. What's right for one group is not necessarily going to translate to another. And we have to have a range of approaches and methods and policies that have some level of commonality, but also allow for some differentiation. [Researcher]*

> *I think it has been a steep learning curve for the NDRP team in making sure that the information is accessible to people with disability, particularly people that may use augmented or alternative forms of communication. [Chief Investigator]*

Members of the Working Party noted COVID-19 had created barriers to outreach, particularly to parts of the disability community, including those in rural and remote areas, people with intellectual disabilities, and people who use alternative or augmented forms of communication.

> *Happened during pandemic and community was under enormous pressure and fighting for survival and government forgot we existed – people didn't have capacity. Disabled people have to come up with the time and the energy, even resourced organisations struggled for survival. Independent assessments [i.e. the government's proposal to introduce independent assessments for the NDIS] interfered... [NDRP Working Party]*

> *Because so much of the Community of Practice was online, it did sometimes make it difficult for people for example who are deaf when the captions were not working that well. It is potentially more difficult for people with cognitive disabilities to engage in that format. And had some of those Community of Practices been held in person, it might have been easier for researchers with cognitive disabilities to participate more fully. [Researcher]*

The consultation conducted for the evaluation, in line with NDRP social media and web engagement data, suggest there is not yet broad awareness and understanding of the NDRP. Some disability organisation representatives and state and territory government representatives approached to participate said they were unable to contribute due to limited interactions with the NDRP. Among those that did participate in interviewers, there were varying levels of awareness and engagement; some knew a lot, while others knew little, and said they had not received sufficient communications to comment on some activities.

> *There's not been huge publicity around it; what's come out of the NDRP so far. I remember a while back I got an email about the projects that had been awarded. That was the last actually I heard. [Sector Representative]*

> *Speaking for our community, we don't hear about it, still a lot of work to be done about information flows – may be some great research but we're not hearing about it in a way that is useful for our community. [Sector Representative]*

Two organisational representatives acknowledged that the NDRP's short timeline to date may have inhibited the ability to engage with organisations.

2.3 TO WHAT EXTENT IS THE WORK UNDER NDRP SEED FUNDING PHASE LAYING A FOUNDATION FOR THE GENUINE INVOLVEMENT OF PEOPLE WITH DISABILITY IN RESEARCH?

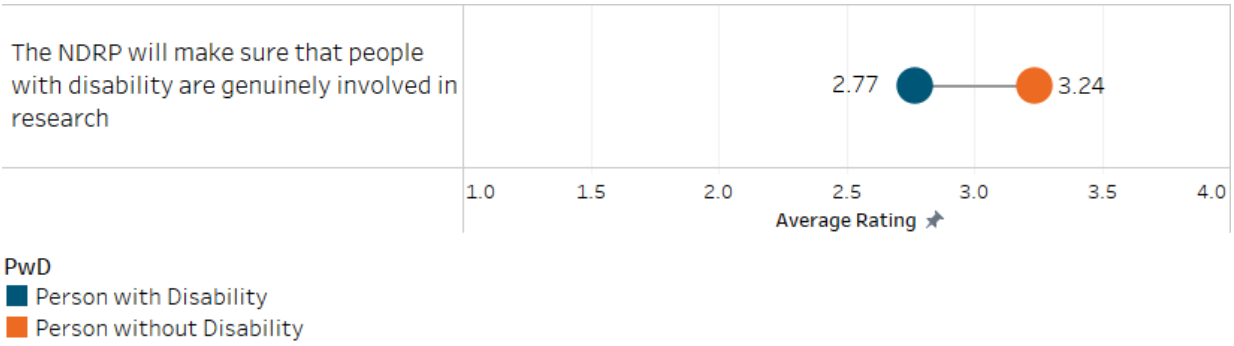
2.3.1 ACTIONS TAKEN BY THE NDRP TO LAY THE FOUNDATIONS FOR ENGAGEMENT OF PEOPLE WITH DISABILITY IN RESEARCH

Along with establishing the principle of recognising the knowledge of people with disability in research, the NDRP Working Party undertook several key actions to lay strong foundations for the genuine engagement of people with disability in research. The research funding guidelines for the pilot projects required that people with disability be included in projects. The NDRP Working Party minutes reflect frequent discussion of how the genuine involvement of people with disability could continuously be promoted and strengthened. For example, they discussed the need for a clear definition of genuine involvement of people with disability that could be assessed in research proposals. The governance structure the Working Party has proposed for the future NDRP also ensures the engagement of people with disability in leadership roles in the NDRP.

2.3.2 PERCEPTIONS OF THE FOUNDATIONS LAID

When asked to assess their confidence that the NDRP will make sure that people with disability are genuinely involved in research (based on their own definition of genuine), consistent with their assessment of the engagement of people with disability to date, respondents with disability were less positive than those without disability (Figure 9).

FIGURE 9. PERCEPTION OF THE EXTENT PEOPLE WITH DISABILITY WILL GENUINELY BE INVOLVED IN RESEARCH, BY PERSON WITH DISABILITY STATUS



Person with disability: n=39. Person without disability: n=85.

Consistent with their assessment of the engagement of people with disability to date, those who were more directly involved in NDRP activities (those in the 'Not any of the above' category) were more positive about people with disability being genuinely engaged, at least partially because they were more aware of the work undertaken (Figure 10).

FIGURE 10. EXTENT OF INVOLVEMENT OF PEOPLE WITH DISABILITY IN RESEARCH BY RESPONDENT GROUP



Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

Interview respondents identified indicators that the NDRP will ensure that people with disability are genuinely involved in research including:

- the requirements that funded projects genuinely engage people with disability
- the principles, which include recognising the knowledge of people with disability
- the governance structure, which includes people with disability
- the people involved, who are very committed to the genuine engagement of people with disability.

Some researchers and one Government respondent thought that involvement of people with disability will be inhibited if co-design is not adequately integrated throughout the NDRP's entire operations. Some Government and NDRP Working Party respondents thought achievement of inclusion will be driven by NDRP Working Party membership, saying that if some individuals become less involved than they are currently, it could lead to less inclusion of people with disability in NDRP research.

Organisational representatives emphasised the barriers to people with disability being involved in developing research proposals and delivering research if these roles are not funded. Some respondents highlighted the accessibility of the proposal and project materials for the pilot projects funding round and short timelines for proposals and projects as barriers to involving people with disability. Some stakeholders suggested more tailored communication and widespread use of Easy Read to assist with the grant application process and project activities.

> *They've put something out around community participation. But, how likely is it that the sector would be able to pull a project proposal together with a uni[versity] that would be the focus of an NDRP research funded initiative'? The likelihood is probably not much. [Sector Representative]*

> *In all of their communications to ensure that when they're communicating with a project team, particularly than somebody with an intellectual disability, that they're communicating in an accessible way, using plain English and Easy Read documents, so they'd make that part of their code of practice rather than it's an output of the research practice, but it's built into their systems. [Researcher]*

However, while this made some respondents less confident that the NDRP will involve people with disability in research in the future, other respondents were completely confident that the NDRP will do so in future.

The primary steps respondents suggested the NDRP take to ensure people with disability are genuinely involved in research were:

- require clear demonstration of involvement of people with disability in funding requirements
- ensure that funded research is of interest to people with disability
- involve a broad range of people with disability, which will require:
  - allowing more time if that is needed, both for projects and proposals
  - funding for alternative forms of communication
  - funding for involvement of people with disabilities in terms of paid wages, or where a person with disability requires a support worker, scribe or other accommodations
  - funding for, and focus on, accessibility of the information provided and activities required by the NDRP (with some concern ethics applications are currently inaccessible to people with intellectual disabilities)
- ensure that co-design and involvement occurs at every stage and level of the NDRP leadership and decision-making (e.g. working groups, committees, chief investigators)
- strengthen relationship and communication with the broader disability community, including advocacy organisations.

This is only a principle until something tangible is put into place. Fair payment is threshold into all of these other things. "Valuing people" is all well and good, but you need tangible results. Make NDRP an exemplar in how to treat people with disabilities. [Sector Representative]

To make sure people with disability are genuinely involved, they need to ensure that they fund people's accessibility needs, the accommodations and the support needs. You're not just funding the research, and the research team and the co-researcher. You may need to find a scribe or a support worker, or other things that need to be taken into account. [Researcher]

When you're working with people with intellectual disability, you need to support them; in terms of getting ready to do the project work and do the project meetings and building on that… you need to really fund the accessibility needs. And the budgets need to reflect that and the timing needs to reflect that. [Researcher]

And building accessibility into the process of applying. So that the actual funding application is valued and is accessible, and that there's a lived experience piece and that work is given the same wage as an academic publication, or their previous grants. [Researcher]

…You need to have a declaration statement from the organisation and the researchers, that they are working with people with disabilities and that it is done in such a way that it is participatory as much, structurally, as possible. Just like when you work with Indigenous First Nations people, they need to be involved in the research proposal from the very beginning. They need to help construct the parameters of the research. It needs to be signed off by the disability representative organisation's senior membership. [Sector Representative]

2.4 TO WHAT EXTENT HAS THE NDRP LAID THE FOUNDATION FOR THE DEVELOPMENT OF ACCESSIBLE, TAILORED INFORMATION THAT CAN HELP PEOPLE WITH DISABILITY, POLICY MAKERS AND PRACTITIONERS MAKE EVIDENCE-INFORMED DECISIONS?

2.4.1 ACTIONS UNDERTAKEN TO SUPPORT RESEARCH USE BY PEOPLE WITH DISABILITY, POLICY MAKERS AND PRACTITIONERS

The NDRP Working Party has clearly communicated research translation as one of the key functions of the NDRP and this has been supported by key Australian Government stakeholders, as outlined in *Australia's Disability Strategy 2021-2031*.[8]

[8] Commonwealth of Australia (Department of Social Services) (2021). Australia's Disability Strategy 2021-2031.

During the NDRP seed funding phase, development began on a translation and dissemination framework. One output was a draft best practice guide to research translation, developed with input from the Community of Practice.

In addition to NDRP core deliverables, the APO disability collection was established in November 2020. There are currently over 800 resources in the collection, which provides evidence on a range of topics to a public audience. However, as the NDRP Working Party notes in its learning and recommendations report, there is scope to increase its usefulness and accessibility with careful curation as well as the development of editorials.

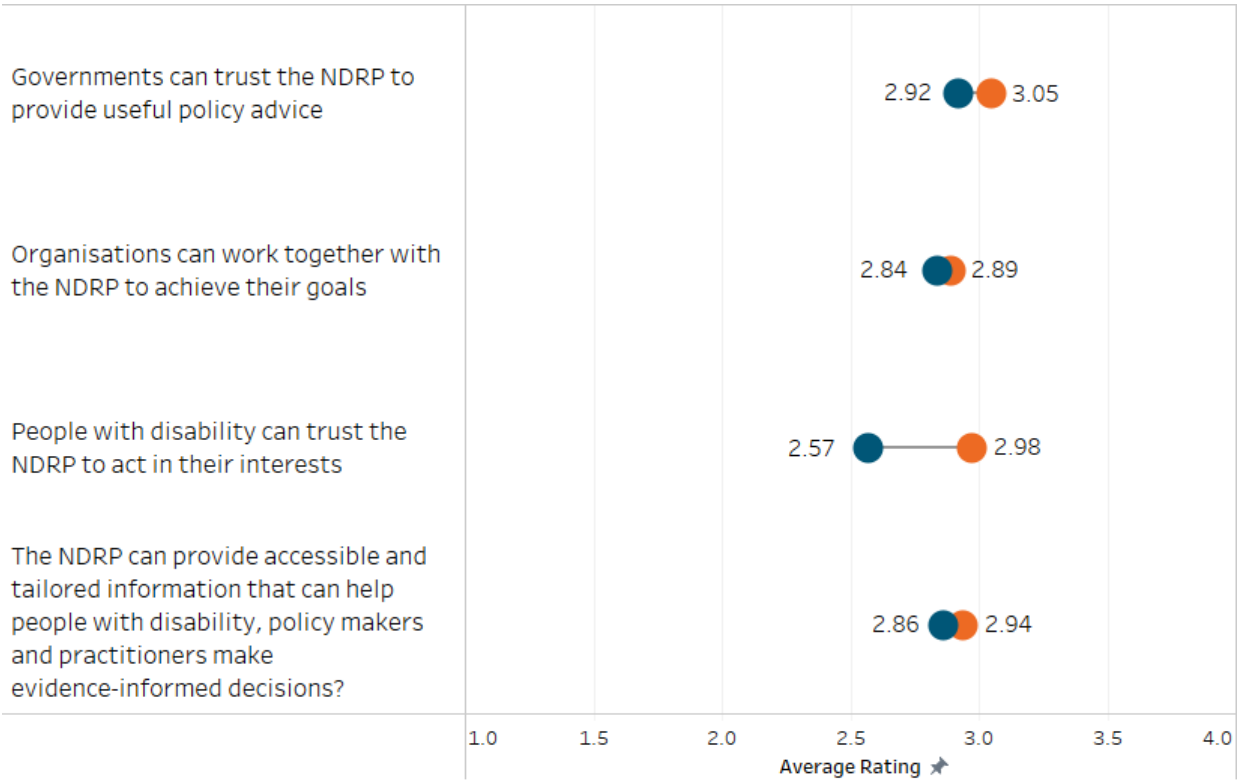
For the pilot projects, a clear and thoughtful research translation strategy with accessible findings was a selection and reporting criterion. However, it was not clear to the research teams what type and level of support they could expect from the NDRP Working Party to put their translation and dissemination plans into action. In their project reports, several researchers asked what would happen with their project results once completed and enquired if and how the NDRP Working Party would assist in broader dissemination and engagement with policy makers. While it is reasonable that these processes were not yet in place, there could have been clearer communication with project teams about what was possible in the seed funding stage.

