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GOVERNANCE ISSUES PAPER

National Disability Research Partnership

Foreword by

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Background research by

NDRP Working Party

For the purpose of

Outlining key issues which need to be considered as part of
identifying a future governance model for the NDRP



NDRP

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IDENTIFYING A FUTURE GOVERNANCE MODEL FOR THE NDRP

FOREWORD

The announcement on 14 November 2019 by the Minister for the National Disability Insurance Scheme, Minister Stuart Robert, that the Commonwealth Government had committed \$2.5 million to the establishment of a National Disability Research Partnership (NDRP) marked the start of an extraordinary opportunity for the future of disability research in Australia.

We were honoured that the Melbourne Disability Institute (MDI) from the University of Melbourne was invited to lead this nationally significant initiative. At the same time, we realised that we could not undertake this initiative alone and so we thank the members of the Working Party who have joined us to lead this work.

It gives us great pleasure to provide you with a copy of this Governance Issues Paper for the National Disability Research Partnership. This paper aims to outline key issues which need to be considered as part of identifying a future governance model for NDRP and precedes a broad consultation process. Governance, funding and the scope of activities of NDRP are all closely inter-related issues and so all three issues are canvassed in this paper, with the principal purpose of determining future governance arrangements for NDRP.

The overarching objective of the Working Party is to secure long-term funding for disability research. Funding will be used to generate research that is collaborative with people with disability at the centre. Funding must be sufficient to address the current evidence gaps in a timely way, align with key policies and strategies like the National Disability Strategy and the National Disability Insurance Scheme and build research capacity.

The necessary funding will only be secured if the scope and objectives of NDRP meet the objectives of stakeholders and if governance arrangements enable true collaboration between people with disability; families and carers; universities and research organisations; disability representative organisations; governments; non-government organisations; industry; and the service sector.

Associate Professor Jennifer Smith-Merry from The University of Sydney is leading a separate piece of work developing the research agenda that will underpin the activities of the NDRP in the next ten years. This year, the Working Party will conduct work to identify current research capabilities and identify strategies to build research capacity into the future.

This paper includes questions about the funding and governance of NDRP and critical success factors. We invite you to respond to the questions and make additional comments and offer advice through direct discussions and an online survey.

Additional background information about NDRP can be found on our website in a range of formats. In March we will hold webinars to provide background information and answer questions. We will meet separately with individuals and organisations who are interested in deeper discussions. We are providing this



Professor Anne Kavanagh
Co-Director NDRP

paper in advance of these discussions to give you the time to reflect on the issues.

The Working Party will synthesise all feedback and share how we have incorporated the feedback into our recommendations to government on the preferred future governance model for NDRP.

On behalf of the Working Party, we would like to thank you for your interest, look forward to your active engagement and feedback and hope you share our excitement.



Professor Bruce Bonyhady AM
Co-Director NDRP

GOVERNANCE ISSUES PAPER

Introduction

The aim of this Governance Issues Paper is to inform the future governance arrangements for NDRP. It also provides a starting point for discussions with potential stakeholders to help them decide if they would like to explore in more detail whether they would like to become closely involved in the activities of the NDRP. Stakeholders can get involved as a major research contributor, as a funder through contributions in cash or in-kind.

We are seeking your input on:

- The NDRP's mission and critical success factors

- The scope of NDRP
- Funding arrangements for NDRP
- The governance principles and model for NDRP

Each section includes questions for consideration. All of these questions are included in a survey at this link: [NDRP governance survey](#).

The survey is open to organisations and individuals.

Questions and feedback on the future research activities of NDRP are part of a separate consultation process on the research agenda (follow this link for more information: [research agenda](#)) and are not addressed in this Governance Issues Paper.

WHAT IS THE NATIONAL DISABILITY RESEARCH PARTNERSHIP?

Background and Context

The [NDRP](#) has been established by the Australian Government through the Department of Social Services (DSS), with initial funding for two years until mid-2022, through a grant to the Melbourne Disability Institute (MDI) at the University of Melbourne¹.

The NDRP will drive a collaborative and inclusive national disability research program that delivers the evidence to enable innovation in policy and practice.

During this current phase, the NDRP is operating under the terms of the NDRP Funding Agreement between DSS and MDI, which requires MDI to deliver the following key outcomes:

- A future governance model for the NDRP designed to involve a range of stakeholders across the disability community, academics, advocacy bodies, governments, philanthropy, service providers
- A research agenda that builds on existing strategies and policies
- Map Australia's research capability, identify what capacity needs to be built to meet the vision of the research agenda and develop a plan for building research capacity
- A practical guide to disability-inclusive research
- Pilot projects that demonstrate the capacity of the NDRP to deliver on its principles, and
- Facilitate international research partnerships and collaborations.

and industry which will attract ongoing funding for high-impact disability research. This is the subject of this Governance Issues Paper.

