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the **SOCIALDECK**

NDRP preliminary research agenda

Consolidated report of targeted consultations

July 2023



1 This artwork was designed and produced by Gubbi Gubbi and Githabul artist Shauna Hill for The Social Deck.

Acknowledgement of Country

This report was compiled on the unceded lands of First Nations peoples. The Social Deck acknowledges the traditional custodians who have lived on and cared for Country for thousands of generations, and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures, and to Elders past and present.

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Executive summary

The National Disability Research Partnership (NDRP) Working Party released the [NDRP preliminary research agenda](#) in December 2022.

Once complete, the NDRP research agenda will be the foundation for the NDRP to deliver on its vision. It will guide NDRP funding for collaborative and inclusive disability research led by and with people with disability. This research will build evidence for disability policy and practice in Australia.

The preliminary research agenda was developed based on extensive consultation by a University of Sydney-led consortium, who undertook a three-phase agenda setting project between 2020 and 2022.

From April to June 2023, The Social Deck was engaged by the NDRP Working Party to undertake targeted consultations with people with disability about the preliminary agenda. This targeted engagement was to reach groups of people with disability who weren't well represented in the initial consultation process to inform the research agenda.

Participants were provided with an [engagement paper](#) to help give feedback on the research agenda. The paper outlined 12 research areas and examples of research topics under each area.

This report provides insights into the areas of the preliminary agenda that people said were important to them and some specific topics and areas that were identified by participants as missing from the agenda. The report is based on findings from:

- workshops with people with disability from priority groups –7 audience groups (9 sessions)
- an open feedback form available for people to provide feedback on the research agenda (published on NDRP website) – 50 responses
- written submissions - received by three organisations

As part of this engagement process, a webinar was also held with government staff with all levels of government in attendance.

What we learned about the research areas

In general, people expressed support for the research areas identified. They acknowledged these are broad and align with areas of Australia's Disability Strategy (ADS).

While all research areas were identified as important, the research areas most often noted as being important for disability research (includes results of the feedback form and across workshops) were:

- safety of people with disability
- upholding and promoting rights of people with disability
- health and wellbeing
- housing
- employment
- accessible communities.

Community attitudes was often raised but sometimes in the context of other research areas, and in particular relating to rights and discrimination.

Things missing from the research agenda

People from across all groups had a number of suggestions about topics that were not yet included in the NDRP preliminary research agenda. In the feedback form, 31 of the 50 respondents identified things they said were missing from the current research agenda.

The area where the most missing topics were identified was in relation to health. Safety, accessible communities and employment were other areas where a substantial number of new topics or research questions were suggested.

Topics and questions participants suggested were missing are outlined in [Table 2](#).

Other considerations and feedback about the NDRP and preliminary research agenda

Feedback showed most people are excited about the NDRP and its research agenda, especially the opportunity for people with disability to lead and be involved in setting a national research agenda.

However, participants suggested the following should be considered as part of finalising the next version of the NDRP research agenda:

- Better alignment with Australia's obligations under the **UN Convention on the Rights of Persons with Disabilities** and other human rights frameworks.
- Being clear how the research agenda will be maintained as a living document, reviewed and updated as new information or findings of inquiries (e.g. Disability Royal Commission) become available.
- Better represent research priorities for marginalised and intersectional groups.
- Fully involving people with disability in design of research and making sure it is accessible for a range of people with disability to lead, co-lead or engage in research projects. Many people suggested the research agenda should guide how inclusive research is done.

Recommendations

- Set more context up front about linkages with other strategies, including Australia's Disability Strategy.
- Align research areas more strongly to the obligations of Convention on the Rights of Persons with Disabilities (CRPD) and human rights frameworks.
- Adding missing research topics and considering new areas and/or introducing sub-topics.
- Making sure language is right, including reviewing and testing with people with disability.
- Prioritising research topics into shorter, medium and longer term.
- Consider updating the structure to categorise research topics and tag linkages with ADS outcome areas.

Methodology and participation

Summary of participation

Around **119 community members and stakeholders** took part in targeted consultations during April and June 2023.

Of these, **95 were people with disability**:

- 68 people with disability participated in workshops (across 9 different sessions)
- 27 people with disability gave input through the online feedback form.

In addition, **153 government staff** participated in a webinar presentation to brief government on the progress of the NDRP and get feedback on the research agenda.

Participation included people from all states and territories, and from metropolitan, regional, rural and remote locations.

People with disability who participated represented specific population and intersectional groups, from different cultural backgrounds, ages and experiences.

People had lived experience of a range of disability, including physical disability, intellectual disability, acquired brain injury, Deaf/hard of hearing, blind/low vision, neurodivergent (autism, ADHD and Tourette’s Syndrome) and psychosocial disability. This also included some participants who experience co-occurring disabilities.

Participation by activity

| Target audience group | Number of participants | Type of event | Facilitation |
|---|------------------------|---|---|
| People with disability living in rural and remote areas | 14 | Online workshop | The Social Deck |
| People who use augmentative and alternative communication | 5 (over 2 sessions) | Online small group discussions | Scope / The Social Deck |
| People with disability affected by bushfires and floods | 11 (over 2 sessions) | Face-to-face workshops (Moreton Bay, QLD) | Queenslanders with Disability Network (QDN) / The Social Deck |
| Young people with disability (including people who identified as LGBTIQ+) | 9 | Online workshop | Children and Young People with Disabilities Australia |

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| Culturally and Linguistically Diverse (CALD) people with disability | 14 | Online workshop | The Social Deck |
| People with disability accessing assistance from housing, flood relief and family violence support agencies (including with intellectual disability) | 9 | Face-to-face workshop (regional Tasmania) | Speak Out |
| People with intellectual disability | 7 | Online workshop | Inclusion Australia |
| Online feedback form | 50 | Online | - |
| Webinar with government staff | 153 | Online (Zoom broadcast) | The Social Deck with NDRP Working Party |
| TOTAL PARTICIPATION: | 253 | | |

Table 1. Participation by type of activity

Three organisations also made submissions.