2.4.2 PERCEPTIONS OF THE FOUNDATIONS LAID FOR RESEARCH TO BE USED BY PEOPLE WITH DISABILITY, POLICY MAKERS AND PRACTITIONERS

To understand the foundations laid towards research useful to the various NDRP stakeholders, stakeholders were asked to consider whether people with disability can trust the NDRP to act in their interests, whether governments can trust the NDRP to provide useful policy advice, and whether organisations can work together with the NDRP to provide their goals (Figure 11).

Ratings were generally positive, suggesting that good foundations have been laid. Consistent with their ratings of other questions, people with disability were less positive than those without disability that people with disability can trust the NDRP to act in their interests.

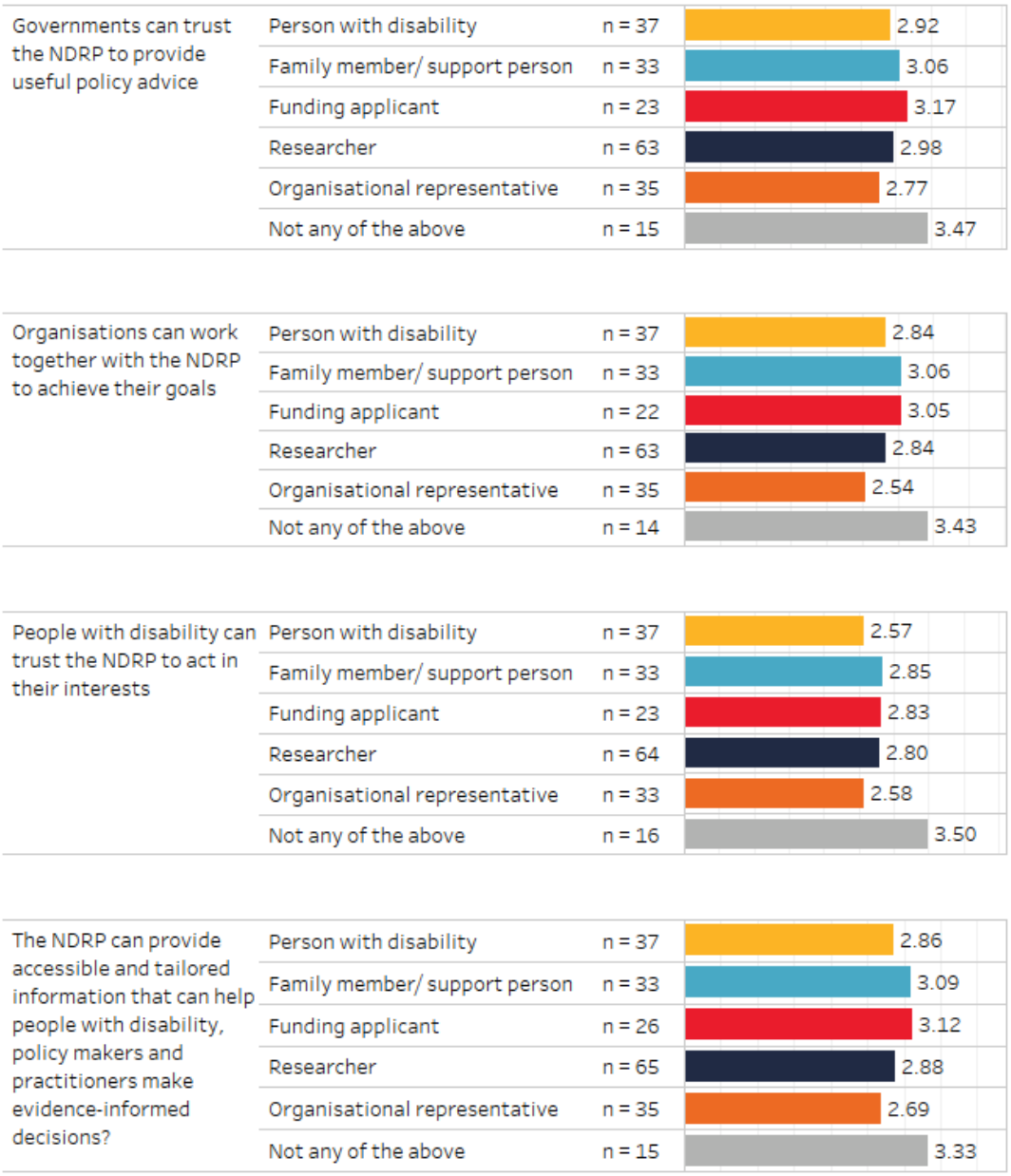
FIGURE 11. EXTENT TO WHICH KEY STAKEHOLDERS CAN TRUST THE NDRP TO MEET THEIR REQUIREMENTS



Number of respondents: (person with disability, person without disability)
Governments can trust the NDRP (37, 84); Organisations can work together (37, 82); People with disability can trust the NDRP (37, 83); NDRP can provide accessible and tailored information (37, 83).

As in other questions, those directly involved in NDRP (in the 'not any of the above' category) were more positive about the foundations laid activities, at least partially because they were more aware of the work undertaken. Organisational representatives were the least positive group, generally because they lacked detailed knowledge of the NDRP (Figure 12).

FIGURE 12. RESPONSES ON TRUST AND INFORMATION BY RESPONDENT GROUP



Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

PEOPLE WITH DISABILITY CAN TRUST THE NDRP TO ACT IN THEIR INTERESTS

Respondents from different groups indicated there was an unintended tension between achieving the objectives of the seed funding phase in the limited timeframes and being able to take the time needed to fully understand the interests of people with disability. There was a perception more would need to be done to engage people with disabilities in the long term.

> *There's been a genuine offer, asking 'what do you think? Tell us what you think'. The invitation is just the beginning. It can sometimes be like putting someone on the spot rather than giving them a genuine chance to speak and say what they want to say, on their own terms. [Researcher].*

GOVERNMENTS CAN TRUST THE NDRP TO PROVIDE USEFUL POLICY ADVICE

Some Government respondents were positive about the foundations laid for the NDRP to inform policy, flowing on from setting up an effective structure and then entrusting this will deliver the intended outputs.

> *If you set up governance properly at the start, then you need to rely on it delivering to purpose. [Government respondent]*

However, other Government respondents identified a need for more involvement of all levels of government in identifying research priorities, so research is on topics to inform policy, as well as regular reviews of the research agenda to enable responsiveness to change in the policy environment and opportunities for change. It was also noted research is needed to inform other policy areas besides health and disability, for example housing and employment.

To best enable research to inform policy, there is also a need for more clarity about how outputs will be used and how best to align the timing of outputs – respondents noted this will be most effective if timing of information can be aligned with the policy cycle.

While there has been communication with state and territory governments about the NDRP, the evaluation suggests a need to engage more with state and territory governments because several key representatives were unaware of NDRP activities.

ORGANISATIONS CAN WORK TOGETHER WITH THE NDRP TO ACHIEVE THEIR GOALS

Some respondents lacked clarity on the type of organisations the NDRP would work with, and how this would be approached.

> *I'm not so clear on that. Are they really looking at what the goals are of organisations? Or is it more influenced by what DSS wants and what they have to report? [Researcher]*

> *How do we value disabled people's organisations as a collective? And what is our relationship with them? Because that alters the power relationship, dealing with their organisation, compared to dealing with individual people. [NDRP Working Party]*

Others pointed out working with organisations closely would support knowledge translation. When partnering on projects, if consulted throughout the process, organisations can be a rich source of information.

> *When you're talking about research, those sorts of [organisational] partnerships can be helpful, because you're a lot closer in terms of when you're thinking about policy and getting it happening. To actually be able to work through the practicalities. [Sector Representative].*

THE NDRP CAN PROVIDE ACCESSIBLE AND TAILORED INFORMATION THAT CAN HELP PEOPLE WITH DISABILITY, POLICY MAKERS AND PRACTITIONERS MAKE EVIDENCE-INFORMED DECISIONS

Generally, while interviewees understood a central intent of the NDRP is to inform policy and practice, they also identified significant differences in culture and priorities between academic and other communities that affect the ability to drive change.

> *I think researchers have been pretty good at talking to themselves. And having accessible formats, not just accessible to people with disability, but to people outside the research community, is a critical aspect. [Researcher]*

> *Certainly, anecdotally, we hear from our members, they really will watch for the latest evidence, in terms of service models, in terms of support, and so forth. And that's where we really need information. [Sector Representative].*

Respondents said it would be important for the NDRP to make information available in many formats and acknowledged it will be challenging to meet the requirements of varying stakeholders who could use the information.

> *We're part of the disability sector, we're very interested in the actual research itself. But our other lens is: how easily is this translated through to our members as end users? What does it mean for the people they support, how might they translate it and build it into their practice, and what could our role be in getting this out there and how easy is it for us to do that? There are multiple end users, there are multiple channels, and there are multiple translators, that probably require a range of products, produced in different ways. [Sector Representative]*

Respondents were unclear whether the end users of research are yet sufficiently involved, and whether there is a plan for understanding the needs of end users of research, particularly those in the sector with limited resources.

Disability sector representatives suggested the best way to create change was for providers and researchers to work together to develop practical findings to discuss with government.

At the same time, they noted the NDRP could play a central role in coordinating an understanding of current disability research activities and outputs.

