NDRP

2022

NATIONAL DISABILITY RESEARCH PARTNERSHIP

Preliminary Research Agenda

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Executive Summary

The vision of the National Disability Research Partnership (NDRP) is to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice. It will achieve this by funding research that is informed by a research agenda; ensuring all research is inclusive of people with disability; building disability research capacity; and supporting the uptake of research findings into policy and practice. A two-year Establishment Phase was tasked with setting up the structure and processes for a longer-term disability research partnership in Australia. This phase was steered by a Working Party made up of advocates, academics and independent advisors, with six of the 13 members being a person with disability.

This report includes the process, context, preliminary agenda and next steps for the NDRP research agenda, which is intended to guide the allocation of research funding by the NDRP over a ten-year time period.

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

A preliminary research agenda was developed over a two-year period through a multi-step process. First, the NDRP Working Party appointed a consortium led by the University of Sydney to undertake a three-phase process to map Australian disability research, survey consult with stakeholders and initiate a process to synthesise and refine findings. The large consortium included academics from across Australia and non-governmental organisations, including Disabled People's and Representative Organisations. As a first step in this process, a sub-committee of the Working Party drew on the Consortium's findings and mapped these to the outcome areas and policy priorities of Australia's Disability Strategy. The preliminary research agenda presented in this report will be expanded and refined in consultation with stakeholders. Subsequently the NDRP Working Party will produce a fit-for-purpose NDRP Research Agenda which will be made publicly available once the new NDRP entity is established.

It is anticipated that the NDRP Research Agenda will encourage research focused on developing policy and informing practice decisions. It will be inclusive, driven by the NDRP principle of research by and with people with disability and will provide the processes and frameworks that enable research to contribute to policy and practice. It will provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.

1. About the National Disability Research Partnership

The National Disability Research Partnership's vision is to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice. The NDRP research agenda is one of the key deliverables of the two-year Establishment Phase of the NDRP, which has been overseen by a Working Party with 13 members. The Working Party includes academics and independent advisors with expertise in advocacy, government, and services; six members identify as having a disability.

The Establishment Phase of the NDRP was funded by the Commonwealth Department of Social Services.

Purpose of the research agenda

The NDRP research agenda is being developed to guide the allocation of research funding by the NDRP over a ten-year time period. The NDRP research agenda will set out short, medium and long-term research priorities for NDRP research.

The NDRP research agenda is also being designed with a view to its potential to inform funding priorities for agencies outside of the NDRP such as the National Health and Medical Research Council (NHMRC), Australian Research Council (ARC), Medical Research Future Fund (MRFF), Australian Housing and Urban Research Institute (AHURI), the Australian Research Organisation for Women's Safety (ANROWS), and philanthropy, research institutions, the not-for-profit and private sectors, and all levels of government.

The UNCPRD

In developing the NDRP research agenda, we have sought to ensure that the activities carried out under this agenda advance the capacity for Australia to meet its obligations as a signatory to the *United Nations Convention of the Rights of Persons with Disability* (UNCPRD) which aims 'to promote, protect and ensure 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'.[i]

NDRP Guiding Principles

The NDRP research agenda will be developed to be consistent with and advance the principles of the NDRP (see image 1), which are to:

- deliver high quality, collaborative research;
- recognise the knowledge of people with disability in research;
- value all forms of knowledge; and
- build research capability.

The NDRP is committed to research that recognises the life experience and contexts in which people are born, grow, live, work, age and die, and the wider set of forces and systems shaping the conditions of their daily life. We recognise and acknowledge that people with disability[1] come from many different backgrounds and communities and

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[1] We use person-first language in this document and refer to people with disability. This is a contested area and some people prefer to use identify-first language. We also use people with disability rather than people with disabilities in line with terminology in Australia's Disability Strategy 2021-2031.

represent the rich diversity of human experiences and perspectives.

The NDRP acknowledges that some people with disability face barriers in communicating their goals and aspirations and making decisions. This may include people with cognitive disability, very young children, or those with episodic disability such as mental illness. In these circumstances the NDRP acknowledges the role that family, caregivers, allies, or supporters may play in supporting decision making and facilitating expression of preference and will.

The NDRP also acknowledges that many people with disability identify with multiple marginalised groups and may experience intersectional disadvantage because of gender, race, ethnicity, sexual preference, age, and location. When people with disability experience intersectional disadvantage there are even fewer opportunities to access services, ordinary community activities and decision making, or to participate in economic and political life. The NDRP research agenda therefore needs to include issues of intersectionality.

Read more about the NDRP Principles at this link: *Principles*

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
- Australian policy to be informed by research and evidence

2 People with disability at the centre

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

3 Value all forms of knowledge

- Recognise and value the knowledge that people with disability contribute to research based on their lived experience
- Respect for different sources and forms of knowledge
- Make knowledge accessible to the community in a range of formats

4 Build research capacity

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

2. Context

In setting out the NDRP research agenda, the NDRP acknowledges that we are not starting from a blank page. Significant work has already been done over the last few decades, providing an important context and foundation to this project. This section offers a high-level overview of previous Australian disability strategies and policies and the current policy and research landscape.

Current policy, strategies and research and data initiatives

The research agenda to be developed by the NDRP seeks to support current government initiatives, notably Australia's Disability Strategy and the First Nations Disability Sector Strengthening Plan. The establishment of the National Disability Data Asset (NDDA) is also expected to provide new data infrastructure to support the realisation of the NDRP research agenda.

Research funded by the NDRP is intended to be distinct from, but complement and ideally align with other disability research initiatives such as the CRC in Autism Research, the NDIA's Research and Evaluation Strategy, the proposed Centre of Excellence in Intellectual Disability Health under the National Roadmap for Improving the Health of People with Intellectual Disability and data activities conducted as part of the Disability Sector Strengthening Plan.

Australia's Disability Strategy (2021-2031)

The vision of *Australia's Disability Strategy* (ADS) is for 'an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community'. ADS has seven outcome areas: employment and financial security; inclusive homes and communities; safety, rights, and justice; personal and community support; education and learning; health and wellbeing; community attitudes. These largely map onto the policy areas of the former National Disability Strategy but with an extension to include a focus on community attitudes.

Each of the seven outcome areas have policy priorities attached to them. For example, in relation to employment and financial security, priority policies include: increase employment of people with disability; improve transition of young people from education to employment; and strengthen financial independence of people with disability. ADS also includes eight guiding principles based on Article 3 of the UNCPRD, and Targeted Action Plans to achieve specific deliverables. Importantly, ADS includes obligations for reporting with a comprehensive Outcomes Framework and Dashboard and reports on the five Targeted Action Plans and Implementation and Evaluation Reports.

Read more at this link: Australia's Disability Strategy

First Nations People with Disability and Closing the Gap

The NDRP research agenda also seeks to support the objective of *the National Agreement on Closing the Gap* 'to enable Aboriginal and Torres Strait Islander peoples and governments to work together to overcome the inequality experienced by Aboriginal and Torres Strait Islander peoples, and achieve life outcomes equal to all Australians'. For the first time, the Commonwealth's Implementation Plan for Closing the Gap recognises disability as a cross-cutting outcome area across socio-economic targets and Priority Reform areas.