Engagement with First Nations people is also a priority. However, due to time and resource pressures, specific targeted engagement with First Nations communities was not able to occur, apart from preliminary meetings to inform priorities. The NDRP Board will work towards this engagement in 2024.

Methods of engagement

Workshops and small group discussions

Targeted workshops and small group discussions (online and face-to-face) were held with people with disability. Each session was designed to suit the needs of the specific group, and co-developed with different partner organisations who supported facilitation of each group (as shown in Table 1).

To support the workshops, an engagement paper was developed which presented the draft NDRP research agenda into **12 main research areas**. This was to enable participants to quickly identify main areas of interest for them.

A semi-structured discussion guide was developed to provide a base set of questioning, which focused on two parts:

1. Getting feedback on the draft NDRP research agenda areas and what topics are most important to people or missing
2. Asking about how people would want to engage with the NDRP and disability research now or in the future.

Not all sessions included questions about how to engage with the NDRP, given the volume of research areas to be covered and time constraints.

In most sessions an introductory video about NDRP was played and people were provided with the engagement paper outlining the 12 research areas being considered prior to the workshop.

A notetaker attended each workshop to take detailed notes. These have been used to produce a background summary report for each session, to be used by the NDRP Working Party to consider specific ideas and feedback of targeted groups.

The Social Deck has done manual thematic analysis across these reports to provide this consolidation of key themes across those targeted audience groups.

Online feedback form

To supplement the targeted activity, The Social Deck produced an online feedback form (short survey) with 7 questions (excluding role and demographic questions). The form was built on The Social Deck's secure Qualtrics platform, with links:

- made available on the NDRP website
- sent via an NDRP newsletter and promoted on NDRP social media
- provided to disability organisations to circulate to members

The online feedback form was open to anyone to give feedback on the draft NDRP research agenda. A rating question asked people to rate how important each of the 12 areas of research from the NDRP research agenda engagement paper were to them. However, the form was primarily to gain qualitative feedback on topics of research people thought were important, and to identify if anything was missing from the preliminary research agenda. People also provided feedback on how they may want to engage with the NDRP in future.

Submissions

The NDRP Working Party and The Social Deck accepted submissions where this was the preferred method of feedback for organisations or individuals. Three organisations provided submissions during this targeted process:

- Women with Disabilities Australia (WWDA)
- Inclusion Australia
- Australian Institute of Family Studies (AIFW).

Government webinar

A webinar was held with government staff to provide an update on the NDRP and ask for areas of interest within the NDRP preliminary research agenda. The webinar was well attended but only a few people (17) responded to the questions via Mentimeter (online engagement tool).

Common themes across engagement activity

Lots of the research areas and topics were important to people, but there were some common themes and issues people raised across engagement activity. These are themes that were raised at least once within all workshops and were a focus of many responses in the online feedback form and submissions.

Impact of ableism and poor understanding of disability:

This theme was described by people in different ways, but participants commonly mentioned **research needs to help improve the understanding of disability so the public, employers, workplaces, health professionals etc. all treat people with disability with respect and uphold their rights**. Specifically, participants mentioned improving society's understanding of:

- value of people with disability in careers and the workforce
- hidden disability
- what disability is and people's experiences of disability
- intersectional barriers that can occur for people with disability when they also, for example, are from a specific cultural or faith background, speak another language, identify as LGBTIQ+.

'I think it is important that this research is taken up, because I think the wider society, a lot of them have very little idea of what it's like to be disabled, especially the invisible disabilities.' Participant, regional, rural and remote workshop

Rights and alignment with CRPD:

Many participants suggested disability research needs to better consider the rights of people with disability, particularly those who are more vulnerable or more likely to be left out. For example, participants specifically mentioned people with disability who are refugees, and people with complex communication needs (including those who speak other languages including Auslan).

A number of participants raised rights within the context of recognising intersectionality and noted people with disability are not one homogenous group but are all individuals with different backgrounds, beliefs, desires and needs. Many participants suggested a greater focus on intersectionality in the NDRP research agenda, both within the context setting and within specific research areas and topics.

Attitudes of the community:

While research about community attitudes wasn't mentioned as often as other areas, people often raised attitudes and discrimination when discussing other research areas. As a result, feedback about

research topics relating to attitudes was often put in the context in which these attitudes existed, for example within workplaces and employment, health care, schooling, justice.

Research to improve health care for people with disability:

Health and wellbeing were discussed in detail at most workshops. People often focused on how research could better help people with disability to engage with health care, including mental health. In particular, this included reducing barriers to accessing health care and improving the way people are treated within health and mental health services and settings. Some suggested research is used to better educate health professionals about disability, and to impact their behaviours and attitudes towards people with disability. It also included the need for research to show the benefits that occur when people are treated well (and appropriately) in health care and are given autonomy and choice and control over their own health decisions and needs.