> *Often service providers will have good policy ideas that come from a very practical standpoint in terms of what works, what we see working in practice or what we see not working. But actually, then backing that up by really good quality research, is how you get governments to sit up and take notice. So marrying of the two; having the really strong evidence base, with the real practical life examples. [Sector Representative]*

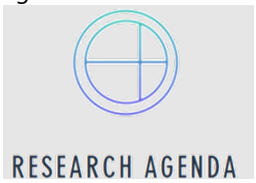
> *We've been saying for some years there really needs to be more disability research. And it's appropriate it's done as a national initiative. When NDIS commenced, all these universities thought, 'Oh, good, here's a new area' and all began setting up – if they didn't have already – little disability-focused hubs, and institutes and so forth, a whole flourishing of them! So you do need nationally, in Australia, some mechanisms to bring stuff together, a central database, so you avoid duplication, and so forth. [Sector Representative]*

> *Ideally, you would have something (and maybe this is the future planning) you go to this place, and you can see everything that's happening. And some of it may be funded by the NDRP. Or some of it may be a University over here doing something, or a research initiative over here. Being able to really nail down where you find that and how easily you find it, particularly for a time-poor sector. That's certainly looking at a way forward, in terms of end-user experience. [Sector Representative]*

3. FINDINGS: EFFECTIVENESS

3.1 HOW EFFECTIVE HAS THE NDRP BEEN IN ACHIEVING ITS INTENDED OBJECTIVES FOR THE SEED FUNDING PHASE?

TABLE 2. DELIVERY OF AGREED OBJECTIVES

Deliverable	Type	Status	Actions taken
Deliver a national disability research agenda 	Core	Preliminary agenda completed	The NDRP Working Party contracted a consortium to undertake a project consisting of three phases: 1) Mapping of current disability research; 2) A survey of 973 people and consultations with nearly 1000 members from the disability community and their representative organisations to identify key issues; 3) Synthesis and refinement of the findings.[9, 10, 11, 12, 13] NDRP Working Party members mapped the resulting findings to *Australia's Disability Strategy 2021-2031* outcome areas and policy priorities. Identified outcome areas include employment and financial security; inclusive homes and communities; safety, rights and justice; and personal and community support. A review of the findings and co-design process to finalise the agenda will follow in the transition phase of the NDRP. The NDRP Working Party acknowledged some challenges with the research agenda deliverable including: communication issues between the agenda consortium and the NDRP Working Party; lack of demarcation between governance and agenda consultations, which caused confusion among stakeholder organisations; some organisations feeling excluded from the agenda setting process or lacking enough time to engage; doubts about whether it was realistic to achieve consensus around 10 research priorities for the next 10 years; project delays; and some methodological issues.
Design a governance model to support the long term NDRP	Core	Governance paper completed	Based on research into appropriate models, the NDRP Working Party presented two potential governance models to stakeholders: 1) a separate, independent entity with a skills-based board; 2) a consortium of partners. Sector organisations, service providers, government institutions, universities and research institutes provided feedback on the options through a survey and consultations.

			The first option – an independent entity – received broad support from stakeholders and was put forward as the proposed model. It is comprised of a membership open to people with disability, their family members, allies, supporters, advocates or representatives, service providers, researchers with an interest in disability and government; and a board of directors will include up to 12 directors (7 elected by members, 3 independent and 2 appointed government representatives). Minimum requirements for the board are that at least 50% (including the chair) are people with disability; 25% are family members, caregivers, supporters or allies of people with disability, or disability service providers; 25% are researchers; and 15% are First Nations or Culturally and Linguistically Diverse people. Establishment of an NDRP Independent Advisory Council to provide advice and link to the wider disability community and sector is also recommended.
Pilot a research funding round to build the evidence base and to demonstrate and refine NDRP processes. 	Core	Pilot projects completed	Originally, funding was planned to support two pilot projects which would be informed by findings from the research agenda. A delay in the research agenda project did not allow for this. Instead, the NDRP Working Party held an open funding round designed to build evidence for successful innovation in disability policy and practice and to test and refine processes for commissioning research, building capacity and translating knowledge. A call for proposals was put out in May 2021 and 123 proposals were received; of these, 9 research proposals were funded. A Community of Practice for research team members was established and held monthly, to enable researchers to share their learnings about inclusive research. Final project reports from 8 of the 9 projects were received in June 2022. See Appendix 4 for a full list of pilot projects.

[9] Smith-Merry, J., O'Donovan, M.-A., Dew, A. et al. (2022). The Future of Disability Research in Australia: Protocol for a Multiphase Agenda-Setting Study. *JMIR Res Protoc*, 11(1).
[10] Smith-Merry, J., Gallego, G., Yen, I. et al. (2022). Mapping disability research in Australia 2018-2020. University of Sydney. Available on https://apo.org.au/node/316397.
[11] Smith-Merry, J., Plum, J., Gallego, G. et al. (2022). Setting an agenda for disability research in Australia: survey results. University of Sydney. Available on https://apo.org.au/node/319356.
[12] O'Donovan, M.-A., Dew, A., Imms, C. et al. (2022). Setting an agenda for disability research in Australia: consultation report. University of Sydney. Available on https://apo.org.au/node/319357.
[13] Dew, A., Plumb, J., Gallego, G., et al. (2022). Setting an agenda for disability research in Australia: synthesis and refinement. University of Sydney. Available on https://apo.org.au/node/319360.

Write a practical guide to NDRP research 	Core	Completed	The NDRP Working Party's final report includes a commitment to inclusive research encompassing definitions of what engagement of people with disability looks like and central characteristics of inclusive research. Rather than developing a new guide on inclusive research, links were made to existing resources, namely *Guidelines for Co-Production of Research with People with Disability* and *Doing Research Inclusively: Co-Production in Action*, developed by researchers at University of New South Wales.
Map and develop disability research capacity in Australia 	Core	Capacity mapping exercise completed	There were ongoing NDRP Working Party discussions about what the capacity building deliverable should look like. To develop a clear concept of this deliverable it was decided to keep it as an internal Working Party project, rather than put the task out to tender. The conceptualisation of capacity and capability were identified as the first step and a report on key definitions and frameworks of disability research capacity was published in April 2021. The second step was a research project that engaged with stakeholders to understand what Australian research capacity could look like and what potential mechanisms might be required to achieve it. A next step is to create a plan to develop disability research capacity based on the recommendations of the capacity report and in consultation with stakeholders.
Establishment of an APO disability research collection. 	Non-core	Completed	This collection was developed by the Analysis & Policy Observatory, which is an open access evidence platform. Designed to improve policies and practices, this Collection is for people with disability, their family, caregivers, allies or supporters, disabled people's organisations, policymakers, researchers, advocacy organisations, 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. It was established in November 2020. It houses over 800 resources and has received over 5,500 front page views.

3.1.1 PERCEPTIONS OF NDRP'S ACHIEVEMENT OF ITS OBJECTIVES

When asked about achievement of the objectives for the NDRP seeding funding phase, respondents with sufficient knowledge to give a rating were most positive about the design of the governance model being achieved and least positive about the guide to research by and with people with disability being achieved (Figure 13). Respondents with disability were generally more positive than others about the achievement of objectives, except notably, they were less positive about the establishment of a process to deliver research by and with people with disability.

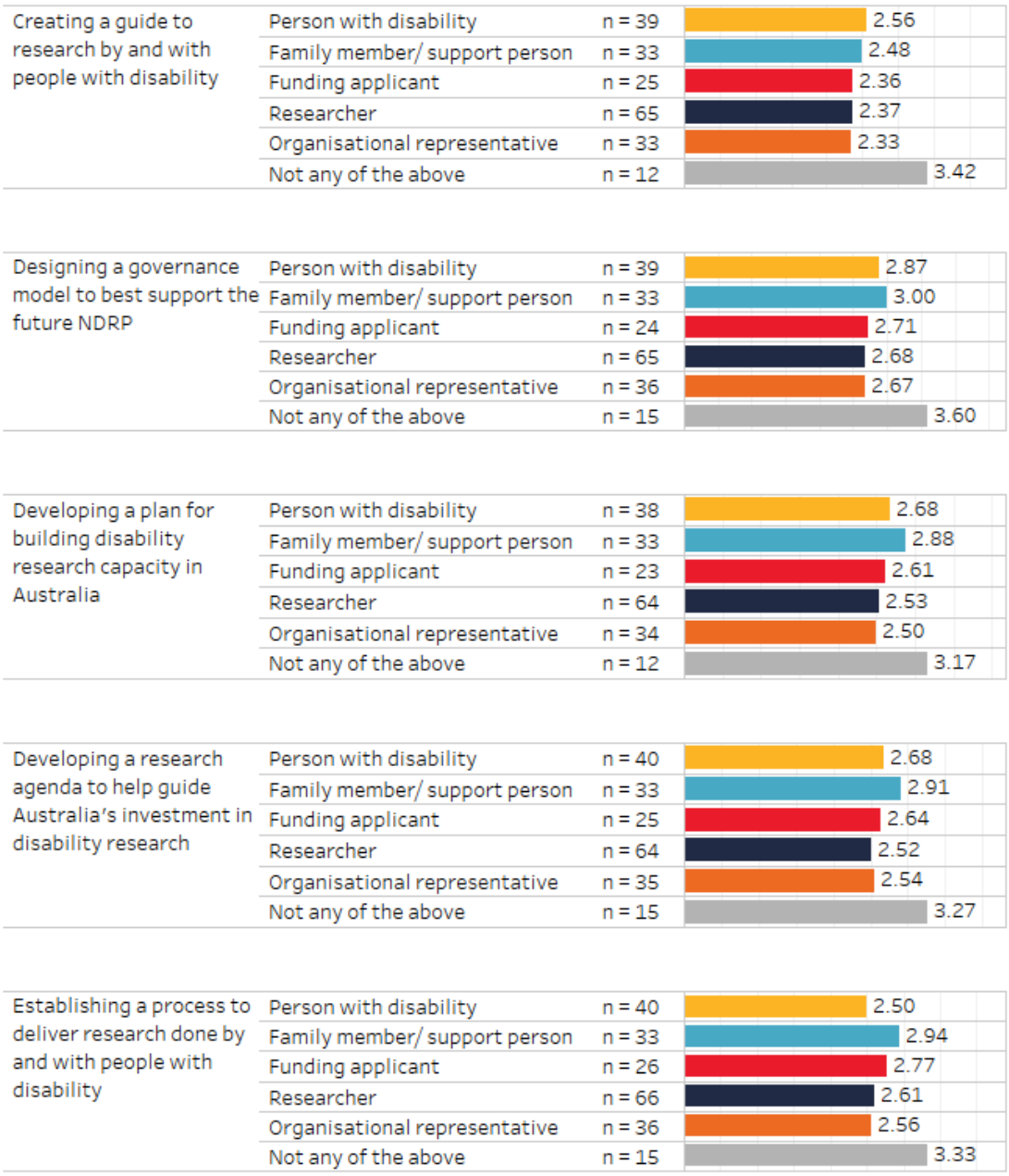
FIGURE 13. ACHIEVEMENT OF NDRP OBJECTIVES BY DISABILITY STATUS



Number of respondents: (person with disability ,person without disability)
Creating a guide to research (39, 79); Designing a governance model (39, 84); Developing a plan for building disability research capacity (38, 79); Developing a research agenda (40, 83); Establishing a process to deliver research done by and with people with disability (40, 85).

Consistent with other questions, those who were more directly involved in NDRP activities (captured in the category 'Not any of the above') were more positive, at least partly because they were more aware of the work undertaken (Figure 14).

FIGURE 14. ACHIEVEMENT OF NDRP OBJECTIVES BY RESPONDENT GROUP



Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

DEVELOPING A RESEARCH AGENDA TO HELP GUIDE AUSTRALIA'S INVESTMENT IN DISABILITY RESEARCH

Respondents mainly noted they were aware work on a research agenda was underway, but that it was not complete or was in a preliminary stage. Some respondents were unsure, at this stage, whether the research agenda would be useful for their policy or practice requirements. Some did not know a research agenda was being developed.

Some of those with more knowledge of the research agenda, noted that a broad approach had been taken to consulting the community and that it was a large task to develop the agenda. Others thought that decisions had been made by a relatively small group.

Some members of the research agenda consortium reported they had not anticipated the NDRP Working Party providing input into its direction and different views created some challenges for the project. The NDRP Working Party suggested a need for greater communication around oversight, roles and responsibilities in projects like this in future.

DESIGNING A GOVERNANCE MODEL TO BEST SUPPORT THE FUTURE NDRP

Generally, the governance model was one of the most clearly visible outputs of the NDRP seed funding phase. The NDRP Working Party put a significant amount of time and effort into its development to ensure a strong foundation and alignment with the NDRP values.

Some respondents noted a need for a clear communication strategy for the governance model, as well as the importance of ensuring diverse membership.

Some interviewees who had not seen the governance model indicated the likely requirements for this type of body.

> *Certainly, a governance model would need to include a mix of voice from people living with disability, from government, from research professionals, and others. It needs to be something with a clear spread of interests, in a way that's quite public facing. People need to know there's a governance group, this is how you can apply to be on it. This is its schedule of meetings, this is where you can go to read about how that governance group is travelling, what issues that governance group is contemplating, what research has been commissioned, and so on. [Sector Representative].*

The model developed by the Working Party reflects this in the following ways:

- membership available across a number of categories (person with disability, family members, advocates, service providers, researchers)
- Board of Directors, including seven that will be appointed by members
- establishment of an Independent Advisory Council to provide advice to the board on a range of topics and link to the wider disability community and sector.