Through a process of co-design and shared decision-making, the Department of Social Services (DSS) and the First People's Disability Network (FPDN) has developed a Disability Sector Strengthening Plan. The Disability Sector Strengthening Plan aims to improve outcomes for and in partnership with First Nations people with disability, including those people who are not in the NDIS. The Disability Sector Strengthening Plan provides a framework for all levels of government to strengthen the community-controlled disability sector, ensure better access to services, strengthen capacities of service providers and ensure they can provide culturally safe and accessible services and supports to First Nations people with disability. The Disability Sector Strengthening Plan acts as a key link between Australia's Disability Strategy 2021-2031 and Closing the Gap by aligning the key priorities of both, and ensuring First Nations people with disability are centred in policies, programs, service delivery systems and reform agendas.

One of the actions within the Disability Sector Strengthening Plan is to strengthen and implement FPDN's Culture is Inclusion Research Agenda, undertaking research to expand Culture is Inclusion's findings, including determinants impacting outcomes, and the identified potential for community and cultural participation.

In the coming months the NDRP Working Party will explore how the NDRP research agenda can advance the aspirations of the Disability Sector Strengthening Plan.

Read more about the National Agreement on Closing the Gap at this link: National Agreement

Read more about the Disability Sector Strengthening Plan at this link: Closing the Gap

Read more about FPDN's Culture is Inclusion at this link: Culture is Inclusion

National Disability Data Asset

In 2020 and 2021, the Commonwealth and State and Territory Governments supported an 18-month pilot for the NDDA that trialled a range of data linkage methodologies to link Commonwealth and state and territory data in five test cases (early childhood, justice, pathways from education to employment, services and supports for people with mental health issues, and measurement of outcomes). The test cases provided a practical demonstration of the value of linked data, and identified technical lessons in data linkage to inform the establishment of an enduring asset. The aim of the enduring NDDA is to use data so that policies, services and supports for people with disability can be improved. The NDDA pilot placed high importance on safeguarding data and protecting privacy, so that governments cannot use the data to identify individuals and analysts cannot see personal information such as names and addresses.

The NDDA pilot was informed by a Disability Advisory Council with expertise in disability policy, data, advocacy, social investment, research, service provision, business, economics and law, and included people with disability. The Council identified six key themes as crucial to the NDDA's use and development in the future: shared decision-making between people with disability, researchers and government representatives; a NDDA charter between people with disability and their representatives, researchers and government; a program for input from people with lived experience and the disability community to support effective decision-making; capability and capacity building support; transparency over uses of the data; and ethical oversight. The Council developed a draft NDDA Charter to set out how the NDDA should be governed, how aspects of the NDDA should be communicated with the disability community, the identification of acceptable and unacceptable uses of the NDDA, and how the community could be sure that these uses would not be changed by future governments.

In December 2021, $40 million was committed over four years by the Australian government to establish the NDDA. The NDDA will provide important data infrastructure for research funded by the NDRP.

Read more at this link: National Disability Data Asset

National Disability Insurance Agency Research and Evaluation Strategy

The primary role of the NDIA's research and evaluation is to conduct, commission and publish research and evaluations to underpin evidence-based decision-making across the NDIA, and ensure policies, practices and priorities are informed by trustworthy and robust evidence to help improve the effectiveness and sustainability of the scheme.

The NDIA's Research and Evaluation branch also develops public facing, evidence-informed resources to help participants, their families or carers understand and use the research evidence as part of conversations about their goals and the types of support that can assist.

The new NDIA Research and Evaluation Strategy (2022-2027) covers four broad topic areas; home and living, early interventions, Information gathering for access and planning, and markets and employment. Each topic area will focus on generating new evidence, measuring outcomes and benefit, exploring innovative approaches and technologies to benefit participants, and research translation. The NDIA's Research and Evaluation Branch is developing a wellbeing index for people with disability including, but not limited to, NDIS participants.

Read more at this link: NDIA Research and Evaluation Strategy

Previous strategies and policies

The NDRP research agenda builds on earlier activities conducted under the previous National Disability Strategy. This provides the historical context for the development of the NDRP research agenda.

National Disability Strategy (2010-2020)

Australia's first National Disability Strategy (NDS) 2010-2020 was an initiative of Commonwealth, State and Territory governments under the auspices of the Council of Australian Governments with the shared vision of an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens. The NDS was a ten-year plan and covered six policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing.

A review of the Strategy in 2019 recognised the major achievement of the implementation of the National Disability Insurance Scheme (NDIS). However, it also noted that other areas of the Strategy had not received sufficient attention. The review agreed with the areas of policy focus but found that stakeholders were critical of the implementation processes, lack of clear accountability, and very limited outcomes. Furthermore, despite commitment to monitoring outcomes under the Strategy, this had not occurred[ii].

National Disability Research and Development Agenda

A National Disability Research and Development Agenda (NDRDA) was developed in 2011 to support the directions and reform priorities of the National Disability Agreement and National Disability Strategy. It was also intended to support the development of robust disability research, influence other research funding programs, and facilitate inclusion of disability in data collection, research, and evaluation.

The NDRDA included Principles and Areas of Inquiry.

The Principles were that research should be:

- Inclusive and rights based
- Responsive and diverse
- Practicable and outcomes orientated
- Collaborative and cross disciplinary
- Accessible and communicated
- Efficient and targeted.

The Areas of Inquiry included:

- Disability data – covering the identification of people of disability in mainstream data systems and the reporting of trends in social and economic inclusion across life stages
- Social and economic inclusion – covering a broad range of areas such as education, employment, participation in community life, discrimination and violence
- Service delivery and support – including measurement of service needs, access to services, quality assurance and continuous improvement
- Sector development and sustainability – covering issues related to development of workforce capacity and supported decision-making
- Diversity – research on the profile and experiences of and issues affecting diverse and/or disadvantaged groups including Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds, women with disability, and people from regional, rural and remote areas.

The Commonwealth, State and Territory governments committed $10 million over 5 years to funding research conducted under that Agenda. Activities under the Agenda were managed by the Australian Government through the Department of Social Services.

Activities conducted as part of the NDRDA included commissioned projects such as the Audit of Disability Research in Australia (2014)[iii] and the Audit of Disability Research Update (2017)[iv] and Living Our Ways: a community-driven Aboriginal and Torres Strait Islander disability research program[v]. Research projects were also funded through the NDRDA in 2012, 2015, and 2020 with different approaches to funding decisions in each round. Projects covered a broad range of issues such as support for community participation for people with intellectual disability[vi] and supported decision making[vii] and unfitness to plead[viii].

Read more about these projects at this link: NDRDA research projects.