Employment research on stages and aspects of life:

Employment featured across all workshop groups. Many people and organisations suggested the focus of research in this area should be on the barriers and factors that cause unemployment or underemployment of people with disability at all stages of life and across other areas. For example, young people receiving the same guidance and support to consider careers and career progression, how systems and services in housing, health and education might better support people with disability to be employed.

It was also noted by a few people that research and reviews into barriers to employment is already heavily invested in.

Summary of feedback relating to NDRP draft research areas and topics

Research areas by importance

The feedback form asked people to rate the importance of proposed research areas from low to very high. The large majority of people who responded said most of the 12 research areas were important or very important to be included in the NDRP research agenda. Figure 1 shows that of all the areas rated, the three most often selected as ‘very high’ were:

- safety of people with disability
- upholding and promoting rights
- health services and wellbeing.

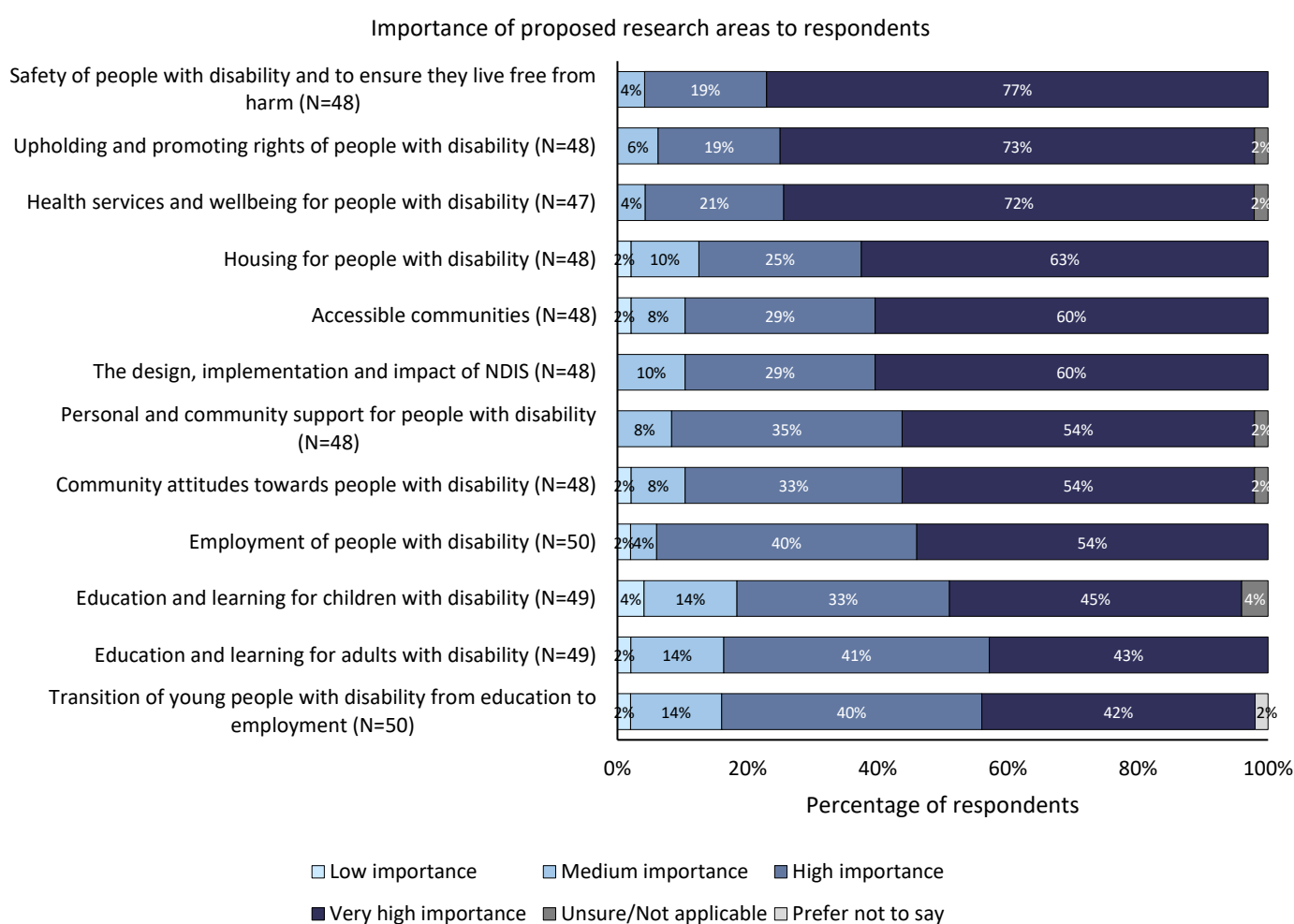


Figure 1: Importance of proposed NDRP research areas to all respondents.

Employment rated slightly higher among respondents with a disability than the overall results.

These levels of importance aren't intended to determine which research areas or topics would be prioritised. However, they do show that consistent with feedback from the workshops, rights, safety and justice are very important areas for the NDRP to take account of in planning for and prioritising its research agenda.

Summary of research topics identified as important by workshop participants

During the workshops people were asked to share what research topics they thought were a priority or important under each research area. Participants were shown or asked to refer to topics in the engagement paper. The following table is a combined list of areas people mentioned in the workshop, which included existing topics in the paper as well as additional or new topics not specifically presented as part of the research agenda.