¹ The establishment of the National Disability Research Partnership was announced by Minister Stuart Robert, Federal Minister for the National Disability Insurance Scheme, Minister for

Government Services on Thursday 14th November 2019, see <https://ministers.dss.gov.au/speeches/5266>. The NDRP website went live on 23 June 2020.

NATIONAL DISABILITY RESEARCH PARTNERSHIP DELIVERABLES & TIMELINE

NDRP

1 SEED FUNDING

In 2019 the Commonwealth Government announced the provision of 2-year start-up funding to establish a National Disability Research Partnership.

2 WORKING PARTY

An initial working party is formed to work closely with stakeholders to design a future governance structure, develop a research agenda, map research capability and deliver two demonstration projects. The working party will exist for two years until mid-2022 and will help facilitate the establishment of NDRP.

3 STAKEHOLDER OUTREACH

The NDRP is committed to working side-by-side with the disability community, government, advocacy bodies, service sector, philanthropy, industry and top researchers who are committed to advancing the rights of people with disability.

4 RESEARCH AGENDA

The NDRP will develop and seek ratification of a future research agenda designed to engage a range of stakeholders to inform the next decade of disability research.

5 GOVERNANCE CONSULTATION

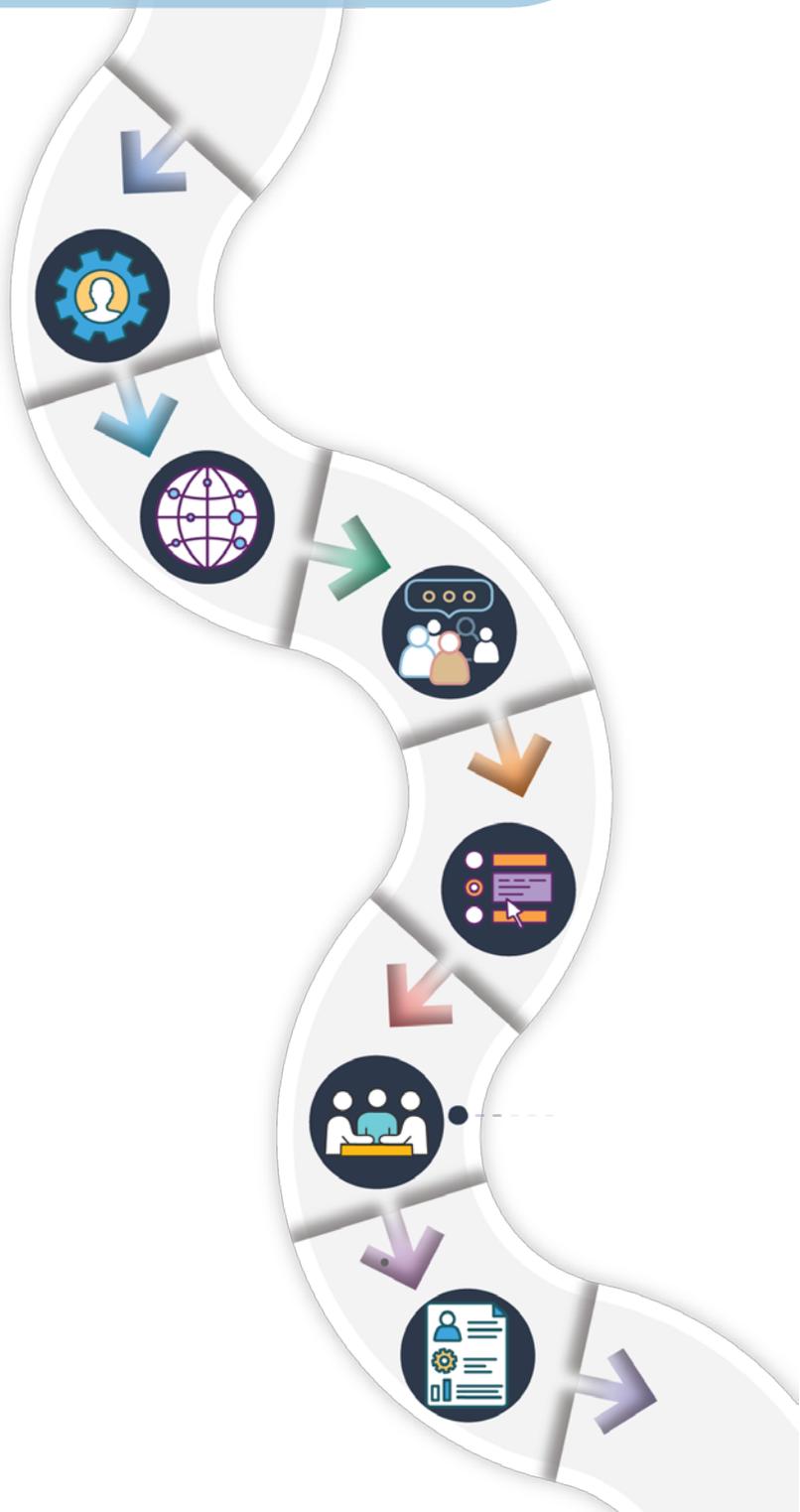
The NDRP will develop and seek ratification of a future governance model for the NDRP designed to engage a range of stakeholders which will attract future on-going, significant funding for disability research.