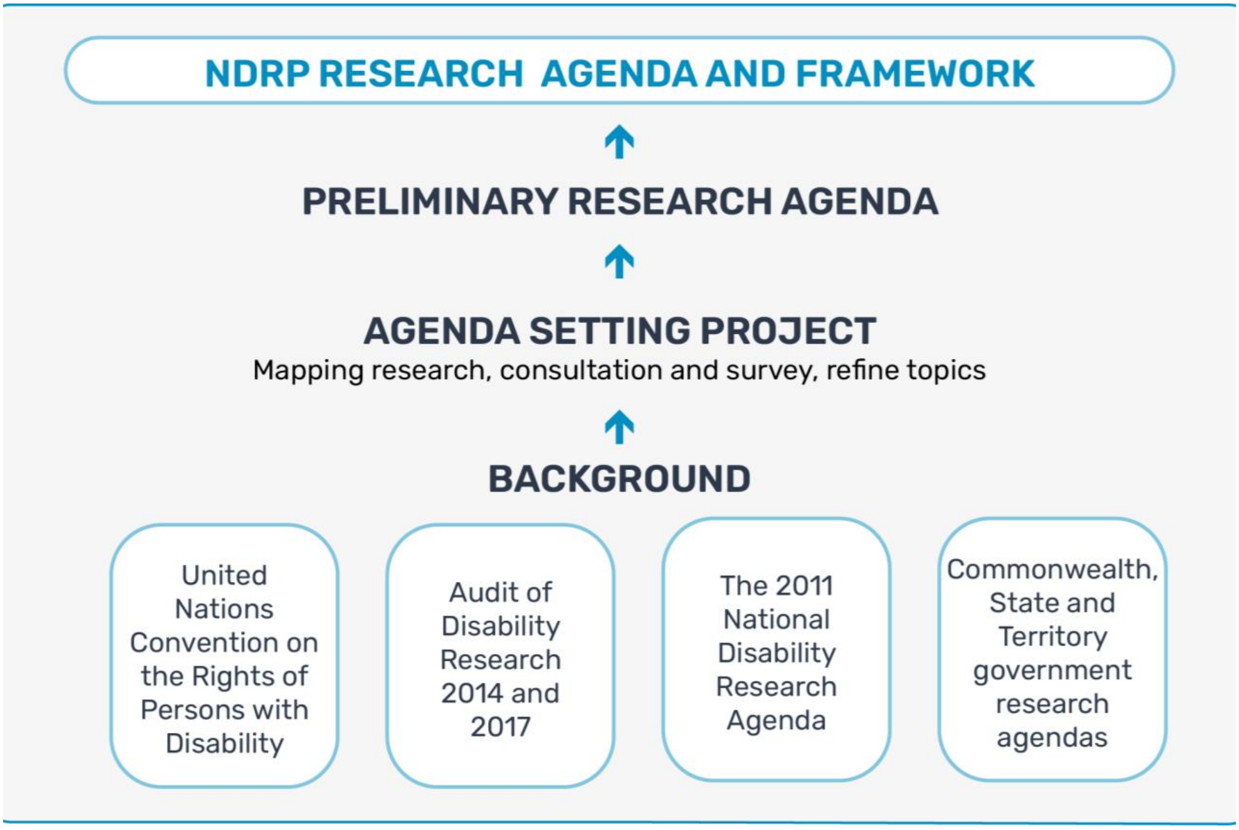
Other research and data initiatives

We note other research and data initiatives relating to disability that receive full or part funding through the Commonwealth Government, including the newly committed funding for the Centre of Excellence in Intellectual Disability Health and the ongoing work of the Autism CRC. We also note the research and policy activities of the Royal Commission into Violence, Abuse, Neglect and Exploitation against People with Disability (Disability Royal Commission). We anticipate that the recommendations of the Disability Royal Commission will have implications for the NDRP research agenda in the next few years.

While the NDDA is a major step forward for disability data, there have been major advances in the availability and quality of disability data in Australia generally because disability data are now included in other major data assets, most importantly the Multi-Agency Data Integration Project managed by the Australian Bureau of Statistics.

Read more about the Multi-Agency Data Integration Project at this link: MADIP

3. Developing a Preliminary Research Agenda



The NDRP has gone through a series of processes to support the development of the preliminary NDRP research agenda.

First, through a competitive tender process, a sub-committee of the NDRP Working Party appointed a consortium led by the University of Sydney (co-leads Professor Jen Smith-Merry and Associate Professor Mary-Ann O'Donovan) to assist in the development of the research agenda. The large consortium included academics from across Australia and non-governmental organisations, including Disabled People's and Representative Organisations (see Appendix). The Consortium mapped recent research related to Australians with disability to identify strengths and potential gaps and sought input from people with disability and their representative organisations, researchers, families and supporters, service providers, Commonwealth and State and Territory governments, and other stakeholders to identify key issues for research.

Second, a sub-committee of the Working Party, the NDRP Research Agenda Guidance group, noted the Consortium's findings and mapped the issues presented to Australia's Disability Strategy outcome areas and policy priorities.

The Consortium reports

The Consortium undertook a three-phase process:

1. Mapping of recent Australian research related to people with disability
2. Consultation with people with disability and their representative organisations; researchers; families and supporters; service providers; governments and other stakeholders to identify key issues

3. Synthesis and refinement of findings from the first two phases to contribute to setting an agenda for disability research in Australia.

The findings from these processes have been published in four reports that are briefly summarised here. The reports can be accessed at this link: research agenda reports.

It should be noted that COVID-19 significantly hampered the capacity of the Consortium to do the work, particularly the Phase 2 consultation process.

Phase 1 - Mapping disability research in Australia 2018-2020

This research mapping focussed on research conducted between 2018 and 2020, building on the research audit published in 2014 and then updated in 2017.[iii, iv] The Consortium conducted a rigorous process to identify the amount and extent of research related to disability in Australia that had been published in academic journals as well as key research reports. Members of the Consortium searched electronic databases to find articles, books and book chapters and reports on research that related to people with disability other than laboratory or clinical research. They also asked researchers to send papers that might have been missed by their search processes. Consortium members coded all the relevant publications in terms of the age group of participants in the study, domain of life covered (e.g. health and wellbeing, education), disability type (e.g. all people, autism), study design, and funding source. Following the approach adopted in the Audit of Disability Research in Australia (2014), the Consortium Mapping report had specific sections on studies about Aboriginal and Torres Strait Islander Australians with disability and people with disability from Culturally and Linguistically Diverse backgrounds. It also had sections on policy research, studies using large datasets, studies about children and adolescents with disability, and papers that took a rights-based approach.

They identified 1241 journal articles and book chapters and 225 reports, suggesting that the amount of research about disability in Australia is increasing when compared to the previous audits in 2014 and 2017.[iii, iv] They found that research taking disability-inclusive approaches and including people with disability in the research was not commonly reported in published studies and key research reports. While the number of reports and papers about disability among First Nations Australians had increased since the previous audits, research about the experiences of people with disability from culturally and linguistically diverse backgrounds continued to be sparse. As in the previous audits, health and wellbeing and education were key foci. Funding was acknowledged in nearly half the research outputs, with investments in programs of research (e.g. ARC and NHMRC Fellowships, NHMRC Centre of Research Excellence) and partnerships (e.g. ARC Linkage) being particularly productive in terms of outputs.

Phase 2 - Setting a disability research agenda consultation process

The Consortium then gathered information on key issues for the NDRP research agenda through a survey (Phase 2a) and consultations led by organisations involved in the Consortium (Phase 2b).

Phase 2a - The Survey

An online survey was designed by the Consortium. The survey included questions about how people are currently using disability research and the areas that research should focus on over the next ten years. The Consortium outlined 46 areas that were developed collaboratively by the Consortium and reviewed by its Advisory Groups. The topics were diverse, covering groups of people (e.g. experiences of people with disability from culturally and linguistically diverse backgrounds), specific domains of life (e.g. employment, education), issues such as consumer protection, and broad areas such as policy development and evaluation. Survey respondents were asked to nominate up to seven topics that they believed should be prioritised. There were opportunities to provide information in free text responses and open-ended questions. Information on how to participate in the survey was distributed through the Consortium's networks via emails and newsletters and promoted on social media.