ESTABLISHING A PROCESS TO DELIVER RESEARCH DONE BY AND WITH PEOPLE WITH DISABILITY

Respondents with disability rated the achievement of the establishment of a process to deliver research by and with people with disability lower than other objectives. Many respondents explained that they were unaware of the NDRP's progress with this outcome. Some suggested some disability groups had stronger advocacy than others, and therefore receive disproportionate representation in terms of participation and projects.

Most respondents indicated that the pilot projects had actively engaged people with disability, even if they did not necessarily consider there to be a formal process.

DEVELOPING A PLAN FOR BUILDING DISABILITY RESEARCH CAPACITY IN AUSTRALIA

Many respondents were not aware of the status of disability research capacity planning at the time of interviews.

Other respondents noted that whilst the NDRP may be involved in planning, this would not necessarily mean being the sole body responsible for developing capacity; as respondents had mentioned when discussing the extent to which the NDRP has achieved the principle of building research capacity, doing so would require buy-in from universities.

> *It is very important to have a plan that we know there will be investment in. The important thing is that the plan isn't all about funding the NDRP to do it. [Government respondent]*

> *Really valuable on informing universities around what needs to be addressed in order for them to bring to build capacity and to facilitate the capacity of academics, including academics with lived experience of disability. [NDRP Working Party]*

3.2 WHAT OUTCOMES, BOTH INTENDED AND UNINTENDED, WERE OBSERVED DURING THE SEED FUNDING PHASE?

Generally, respondents considered that it was too early to expect to see significant outcomes at this stage of development of the NDRP. Interviews and document analysis highlighted that due to the short time frame for the pilot projects stage, and the limited outputs so far, the results of activities have been limited.

Apart from the tangible objectives already discussed, respondents focused on the establishment of the fundamental principles and helping bring about a shift in outlook, in terms of ensuring people with disability are at the centre of research. Australian Government respondents pointed out that the NDRP has provided a chance for them to rethink how research is commissioned, and how research can be translated to policy.

Some respondents suggested that cohesion had been achieved in a sector that is recognised as fragmented, both overall and within the community, academic and policy subsectors, and that this was not an easy task.

> *I think the fact that we're on a journey towards some unification of that is pretty amazing. It's easy to downplay that as an outcome. But to me, it's pretty significant. And I think it's worthy of the years' work. [NDRP Working Party].*

Multiple researchers gave positive feedback on the Community of Practice, which underscores the value of building and maintaining networks as part of future activities. They particularly enjoyed hearing about other projects and developing relationships. However, the reach of the Community of Practice was limited to the researchers involved in the pilot projects.

One Working Party member said they were pleasantly surprised at the extent to which the Working Party prioritised the voice of lived experience:

One of the things that I did find unexpected was the chairs actually made sure that disabled people had their say first before the broader conversation commenced, putting disabled voices to the fore, changed the dynamic of the conversations, really exciting, really wonderful thing, including some difficult conversations on racism and ableism. [NDRP Working Party]

4. FINDINGS: EFFICIENCY

4.1 HAS THE NDRP BEEN OPERATIONALLY AND COST EFFICIENTLY IMPLEMENTED DURING THE SEED FUNDING PHASE?

The NDRP seed funding phase was delivered within its overall allocated budget of $2.5 million. However, only a small proportion of the budget was set aside for deliverables other than the pilot projects, and while this amount was revised, there was still an overspend on these, which had to be offset by underspends on other activities. Table 3 presents a summary of expenditure data for the NDRP during the seed funding stage, comparing budgeted[14] figures with actual spending.

TABLE 3. NDRP SEED FUNDING STAGE BUDGETED AND ACTUAL EXPENDITURE

Item	Original budget	Revised budget	Actual	Variation[15] ($)	Variation (%)
Secretariat	$465,000	$400,000	$342,407	($57,593)	-14%
Administration and Working Party	$240,000	$287,000	$216,887	($70,113)	-24%
Deliverables					
Research agenda; guide to inclusive research; IP arrangements; capacity building; governance; pilot projects	$395,000	$625,000	$833,541	$208,541[16]	33%
Pilot projects	$1,400,000[17]	$1,037,000	$1,030,897	($6,103)	-1%
APO Disability Research Collection (not a core deliverable)	$0	$63,000	$63,000	$0	0%
Total	$2,500,000	$2,412,000	$2,486,732	$74,732	3%
Unallocated		$88,000	$13,268	($74,732)	-85%

[14] The original activity workplan from June 2020 was revised in November 2021 to better reflect the proposed activities of the NDRP; the latter figures are presented.
[15] Variations are presented relative to the revised budget figures.
[16] In the revised and actual budgets, some key deliverables which were initially planned to be subcontracted were instead undertaken in-house. This led to increased budgeted and actual costs for the deliverables.
[17] In the original budget, this funding was allocated to two validation projects rather than a funding round; the revised budget reallocated the funding.

While many key respondents to the evaluation did not feel they could make a direct judgement on the efficiency of the NDRP seed funding stage, interviews suggest there was an extremely lean model for this phase, with limited resources to deliver activities. Moreover, interviews with Working Party members indicated despite the extra allocation of resources to honoraria (under the deliverables category), some members were contributing a significant proportion of their time on a pro-bono basis, in some cases working 1-2 days per week on top of other commitments. This is admirable and shows the dedication of the Working Party to the achievement of the NDRP objectives but is unsustainable as an ongoing operating model. This is compounded by the fact that some administrative overhead costs from MDI were charged at below normal rates, artificially reducing the costs of operation.

Overall, the available data indicate the NDRP was likely under budgeted relative to the amount of work required to deliver on objectives.

4.2 WHAT FACTORS NEED TO BE CONSIDERED IN ORDER TO SUPPORT OPERATIONAL AND COST EFFICIENCY IN FUTURE PHASES?

Based on the analysis of budget data, as well as key internal and external stakeholder interviews, the primary factor to ensure operational and cost efficiency in future phases will be the allocation of appropriate resources to support desired levels of activity. Underneath this, will be a need to prioritise a governance and operational structure that can assure financial and operational stability and efficiency, and the development of a diversified and robust funding model.

The analysis of budget data found some key costs, particularly around deliverables, were substantially underestimated. Looking forward, it will be paramount to ensure the budget accounts for such costs, so these costs do not impinge on spending on other activities.

There will need to be an operational structure with the right mix of skills to deliver activities and provide financial oversight, and sufficient resources to internally monitor and control spending across the range of activities envisaged for the next phase of the NDRP. There will need to be a significant expansion of the permanent workforce to provide ongoing and consistent support to activities, especially communications, partnership development and knowledge translation. As a comparative study, the Autism CRC operates on an annual turnover of $19 million with a permanent staff of 12, and with a smaller remit in terms of policy and research translation.[18] ANROWS has an annual turnover of $6.8 million with a staff of 24;[19] and AHURI has an annual turnover of $5.8 million and a staff of seven.[20]

[18] https://www.autismcrc.com.au/about-us/annual-report
[19] https://www.anrows.org.au/about/
[20] https://www.ahuri.edu.au/sites/default/files/documents/2021-10/AHURI%20Financial%20Report%202020-21.pdf

Alongside this expansion of budget and workforce is the need to create an efficient governance structure to assure oversight of operations. A criticism of the seed funding phase structure raised by respondents was the focus on academic representation at the exclusion of representatives from the disability sector (although this was partially addressed with additional recruitment to the Working Party), governments, and research users. Interviewees indicated a balance of representation (including lived experience) would be critical to future governance. A challenge for the NDRP in future phases will be in creating a governance structure that balances stakeholder representation while ensuring the appropriate mix of skills (such as legal and accounting experience) to maintain effective oversight. Consideration of existing models and frameworks such as those of the Australian Institute of Company Directors could assist in this process. The NDRP Working Party has already acknowledged this challenge and is exploring appropriate models for governance that reflect the above considerations.

Finally, both internal and external respondents mostly agreed that to ensure operational and cost efficiency in future phases, there will need to be a diversification of funding sources to include contributions from both government and non-government sources. This will support the capacity of the NDRP to deliver on its objectives, and also increase the accountability of the organisation in relation to spending and demonstrating efficient allocation of resources. It will also mitigate risks that result from being tied to a single source of funding; for example, government funding may fluctuate as a result of policy cycles, and the need to secure government funding may constrain the agenda of the organisation to meet political imperatives. However, some respondents raised concerns that maintaining diversified funding would require ongoing investment to identify, cultivate and solicit new sources of funding over time.

4.3 WHAT WERE THE ENABLERS AND BARRIERS TO SUCCESS DURING THE SEED FUNDING PHASE?

4.3.1 ENABLERS

Interviewees reported that the Working Party model was a driver of success during the seed funding phase. The selection of a group of committed and engaged individuals and the creation of an environment in which robust and frank discussions could take place was viewed positively by members of the Working Party as well as external stakeholders. One important observation from interviewees was the willingness of the Working Party to recognise areas of weakness and make appropriate changes to address these, for example, with the inclusion of representatives with lived experience of disability and representatives from outside of academia.

> *A really respectful Working Party, even with painful subjects and difficult conversations. No personal animosity and happy to continue relationships and was able to work in a robust way. [NDRP Working Party Member]*

> *These trust-building moments, they can go both ways. But we had those discussions, and I think it changed the dynamic. [NDRP Working Party Member]*

A further enabler of success for the NDRP, especially in catalysing interest from stakeholders, was the national and broad scope of activities. This was viewed positively by respondents as a contrast to state-based and/or condition-specific models for research support. Both interview and survey data, as well as analysis of consultation findings from the NDRP research agenda activities found stakeholders strongly agreed on the need for a national partnership to drive an agenda for disability research. This groundswell of support helped to facilitate engagement.

At the same time, the NDRP's broad scope, coupled with the rapid growth in disability research, could also be a challenge to ensuring that the NDRP can involve relevant organisations while keeping matters manageable. Some respondents suggested a need for more involvement from southern states, and more focus on concerns of rural and remote communities.

The collaboration and engagement activities of the NDRP including the Community of Practice were seen as an enabler of success and collaboration between stakeholders. The Community of Practice provided opportunities for researchers to work in a collaborative [consistent with NDRP principles] way which was not usually available to them.

> *Usually when you're a researcher, you're in competition with other research groups. So you don't really talk to them very much, at least not about the difficulties of the research. So they found this community in which everybody shared the experience of doing this kind of research, very helpful. [NDRP Working Party]*

On the other hand, some respondents found the Community of Practice could be a barrier to success, since it required a significant amount of effort to ensure participation, and it created additional demands during times where members were already under time pressure to deliver. Respondents also suggested the focus of the Community of Practice could be overly geared towards providing the NDRP with information and input, rather than the NDRP supporting researchers. However, a stated purpose of the Community of Practice during the seed funding stage was to inform the NDRP on appropriate models of delivery and to refine processes, so this is not unexpected.

4.3.2 BARRIERS

While the NDRP Working Party approached communications cautiously as they were continuously refining messages, one of the barriers to success noted was a low level of investment in promotional activities and other strategies to increase understanding of the NDRP's role. Interview and survey findings showed a low knowledge of the purpose and role of the NDRP within both academia and the broader disability community. Analysis of social media and the research agenda consultation process suggests relatively less priority was given to promoting the NDRP identity and brand. Analysis of consultations undertaken for the development of the research agenda also showed that while there was strong participation, the actual consultations were delivered by consortium organisations, and consultation instruments and guides made no mention of the NDRP itself. This limited broader awareness.