6 PILOT PROJECTS

The NDRP will demonstrate through a select number of pilot projects the capacity of the NDRP to work together to deliver solutions on priority issues as identified in the research agenda and inform long-term governance arrangements.

7 NDRP ESTABLISHMENT

The end-goal is to create a long-term partnership model that will enable Australia to build capacity and conduct high quality research that helps provide solutions to the many policy and practice challenges in disability policy, service delivery and mainstream services.



VISIT [NDRP.ORG.AU](https://www.ndrp.org.au)
FOR MORE INFORMATION

CONTEXT

Policy and operating context for the NDRP

The NDRP is being established within the context of unprecedented investment and reform to address the persistent inequities and advance the rights of people with disability as well as their families, and carers.

Several national initiatives are occurring within the context of Australia's commitments to meet its obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRDP). These initiatives provide the context for current and future plans for the direction and scope of NDRP.

Key national initiatives relevant to the evolution of the NDRP include:

- [National Disability Strategy \(NDS or Strategy\)](#), which provides the overarching policy framework for meeting Australia's obligations under the UNCRDP. It represents a commitment from all Australian Governments to work together to address the disparity of outcomes experienced by Australians with disability across health, social, economic and wellbeing domains of life. It is therefore a principal reference point for NDRP activities.
- [National Disability Data Asset \(NDDA\)](#), which has been allocated \$15 million to establish an enduring asset, which links multiple administrative datasets

including NDIS, social security, health, employment, tax and justice data, and undertake five research projects in the set up phase as test cases to demonstrate the value of the NDDA.

- The [2014 Audit of Disability Research in Australia and Update 2017](#) which established a baseline on the state of disability research in Australia and will be key to shaping the research agenda for NDRP.
- [National Disability Insurance Scheme \(NDIS\) and Agency \(NDIA\)](#) which has recently undertaken a survey of disability research, as part of establishing its own research functions and a Centre for Knowledge Translation.
- [NDIS Quality and Safeguards Framework](#), which is managed by the [NDIS Quality and Safeguards Commission](#), which registers and regulates providers of NDIS funded services and supports.

Looking ahead, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is likely to influence future research directions.

A recent example is the Royal Commission into Institutional Responses to Child Sexual Abuse, which is leading to the establishment of the National Centre for the Prevention of Child Sexual Abuse and has been allocated \$22 million, as a direct result of the Royal Commission.

The following diagrams illustrate the relationship between the NDRP and these initiatives and the overarching governance framework for disability policy.