A total of 973 people completed the survey. One third identified as a person with disability; 19 per cent were an unpaid carer, supporter, or a family member of someone with a disability; 15 per cent were academics with an interest in disability research; 13 per cent worked in disability services; 7 per cent worked in advocacy groups or peak bodies representing advocacy organisations; and 4 per cent were from government or policy makers. People may have identified across more than one category. 70 per cent of the participants were female and 65 per cent lived in urban areas.

There was some variation between groups in the areas nominated, particularly between government and policy-makers and other groups. Key issues raised by non-government respondents included the design and operation of the NDIS and the personal experiences of people with disability (e.g. of accessing and receiving support, participating in education, employment etc.). The mental health needs of people with disability were nominated as important by all groups (in their top 10) but government and advocacy groups both nominated it at number 12. Both people with disability and advocacy groups rated the rights of people with disability and public attitudes towards people with disability as important areas, while government employees rated integration of care within and across systems as the most important area for future research.

Free text responses emphasised the importance of intersectionality; multiple disadvantage experienced by people with disability across systems such as justice and education; integration (or not) across systems; human rights, in terms of how they are not currently being upheld and what works to ensure they are realised; accessibility of physical environment, technologies and information; and data collection, research and evaluation of whether current supports, services, systems and policies are working or not. The importance of people with disability driving the research agenda, the way research is conducted and broad accessibility of research outputs were also key themes.

While the survey was useful it has some limitations. Research about disability is broad and cannot be synthesised easily into discrete areas. Furthermore, the topics were chosen by the Consortium and their Advisory Groups and may not reflect other groups (not part of the Consortium/Advisory Groups) interested in disability research. While the survey had nearly 1000 responses, it is important to recognise that the experiences of smaller population groups (e.g., people with disability from culturally and linguistically diverse backgrounds) may not be prioritised by others. However, this does not mean that issues prioritised by smaller groups are not important enough to be a focus of research funded through the NDRP.

Phase 2b - Organisation-led consultations

This phase of the Consortium's work involved partner organisations directly consulting with their own constituencies, complementing the survey data. This process provided the opportunity for the Consortium to reach people with disability and other stakeholders for whom the survey was not suitable and to collect information in a more flexible way.

The aim was for the various organisations to gather information on what their members or constituencies thought were the issues the NDRP should research, and how the organisation and its constituency might access and use research. The Consortium created a toolkit for organisations to use, including resources such as an Easy Read leaflet about the aim and purpose of the consultation; guidance on interviews; and accessible surveys. Organisations were free to choose the methods of consultation that best suited their constituencies. Organisations were asked to complete two templates – one detailing how the consultation was conducted and the other on what was said – and return these to the University of Sydney researchers.

A total of 20 organisations undertook the consultations. These organisations included Disabled People's and Representative Organisations (e.g., Australian Federation of Disability Organisations, Inclusion Australian, People with Disability Australia), disability services (e.g. Aruma), university-based research networks (e.g. lived experience group at ANU), networks (e.g. Kindship, a group connecting parents of children with disability) and organisations focussed on specific issues (e.g. Mobility and Accessibility for Children Australia). Although nearly 1000 people took part in the consultations, 676 people came from two organisations – Kindship and Mobility and Accessibility for Children Australia, with the result that most participants in the consultations were family members of people with disability or staff who worked with people with disability.

To better capture the perspectives of people with communication limitations, focus groups and interviews were conducted with 12 adults with disability and eight family members or support workers. The consortium also used social media to recruit people who might not be linked with organisations, and consortium members facilitated sessions with people recruited in this way. In addition, the consortium members carried out consultations with people with intellectual disability, people living in boarding houses and children and young people with disability and their families.

This phase also included a survey of Aboriginal and Torres Strait Islander people with disability through Ninti One – an Indigenous professional services organisation that works with and for Aboriginal and Torres Strait Islander people. The responses of Aboriginal and Torres Strait Islander peoples in this Phase 2b survey were combined with those in Phase 2a, yielding a sample of 31 Aboriginal and Torres Strait Islander peoples across both surveys.

An overarching theme across the consultations was the centrality of disability inclusive research, a core principle of the NDRP. Issues of importance for future research included:

- *human rights* such as issues of accessibility, discrimination, justice systems
- access and experiences of *formal and informal supports* such as foster care, availability and quality of supports in different areas, understanding and intervening in systems that support abuse and neglect, enabling families to provide support
- *participation and engagement* in community, education and employment including addressing barriers to full participation and supports needed at specific transition points (e.g., leaving school)
- *housing* including the prevention of homelessness, safe and secure housing, and housing for people with psychosocial and intellectual disability, looking at outcomes under different housing models
- *health services and systems* including better data on the experiences of people with disability within the health system, and how to improve access to quality services
- *government and policy issues* with a focus on the NDIS (e.g., equity in access and outcomes in the NDIS, benefits of the NDIS, interactions between health and education and the NDIS).

The interviews and focus groups with people with communication limitations found similar issues but also emphasised lack of knowledge in mainstream community agencies about communication strategies and adaptations to assist communication, and the multiple impacts of having a disability resulting in mental health problems among people with disability and family members.

The analysis of survey data by Ninti One found that Aboriginal and Torres Strait Islander peoples wanted to see research on the experiences and needs of Aboriginal and Torres Strait Islander peoples with disability including a focus on mental health, discrimination, violence and abuse and the human rights of people with disability.

Participants in the consultations emphasised the importance of research that takes into account the whole of life from childhood to older age and research that seeks to understand different life stages and transitions including the transition to adulthood life phase and ageing.

A broad range of people were involved in the process including population groups not involved in the survey such as people living in boarding houses. Nevertheless, there were limitations. Consultations were concentrated in the Eastern states of Australia; it is not clear how well this process captured the views of people living in non-urban settings. It is also not evident how well the views of people from culturally and linguistically diverse backgrounds were represented, and there is still need for more input from First Nations Australians. There is no doubt that COVID-19 has had significant impact on the lives of people with disability with many at high risk of poor outcomes, and this may have meant many were unable to participate in the consultations.

Phase 3 – Synthesis and refinement of issues arising from Phases 1 and 2

Given the broad range of issues the Consortium used Q-Methodology as a way of synthesising findings and assessing how different individuals prioritised areas for research. Q-Methodology assesses people's different stances on a topic in terms of priorities. This method is a way of assessing where there are commonalities and differences between respondents in relation to a specific topic.

The Consortium looked at issues that appeared as gaps in Phase 1 and priorities in Phase 2. The findings were summarised in 25 statements such as: How to design buildings and spaces that work for people with disability; ways to address abuse, violence, neglect, exploitation and coercion; and Influences on community attitudes towards disability.

The Consortium recruited people with disability including advocates, academics/researchers, policy makers, and family members/supporters. Demographic data were collected and participants were asked to rank each of the 25 statements according to how they should guide the NDRP research agenda. This involved identifying the statements they agreed with the most and the least, and which they felt neutral about. The Consortium then analysed the data using a statistical technique called factor analysis where each respondent's ranking was compared to others' responses (whether they were similar or different). This approach allowed the researchers to identify any clusters of commonalities and differences around particular statements; such clusters are described as viewpoints. Following the statement sorts, respondents were also asked whether there was anything they wanted to add that might have been missed in the statements.