In general, participants were eager to suggest research topics that would provide information and evidence that could improve aspects of their lives. Rather than research or studies into the issues, participants' suggestions often related to finding out how something can be improved or changed, or research that would support achieving an outcome, (e.g. fairer pay, more opportunities.)

Some of the additional topics also focus more specifically on impacts on marginalised or intersectional groups.

| Existing topics mentioned by participants | Additional / new topics mentioned by participants |
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| Research about employment of people with disability | |
| <ul style="list-style-type: none"> • What are the barriers to employment? • What needs to be done to help people with disability get employment? • What needs to be done to help people with disability maintain employment? • What helps people with intellectual disability to find and maintain employment? • What makes a workplace inclusive and how can workplaces be more inclusive? • How do we improve community and employer attitudes about employment of people with disability? | <ul style="list-style-type: none"> • Ensuring fair pay for employees with disability. • Supporting career growth for people with disability. • Supporting people with disability to have choice and control in their career paths. • Specific research into career entry, development and trajectories for people with diverse disabilities. • Targeted or specific roles for people with disability in workplaces. • The best ways to support employer compliance with obligations to accommodate accessibility needs. • The impact of government policies on long-term employment for people with disability. • How to manage conflicting access needs in a workplace. • Accessible communication within workplaces (including for AAC users). • Training needs of people with disability in workplaces. |

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| | <ul style="list-style-type: none"> • Variety and flexibility in workplace options and job roles for people with disability. • Options for entrepreneurship and self-employment for people with disability. • Rights of people with disability in workplaces. • Investigating the suitability and performance of DESs and ADEs. • Identifying and addressing disincentives to employment, such as loss of benefits. |
| Research about the transition of young people with disability from education to employment | |
| <ul style="list-style-type: none"> • What helps young people to go from school into employment? | <ul style="list-style-type: none"> • What internship, work experience and mentoring opportunities are available for young people with disability. • What attitudes and biases guidance counsellors and other educators have about career options for people with disability. • Availability and efficacy of job-specific learning in school. • Impacts of intersectional identities on barriers and enablers in the transition from education to employment. • Addressing exclusionary or ableist cultural norms that carry through between education and employment. • Support needed for foster children with disability transitioning out of family care. • Experiences and needs of children of parents with disability during transitions. |
| Research about housing for people with disability | |
| <ul style="list-style-type: none"> • What affects access to affordable housing for people with disability? • What are the experiences of people with disability in getting housing that is affordable and accessible? • What are the pathways into and out of homelessness for people with disability and how can homelessness be prevented? | <ul style="list-style-type: none"> • Specific housing needs of people with disability. • Supporting people with disability to achieve home ownership. • Ensuring safety for people with disability in their housing environment. • Ensuring people with disability have choice in their housing options and living arrangements (including who they live with). |

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| <ul style="list-style-type: none"> • What do public housing staff know about the needs of people with disability? • What supports are needed to enable people with disability to live independently? • What models of housing work best? | <ul style="list-style-type: none"> • Improving experiences of people with disability in group homes. • The impacts of public housing and provider staff behaviour on people with disability. • Understanding the diversity of housing needs of people with disability. • Investigating options for more appropriate housing for young people with disability. • The housing needs of people with disability who experience mental health issues. • Including input from people with disability from the beginning of housing design to ensure real accessibility. • Benefits of universal design approaches. • Addressing impacts of housing on the ability of people with disability to socialise. • Supporting people with acquired disability to retrofit their homes for accessibility. • Ensuring residential developments meet safety needs of people with disability, including for emergency responses. |
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Research about accessible communities

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| <ul style="list-style-type: none"> • What are the social and economic benefits of inclusion of people with disability? • What is needed to ensure accessibility of transport systems and the built and natural environment? • How are the experiences of people with disability shaped by place and geography (urban, regional, rural, remote)? • What strategies enable people with communication difficulties to participate in society and to receive the services and supports they need? | <ul style="list-style-type: none"> • Exploring experiences of people with intersectional identities with community accessibility, and ensuring communities are accessible to and inclusive of diverse intersectional groups. • How to ensure accessibility of community events. • Improving awareness and understanding of accessibility by businesses, organisations and other people managing public spaces and events. • Supporting and recognising input from people with disability on accessible practice. • Outcomes, opportunities and learnings from COVID-19 lockdowns for supporting community accessibility. • Experiences of people with multiple disabilities with community accessibility. |
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| | <ul style="list-style-type: none"> • Reviewing accessibility of online information and services for people with disability, and alternative channels for sharing information. • Research into the impact of accessible housing on the ability of individuals with disabilities to live independently and actively participate in their communities. • Accessibility of communications in the public transport system. • Research into the enablers of using public transport for people with disability. • Making community venues and infrastructure more accessible and welcoming for people with disability. • Provision of more accessible information and support to access recreational activities and events people with disability enjoy in their communities. • Making the travel and tourism industry more accessible and easier for people with disability to navigate. |
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Research about safety of people with disability and to ensure they are safe from harm