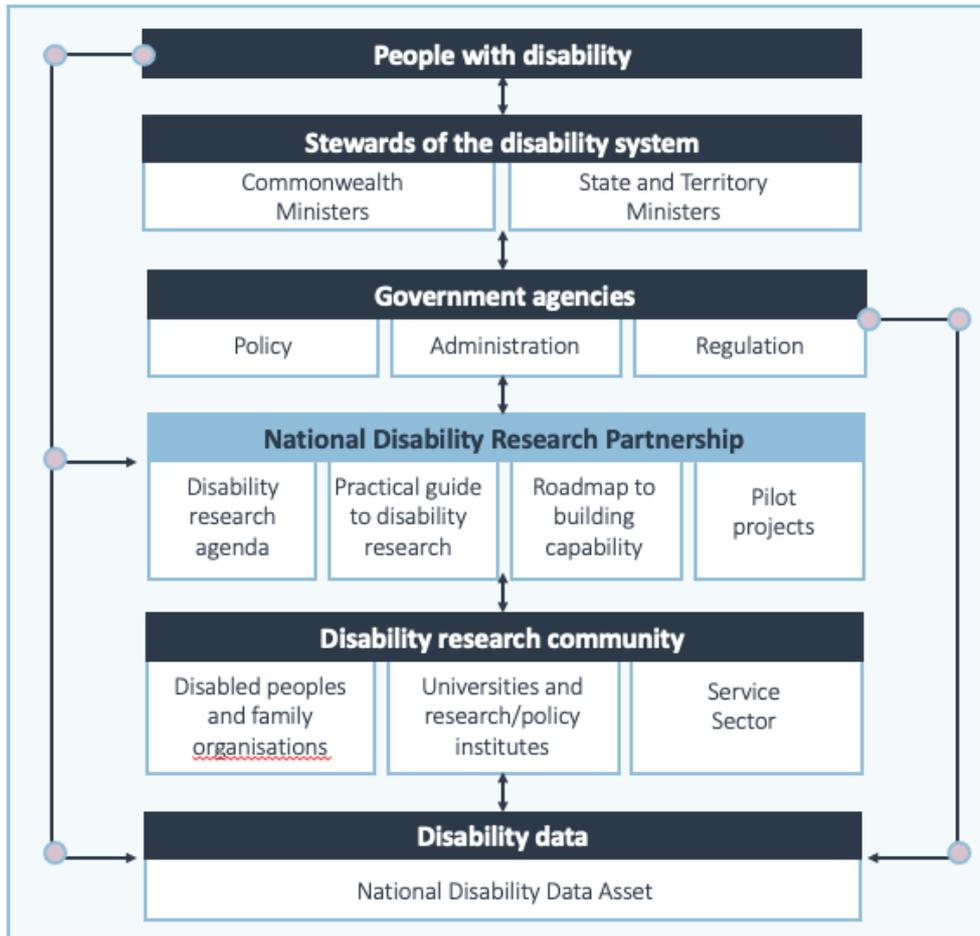


Figure 1: Governance framework for disability policy



Figure 2: accountability, strategy and action

BUILDING A WORLD-CLASS HUB IN DISABILITY RESEARCH

Principles

The NDRP is guided by four key principles. Read more at this link: [guiding principles](#).

1. High quality, collaborative research

- Become a world-leading driver of disability research that builds an evidence base
- Advance disability research in Australia by delivering on the national disability research agenda
- Draw on expertise across Australia through collaborative research teams
- Collaborative approach to finessing research questions

2. Recognise and value the knowledge of people with disability in research

- Research 'by' and 'with' people with disability
- Research that addresses the priorities of people with disability and their families as outlined in the national disability research agenda
- Research which specifically addresses people with disability who:
 - require support to express their will and preference, and to implement their decisions
 - experience intersectional disadvantage
- Genuine, paid for, co-design

3. Value all forms of knowledge

- Value knowledge creation from many different sources
- Knowledge that is accessible to the community: including journal articles, podcasts, videos and easy read summaries
- Australian policy will be informed by research and evidence

4. Build research capability

- Build a vibrant, connected and thriving disability research ecosystem
- Create career pathways and targeted support for researchers with disability
- Build capacity of the disability sector to create and use knowledge.

Critical success factors

A successful NDRP would be: a world-class hub in disability research; independent of government; trusted and responsive; and well-resourced to achieve its objectives.

As a world leading hub in disability research the NDRP will:

- Facilitate high quality, inclusive research that drives innovation in policy and practice
- Drive the development of extensive national and international networks of

researchers and stakeholders working together

- Strategically and systematically address priorities identified in the research agenda
- Enable the provision of evidence-based advice to stakeholders based on current research
- Facilitate the translation of knowledge by mobilising research findings and learnings
- Build the research capacity of individuals, teams and organisations across Australia, particularly among people with disability, and also their families, allies or supporters
- Build research infrastructure, such as contributing to the development of enduring data assets.

NDRP's independence will be demonstrated by:

- An ongoing commitment to contribute to an evidence base relevant to people with disability
- Aligning the activities of NDRP with the research agenda developed in collaboration with stakeholders including people with disability; their families, allies and supporters; academics; governments; mainstream and disability services; and, industry.

To be trusted and responsive the NDRP will:

- Maintain good governance, transparency, and clear processes for managing conflicts of interest

- Build trust with governments to provide advice and evidence to support the National Disability Strategy and that builds on the National Disability Data Asset
- Build trust with people with disability, their families, allies and supporters through a commitment to research that promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity
- Be responsive to multiple stakeholders to provide timely, accessible and trustworthy advice, balancing emerging, more immediate issues with the long-term research agenda.