In total 52 people provided responses to the Q sort survey and were included in the data analysis. The researchers classified the respondents into the following categories: 18 identified as a person with disability, 12 identified as an unpaid carer, family member or supporter of someone with disability, 10 identified as an academic with an interest in disability, 10 identified as disability service providers or advocacy organisation representatives, and 1 identified as a policy maker or government employee. Respondents were only given one option to select, however in a free text box, two respondents explained they were both people with disability and academics.

The researchers identified four overlapping viewpoints about research priorities, which they named as follows:

- *Design and delivery of services and systems* which involved the design and delivery of integrated, safe, and equitable services and systems (health, education, employment, disability) that contribute to inclusive communities benefitting people with disability and family members across the life course.
- *Intersecting experiences and disability* which prioritised research about the complex and intersecting needs of people experiencing multiple disadvantage or marginalisation, including people from culturally and linguistically diverse backgrounds, First

Nations Australians with disability, and people with disability in the criminal justice system or experiencing homelessness
- *Systems outcomes and/or impact* which focussed on how services and systems were designed and their broader impacts on people with disability as well as society more broadly (e.g., societal impacts of the NDIS)
- *Mental health and well-being* which prioritised research on designing services and supports across a range of domains (e.g., violence, mental health, housing) and across the life course, to support people with disability experiencing mental ill-health and to promote mental health among people with disability. What these viewpoints demonstrate is that respondents wanted to prioritise research agendas that look at how systems (e.g., service systems, systems of disadvantage) operate together to support people with disability, or not. There is a strong emphasis on interconnectedness and not simply examining different life domains (e.g., health, education, employment) in isolation. However, there is less granularity as to how these viewpoints should translate to research questions.

Further work might be done to unpack these broad viewpoints into more specific research questions. While the consortium has identified which statements these groups ranked similarly in a positive way, they have not undertaken a similar exercise for negatively ranked statements, which may help further differentiate these views. It may also be helpful to analyse the data by the different stakeholder groups to explore whether different groups prioritised statements in similar or divergent ways.

For a number of reasons, the research in Phase 3 has limitations: relatively few people with disability and only one government representative was included. The Q-sort was conducted online and this may have excluded people with particular impairment types, as might the complex method of ranking that this method entailed. The statements used were based on Phase 2, and are therefore affected by the issues considered in that phase.

A preliminary research agenda

As the NDRP research agenda seeks to support the aspirations and implementation of the Australian Disability Strategy, we used the outcome areas and priorities of the ADS to organise the preliminary NDRP research agenda. As a first step, the NDRP Research Agenda Guidance group took the findings reported in the Consortium and mapped these onto the ADS's outcome areas and policy priorities (see below). This process showed that the Consortium's work identified the importance of research in areas aligned with the ADS but that some areas of importance for the ADS did not arise in the Consortium's work[2]. For example, through the Consortium's consultation processes the NDIS was emphasised but financial security – a key element of the ADS – did not emerge. This initial mapping will be reviewed by the Consortium in the Transition Phase. The NDRP Working Party will then engage in a co-design process which will enable the complete research agenda to address under-developed areas.

While this approach has the advantage of aligning areas and priorities with Australia's Disability Strategy, it has limitations. With the exception of Community Attitudes, the outcomes areas represent different life domains (e.g., education and learning, employment and financial security) as though they are separate although in reality, and in the life experiences of people with disability, these are interconnected. The Consortium's consultations have revealed there is a strong desire for research that looks at the experiences of people with disability across all domains and investigates how policies, practices, service and supports in one domain interact with each other. The Consortium's consultations also demonstrate the importance of integrating services and supports across sectors such as education and health or health and disability.

Other aspects that appear underemphasised by categorising according to the ADS are life course, and intersectionality and marginalisation. The Consortium's consultations revealed significant support for research that provided knowledge about how policies and strategies can support people with disability at different life stages (e.g., children, older people) and at life transition points. There was also an emphasis on the importance of understanding and responding to intersectional disadvantage experienced by First Nations people with disability as well as people with disability from culturally and linguistically diverse backgrounds, women with disability, people with disability in rural and remote Australia, people with disability experiencing socio-economic disadvantage, LGBTI+ people with disability, and people with disability who have difficulty expressing their will and preference.

The final NDRP research agenda must foreground the importance of research that investigates the interconnectedness of people's lives across the domains as well as intersectional and life course approaches to research.

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[2] We note at the time of the Consortium's work the ADS had not been finalised.

Preliminary research agenda structured around Australia’s Disability Strategy outcome and policy priorities

As the NDRP research agenda will seek to support the aspirations and implementation of the Australian Disability Strategy, we used the outcome areas and priorities of the ADS to organise the NDRP research agenda.

Australia’s Disability Strategy outcome areas are:

- Employment and Financial Security
- Inclusive Homes and Communities
- Safety, Rights and Justice
- Personal and Community Support
- Education and Learning
- Health and Wellbeing
- Community Attitudes

In developing this preliminary research agenda, findings reported by the Consortium were mapped onto the ADS’s outcome areas and policy priorities.

This list of research questions aligned with ADS outcome areas and policy priorities forms the preliminary research agenda. Through a consultation and engagement process this list will be modified and expanded; stakeholders will be asked what’s missing and if anything should be worded differently. The revised list will be organised into broad areas of priority topics with suggested although not exhaustive research questions to underpin the 10 year NDRP research agenda. The process for this is outlined in section 4: Method for co-design of NDRP research agenda.

Outcome Area 1: Employment and financial security

People with disability have economic security, enabling them to plan for the future and exercise choice and control over their lives

Policy priority 1: Increase employment of people with disability

Aligned research questions:

- What adjustments and accommodations can support people with disability to obtain and maintain employment?
- How are current services and supports working and how could they be improved?
- What are the barriers and facilitators of employment for people with disability? What are the best approaches to overcoming barriers to employment?
- What makes a workplace inclusive of people with disability? How can workplaces become more inclusive? What are the benefits of inclusive workplaces for people with disability and others?
- What services and systems are effective in enabling people with intellectual disability to find and maintain employment?
- What are the career pathways of people with disability? What enables people with disability to progress in their careers and obtain leadership positions? (also see community attitudes)
- What strategies will challenge and shift community attitudes towards employment of people with disability? (also see community attitudes)

Policy priority 2: Improve the transition of young people with disability from education to employment

- How has access to NDIS supports influenced the experiences of NDIS participants after they leave school? (see employment and financial security and personal and community supports)
- What enables young people with disability to be able to make positive transitions from education to employment?

Policy priority 3: Strengthen financial independence of people with disability

No research questions from the Consortium's work specifically aligned with this policy priority area.

Outcome Area 2: Inclusive homes and communities

People with disability live in inclusive, accessible and well-designed homes and communities

Policy priority 1: Increase the availability of affordable housing

Aligned research questions:

- What are the experiences of people with disability in terms of housing security and affordability?
- What are the pathways into and out of homelessness for people with disability? How can homelessness be prevented?
- What are the knowledge, skills and attitudes of public housing staff working with people with disability? (see also community attitudes)
- How do market factors affect access to affordable housing for people with disability?

Policy priority 2: Housing is accessible and people with disability have choice and control about where they live, who they live with, and who comes into their home

- What supports are needed to enable people with disability to live independently?
- What models of housing promote the inclusion of people with disability with mental health issues?
- What are the outcomes of different housing models such as semi-institutional, supported independent living and customised options such as Individualised Living Options? (see also personal and community supports)

Policy priority 3: People with disability are able to fully participate in social, recreational, religious and cultural life

- What are the social and economic benefits of inclusion of people with disability?