A second barrier was the short timelines for delivery, especially for pilot projects. The NDRP Working Party and staff had commenced activities for all identified objectives, but whilst core deliverables were completed on time, they had not yet been broadly disseminated. For pilot projects, interviews identified an underestimation of the time needed to organise, facilitate and leverage genuine co-design processes with the disability community, especially where there were limited incentives for participation. Interviews indicated some project applications could not successfully include people with disability, due to short timeframes given for engagement. Constrained timelines also impacted on project deliverables; interviewees noted that alongside the need to deliver genuine engagement, requirements for ethical clearances and contract negotiations created delays in the approval and commencement of research activities. This is a consistent finding in relation to the development and delivery of co-designed research. Interviews also emphasised the importance of appropriate investment in remuneration for organisations and individuals engaged as part of research, and investment in accessibility.

> *The researchers and academics and so forth, need to really understand that you can't get people out of thin air and demand them to answer your questions for your research for a fifty-dollar gift voucher. Academia lacks a lot of things in terms of capacity in research with people with disability… a lot of existing practices are not inclusive, it's still very much a top-down approach. [Sector Representative]*

The time period in which the seed funding phase took place coincided with a period of massive social and economic upheaval caused by the COVID-19 pandemic. This disproportionately impacted the disability community, as reflected in the interviews and survey, which noted the difficulties in delivering consultation and awareness-raising with the community (especially in person), the strain on available resources due to the need to manage impacts of lockdowns and other government requirements, and the general deprioritisation of long-term policy discussions relative to immediate responses to the pandemic.

Additionally, prolonged management of additional pressures for people with disability also depleted inner resources in a way that affected their participation in key issues affecting the community. One researcher outlined these difficulties as follows:

> *This reminds me of something from a different consultation, about looking for submissions. 'And the person with disability was saying, "we're in the middle of COVID; people with disabilities are really disadvantaged, high health risk for a lot of the population, and the whole stress over getting vaccines, or not getting vaccines, and then being de-prioritised. And then, this really small timeline in order to make submissions, about some policy document. How are we meant to get ourselves together to submit, and have our voice heard, when we're just trying to survive, and that's taken all of our energy?" And that really resonated with me and made me think, and yes – not as many people with disabilities had responded to certain parts of the research as we had hoped. But we were in a pandemic, and people were trying to survive that. [Researcher]*

Some respondents highlighted the difference in cultures between academia and government policy making could be a barrier to success, particularly in terms of the setting of the

research agenda. Some Government respondents reported past experience with other department funded research where the priorities of policymakers may not be properly addressed by research outputs.

At the same time, some academics reported general concerns, based on past experience with other funders, that efforts to adjust outputs too far to meet a wide range of stakeholder expectations may result in overly generalised findings and dilute research quality. Differences in cultural drivers are a commonly identified barrier to research uptake, with academic reward systems based on publications, and policy environments often being affected by urgent matters that can disrupt the time available for reaching longer-term goals.

4.4 HOW MIGHT THE PILOT PROJECTS HAVE BEEN DELIVERED MORE EFFICIENTLY (TIME AND COST-EFFICIENCY)?

At the time of writing, there were no data available on pilot projects' actual spending beyond aggregated data from the NDRP. To make a fulsome assessment of cost efficiency, it would be necessary to analyse final acquittals to understand expenditure data and to characterise output KPIs related to grants.

Budget analysis data show that cost estimates and the reasonableness of costs for projects were considered by the project selection committee, and that this did impact on decision-making about funding. However, there did not appear to be strong guidance on what constituted "reasonable" costs for activities. The development of indicative costs for projects could help support the decision-making process in future research funding rounds.

Respondents surveyed were generally positive about the ease of the grant application process and the support received from MDI/ the Working Party in managing the application. MDI/ the Working Party has identified the following items which need to be addressed before the next grant round:

- better definition of 'involvement with people with disability'
- potential weighting of selection criteria
- tie-breaker process for where projects are rated the same
- acceptable compromise when an excellent project on an important topic is proposed but no people with disability are available to be a researcher or project lead
- find a process that best involves stakeholders, such as policy makers, service providers or advocacy organisations in the review process.

The findings from interviews, including with Government respondents and other research organisations, support this last recommendation, to help ensure projects can inform policy and practice. Only successful grant recipients answered questions on the ease of the grant process and respondents did not provide much detail, so the evaluation does not have further data to support the other recommendations.

Although the Community of Practice was viewed positively, some respondents mentioned the level of preparation required to participate was greater than expected.

There is insufficient detail in budget data to consider metrics around the administrative cost per pilot project, and benchmark these against other programs. However, qualitative data from interviews indicate that much of the work relating to NDRP delivery (including grant assessment and management) was completed on limited resources or on top of existing commitments, which may be efficient from a cost standpoint but is ultimately unsustainable as a model for future delivery. Greater efficiencies may be achievable through the provision of dedicated supports for grant management.

There were some delays in the commencement of the pilot projects, due to issues with arranging contracts between MDI and the projects:

> *[Finalising the funding agreement] was very difficult. I think we were waiting three months to sign it. But I think that was a lot to do with the universities. I don't think it was the NDRP, so I don't want to put that on them. But it was a difficult process. It delayed us getting started, and getting our co-researchers, who were crucial. But it wasn't difficult because of anything that the NDRP did. [Researcher]*

The timelines for pilot projects were shorter than they will be in future, and while the NDRP aimed to select projects that could be completed within these constraints, the document review and interviews with researchers indicate that the short timelines were a major constraint on projects, their efficiency, and their capability to be co-designed and co-delivered effectively. Researchers said constrained timelines impacted on the depth and quality of research that could be conducted, which may also negatively impact the applicability and transferability of findings. While it may appear counterintuitive to enhance efficiency by allowing for more time for projects, the allocation of appropriate periods for the initial engagement of stakeholders, project planning and ethical clearance allows for potential cost and time risks to be identified, characterised and mitigated. This produces greater efficiency over the lifetime of research projects and assures that stakeholders are effectively engaged as part of research activities.

> *It's top heavy, academic heavy, but there are some really good partnerships being done with the projects. I think the main problems was the criteria of the project, the grant thing was way too tight in terms of timeframes, so the intended outcomes are affected. So nine months in which the project had to be delivered and completed really isn't enough time to develop genuine co-design. [Sector Representative]*

A further observation from key respondents was that while the pilot project funding was oversubscribed, the breadth of research topics and the size of funding indicated that this model as the sole funding model for future stages of the NDRP might limit the ability of the NDRP to deliver on its objectives. This fact is recognised by the NDRP Working Party in their final report, which recommends the need to operate a competitive funding model that can support projects with both longer and shorter scopes and timeframes, as well as a targeted funding model that can address key policy priorities for end users.

In addition, for research to inform policy, greater consideration could be given to processes for sharing emerging findings, and to timing research milestones to inform policy.

5. LEARNINGS AND RECOMMENDATIONS

The evaluation identified some key learnings from the NDRP seed funding stage that can be used to inform future delivery of the NDRP. This section provides a set of recommendations for the future development of the NDRP based on these learnings. Our findings broadly support the recommendations made by the NDRP Working Party in its final report. In addition to these, our evaluation process has identified further recommendations for consideration in five categories.

Where relevant, our recommendations have been grounded in evidence drawn from organisations and initiatives with similar objectives and models of delivery to the NDRP Working Party's recommendations for the NDRP and related literature. The literature highlights eight important considerations to optimise the success of collaborative initiatives (Table 4), which may be useful to inform future discussions of what successful delivery looks like for the NDRP, as well as monitoring, evaluation and learning.

TABLE 4. ACHIEVING COLLECTIVE ACTION FOR IMPLEMENTATION: A MID-RANGE THEORY [21]

Theme	Description
Working relationships	If these are well-developed, or if there is pre-formative investment to develop them, this is likely to lead to quicker wins, increased appreciation of others' positions, creating a platform upon which to build plans and activities.
Attention to evaluation and learning	If attention is lacking and/or leadership teams are not reflective, the initial interpretation of the mission can create a path dependency that is difficult to alter. Therefore, it is important to build in mechanisms for evaluation, learning and meta-learning to enable adaptation to changing contexts.
Governance framework	If this facilitates opportunities for physical, social and intellectual connectivity between stakeholders, it enables productive conversations and conducive conditions for implementation-related activities that resonate with stakeholder groups.
Vision and strategy	A shared vision that is aligned across stakeholders in relation to knowledge production and use can unblock barriers to purposeful collective action.
Motivation for engagement	If the 'what's in it for me' motives are made visible, implementation activity can be planned so that engagement is appropriately incentivised.
Boundary spanning	If resources are invested in boundary spanning mechanisms, this can help to bridge boundaries and catalyse implementation activity.

[21] Kislov R, Wilson PM, Knowles S, Boaden R. Learning from the emergence of NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs): a systematic review of evaluations. *Implement Sci*. 2018;13(1):111. doi: 10.1186/s13012-018-0805-y.

Collaboration versus competition	Tension between collaboration and competition can act as both a facilitative and an inhibitory force. As such, it is important to find the right balance between the two.
Leadership	There is a need for both strong central and distributed leadership as this facilitates collaboration and the potential for implementation.

5.1 OPERATIONS AND GOVERNANCE

1. **Continue to put people with lived experience of disability at the heart of the NDRP, with people with disability at all levels, guiding all activities.**



It is important for the NDRP and the research agenda to be driven by people with disability, so that research outcomes reflect what is meaningful to their lives and that the past negative impacts of research on people with disability are avoided. Across the stakeholder survey, interviews, and analysis of consultation activities for the development of the research agenda, the strongest priority raised was the need for the NDRP to continue to seek to be a best practice example of inclusive engagement of people with disability across all its activities. This includes the engagement of people with disability as leaders and staff in the NDRP as it is established as an independent entity, as well as the development and promotion of resources to support genuine engagement and co-design for funded activities.

2. **Ensure that the governance structure is transparent, independent and reflective of the stakeholders served.**

The evaluation has identified a need for the NDRP governance structure to be accountable to the disability community and resilient to the competing needs of different stakeholder agendas. The literature also highlights the value of governance structures that facilitate connectivity between stakeholders, which enables productive conversations and conducive conditions for implementation activities that resonate with all stakeholder groups.

The NDRP Working Party has already given substantial consideration to possible governance structures that enable a balance of stakeholder perspectives while still assuring that governance is transparent, accountable, and sufficiently skilled to ensure the integrity of the NDRP. Ideally, an independent oversight structure will comprise individuals with sound understanding of the objectives and policy goals of the NDRP, as well as collective skills in financial, risk and legal management.

3. **Ensure that appropriate time, operational and financial support is available to deliver NDRP activities.**

A key finding of the evaluation has been that across all deliverables, activities and pilot projects have been constrained by timeframes. Moreover, analysis of budget and interview data indicate that a substantial amount of the work completed by some Working Party members was on a pro-bono basis. Among other things, respondents identified the need for additional operational assistance and assistance for evaluation of funding applications and for supervision/ guidance of pilot projects.

'This work is time-consuming, but it is also very important. It requires a team, resources, funding and time, and they need to work in conjunction with each other, in order for it to really work.' [NDRP Working Party]

Future stages of the NDRP will need to be adequately funded and budgeted to ensure that both time and money are available to support the delivery of core activities. An analysis of similar organisations indicates that delivery of genuine and impactful partnership activities requires significantly higher levels of funding than is currently earmarked for the NDRP in its next stage. Consideration will need to be given to prioritisation of activities within allocated resources when these are confirmed.

One option for improved NDRP budgeting may be the adoption of activity-based costing practices, which can provide financial transparency in relation to the allocation of resources to activities. This in turn can enable executive oversight of efficiency of delivery. It will also be important to develop forecasting for budget purposes that considers impacts of policy, demographic and economic changes on operating costs.

4. **Implement an appropriate organisational structure to support NDRP operations.**

As the NDRP is established as an independent entity, consideration needs to be given to determining the operational structure that will most effectively and efficiently enable a fully operational NDRP to deliver its objectives in line with its principles. This would likely include dedicated roles for communications, grant management, capacity building, and research translation. Ideally, people with lived experience of disability should be engaged to fill these roles.