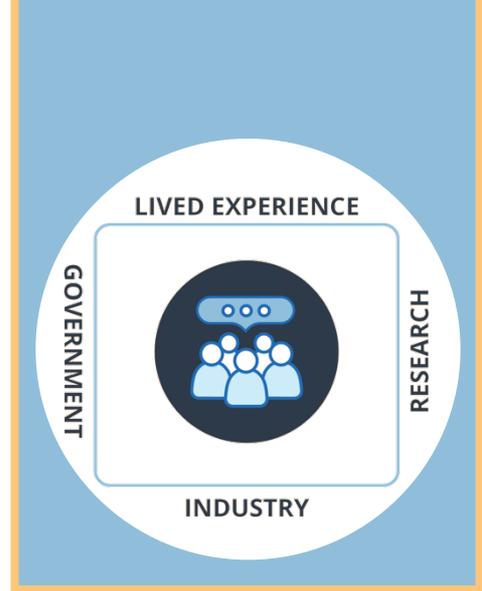
The NDRP can only be successful if it is well resourced with sufficient funding to:

- Facilitate high quality research that addresses issues in a timely way
- Enable substantial investment to build enduring research capacity and that is 'fit for purpose'
- Resource people with disability, their families, allies and supporters, and disability representative organisations to participate in research activities
- Undertake highly effective knowledge translation and communications that is accessible to all.

Suggested question for feedback

- What do you think about the proposed NDRP principles and critical success factors?

NDRP STAKEHOLDERS



NDRP scope of activities

The scope of the NDRP work is broadly defined by its key stakeholders, a national disability research agenda, capacity building and research and knowledge translation activities.

Key Stakeholders

Key stakeholders and close collaborators are expected to include:

- people with disability as the beneficiaries of innovative, evidence-informed improvements in policy and practice
- families and carers
- universities and other research institutes, including existing major national disability-focused research collaborations
- Disabled People's Organisations, relevant peak bodies, advocacy groups, consumer bodies, disability service providers, mainstream services, industry, and
- the Commonwealth, State and territory Governments, the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission

Suggested questions for feedback

- Is this list of key stakeholders correct? Who else should be added?
- What should NDRP to do exceptionally well? How should it balance key activities:
 - Deliver and address priorities of a national disability research agenda
 - Bring people together
 - Build on the existing evidence base
 - Build capacity
 - Translate knowledge: ensure the information reaches the right people in an accessible format
 - Other?

NATIONAL DISABILITY RESEARCH AGENDA

The NDRP has been funded to develop a national disability research agenda. The University of Sydney in partnership with other Australian universities, research institutes and disability representative organisations and service providers is undertaking this research and will be consulting on this key aspect of NDRP. It is therefore only briefly described here and described in more detail on the NDRP website at this link: [research agenda](#).

The research agenda has a social research and policy focus, linked to the National Disability Strategy.

The following areas are in scope for research topics within the research agenda:

- Research that advances the rights of people with disability
- Research that improves quality of life for people with disability and families and carers

- Research that improves the participation in community life of people with disability
- Research into practice and policy improvements
- Research into systems of support for people with disability, their families and carers,
- Research that improves service delivery and interface issues between specialist and mainstream services.

Medical research into causes of disability is not within the scope of the national disability research agenda.

Read more about the research agenda and the four project phases: pre-planning, research mapping, consultation and prioritisation for the final research agenda, to inform the next decade of Australian disability research on the NDRP website here: [research agenda](#).

Funding arrangements for the NDRP

Funding will need to be sufficient to make meaningful progress to address the major research questions identified in the research agenda and to build the capacity for disability-related research across multiple disciplines and research techniques.

Australian governments have a successful track record of participating in research collaborations through Co-operative Research Centres and a range of other initiatives across funding bodies such as NHMRC and ARC.

Ideally, NDRP should receive funding and resources from multiple sources to provide long term security and facilitate NDRP's independence. In addition to core funding from governments, additional financial and in-kind contributions could be sourced from:

- Universities
- Sector stakeholders, and
- Philanthropy.

Funding from a single source can create dependencies and future uncertainty. There is much greater durability in activities and organisations supported by a diverse range of funders. While it will be essential for NDRP to be fully accountable to all of its funders, funders may not be directly represented in the governance arrangements.

The discussion about NDRP funding will ideally draw on learnings from precedents, examples and currently accepted practices to develop the optimum funding model for the NDRP. It could also develop a unique funding model and break new ground.

Suggested questions for feedback

- What principles should underpin the NDRP funding model?
- What can the NDRP learn from existing initiatives and funding streams that support quality research programs?
- Should the NDRP aim to break new ground with its funding? If yes, what should it do and why?
- How should NDRP ensure that it has a diverse funding base?

FUTURE GOVERNANCE

What might the future governance arrangements look like for the NDRP?

The NDRP Working Party has conducted a desktop review of governance models from a range of Australian research institutes and partnerships that have a similar purpose as the NDRP, and then conducted interviews with key staff.

These include:

- Australian Housing and Urban Research Institute (AHURI)
- Australia's National Research Organisation for Women's safety (ANROWS)
- Australian Research Alliance for Children and Youth (ARACY)
- Sax Institute
- National Health and Medical Research Council (NHMRC) Special Initiatives
- Centre of Excellence in Bio-security Risk Analysis (CEBRA)
- Lowitja Institute
- Co-operative Research Centres (CRCs), and
- Australian Research Council (ARC) Centres of Excellence.