Policy priority 4: The built and natural environment is accessible

- How can the physical environment enable people with disability to be able to participate in society on an equal basis to others?
- What supports and regulations are needed to ensure inclusive design practices are used to support people with disability to access public spaces?
- How are the experiences of people with disability shaped by place and geography (urban, regional, rural, remote)?

Policy priority 5: Transport systems are accessible for the whole community

- What motor vehicle restraint options (harnesses) can be used to protect children with disability from injury?

- What are the transport needs of children and adults with disability and how can they be addressed?

Policy priority 6: Information and communication systems are accessible, reliable and responsive

- What are the existing capacities and demands for Auslan interpreters and how can capacity be built?
- What strategies enable people with communication difficulties to have the to participate in society and to receive the services and supports they need across all aspects of their life (health, legal, disability, education, employment)?

Outcome Area 3: Safety, rights and justice

The rights of people with disability are promoted, upheld and protected, and people with disability feel safe and enjoy equality before the law.

Policy priority 1: People with disability are safe and feel safe from violence, abuse, neglect and exploitation

- How can family violence against women and girls with disability be reduced?
- What institutional settings and practices promote violence and abuse against people with disability? What reforms are needed to prevent violence and abuse in these settings?
- What supports children and young people as they transition to adulthood and supports them develop their sexuality and develop positive relationships?
- What policies, practices and strategies are needed to ensure that people with communication difficulties are safe from violence, abuse and neglect?

Policy priority 2: Policies, processes and programs provide better responses to people with disability who have experienced trauma

- What are the experiences of First Nations Australians with disability who have experienced trauma? What policies, practices and strategies are needed to support First Nations Australians with disability who have experienced trauma?

Policy priority 3: Policies, processes and programs for people with disability promote gender equality and prevent violence against groups at heightened risk, including women and their children

- What services, systems and policies are effective in preventing violence and abuse against people with disability?

Policy priority 4: The rights of people with disability are promoted, upheld and protected

- Are current guardianship systems upholding and protecting the rights of people with disability? How should they be reformed?
- What models of supported decision-making enable people with disability to exercise their rights?
- Are current systems for substitute decision-making protecting and upholding the rights of people with disability? How could they be reformed?
- How can the capacity for self-advocacy of people with disability be developed and supported?
- How can people with disability be supported to make decisions about their own end of life care?

- To what extent are people with disability having their human rights upheld in Australia? What actions might improve Australia's performance with respect to upholding the human rights of people with disability?

Policy priority 5: People with disability have equal access to justice

- Does Australia's legal and justice uphold the rights of people with disability? What changes are needed?

Policy priority 6: The criminal justice system responds effectively to the complex needs and vulnerabilities of people with disability

- What are the experiences of people with intellectual disability with the legal and criminal justice system? Are their rights being upheld? What are the impacts of these experiences on people with intellectual disability?

Outcome Area 4: Personal and community support

People with disability have access to a range of supports to assist them to live independently and engage in their communities

Policy priority 1: People with disability are able to access supports that meet their needs

- How do we design services systems so people with disability don't 'fall through the cracks'? (e.g., between health and disability services systems, education, and disability).
- How can people with disability be supported to access to needed services and supports across systems such as disability and health, education, justice, and education?
- How can services systems be better integrated so that people with disability have their needs met?
- How can services and supports adapt across the life course and as people with disability transition to different life stages (e.g., moving out of home)?
- What are the experiences of children with disability in out of home care? How can they be best supported?
- What are the experiences of older Australians with disability and how can they be supported?

Policy priority 2: The NDIS provides eligible people with permanent and significant disability with access to reasonable and necessary disability supports

- How can the NDIS be designed and implemented to achieve the best outcomes for people with disability?
- What are the impacts of services and supports currently being used funded through the NDIS?
- What are the examples of innovative practice in disability services and supports? How could we learn from these? How could they be implemented more broadly?
- How has access to NDIS supports influenced the experiences of NDIS participants after they leave school? (see employment and financial security and education and learning)
- What are the outcomes of different housing models such as semi-institutional, supported independent living and customised options such as Individualised Living Options? (see also personal and community supports)
- What are social and economic costs and benefits of the NDIS on participants, families and society?
- How do people's expectations of people with disability prior to the NDIS align (or not) with their experiences?
- What are the barriers to community participation for NDIS participants?
- Is the NDIS equitable? Are people who are better able to advocate faring better?
- What are the experiences of people with psychosocial disability in accessing and managing NDIS services and supports?

- What are the experiences of people with disability from culturally and linguistically diverse backgrounds in accessing and managing NDIS supports?
- Is NDIS providing the support needed to prevent avoidable hospitalisations among participants? (see also health and wellbeing)
- How are the interactions between the NDIS and health and education systems? How could they be improved? (see health and wellbeing and education and learning)
- Quantify the number of disability support workers and their economic contribution to the community

Policy priority 3: The role of informal support is acknowledged and supported

- How can parents, siblings, other family members and allies be supported to provide supports to the people with disability they care for?
- Track the long term health and financial impacts of caring on carers, including between generations on sibling carers?
- What are the financial circumstances of families with someone with disability? What are the financial impacts of caring on ageing carers, particularly women?

Policy priority 4: People with disability are supported to access assistive technology

- How can assistive technology be used to support people with disability to live independently and to participate in society on an equal basis to others? How can they be affordable and accessible to people with disability who need them?
- How might new advances in assistive technology focus on innovations that enable people with disability to have equal opportunity to others?

Outcome Area 5: Education and learning

People with disability achieve their full potential through education and learning

Policy priority 1: Children with disability can access and participate in high-quality early childhood education and care

Aligned research questions:

- What are current government policies and practices with respect to supporting children with disability in early childhood education and care? How could they be improved?

Policy priority 2: Build capability in the delivery of inclusive education to improve educational outcomes for school students with disability

- How do supports and 'reasonable adjustments' for students with disability affect their access, participation and educational outcomes?
- What are current government policies and practices with respect to supporting students with disability? How could they be improved?
- How can teachers promote independence for students with disability across many areas of life?
- Where are the major problems with the education system and how is this affecting transition to further training and education?
- How can assessment practices be modified so students with disability are not disadvantaged?
- How are the interactions between the NDIS and health and education systems? How could they be improved? (see health and wellbeing and personal and community support)

Policy priority 3: Improve pathways and accessibility to further education and training for people with disability

- How do supports and 'reasonable adjustments' for students with disability affect their access, participation and educational outcomes?
- What are current government policies and practices with respect to supporting students with disability? How could they be improved?
- What are the experiences of First Nations Australians with disability and Australians with disability from culturally and linguistically diverse backgrounds in tertiary education?
- How can the voices of students with disability and their storytelling better inform the tertiary sector so that it is more responsive to their needs?
- What teaching practices in TAFEs and universities are most effective in supporting students with disability?

- How can assessment practices be modified so students with disability are not disadvantaged?
- How has access to NDIS supports influenced the experiences of NDIS participants after they leave school? (see employment and financial security and personal and community supports)

Policy priority 4: People with disability have increased opportunities to participate in accessible and inclusive lifelong learning

- What are current government policies and practices with respect to supporting students with disability? How could they be improved?