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| <ul style="list-style-type: none"> • How can we reduce and prevent violence, abuse, neglect and exploitation of people with disability? • What types of services, systems and policies best prevent violence and abuse against people with disability? • What supports children and young people as they transition to adulthood, including to support them to develop their sexuality and positive relationships? • What are the experiences and barriers for people with disability accessing the justice system? | <ul style="list-style-type: none"> • Identifying and addressing cultural and social factors that perpetuate violence and abuse against people with disability. • Ensuring a balance between duty of care and dignity of risk for people with disability. • Educating people about safely interacting with people with disability. • Ensuring online safety for people with intellectual disability. • Ensuring people with disability feel safe, including supporting them to feel confident and emotionally safe. • Identifying and addressing early life factors that contribute to young people with disability, particularly people with invisible disability and from First Nations backgrounds, entering the criminal justice system. |
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| | <ul style="list-style-type: none"> • Ensuring proactive emergency and evacuation planning with people with disability. • Ensuring safety of people with disability in natural disasters is appropriately accounted for in town planning. • How we can ensure safety features and technology are incorporated into housing for people with disability. • Ensuring people with disability are safe in all areas of the community and community life. • Investigation of circumstances where lack of accessibility in the community results in lack of safety for people with disability. |
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Research about upholding and promoting rights of people with disability

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| <ul style="list-style-type: none"> • To what extent are the human rights of people with disability being upheld in Australia? What actions might improve Australia’s performance with respect to upholding the human rights of people with disability? • What models of supported decision-making are working best? • How are current guardianship systems and systems for substitute decision-making upholding and protecting the rights of people with disability? • 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? | <ul style="list-style-type: none"> • Ensuring people with disability know their rights. • Ensuring people without disability know the rights of people with disability. • Researching how well people understand the rights of people with disability. • Ensuring people with disability are able to give feedback about things that need to change. • Reducing cost barriers for people with disability to make complaints about breaches of rights. • Improving direct accountability of businesses for compliance with rights, without involving government intervention. • Exploring dating and relationships for people with disability. |
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Research about personal and community support for people with disability

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| <ul style="list-style-type: none"> • How do we design service systems so they are integrated and people with disability are not ‘falling through the cracks’ between systems such as disability, health and education? | <ul style="list-style-type: none"> • Ensuring the support people with disability need to participate in the community is not impacted by the lack of accessibility and universal design. • How improved employment and pay rates can result in improved personal and community support for people with disability. |
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| <ul style="list-style-type: none"> • How can people with disability be supported to access the services and supports they need across disability, health, education and justice? • How can parents, siblings, other family members and allies be supported to provide supports to the people with disability they care for? • What are the finances of families like when there is a family member with disability? • How can assistive technology support people with disability to live independently and participate equally in society? | <ul style="list-style-type: none"> • The importance of continuity and reliability of support for people with disability. • Attraction and retention of skilled support workers and carers, including outside of the NDIS. • Ensuring care and support is appropriate to a person’s actual needs and capabilities. • Supporting effective relationships between support workers and people with disability. • Recognising and finding out more about two-way, reciprocal support between family members and people with disability. • Impacts of funding on financial dependence of people with disability on family members. • Identifying and addressing the impacts of social isolation. • Recognising the value of different areas of participation. • Ensuring accessibility of Centrelink services. |
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Research about the NDIS

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| <ul style="list-style-type: none"> • How can the NDIS be designed and implemented to achieve the best outcomes for people with disability? • What are the impacts of NDIS funded services and supports currently in use? • 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? • What are the social and economic costs and benefits of the NDIS for participants, families and society? • Is the NDIS equitable? How do we make sure everybody gets fair outcomes? • What are the experiences of people with psychosocial disability in accessing and managing NDIS services and supports? | <ul style="list-style-type: none"> • What barriers people with disability experience to accessing NDIS plans. • Supporting people with disability to have a say in their NDIS plans and goals. • Addressing the impact of limited funding on reducing access to community and services. • Ensuring providers and vendors do not exploit the NDIS and participants. • Improving how the NDIS interacts with My Aged Care. • Ensuring NDIS participants understand how to use their plans. • Research into negative community attitudes about, and perceptions of, the NDIS. • Extending NDIS criteria to include ADHD. • Providing data/evidence regarding sensory equipment to encourage NDIS funding. • Extending NDIS funding to include sex-related services and products. |
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| <ul style="list-style-type: none"> • Are there additional barriers for people with disability who are First Nations or from CALD backgrounds in accessing and managing NDIS supports? • What could be improved about how the NDIS interacts with the health and education systems? | <ul style="list-style-type: none"> • Including more people with disability in the NDIS workforce. |
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Research about education and learning for children with disability

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| <ul style="list-style-type: none"> • How could governments improve their policies and practices for supporting children with disability in early childhood education and care? • How do supports and ‘reasonable adjustments’ for students with disability in school affect their access, participation and educational outcomes? • How could governments improve their policies and practices for supporting school students with disability? • How can teachers promote independence for students with disability? • What are the major problems with the education system? How is this affecting transitions to further training and education? • How can assessment practices be modified so students with disability are not disadvantaged? | <ul style="list-style-type: none"> • Improving sex education to be more inclusive of and for people with disability. • Mental health support needs of children with disability when at school. • Building improved understanding and empathy for children with disability in school settings. • Improving support for teachers to work effectively with students with disability. • Identifying different needs students with disability might have in classroom and school settings. |
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Research about education and learning for young people and adults with disability