A summary of the research is available on the NDRP website at this link: [Governance](#)

A common feature of the governance arrangements for other research

institutes is that their governance arrangements have generally evolved over time - to meet changes in mission, aims or objectives, stakeholder expectations, facilitate organisational growth (scale and scope), and grow and diversify funding. Therefore, future governance arrangements for NDRP should ideally evolve seamlessly out of experience with the current arrangements.

As noted earlier, a key aim and deliverable during the current phase of NDRP is broad consensus on a governance model that best supports the next stage of NDRP development. This includes genuine stakeholder consultation on potential governance arrangements and structures, governance protocols and intellectual property arrangements. The deadline for proposing a new governance model is mid-2021.

A governance model that has broad support will need to ensure that the NDRP is inclusive, leveraging capacity across the sector while having structures that are not so cumbersome that it impedes effective and timely research and knowledge translation.

Protocols will need to be developed outlining prioritisation of activities, procedures for handling conflicts of interests and how interdisciplinarity and cross-institutional collaborations should be facilitated across the NDRP.

GOOD GOVERNANCE AND REGULATORY COMPLIANCE

Governance Objectives

Governance objectives should be put in place that are consistent with the NDRP mission and purpose, the critical success factors, so that key stakeholders can have confidence that the NDRP will achieve its aims.

As a new initiative with ambitious objectives and an important mandate to deliver world-class disability research, the NDRP will need to gain the confidence of the disability community, government, and sector stakeholders.

The Working Party's analysis of the arrangements of other research organisations with a similar purpose to the NDRP found they pursued common governance objectives regardless of the focus or intended beneficiaries of their work. These include meeting commonly understood standards

of good governance and regulatory compliance, maintaining the right balance of skills and experience within their governance arrangements, remaining focussed on inclusion and engagement for intended beneficiaries, and having arrangements that are sufficiently adaptable to allow the organisation to grow and diversify their collaborations, functions, activities and funding sources over time.

Our findings include: the need for trusted, stable, open, long-term relationships between key stakeholders; the need for leadership built around a shared vision; that there must be transparent and clear processes, especially in relation to managing conflicts of interest; and that there must be strong in-built mechanisms to ensure that all research is high quality and timely.

Based on these findings, the following are the proposed governance objectives for the NDRP that we seek feedback on:

- 1. Good governance:** meeting commonly understood standards of good governance and regulatory compliance commensurate with the legal, company, or research collaborative structure adopted. For example, if the future governance arrangements require a company structure, it will need to operate under the established rules of governance and relevant company laws as produced by the Australian Securities and Investments Commission (ASIC)².
- 2. Balanced skills-based governance:** achieving a governance structure (for instance a Board of Directors or Steering Group) that is inclusive and contains the right balance of skills and experience of people with a shared vision for the NDRP. There are many stakeholders with a potential claim to being included on the Board or Steering Group for NDRP. The disability community will reasonably expect that the maxim of “nothing about us without us” will be a core operating principle of the NDRP. Similarly, Australian governments will reasonably expect to have oversight of the investment of public funds, as will universities, research institutes and organisations making financial and/or in-kind contributions. The need for stakeholder representation needs to reflect a skills-based approach to governance, in line with best practice. This means that not every stakeholder has a ‘representative’ on the Board or Steering Committee but rather that

the diverse skillsets of the stakeholder groups are harnessed through individuals appointed to these bodies. The NDRP’s next stage of governance arrangements should continue to involve people with expertise in governance, management, current disability issues and the role of research in enhancing reforms, policy, and practices. The NDRP takes the view that lived experience of disability is an essential ‘skill set’ that is germane to the aims and objectives of the NDRP and the context in which it will operate. Achieving a skills-based Board or Steering Group with an understanding of the interests of end users and beneficiaries and research and accountability standards is therefore proposed as a key governance outcome.

- 3. Inclusive governance:** people with disability, their families and carers should be engaged in NDRP activities in several ways, not just as part of the NDRP Board or Steering Group. For example, there should be significant opportunities for people with disability, their families and carers to be employed as NDRP staff and to participate in sub-committees, expert advisory committees or specialist advisory roles. The NDRP will demonstrate global best practice in co-producing and implementing a research agenda that speaks directly to the priorities of people with disability, their families, and carers. NDRP will need to be sufficiently funded to undertake and build the capacity of the disability sector to engage in co-production. The NDRP

² See requirements for a public company at <https://asic.gov.au/for-business/registering-a->

[company/steps-to-register-a-company/registering-not-for-profit-or-charitable-organisations/](https://asic.gov.au/for-business/registering-a-company/steps-to-register-a-company/registering-not-for-profit-or-charitable-organisations/)

will also develop governance arrangements that are clear about the scope of co-production and what should and can be achieved, involving people with disability, families, and carers and their representative organisations in the decision-making. The NDRP is therefore developing a practical guide to disability-inclusive research.