Outcome Area 6: Health and wellbeing

People with disability attain the highest possible health and wellbeing outcomes throughout their lives

Policy priority 1: All health service providers have the capabilities to meet the needs of people with disability

Aligned research questions:

- What are the perceptions of health care providers towards people with disability and how can they be improved? (also community attitudes)

Policy priority 2: Prevention and early intervention health services are timely, comprehensive, appropriate and effective to support better overall health and wellbeing

- Is NDIS providing the support needed to prevent avoidable hospitalisations among participants? (see also personal and community supports)
- How are the interactions between the NDIS and health and education systems? How could they be improved? (see health and wellbeing and education and learning)
- What are the experiences of people with disability with the health system?
- What are the barriers to access to mainstream health services and how can these be overcome?

Policy priority 3: Mental health supports and services are appropriate, effective and accessible for people with disability

- What mental health supports are needed for people with intellectual disability?
- How are the interactions between the NDIS and health and education systems? How could they be improved? (see health and wellbeing and education and learning)
- What mental health supports are needed for young people with disability?
- What are the barriers to access to mainstream health services and how can these be overcome?
- What strategies will improve the competency of mental health service providers to provide services for people with disability?

Policy priority 4: Disaster preparedness, risk management plans and public emergency responses are inclusive of people with disability, and support their physical and mental health, and wellbeing

- What were the experiences of people with disability during COVID-19? What can be learnt for future health system reform for people with disability?
- How might climate change impact people with disability and how might we best prepare?

Outcome Area 7: Community attitudes

Community attitudes support equality, inclusion and participation in society for people with disability

Policy priority 1: Employers value the contribution people with disability make to the workforce, and recognise the benefits of employing people with disability

Aligned research questions:

- What strategies will challenge and shift community attitudes towards employment of people with disability? (also see employment and financial security)

Policy priority 2: Key professional workforces are able to confidently and positively respond to people with disability

- What are the perceptions of health care providers towards people with disability and how can they be improved? (see also health and wellbeing)
- What are the knowledge, skills and attitudes of public housing staff working with people with disability? (see also housing and inclusive communities)

Policy priority 3: Increase representation of people with disability in leadership roles

- What are the career pathways of people with disability? What enables people with disability to progress in their careers and obtain leadership positions? (also see employment and financial security)
- How can people with disability be supported to assume leadership positions?

Policy priority 4: Improving community attitudes to positively impact on Policy Priorities under the Strategy

- What are the experiences of discrimination of people with invisible disability, people with mental health problems and people with intellectual disability?
- How might society better understand the strengths of people with disability and how they contribute to the community?
- What strategies will shift community attitudes to be inclusive?

4. Method for co-design of NDRP research agenda

In this section we outline how the NDRP Working Party will use this preliminary research agenda to co-design a NDRP research agenda during the Transition Phase. The proposed process will be sensitive to the opportunity to build on work to date and advance the NDRP research agenda as much as possible, including priorities, and recognition that once NDRP is established as an independent entity, its Board will have full authority under the NDRP Constitution.

First, it will be important to build on the Consortium's reports, while also being sensitive to their limitations. These are due in part to difficulties in conducting survey and consultations during the COVID-19 pandemic when many people with disability were (and continue to be) at significant risk of poor health outcomes. This has meant:

- some groups of people with disability and their supporters and representative bodies have not had sufficient opportunity to shape the NDRP research agenda: notably First Nations people, people from culturally and linguistically diverse backgrounds, people living in non-urban settings, and children and young people
- it is possible that the perspectives of non-disabled academics, services and/or family members were more prominent
- the topics are at a level of generality that is difficult to operationalise in a research agenda and are not yet organised in way that aligns with key policies and strategies, and
- some topics may be missing because of the way the survey and consultations were conducted.

Second, we need to consider the current policy, strategies and research and data initiatives, as detailed above. In addition, the Disability Sector Strengthening Plan for Closing the Gap and associated research will be implemented from July 2022. We also recognise that we need to consider research gaps emerging from the Disability Royal Commission as well as government reviews of people's experiences with the COVID-19 pandemic and the 2021 and 2022 flood response.

We anticipate the refinement of the NDRP research agenda will be a two-step process undertaken during the transition phase. The NDRP research agenda will then be provided to the NDRP Board for implementation. The following provides an overview of anticipated processes, subject to further consideration once the NDRP Working Party commences the Transition Phase.

In Step 1 the Working Party will modify and potentially expand the preliminary NDRP research agenda outlined above by seeking feedback on whether there are additional areas to include or whether some currently included are less relevant. This step will focus on seeking any perspectives not fully captured to date and taking policy developments into account. The NDRP Working Party will do this by meeting with and seeking input from a broader group of Disabled People and Representative Organisations including but not limited to DPOs that represent the interests of those not currently captured such as children and young people with disability, First Nations people with disability, people with disability from culturally and linguistically diverse backgrounds, women with disability, people with disability living in rural and remote Australia, people who use augmentative and alternative communication, from those regularly seeking assistance from housing and food relief and family violence support agencies, and people with disability and the disability sector affected by recent bushfires and floods. We will also closely consider the newly released Disability Sector Strengthening Plan in Closing the Gap and will work with First Peoples with Disability Network to identify the topics and questions for research on disability among First Nations Australians that should be included in the NDRP research agenda. Other national plans and frameworks such as *Safe and Supported. The National Framework for Protecting Australia's Children 2021- 2031* will also be closely considered, given that one of the four priority groups in this Framework are "children and young people and /or parents/cares with disability experiencing disadvantage or who are vulnerable"[ix].

In addition, the NDRP Working Party anticipates seeking input from governments through officials in the first instance regarding research priorities and then, potentially, through a Disability Reform Ministers' Meeting and Ministerial offices; reviewing findings to date from the Disability Royal Commission; and considering the findings of internal and external reviews of government responses to COVID-19 to identify research gaps.

In the second step the NDRP Working Party will take the revised NDRP Preliminary Research Agenda and prioritise questions and topics based on agreed criteria. It will be important to identify areas of agreement and disagreement about priorities and, if possible, unpack where and why there are different views.

At this stage, the NDRP Working Party is considering using a modification of the Child Health and Nutrition Research Investments (CHNRI) method to set the priorities. [x, xi] The advantage of this approach is that it is systematic, transparent and inclusive, fostering ownership of the results. The method has been successfully used by the World Health Organization to set global research priorities for developmental disabilities, including intellectual disabilities and autism and could be adapted for NDRP purposes. The five criteria we propose are based on the purposes and principles of the NDRP and the UNCPRD (criterion 1), as well as criteria from the CHNRI method.

Research questions will be rated in terms of the likelihood that research addressing each topic will be fit-for-purpose for the NDRP research agenda:

1. Will it advance the rights of people with disability? (rights)
2. Can the question be answered, taking into consideration how it is framed, ethics, research capacity, availability of data and feasibility? (answerability)
3. Will it generate findings that can be translated into policy and practice in the Australian context, and can it be sustained? (translatability)
4. Will it result in policy significant improvements? (effectiveness)
5. Will it reduce inequity? (equity)

We propose a survey and a workshop during the Transition Phase to undertake the rating task according to these criteria. These will involve stakeholders from advocacy, government (state, federal, local), non-government sector including services, and researchers. At least half of the workshop participants will identify as having a disability and we will ensure that participants come from diverse backgrounds and experiences. The workshop will provide the opportunity to discuss the results of the survey, and to identify the priorities over the short (1-5 years) and medium to longer term (5-10 years). The NDRP will ensure that the workshop is accessible for people with disability, providing Auslan interpretation, live captioning, description of visual materials and materials in Easy English, and make every effort to accommodate individual support needs as requested.