5. **Diversify funding sources to assure long-term stability of the NDRP.**

The Australian Government should not be the sole source of funding for the NDRP, given the risks that this places on assuring ongoing support over policy cycles, and the potential perception risks relating to influence on the NDRP's agenda. Future stages of the NDRP should include the identification and implementation of operating models that enable funding from a range of government and non-government sources, including academia, non-profits, foundations and corporates. Considering models for similar organisations, this may be delivered through a combination of membership models (similar to those being considered by the NDRP Working Party) and direct unrestricted and restricted funding to enable research and research translation activities. While it may also be possible to consider other ways to earn money (such as conferences and paid-for resources and services), these should not be developed in a way that compromises access by the disability community.

6. **Consider models for appropriate support and remuneration of disability organisations and people with disability**.

A key priority raised by respondents was ensuring that the NDRP did not exacerbate the existing and long-term under-resourcing of the disability sector, especially when engaging organisations and people with lived experience in consultation and research processes. The need to provide appropriate operational support and, where relevant, adequate remuneration for time and contributions should be built into budgets and estimates, noting

that the time requirements for delivery of this support may be longer than for other stakeholders. This extends to considering how people with disability and disability organisations can be supported to prepare proposals for research.

5.2 THE NDRP PRINCIPLES



7. **Further clarify key terms, such as "high quality" and "value all forms of knowledge" to enhance shared understanding of the NDRP principles and the ability of future evaluations to assess the extent to which the principles are being applied.**
8. **Strengthen descriptions of the NDRP principles to broaden their adaptability to inform all decision making within the NDRP.**

The NDRP principles are important to guiding all the activities of the NDRP, not only funded research projects. The principles generally reflect the evaluation literature on what makes an effective principle, but the evaluation identified some opportunities to further strengthen them. Respondents often seemed to conceptualise all of the principles as being about involvement of people with disability in research, suggesting some opportunities for further clarification. Further, interviews identified some differing perceptions of what constitutes "high quality" research and what was meant by "value all forms of knowledge".

5.3 STAKEHOLDER ENGAGEMENT



9. **Invest in marketing and communication of the NDRP to build reach, awareness and engagement, especially in the disability community.**

A key finding of stakeholder consultations and of analysis of NDRP social media and web data was that the awareness of the NDRP is very low, both among academia and the disability community. This can be attributed to a number of factors, including the decision to limit promotion at this early stage and the limited resources for marketing and communication of the NDRP and the APO collection. However, the future success of the NDRP will be intrinsically linked to the engagement and support of stakeholders in research creation, translation and usage, something which is only possible through widespread awareness of the NDRP. In the next stage, a strong investment in marketing and communications will be needed to ensure that target stakeholders are aware of the NDRP, its principles and objectives, to make the case for participation in the face of many other competing demands on the time of people with disability, and to garner support for, and involvement in, the NDRP's activities.

10. **Increase engagement with the Australian Government, and state and territory governments.**

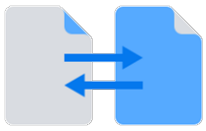
One notable finding from the evaluation was that state and territory governments were reluctant to be interviewed, often citing a lack of prior engagement with the NDRP. Some Australian Government respondents also highlighted a desire for more engagement with the NDRP. This presents an important opportunity for future stages of the NDRP to ensure that

all levels of governments play a role in shaping the research agenda and in translating research to policy. This may be achieved through inclusion of government representatives as part of governance structures, solicitation of joint funding support, and ongoing engagement with federal, state and territory government agencies to facilitate research translation to policy.

11. **Continue to address the intersectionality of disability with other aspects of identity subject to discrimination and marginalisation, and the impact of this on research access, policymaking and translation to practice.**

Stakeholder consultation for the evaluation and the disability community consultations for the research agenda development identified that disability research must continue to consider the intersectionality of disability with other aspects of identity subject to discrimination and marginalisation, (such as gender, culture, Aboriginality and LGBTQIA+). The experiences of disability within and across these groups can differ significantly and can integrate a range of cultural and social factors, which must be considered when conducting research and then translating research to policy and practice. This also applies when considering access to research findings within these communities, ensuring that materials are culturally appropriate and, where required, translated.

5.4 RESEARCH TRANSLATION AND MOBILISATION



12. **Consider an additional NDRP principle about focusing on research use and outcomes for people with disability.**
13. **Further consider appropriate roles for the NDRP in knowledge mobilisation, recognising that knowledge flows in both directions between researchers and end users.**
14. **Build NDRP investment in activities that support research translation.**

The use of research funded by the NDRP to inform policy and practice will be important to demonstrating the NDRP's impact and value. The NDRP seed funding has demonstrated the complexities of the disability research field and its communities. Barriers to research use are more complicated than a lack of time to implement outputs – as identified by NDRP stakeholders and the literature on barriers to research use.

> *'One of the key theories we have is that people in policy roles use research, so we've made those assumptions. But it would be really great to finesse that and have a better understanding of what are the other considerations that are in play. We know that the barriers [to research uptake] for service providers is being time poor, but in the policy landscape, it is about contest and the framing of ideas… it's not just 'if I had more time, I'd use the research better'. That's not the calculus. It's also, 'well, we've got to think about budget. We've got to think about whether this is a palatable option to sell.' So, it's a bit more complex. And it changes what we want to lean into.' [Research Organisation]*

Some Government respondents suggested a need for further consideration to best enable use of research funded through the NDRP to inform policy, as did disability organisations.

The importance of research translation to the NDRP is identified through the description of the NDRP principle "value all forms of knowledge", which includes the point that '*Australian policy will be informed by research and evidence.'* However, an additional NDRP principle focused on ensuring decisions and actions are guided by a focus on research that is used to benefit people with disability, their families and community could help to ensure the NDRP guiding principles best support the NDRP's intended outcome of influencing policy.

The NDRP has recently created a draft strategy for research translation with 5 key elements:

a. Set expectations: for a range of outputs from projects, tailored to end users.
b. Build capacity: workshops on research outputs production, development and maintenance of an accessible translation resource hub.
c. Support collaborations: ensure research teams work with advocates, policy makers or service providers.
d. Share findings: disseminate through network & APO Disability Research Collection, and support interactive ways to make knowledge available.
e. Spark conversations: regular public dialogues to explore evidence and research findings on particular topics from different perspectives.

While knowledge translation outlines the linear flow from researchers to end users, the concept of *knowledge mobilisation*[22] allows for recognition of a more dynamic process that accounts for more complex inter-relationships. Within this concept, organisations may consider a number of roles that can go beyond the production of research outputs to allow for more effective uptake. Brokers, intermediaries and boundary spanners (Figure 15) are all terms that relate to the facilitation of communication between researchers and practitioners.[23]

22 Edelman, A., Clay-Williams, R., Fischer, M., Kislov, R., Kitson, A., McLoughlin, I., Shouters, H., & Harvey, G. (2022). Academic Health Science Centres as Vehicles for Knowledge Mobilisation in Australia? A Qualitative Study. *International Journal of Health Policy and Management, 11*(6), 840–846. https://doi.org/10.34172/ijhpm.2020.247

23 Neal, J.W. Neal, Z.P. and Brutzman, B. (2021). Defining brokers, intermediaries, and boundary spanners: a systematic review. *Evidence & Policy*, DOI: 10.1332/174426420X16083745764324. [Open Access]

FIGURE 15. ROLES IN KNOWLEDGE MOBILISATION



Source: Neal, J.W. Neal, Z.P. and Brutzman, B. (2021). Defining brokers, intermediaries, and boundary spanners: a systematic review. *Evidence & Policy*, DOI: 10.1332/174426420X16083745764324. [Open Access].

Considering the most useful and appropriate of these roles for the NDRP, in consultation with stakeholders and government, may be a useful action for the next stage of the NDRP.

Whatever role the NDRP has, facilitating research use will require a dedicated investment by the NDRP. For comparison, organisations with similar objectives to the NDRP (such as the Autism CRC) have dedicated staff for managing research translation; these roles include working with communications staff, liaising with both researchers and policymakers to ensure that research is appropriately translated to practice, and supporting the uptake of research findings by community organisations. Some NDRP stakeholders suggested that the NDRP could support the existing policy and research functions within disability peak organisations through funding for extra staff to deliver research translation activities, and to create a Community of Practice across peak organisations.

5.5 MONITORING, EVALUATION AND LEARNING



15. **Ensure the NDRP monitoring, evaluation and learning (MEL) framework includes a focus on collaboration and partnerships, informed by frameworks for the evaluation of collaboration-focused activities.**

A key observation from the analysis of governance documentation for the NDRP, along with the stated objectives of the NDRP, is the fact that the NDRP seeks to position itself as a facilitator of collaboration and partnership between researchers, policymakers and the disability community. To reflect this, the NDRP monitoring, evaluation and learning framework should include a focus on collaboration and partnerships. There are a range of potential frameworks for the evaluation of collaboration-focused activities, which recognise that stakeholder partnerships are the fundamental driver of activity rather than specific

program activities and build their approach to monitoring, evaluation and learning accordingly.[24]

16. **Extend the NDRP MEL framework to incorporate board/ governance performance.**

Given the pivotal role that a governing board will play in managing stakeholder relationships, overseeing the research agenda, and assuring the operational performance of the NDRP, there need to be appropriate mechanisms in place for monitoring and evaluating board performance. Two key areas of importance are monitoring of the board skills to ensure that gaps in key areas (such as financial knowledge, risk management and diversity) are identified and addressed, and determining the overall performance of the board in assuring the integrity of the organisation through processes of self-reflection, as well as input from organisational staff and external stakeholders.

17. **The NDRP MEL framework should include assessment of the appropriateness of the NDRP principles, the extent they are adhered to, and how this affects outcomes.**

As the NDRP is guided by principles that are intended to support its outcomes – rather than a set program model – it would likely be helpful for future monitoring and evaluation to reference the literature on principles focused evaluation.[25] Following this, future monitoring and evaluation would include a focus on the extent to which the NDRP principles are appropriate, the extent to which they are understood and applied at all levels of NDRP activity, and how the application of the principles supports the NDRP's intended outcomes.

18. **Ensure that reporting requirements for NDRP research projects enable and support monitoring, evaluation and learning.**

The role of the NDRP as *both as a funding administrator and a facilitator of research translation* gives it a relatively rare opportunity to provide oversight and outcomes measurement for research projects over time, as well as for tracking research translation. The NDRP should ensure that reporting requirements set for research projects enable effective oversight by the NDRP, identify learning opportunities for future research, as well as its translation to practice and communication by stakeholders, and capture direct outcomes of the research.

19. **The NDRP MEL framework should draw on implementation science to support and measure capacity building and research translation outcomes among stakeholders.**

Much NDRP activity will be focused on capacity building and research translation. Moving into future phases, the evaluation of capacity building and research translation activities can

[24] See for example, Woodland, R. H., & Hutton, M. S. (2012). Evaluating organizational collaborations: Suggested entry points and strategies. *American journal of evaluation*, 33(3), 366-383.
[25] Patton, M.Q. (2017). Principles Focussed Evaluation. Guildford University Press, New York.

draw upon the existing body of research around implementation science, including approaches used to monitor and improve the performance of "what works" initiatives.[26]

[26] See Abdo, G. et al. (2021). What works for "what works" centres: Learnings from system-level efforts to cultivate evidence informed practice. Centre for Evidence and Implementation.