4. **Flexible governance:** having a legal, company or research collaborative structure that is sufficiently adaptable to allow the NDRP to grow and diversify its functions, activities and funding sources over time and also to include new key stakeholders/partners (and, potentially, allow initial key stakeholders/partners to leave, if priorities change).
5. **Diverse and broad-based governance:** the NDRP will need to be a diverse, broad-based and close collaboration bringing together universities,

governments, advocacy organisations, and industry/sector partners, including specialist disability service providers and industry partners from outside the traditional disability sector (e.g. housing providers, technology and telecommunications companies)³. This will involve developing a structure that is sufficiently diverse to reflect the range of stakeholders that need to be involved in the NDRP if it is to be a world class disability innovation policy and research hub. Several well established and effective research collaborations in the health and human services sectors and in other sectors provide useful examples. The underlying principle will be that governance arrangements should be inclusive of the range of expertise available so that the NDRP has connections that enable access to the best quality skills and expertise. The aim will also be to ensure there are multiple opportunities for stakeholders to engage with the NDRP.

Suggested questions for feedback

- Are the suggested governance objectives right for the NDRP? If not, which criteria should be omitted and what other criteria need to be added?
- How should people with disability be embedded in the governance of NDRP?
- How should families, carers, and representative organisations be embedded in the governance of NDRP?

³ See for example the Sax Institute, ARACY, ANROWS, AHURI, NHMRC Special Initiatives, Co-

operative Research Centres, and ARC Centres of Excellence.

New separate legal entity	Consortium of partners	Other
<ul style="list-style-type: none"> • Small team to guide and oversee delivery of research agenda • Input from partners • Board of Directors • Similar to AHURI, ANROWS, ARACY, Sax Institute and Lowitja 	<ul style="list-style-type: none"> • Partners from as many states and territories as is feasible • ‘nodes’ or ‘centres’ part of the consortium • Steering group • Similar to ARC Centres of Excellence or Centre of Excellence for Biosecurity Risk Analysis (CEBRA) 	<ul style="list-style-type: none"> • Ideas and suggestions for additional governance models which are consistent with the NDRP’s aims, critical success factors and scope, and that are thought likely to create the conditions for the long-term success of the NDRP

Figure 3: Possible governance models

Governance Models

The review of existing governance models (at this link: [governance](#)) identified the key attributes, strengths, and weaknesses of a range of governance models currently in use to facilitate impactful collaborative research. These have been developed into two principal governance models for consultation:

- Model A:** a new and separate legal entity/company which would include a small team who would have oversight and steer the delivery of the research agenda, with mechanisms to provide input from partners and key stakeholders including universities, research institutes, advocacy organisations and other organisations from around Australia. Governance would be led by a Board of Directors which would also ensure that strategically and operationally there are close collaborations with people with disability; families, carers; representative organisations; governments; and industry. Potential current models for this wider engagement can be found in Cooperative Research Centres, such as the Autism CRC, which includes autism organisations and governments amongst its members.
- Model B:** a consortium of partners, from as many states and territories as is feasible, in which there would be ‘nodes’ or ‘centres’ who are part of the consortium. This structure, which is like an ARC Centre of Excellence, would allow future governance and operations of the NDRP to leverage off existing administrative and other infrastructure. The governance would consist of a Steering Group with overall responsibility for strategy, oversight of activities and responsibility for building close collaborations. Each ‘node’ would need to meet a certain set of criteria related to capacity, local partnerships with people with

disability, families, carers, their community, disability representative organisations, governments and industry and agree to adhere to core principles.

- **Other Model(s):** The NDRP is interested to hear from stakeholders about their ideas and

suggestions for additional governance models which are consistent with the NDRP's aims/mission, critical success factors and scope, and that are thought likely to create the conditions for the long-term success of the NDRP.

Suggested questions for consideration

- Which model do you think is most likely to support the success of a future NDRP?
- Are there other governance models likely to create the conditions for the long-term success as per the critical success factors suggested for the NDRP?
- If your preferred model includes core organisations, which types of organisations should be partners and what should be the selection criteria?
- Are there other important governance matters which should be considered?

WHAT'S NEXT?

Conclusion and next steps

The NDRP Working Party is interested in views from as wide a range of stakeholders as possible about the NDRP governance options and would especially like to hear from organisations which are interested in becoming closely involved.