The NDRP Working Party will synthesise the findings and produce a fit-for-purpose NDRP research agenda which will be made publicly available and provided to the Board and Management of NDRP, once the entity is established.

5. Governance and accountability for the NDRP research agenda

The NDRP research agenda will provide a framework for, and guidance on, priority areas of research and research topics for the disability community, academics and researchers complemented by the research agendas of research funding bodies and governments. This research agenda will provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.

Broadly speaking, it is anticipated that the completed NDRP research agenda will aim to encourage research focused on policy and practice design. It will be inclusive, driven by the NDRP principle of research by and with people with disability. It will emphasise that research should contribute to the evidence base to inform future systems reform, policies and programs. In this way, the NDRP research agenda will be relevant to the lives of people with disability and be practical and outcomes-oriented while remaining informed by and informing theoretical development. The co-design process will give careful consideration to issues such as research types and methods that are appropriate for the development of an evidence base for change. It is anticipated that this NDRP research agenda will comprise clear definition and description of priority topics, recognising the need for iteration and flexibility in response to changing contexts and circumstances. For example: the advent of another global pandemic or an increase in more local natural hazard disasters disproportionally affecting people with disability and the disability community could require a recalibration of priorities.

It is also anticipated that NDRP will maintain a register of active research along the lines implemented by ANROWS.[xii] This would provide a useful resource and offer a mechanism for monitoring progress on implementing the NDRP research agenda. Other mechanisms that could be considered as the NDRP research agenda is expanded and refined during the Transition Phase include continuing one or more communities of practice in priority areas, ensuring linkages between research underway and completed with the proposed more active curating of the APO Disability Research Collection, and the introduction of editorials and timely, context-specific sub-collections. Finally, it is also anticipated that regular reviews of the NDRP research agenda with the opportunity for refining or refreshing would be undertaken to ensure that it continues to be fit-for-purpose over the proposed ten-year time frame.

Subject to finalisation of the NDRP governance structure, it is anticipated that these research activities will be led by the NDRP Research and Development Committee of the NDRP Board once the Board is established. The NDRP Research and Development Committee will have responsibility on behalf of the Board for:

- facilitating a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice
- building, translating and disseminating the evidence base to inform policy and practice on issues and concerns

impacting the lives of people with disability
- maintaining an up-to-date NDRP research agenda
- maintaining up-to-date guidance on inclusive research
- conducting regular Category 1 grant funding rounds
- considering the impact of research findings, who might benefit from what evidence and supporting connections between those who produce evidence, and those who use it,
- advising the Board on how to influence other funding bodies to increase support for disability research and
- building capacity, including awards or other supports, to promote the development of research skills and opportunities for emerging researchers with disability.

Thank you

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

A big thank you to the University of Sydney-led Consortium (see members in Appendix) and everyone who was involved with or provided input to the three-phase agenda setting project.

The next steps of this journey will require even greater collaboration. We look forward to working with all NDRP stakeholders to expand and refine this NDRP preliminary research agenda and other aspects of the NDRP, as it transitions to a permanent and fully operational organisation with its own independent Board in 2023.

If you are interested in being involved in consultations to develop the next phase of the NDRP including refining this preliminary research agenda, register your interest here: contact NDRP

Appendix: Consortium members

The research agenda setting project was delivered by a consortium of academic and non-government partners who were contracted to work with the NDRP on the agenda. The consortium of partners on the research agenda project are listed below.

- The University of Sydney, Centre for Disability Research and Policy and Centre for Disability Studies (lead)
- Ability First Australia
- Australian Association of Special Education
- Australian Catholic University
- Australian Federation of Disability Organisations
- Australian National University: Lived Experience Research Unit
- Autism Awareness Australia
- Centre for Social Impact (CSI)
- Community Resource Unit
- Council of Regional Disability Organisations
- Deaf Victoria Inc. (and Expression Australia)
- Deakin University
- Disability Advocacy Network Australia
- Disability and Inclusion team, Deakin:
- Elizabeth McEntyre, Independent Aboriginal researcher
- Family Advocacy
- Inclusion Australia
- Inclusion Melbourne
- Kindship
- Macquarie University
- Mobility and Accessibility for Children in Australia Inc.
- Monash University
- Motor Neurone Disease Australia
- Murdoch Children's Research Institute
- National Disability Services
- Neurodevelopment Australia
- NSW Council for Intellectual Disability
- Onemda Research and Innovation Centre
- Queensland Disability Network
- Settlement Services International
- Swinburne University of Technology
- The University of Queensland
- University of Technology Sydney Disability Research Group
- University of New South Wales
- University of Western Australia
- University of Alberta
- University of Melbourne
- Vision Australia
- Women With Disability Australia

References

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[i] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106, available at: https://www.refworld.org/docid/45f973632.html [accessed 29 June 2022]

[ii] Review of the Implementation of the National Disability Strategy (2019) at https://www.dss.gov.au/review-of-implementation-of-the-national-disability-strategy-2010-2020

[iii] Audit of Disability Research in Australia (2014) at https://www.dss.gov.au/disability-and-carers/audit-of-disability-research-in-australia

[iv] Audit of Disability Research in Australia Update 2017 ISBN: 978-1-74210-429-4 at https://nla.gov.au/nla.obj-640802934/view

[v] Avery, S (2020) Living our ways: a community-driven Aboriginal and Torres Strait Islander disability research program. First Peoples Disability Network

[vi] Bigby, C., Anderson, S., Cameron, N. (2018). Full report: Designing effective support for community participation for people with intellectual disabilities. Report for Disability Research and Data Working Group. Melbourne La Trobe University, Living with Disability Research Centre.

[vi]iLaurens, J., Bates, S., Kayess, R., Karen R Fisher , K.R. (2021). Good Practice in Supported Decision-making for People with Disability . Final Report at this link: UNSW Social Policy Research Centre

[vii] McSherry, B., Baldry, E., Arstein-Kerslake, A,, Gooding, P,, McCausland, R., and Arabena, K, (2017). *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Institute, University of Melbourne. ISBN 0 9942709 7 9 at https://apo.org.au/node/312445

[ix] Safe & Supported: the National Framework for Protecting Australia's Children 2021 - 2031 (Safe & Supported: the National Framework) at this link: National Plan for Supporting Australia's Children 2021-2031

[x] Tomlinson M., Rudan I., Saxena S., Swartz L., Tsai A. C. & Patel V. (2009a) Setting priorities for global mental health research. *Bulletin of the World Health Organization 87*, 438–46.

[xi] Tomlinson M., Swartz L., Officer A., Chan K. Y., Rudan I. & Saxena S. (2009b) Research priorities for health of people with disabilities: an expert opinion exercise. *Lancet 374*, 1857–62.

[xii] Australia's National Research Agenda to Reduce Violence Against Women and their Children: ANRA 2020-2022 (2020). Australia's National Research Organisation for Women's Safety (ANROWS) at https://www.anrows.org.au/about/national-research-agenda-to-reduce-violence-against-women-and-their-children/