APPENDIX 1 MONITORING, EVALUATION AND LEARNING FRAMEWORK STRUCTURE

A1.1 INTRODUCTION

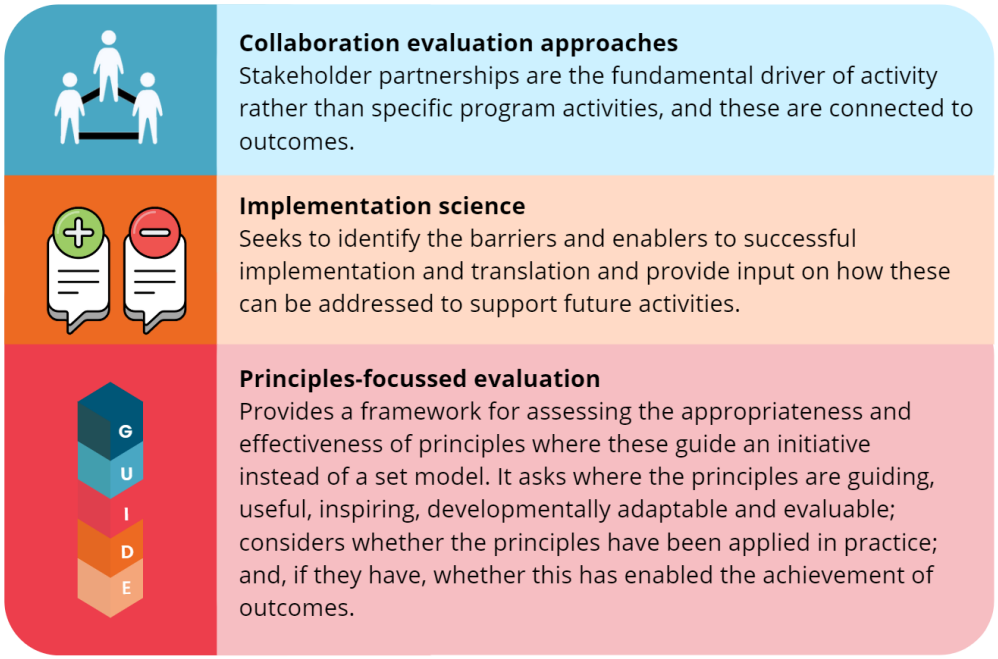
As the NDRP is established as an independent entity, it will be critical for a system to be in place to monitor and evaluate its activities, and to integrate findings from monitoring and evaluation into ongoing activities through a process of learning.

This appendix is designed to provide an indicative approach and roadmap for a future monitoring, evaluation and learning (MEL) framework to support the next phase of implementation of the NDRP. It is based on the recommendations of the final report for the NDRP Working Party, as well as an understanding of the NDRP principles and objectives drawn from the Working Party and the evaluation process, and the literature on appropriate evaluation approaches. The framework will need to be refined based on contextual factors, including the structure and activities of the NDRP, available funding, as well as whether evaluation will be delivered internally by NDRP staff, externally through independent evaluators, or some combination of the two.

A1.2 THEORETICAL BASIS

ARTD have identified three theoretical approaches to evaluation appropriate to the nature and intended aims of the NDRP (Figure 16).

FIGURE 16. THEORETICAL APPROACHES TO EVALUATION



Sources: Woodland, R. H., & Hutton, M. S. (2012). Evaluating organizational collaborations: Suggested entry points and strategies. American journal of evaluation, 33(3), 366-383; Abdo, G. et al. (2021). What works for "what works" centres: Learnings from system-level efforts to cultivate evidence informed practice. Centre for Evidence and Implementation; Patton, M.Q. (2017). Principles Focussed Evaluation. Guildford University Press, New York.

A1.3 COVERAGE OF MONITORING AND EVALUATION

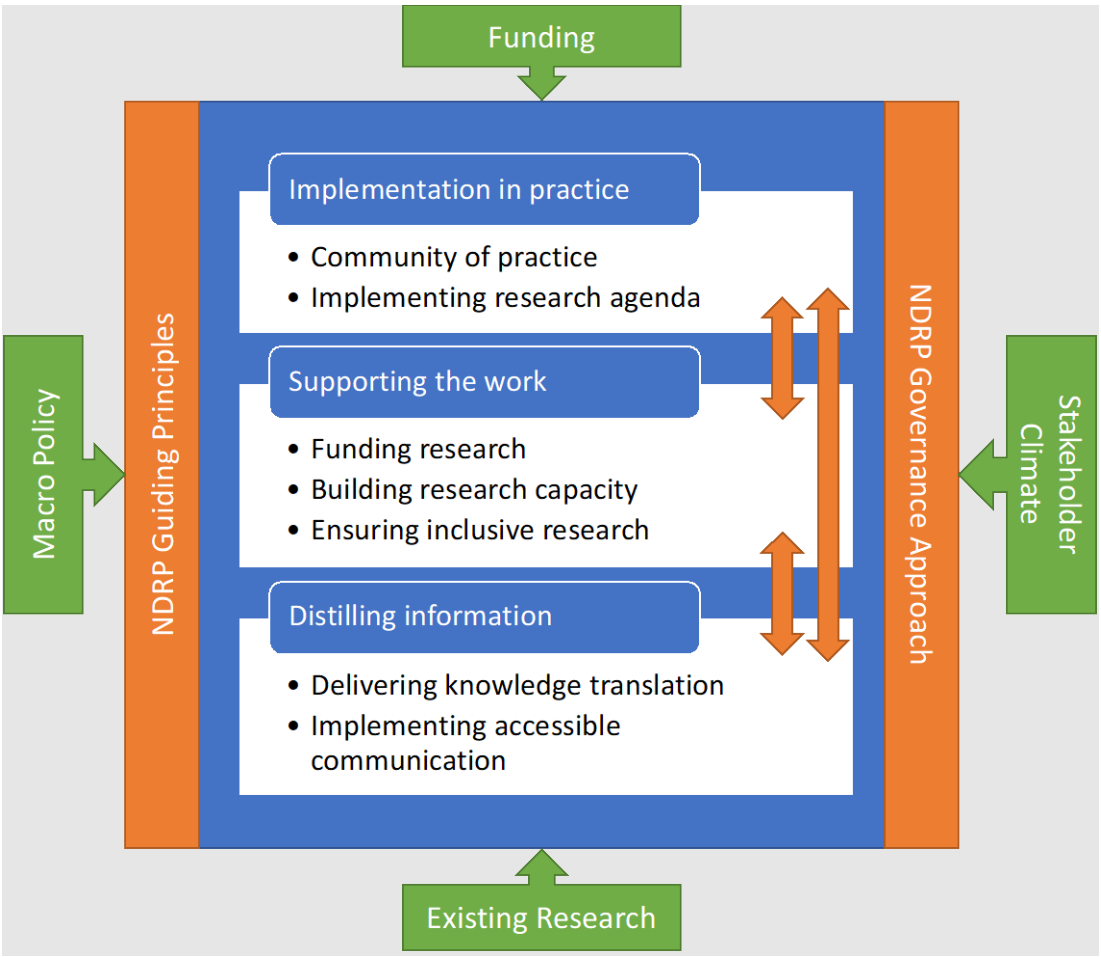
The final report for the NDRP seed funding phase identifies nine areas of focus for future activities:

- adhering to guiding principles
- establishing a governance approach
- ensuring a commitment to inclusive research
- implementing the preliminary research agenda
- funding research
- building research capacity
- delivering knowledge translation
- establishing and supporting a Community of Practice
- developing and implementing accessible communication.

Each of these areas represents a potential focus for evaluation activities. The work of Wandersman et al. (2008)[27] develops an interactive systems framework for similar initiatives that seek to build, translate and implement research evidence in practice. Figure 17 presents an adaptation of this framework to the NDRP's focus areas, classified into three categories.

[27] See Wandersman, A., Duffy, J., Flaspohler, P., Noonan, R., Lubell, K., Stillman, L., ... & Saul, J. (2008). Bridging the gap between prevention research and practice: the interactive systems framework for dissemination and implementation. *American journal of community psychology*, 41(3), 171-181.

FIGURE 17. INTERACTIVE SYSTEMS FRAMEWORK



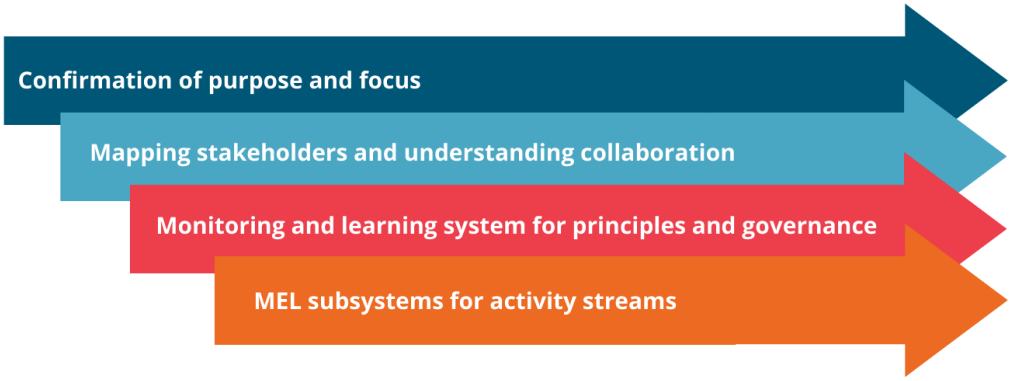
Source: Adapted from Wandersman, A., Duffy, J., Flaspohler, P., Noonan, R., Lubell, K., Stillman, L., ... & Saul, J. (2008). Bridging the gap between prevention research and practice: the interactive systems framework for dissemination and implementation. American journal of community psychology, 41(3), 171-181.

In the above figure, the areas represented in blue and orange represent the scope of a future NDRP monitoring, evaluation and learning (MEL) framework. The orange arrows note that the three streams of activities interconnect and influence each other, and it will be important to understand these interactions in monitoring and evaluation. The green elements in the figure define interactions with external systems that will influence the findings of monitoring and evaluation activities. The orange arrows note that the three streams of activities interconnect and influence each other. Marketing and communications activities underpin other activities in the figure.

A1.4 ROADMAP FOR AN NDRP MEL FRAMEWORK

Figure 18 represents an overview of the key stages and components that ARTD recommends be part of a whole-of-organisation NDRP MEL framework. It builds upon the above systems framework, and integrates the core concepts of collaboration, evaluation and improvement frameworks of Woodland and Hutton (2012).

FIGURE 18. RECOMMENDED KEY STAGES OF AN MEL FRAMEWORK



A1.5 CONFIRMATION OF PURPOSE AND FOCUS

The first step is for the NDRP to engage with key stakeholders to build a shared understanding of what success looks like for this next phase and identify the questions that need to be answered to guide ongoing monitoring and evaluation activities.

It will also be important to confirm the resources and model for monitoring and evaluation. This could be internally delivered, externally sourced or a hybrid model in which the choice whether to deliver monitoring and evaluation internally or externally is made on a case-by-case basis by following a set of guidelines. A comparison of the advantages and disadvantages of these models is provided in Table 5.

TABLE 5. COMPARISON OF MEL MODELS

Model	Description	Advantages	Disadvantages
Internal	Monitoring and evaluation are delivered by NDRP staff members, either as a dedicated team, or with program staff being guided by an evaluation expert.	• lower cost • knowledge retained in-house.	• perceived or real lack of independence • some evaluation activities may be larger than available resources • internal evaluation capability may be hard to source, and has to be maintained full-time.
External delivery	Monitoring and evaluation are delivered by external parties that are procured by the NDRP.	• independence of findings • resources can scale to needs • access to a range of providers and approaches • lower ongoing resource costs	• knowledge may not be retained in the organisation • quality procurement requires staff with working knowledge of evaluation • can be more costly depending on the required work.

Hybrid	Evaluation is delivered both by internal staff and through contracted evaluators, with the choice determined by a set of guidelines that set out thresholds and conditions for decision-making.	• balances cost and resourcing constraints • retains in-house knowledge • allows for evaluation approaches to be flexible to the needs and scope of activities.	• requires development and implementation of robust and usable guidelines • requires internal staff with evaluation knowledge • often requires a program of internal capacity building.

A1.6 MAPPING STAKEHOLDERS AND UNDERSTANDING COLLABORATION

In future it will be important to have a system for updating and monitoring stakeholders and communities of practice over time, to understand where the NDRP can direct its influence and activities as an organisation.

This will involve updating stakeholder mapping undertaken in the seed funding phase, along with the communities of practice that already exist in relation to disability research in Australia. An example of a mapping process is provided in Woodland and Hutton (2008).[28]

The NDRP MEL framework should include a focus on this activity. As an agent within the system of stakeholders seeking to influence disability policy and practice, it will be important to understand the level to which the NDRP collaborates and shares information with its stakeholders. Tools such as the Levels of Organisational Integration Rubric or partnership assessment surveys can be applied to identify, monitor and act on the understanding of the NDRP's relationships with stakeholders. Alongside this is the need to understand how teams and groups within the NDRP (including the board, organisation staff, and NDRP-initiated communities of practice) collaborate with each other, and to understand at a team level how collaboration can be improved over time. At an organisational level, assessment of collaborative capacity within teams over time can demonstrate both the evolution of collaborations, as well as identify driving factors for strong collaborations and organisational outcomes.