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| <ul style="list-style-type: none"> • How could governments improve their policies and practices for supporting students with disability in tertiary education? • How can the voices and stories of students with disability better inform | <ul style="list-style-type: none"> • Ensuring accessibility of adult learning environments. • Understanding education and learning needs of adults with recently acquired disability. |
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| <p>the tertiary sector to be more responsive to their needs?</p> <ul style="list-style-type: none"> • What teaching practices in TAFEs and universities are most effective in supporting students with disability? • How could governments improve their policies and practices for supporting students with disability in lifelong learning? | |
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| Research about health and wellbeing | |
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| <ul style="list-style-type: none"> • How do health care providers perceive people with disability? How can this be improved? • What are the experiences of people with disability with the health system? • What are the barriers to access to mainstream health services? How can these be overcome? • What mental health supports do people with intellectual disability need? • What mental health supports do young people with disability need? • How can the interaction between the NDIS and the mental health system be improved? • What are the barriers to access to mainstream mental health services. How can these be overcome? • How could mental health providers get better at providing services for people with disability? • What were the experiences of people with disability during COVID-19? What can be learned for future health system reform for people with disability? • How might climate change impact people with disability? What should we do to prepare? | <ul style="list-style-type: none"> • Research into how the health system can be more understanding of the needs of people with a range of disabilities. • Investigating how stigma affects treatment and the differences in treatment received by people with disability when compared with the wider population. • Exploring strengths-based over deficit-based healthcare. • Improving communication in health care settings, including use of Auslan interpretation, Easy read materials and culturally appropriate communication. • Improving the understanding of the needs of people with communication disability among health professionals. • Ensuring people with disability receive equitable health support and access. • Investigating the intersection between poverty and poor health outcomes for people with disability. • Exploring costs of health services for people with disability and the options people with disability have access to. • Enabling supported decision-making in healthcare contexts. • How health services could adapt to better support the individual needs of people with disability. |
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| | <ul style="list-style-type: none"> • Recognising the role of alternative therapies and supporting access by people with disability. • Ensuring continued access to support workers in healthcare settings, including during hospital stays. • Investigating and addressing medical trauma among people with disability. • Exploring the mental health impacts of long wait times for healthcare. • Ensuring inclusivity and safety in medical settings for people with mental illness. • Delivering preventative healthcare for people with intellectual disability. • Improving health autonomy and access to care for minors with disability. • How greater representation of people with disability in emergency response services and planning can be enabled. • Exploring substance abuse among people with disability for self-medication. • Improving understanding of chronic fatigue. • Investigating health effects of social isolation for people with disability, and how this can be improved. • Health services required to support migrants and refugees with disability. |
| Research about community attitudes | |
| <ul style="list-style-type: none"> • What helps people with disability to move forward in their careers and gain leadership positions? • What types of discrimination do people with invisible disability, mental health problems and/or intellectual disability experience? • How can society better understand the strengths and contributions of people with disability? • How can we make community attitudes more inclusive? | <ul style="list-style-type: none"> • What causes fear of, or reluctance to engage with, people with disability in the wider community. • Identifying and addressing impacts of cultural attitudes to disability. • Community attitudes towards, and understanding of, people with hidden disabilities. • Supporting people to understand the experiences of people with disability. • Improving media representation of and about people with disability. |

Table 2. Summary of research topics identified as important by workshop participants

Other research topics missing

Topics people said are missing that are not directly linked to the 12 research areas in the engagement paper include:

- addressing fraud and financial abuse of people with disability
- causes of homelessness
- causes of and impacts of poverty
- investigating disability and faith communities and how religious and other world views influence community attitudes to, and support for, disabled people
- research focusing on assistive technology, engineering and access to digital infrastructure.

'IT and auditable technology for people with high physical disabilities and how home automation can increase independence.' Respondent to feedback form

'How can access to assistive technology (AT) be more fair, equitable, timely and streamlined?'
Respondent to feedback form

- research into the long-term sustainability of the disability support worker workforce
- investigating and supporting parental capacity for families of children with disability
- how to enable more disability leadership and disability lead research.

Research about sex and relationships for people with disability was a distinct topic identified across several workshops as important and missing from the proposed research areas. Participants made specific suggestions about inclusive sex education and supporting dating and sexual activity. Participants also raised the topic of people with disability as parents.

Human rights

WWDA strongly reiterated the need for the NDRP research agenda to build the evidence base for Australia to respond to human rights violations and recommendations made to the CRPD (as well as findings of the Disability Royal Commission).

WWDA states 'There is nothing in the draft NDRP research agenda that prioritises, nor aims to examine, the many egregious human rights violations people with disability in Australia continue to experience and be at risk of.' A list of related areas and recommendation is within point 12 of the [WWDA submission](#).

Feedback relating to principles and how research is done

The following points were noted across engagement activity as important for how the NDRP research agenda will operate:

- Being clear about what the NDRP is (and isn't) when people with disability are engaging with it.
- Transparency about the relationship between NDRP and Government when funding and commissioning research.
- Being clear about how the research agenda will be measured, including over the next 12 months and beyond, in order to track progress.
- Having mechanisms in place to update the research agenda as new information is available (including when findings of other research/inquiries are released).

Some participants suggested having principles for the NDRP research agenda.

Inclusive and recognising intersectionality

Participants in the sessions with people who had experienced bushfires or other natural disasters (through QDN) indicated the research agenda needs to have **overarching principles** embedded in, and helping to guide research in all areas to ensure key underlying priorities are reflected in decisions and approaches to research. Specifically, participants identified the following would be important to apply across any and all research areas:

- recognising intersectionality
- approaching research with different 'lenses', such as culture and gender.

Making research accessible

Participants in the workshop with Inclusion Australia (intellectual disability) spent some time discussing their experiences of what makes research accessible and equitable for them. They reported things that are helpful include:

- having opportunities to talk things through together with the rest of their team
- the team getting to know each other as individuals, so they understand each other's different preferences and needs
- making sure each person has a voice and a say in things
- having information available in Easy Read and making sure people have plenty of advance time to go over it.