In April 2021, the Working Party plans to meet with interested parties to discuss the issues raised in this Governance Issues paper. All of the governance questions are included in a survey at this link: [NDRP governance survey](#).

The aim of this consultation is to develop a governance model that has strong support, provides the foundation for future disability research in Australia and aligns with the collaboratively developed national disability research agenda.

Following the webinars, subsequent discussions with interested stakeholders and the completion of survey responses,

the Working Party will provide feedback on the responses and make recommendations to governments on a preferred future governance model for NDRP.

Ultimately, the preferred governance arrangements for NDRP will need to be ratified and approved by governments and those organisations that contribute resources.

We would love to hear your ideas. If you have questions or comments please send them to info@ndrp.org.au. You are also very welcome to send us your responses in any format you prefer.

Responses to frequently asked questions can be found on the NDRP website at www.ndrp.org.au and more information can be found under the Governance tab here at this link: [Governance](#).

[Complete the Governance Issues Survey](#)

Appendix A | Working Party Membership

Professor Anne Kavanagh

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Dr Scott Avery

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Mr Gordon Duff

Independent Advisor

Ms Ellen Fraser-Barbour

Independent Advisor

Ms Keran Howe

Independent Advisor

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Professor Jackie Leach Scully

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Director, Disability Innovation Institute
University of New South Wales

Professor Gwynnyth Llewellyn

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Systems
Stream Leader Disability and Inequity,
Centre for Disability Research and Policy
University of Sydney

Ms Christina Ryan

Independent Advisor

Dr Ian Watt AC

Independent Advisor

Appendix B | NDRP Working Party Terms of Reference

Establishment	
Document	Terms of Reference V1
When:	23 June 2020
By what authority:	As agreed between the Department of Social Services (DSS) and the Melbourne Disability Institute (MDI) which has been appointed by DSS to lead NDRP
For what period:	January 2020 to June 2022
Role/Terms of Reference	
Nature:	Guide establishment and consultation phase of the NDRP
Terms of Reference:	<p>The NDRP Working Party will:</p> <ul style="list-style-type: none"> ● promote and facilitate the mission and activities of the NDRP ● actively engage with key stakeholders to facilitate collaborative and interdisciplinary research by facilitating connections and introductions with universities (including international universities), advocacy bodies, people with disability, their families and carers, service providers and government departments ● help guide the initial deliverables ● advise on specific strategic or operational issues as required.
Quorum:	A majority of the full membership
Operating procedures prescribed / determined by itself:	<p>The NDRP Working Party will:</p> <ul style="list-style-type: none"> ● work in the best interests of the NDRP ● be available on a timely basis ● declare any conflicts of interest as soon as possible
Confidentiality	<ul style="list-style-type: none"> ● As the aim of the NDRP is to facilitate collaboration and be transparent, Working Party members will not be asked to sign confidentiality deeds. ● If Confidential Information is discussed, the NDRP Secretariat or Disclosing Party will clearly state the boundaries of confidentiality. ● All Working Party members: <ul style="list-style-type: none"> ○ may exchange confidential information relevant to NDRP with other members of the Working Party;

	<ul style="list-style-type: none"> ○ acknowledge that they may be given access to certain Confidential Information for the purpose of progressing the NDRP aims; ○ will keep all Confidential Information confidential unless strictly required otherwise by law; ○ take all reasonable precautions to maintain the confidentiality of and to prevent the unauthorised disclosure or use of the confidential information; ○ will if any doubt about the purpose for which the Confidential Information can be used seek clarification and direction from the NDRP Secretariat or Disclosing Party.
Frequency of meetings:	Approximately monthly, or as needed
Membership	
Composition:	<p>The NDRP Working Party will comprise up to 12-15 people. All individuals will have interests in growing collaborative disability research. The ideal composition in terms of experience/skill sets will be:</p> <ul style="list-style-type: none"> • Representatives of universities, peak bodies, government agencies and advocates • Three to six independent advisors including people with disability • Experience in disability research and/or advocacy, government or the disability service sector.
Term of office:	Until June 2022 or until the long-term NDRP governance structure is implemented, whichever comes first.
Membership:	<ul style="list-style-type: none"> • Anne Kavanagh, University of Melbourne • Bruce Bonyhady, University of Melbourne • Scott Avery, independent advisor • Lesley Chenoweth, independent advisor • Helen Dickinson, University of New South Wales • Gordon Duff, independent advisor • Ellen Fraser-Barbour, independent advisor • Keran Howe, independent advisor • Elizabeth Kendall, Griffith University • Jackie Leach Scully, University of New South Wales • Gwynnyth Llewellyn, University of Sydney • Christina Ryan: independent advisor • Ian Watt, independent advisor

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