A1.7 MONITORING AND LEARNING SYSTEM FOR PRINCIPLES AND GOVERNANCE

Given that the NDRP principles and governance structure will both play a pivotal role in the operation of the NDRP and the achievement of its objectives, the establishment of a robust

[28] See page 372 of Woodland, R. H., & Hutton, M. S. (2012). Evaluating organizational collaborations: Suggested entry points and strategies. *American journal of evaluation*, 33(3), 366-383.

MEL system for understanding performance against these principles and the consistency and quality of governance should precede the evaluation of NDRP activities.

As noted in the recommendations for this report, there needs to be a system in place for monitoring the skills, performance and diversity of the board to ensure that risks to governance are identified and managed actively. There are in place existing systems for board and governance evaluation, such as those recommended by the Australian Institute of Company Directors, that can be applied in the context of the NDRP.

Alongside this is a need to create a system for monitoring the adherence of the NDRP to its principles over time and how adherence to its principles supports its intended outcomes. This system needs to be flexible to evolve as the NDRP principles evolve over time, but it also needs to have the capacity to be applied to evaluations of NDRP activities.

The NDRP principles can be assessed against the criteria for appropriate principles set out by Michael Quinn Patton in *Principles Focused Evaluation* (see Section 2.1). Additionally, stakeholders can be engaged through surveys and interviews to identify the extent to which the principles are understood and adhered to in practice. Internal stakeholders would report on the extent to which the principles guide them, while external stakeholders would report on perceptions about the extent to which the principles have been adhered to. This data would then be considered alongside outcomes data to begin to identify the relationship between adherence to the principles and achievement of intended outcomes.

Alternatively, rubrics could be used to drive reporting and analysis of adherence to principles across activities. A rubric would be developed with stakeholders to set out a transparent framework for levels of performance for each principle that could be flexibly applied across a range of NDRP activities.

A1.8 MEL SUBSYSTEMS FOR ACTIVITY STREAMS

Following the establishment of a MEL system for principles and governance, MEL subsystems for individual activity streams can be developed. These should draw on and link back into the broader NDRP MEL systems focused on collaboration and adherence to NDRP principles. This means the design of these MEL systems and individual evaluations should integrate questions and methods that enable reporting on collaboration, adherence to and effectiveness of principles, as well as questions specific to each activity stream and initiative.

The following presents indicative subsystems that consider the three streams of activity under the NDRP (identified in Figure 17).

A1.8.1 ASSESSMENTS OF IMPLEMENTATION

Key implementation activities will include development of communities of practice and the implementation of a research agenda.

Monitoring and evaluation for communities of practice will link strongly with the mapping activities that form the second stage of the roadmap. Evaluation approaches for individual communities of practice are likely to follow some form of collaborative evaluation approach.

For the implementation of the research agenda, this will require monitoring of both the activities of the NDRP in implementing the research agenda and the outcomes of application to policy and practice by stakeholders. This will likely combine an ongoing stream of engagement with stakeholders who will implement research, as well as point-in-time evaluations that consider outcomes from a whole-of-system perspective.

A1.8.2 ASSESSMENTS OF SUPPORTING RESEARCH WORK

Supporting research work covers both the funding of research through grants and direct investment, as well as the development of research capacity and inclusive research approaches within the community.

For research funding, more traditional grant program evaluation approaches are likely to be most suitable, especially where funding is being directed to address specific research objectives and outcomes. Reporting requirements for funded research projects should be set up in a way that enables effective oversight by the NDRP and learning (for long-term grants) as well as outcomes measurement, and mapping back to the broader MEL framework.

For the development of research capacity, there is likely to be a combination of evaluation of specific capacity-building initiatives and ongoing monitoring of the inclusive research capacity across the stakeholder base. The latter would cover the extent to which the NDRP is supporting inclusive research.

A1.8.3 ASSESSMENT OF DISTILLING INFORMATION

Communications and marketing activities should be monitored, drawing on established metrics for reach, recall and comprehension. This should be augmented by market research/ evaluation studies of perceptions of the NDRP among stakeholders, especially in relation to core objectives and principles, and perceived level of influence.

For the delivery of knowledge translation, a monitoring system should capture activities undertaken and their link to and consistency with NDRP principles. Evaluation should capture the outcomes of activities in terms of the uptake of information by target stakeholders.

Similarly, for ensuring accessible communication there needs to be ongoing monitoring of accessibility, linked to the establishment of sound processes for the design, testing and implementation of communication activities for NDRP information.

A1.9 INDICATIVE TIMELINE

The following section presents an indicative timeline for the development of each stage of the roadmap. In practice, for each stream, it will be necessary to characterise existing and needed sources of data, and prepare outcomes matrices that link data sources with key evaluation questions.

TABLE 6. INDICATIVE TIMELINE

Stream	Activity	Timeline
Confirmation of purpose and focus	Engage with stakeholders to confirm focus for evaluation	At establishment of NDRP as a legal entity
Stakeholders and Community of Practice	Establishment of approach and initial mapping	At establishment of NDRP as a legal entity
	Ongoing mapping exercises	Annually
Principles and Governance MEL	Development of Board skills matrix and MEL framework	At establishment of board
	Board risk management	Ongoing (updated at every board meeting, with annual review)
	Board skills matrix analysis	Annually or as needed as a result of board transitions
	Principles MEL development	At establishment of NDRP as a legal entity
	Principles review	Annually
Implementation subsystem	Evaluations of Communities of Practice	Formative and summative evaluations at 12 and 36 months respectively, with ongoing monitoring
	Evaluation of Research Agenda	Formative and summative evaluations at 12 and 36/60 months respectively, with ongoing monitoring and adaptation as agenda evolves
Supporting research work subsystem	Research grant funding	• Post-round process evaluation (after funding decisions) • Post-grant outcomes evaluation (after acquittal of funding)
	Research capacity building	• Process and outcomes evaluation for specific initiatives (as defined by initiative timelines) • Ongoing monitoring across all capacity and inclusivity initiatives of the NDRP
Distilling information subsystem	Communications and marketing	• Campaign monitoring across campaign periods • Ongoing monitoring of social and web channels,

		and media monitoring of NDRP profile • Annual evaluations of communications strategy and outcomes for key target markets
	Knowledge translation	• Ongoing monitoring of activities and reporting to board and public • Evaluation of outcomes of NDRP activities on knowledge translation at 36 months
	Accessibility assurance	• Ongoing monitoring of activities and reporting to board and public

APPENDIX 2 NDRP PRINCIPLES

Principle	Description
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 NDRP research agenda. • Draw on expertise across Australia through collaborative research teams. • Collaborative approach to refining research questions.
Recognise the knowledge of people with disability in research	• Research by and with people with disability. • Research that addresses the priorities of people with disability as outlined in the NDRP research agenda. • Research which specifically addresses people with disability who: o require support to express their will and preference, and to implement their decisions o experience intersectional disadvantage. • Genuine, paid for, co-design with people with disability.
Value all forms of knowledge	• Value knowledge creation from many different sources. • Promote knowledge that is accessible to the community: including journal articles, podcasts, videos and easy read summaries. • Promote Australian policy that is informed by research and evidence.
Build research capacity	• Build a vibrant, connected and thriving disability research community in Australia. • Create career pathways and targeted support for researchers with disability. • Build capacity of the disability sector to create and use knowledge.

APPENDIX 3 DESCRIPTION OF DATA SOURCES

A3.1 RESPONDENT GROUPS IN SURVEYS AND INTERVIEWS

Respondent Group	N
Person with Disability	40
Researcher	68
Organisational representative	38
Family member/ support person	34
Funding applicant	27
Not any of the above	19

Respondents could fall into multiple categories. 'Not any of the above' includes those directly involved in the NDRP and those closer to its activities who did not fall into the other categories.

A3.2 LIST OF ANALYSED DOCUMENTS

Document Type	Number
Activity work plan and reports	6
Attendance list from NDRP presentation to Universities Australia	1
Community of practice brief	1
Evaluation workshop transcript	1
Early NDRP proposal	1
Final recommendations and learning report	1
Governance structure	1
Journal article – Research agenda method	1
Australia's Disability Strategy 2021-2031	1
Overview of deliverable status	1

Pilot project funding round – Research proposals	10
Pilot project funding round – Project progress report	9
Pilot project funding round – Final project reports	8
Pilot project funding round – Selection report and learnings	1
Preliminary research agenda report	1
Program logic	2
Reflections from project progress reports	1
Relationship overview between NDRP, ADS and NDDA	1
Request for proposals	2
Research paper – Conceptual framework of disability research capacity, capacity mapping proposal and final paper	3
Stakeholder feedback documents	7
Stakeholder list and map	2
Social media data	1
Working Party – Minutes	30
Working Party – Terms of reference	1

A3.3 MAP OF METHODS TO EVALUATION QUESTIONS

Question	Document review	Administrative data	Social/ web data	Internal interviews	External interviews	Survey	Existing surveys and submissions
Appropriateness							
To what extent have the current NDRP principles been applied in NDRP seed funding activities, projects and practices?	✓	✓		✓	✓	✓	✓
To what extent is the work under NDRP seed funding phase laying a foundation for the genuine involvement of people with disability in research?	✓	✓		✓	✓	✓	✓

Question	Document review	Administrative data	Social/ web data	Internal interviews	External interviews	Survey	Existing surveys and submissions
What is the extent and quality of engagement by people with disability and other stakeholders in the NDRP seed funding activities?	✓		✓	✓	✓	✓	✓
To what extent has the NDRP laid the foundation for the development of accessible, tailored information that can help people with disability, policy makers and practitioners make evidence-informed decisions?	✓	✓	✓	✓	✓	✓	✓
Effectiveness							
How effective has the NDRP been in achieving its intended objectives for the seed funding phase?	✓	✓		✓	✓	✓	
What outcomes, both intended and unintended, were observed during the seed funding phase?		✓	✓	✓	✓	✓	
Efficiency							
Has the NDRP been operationally and cost efficiently implemented during the seed funding phase?	✓	✓		✓			
What factors need to be considered in order to assure operational and cost efficiency in future phases?	✓	✓		✓	✓	✓	
What were the enablers and barriers to success during the seed funding phase?	✓	✓		✓			
Were the pilot projects delivered efficiently (time and cost-efficiency)?	✓	✓		✓	✓	✓	
Sustainability							

Question	Document review	Administrative data	Social/ web data	Internal interviews	External interviews	Survey	Existing surveys and submissions
What can be learned from the seed funding phase that can inform future delivery of the NDRP?	✓	✓		✓	✓	✓	✓

APPENDIX 4 LIST OF NDRP PILOT PROJECTS

Project Title	Institution	Chief Investigators
Stepping out in the world – the new adulthood for Gen Zs with Down syndrome.	University of Queensland	Associate Professor Rhonda Faragher
Designing a Continuum of Best Practices for the Inclusion of Students with Intellectual Disabilities in Higher Education.	University of Sydney	Dr Nikki Wedgwood
Giving voice to rural and remote First Nations NDIS participants who are Deaf or hard of hearing in the Northern Territory.	University of Melbourne	Dr Alexandra Devine; Ms Jody Barney
'Bringing It Home': The exploration and co-design of consumer-led methodologies to understand lived experience of home and living within a National Disability Research Partnership.	Monash University	Associate Professor Libby Callaway
The eternal child: When best interests are not in the best interests of young people with disability.	University of New South Wales	Prof Ilan Katz; Rosemary Kayess
Experiences of police apprehension for psychosocial disability: a co-designed investigation.	RMIT	Mr Rory Randall
"Saying who you are": Identifying best practice to support positive identities for LGBTQ people with intellectual disability.	Deakin University	Amie O'Shea
Supporting the woman, supporting the mother: Examining the interface between the NDIS and family support services for mothers with intellectual disability in New South Wales.	University of Sydney	Dr Susan Collings
Co-designing Resources to Increase Access to Information and Services: Syrian and Iraqi people with disability from refugee backgrounds and service providers.	Deakin University	Associate Professor Angela Dew