Engagement of people with disability in research and the NDRP

Almost all participants who answered these questions spoke about the importance of people with lived experience being involved in research through the NDRP.

'I think to have people who have actual experience having input into this sort of research is very valuable.' Participant, regional, rural and remote workshop

Many said the NDRP would need to be active in setting advice about how to ensure people with disability are involved and listened to.

'The valuing of people with disability's experience and insights in research, including those who are often left out or are not well represented in research, sets the NDRP apart from other research projects.' Inclusion Australia submission

In the QDN workshop, participants highlighted formal research has often overlooked or undervalued different sources and forms of data, particularly the lived experience of people with disability. They indicated an objective of the agenda should also be to promote and support collection and prioritisation of different types of evidence.

'It's hard to put those ideas through to those writing the reports on your behalf, because you really can't say it in five minutes. There's so much out there that you don't see that we have to live with.' Participant, people affected by bushfires, floods and other natural disasters

People with disability in Tasmania who participated in the Speak Out workshop suggested involving people with disability in NDRP research should include:

- employing people with disability in research projects
- giving people with disability opportunities to give input
- having researchers go into communities and talk to people.

They also noted the expertise of people with disability needs to be valued and they need to be paid for their time.

'People with disabilities are extremely important to be involved in any type of research, because we've all got a lot of wisdom, and it's so untapped.' Participant, people with intellectual disability workshop (Inclusion Australia)

Many respondents to the feedback form also noted the importance of people with disability being involved in, and at the centre of, all NDRP work, planning and all resultant research.

'I believe the most important area of focus is on valuing the contributions of people with disability in research and ensuring they have real decision-making power, not token involvement.' Respondent to feedback form

The importance of co-design of research was also noted in responses to the feedback form, along with involving people with disability with existing qualifications in a range of fields. It was suggested

academics could work with consultative groups of people with disability, and there needs to be a national body working with people with lived experience.

Related to this, some respondents noted the need for support, training and education for people with disability to ensure they are actively involved in research and employed in research roles.

'Importance of ensuring people with disability have access to education in research.' Respondent to feedback form

A specific area of feedback was about the engagement of people with intellectual disability. In the Inclusion Australia submission they stated:

'People with an intellectual disability have historically been excluded from research and the academic world. Largely, research is written about people with an intellectual disability, rather than with them as co-researchers, experts, or key stakeholders and decision makers. Not only does this conflict with the principles and vision of the UN Convention on the Rights of Persons with Disabilities and Australia's Disability Strategy that shape our policy context, but simply, it also means that much of local research that is being produced is glaringly missing important narratives and evidence.'

The NDRP holds an integral role in reshaping the standard of Australia's disability research. We are encouraged to see the broad consultation the NDRP is doing to better understand and improve inclusive research practices.'

However, because of the historic marginalisation of people with an intellectual disability in research and academia, this inclusive practice work must be coupled with proactive engagement and educative work to bring people with intellectual disability into the conversation. There needs to be investment in educating community members with an intellectual disability on what research is, the impact it can have, and the strengths of peer-led research. With this, the voices heard in research will be more far-reaching, the evidence more comprehensive, and the policy implications more powerful.'

Putting engagement into practice

Participants across engagements mentioned the NDRP would need to guide practical ways for research to better involve and be led by people with disability.

For research by and with people with an intellectual disability, Inclusion Australia highlighted in its submission:

- 'In selecting what projects will be funded, the NDRP should scrutinise proposals and their ability to prove that inclusion has been considered from the outset and is not an 'add on' to a predetermined design.
- Reference to and use of guidance such as the *Working with people with an intellectual disability – a guide for researchers* and accompanying *Guidance for Researchers – Project Information Form* resources to support inclusive research.

- Use of the new Towards Inclusive Practice website, co-designed by an Inclusion Advisor Network comprising people with an intellectual disability across Australia to give advice to government departments and other organisations about working in a way that is more inclusive of people with an intellectual disability.’

The AIFS also mentioned in its submission ensuring funded organisations have clear strategies for engaging people with disability which align with better practice research. For example, accommodations for people who identify as neurodiverse or who have intellectual disability. Further, ensure reporting mechanisms include the voice of people with disability, and where possible, people with disability are involved in steering and overseeing research projects. Ensure research projects involving people with disability use accessible resources, co-designed and tested with people with disability. Finally, fund disability organisations to be involved in and contribute to research, and to build their capacity to conduct research.

Accessing support

Participants in the workshop with Inclusion Australia (intellectual disability) discussed the role family members and carers can have in contributing to research. They noted people with disability should be able to make the decision about whether someone else speaks for them or about their experience, but in some cases it can be helpful to have family or carers involved, especially where they can provide a support system and where they can help to advocate for the person with disability.

‘There’s nothing wrong with having a bit of support.’ Participant, people with intellectual disability workshop (Inclusion Australia)

Sharing research findings

Participants in the workshop with Inclusion Australia (intellectual disability) indicated sharing research findings in accessible ways is very important and needs to be done considerately. They emphasised findings need to be shared within reasonable timeframes, and people must be told what those timeframes will be. They commented it can make them feel annoyed or hurt if researchers never share results back to people. They reported they like to get feedback about research. They also said findings need to be shared in inclusive ways and it should not just be in written form but should involve talking to people about the outcomes and giving them opportunities to ask questions.

Collaboration

Across engagements, but particularly in responses to the feedback form, people suggested the NDRP could support the development of collaborations between people with disability, researchers and organisations, and could ensure there are pathways for people with disability to work on research projects. The importance was noted of emphasising research as employment for people with disabilities and ensuring fair payment for work.

Research proposals

While feedback about how research is funded and commissioned was limited, Inclusion Australia noted in their submission an interest in seeing how the NDRP may be able to work in different, non-traditional ways, such as accepting research proposals in different formats (videos can often be more accessible for people with an intellectual disability) and employing people with an intellectual disability as part of the NDRP team, including to assess incoming proposals.

Showing value and results

Some respondents to the feedback form emphasised the **importance of research resulting in tangible and measurable outcomes** which improve the lives of people with disability, including ensuring research grants include dissemination and work to translate research into action.

'Research is useless if it is implemented. The findings can be shared in all sorts of ways, but if they are not implemented then, so what. The NDRP needs to ensure that there is facilitation for the implementation step.' Respondent to feedback form

'A focus on action rather than questions. For example, under health and wellbeing there already exists considerable knowledge on health care provider perceptions, the known barriers and peoples' experiences. We have been asking people with disability to share their experiences for decades. We need research that is solutions focused.' Respondent to feedback form

'There needs to be more understanding of life in regional centres. Too many of the ideas and reforms are perfect for Melbourners, but don't work for anyone outside of a capital city.' Respondent to feedback form

It was noted it is important that research topics which are not 'flavour of the month' are not ignored or prioritised at a lower level, and research for the sake of research is avoided. It was also suggested research topics and priorities could be much more practical and based on interventions that can be replicated (with individual adjustments) and adapted to settings, cultures and ages of people with disabilities.

Other

Other suggestions from respondents regarding the way the NDRP is planning to support disability research included:

- ensuring there is a stronger focus on partnerships with unions and employers and their peak bodies with the aim of conducting innovative research to improve access and attitudes in the workplace
- recognising (and educating governments about) the time and cost of inclusive research
- offering a fellowship program to recognise researchers with disabilities who are conducting disability research

- ensuring involvement and representation of disability service providers and disability advocacy organisations
- including families of people with disability in research
- promotion and advertising of opportunities for people with disability to be involved in ongoing NDRP work and consultations.
- ensuring the impacts of long COVID are considered in multiple areas of research.

Issues with the NDRP preliminary research agenda

The following are specific issues identified by participants and organisations relating to the preliminary research agenda. [WWDA's submission](#) provided more detail about the context of these issues and this section should be read in conjunction with the submissions.

Accounting for different environments and contexts

Some feedback highlighted many of the current research topics and questions are very general and don't account for different contexts, environments or priority populations. Some of the feedback suggests specific areas of research are needed to understand specific impacts across many of the research topics for:

- **First Nations people with disability and their communities:** adding the context for Closing the Gap agenda and initiatives around Strengthening Indigenous research capacity and capability
- **families and children:** ensuring a focus across research areas for the context for families and how different family environments impact people with disability, (e.g. how factors at home or in early years impact pathways and employment later on)
- **people who identify as LGBTIQ+:** understanding more about additional barriers and the intersections that cause discrimination (e.g. among healthcare, other professionals)
- **people from multicultural and CALD backgrounds:** incorporating more on new migrants and refugees who face multiple additional barriers, including in recognising disability in some cultures and in access to information and services/supports.

One aspect of this was the feedback from WWDA about the **need for a gendered lens and approach** to be embedded in the NDRP research agenda and across research areas.

'The draft NDRP is not gendered in any way, which is of serious concern, given the obligations under Article 6 of the CRPD, along with CRPD General Comment 3. The lack of a gendered lens and approach is also concerning given the context of the Australian Government's current work to develop a National Gender Equality Strategy, and its emphasis on the requirement for Gender Responsive Budgeting (GRB) across Australian Government policies and programs.' WWDA submission

Other feedback suggested a stronger emphasis in research areas on impacts on specific population groups and demographics where they are known to be heavily affected, for example:

- Impacts of violence against women and children – including acknowledging ‘women with intellectual disability are 50-90% more likely to experience sexual violence than women without disability.’
- Rights of children, and how they are upheld, including from the early years
- Ageing and aged care – to understand acquired disability related to ageing. For example, cognitive impairment and Alzheimer’s disease, and how aged care staff are trained to care for older people with cognitive disability.

Avoid duplication

There were some concerns, and confusion, among people who responded to the feedback form and in submissions about how the NDRP would ensure its research agenda priorities or topics wouldn’t just duplicate existing efforts or areas where research is already heavily invested in. For example, while employment was identified as an area of high interest for most participants, a number of stakeholders noted the extensive amount being done in this area through other organisations.

‘There has already been a substantial amount of research on barriers to employment for people with disability in recent years.’ WWDA submission

Language matters

The wording of the research topics and questions is very important and can impact support for the NDRP research agenda. It was evident during these targeted consultations that language used for research topics matters as it:

- can cause people to interpret research topics in different ways and create confusion or be unclear what is meant
- can lead people to feel they, or a particular group, are excluded from the research topic (e.g. one participant suggested that where gender is mentioned, it excludes men)

It was suggested language be tested (if possible) or reviewed by disability representative organisations.

‘The draft NDRP Research Agenda does not use human rights language and in parts, reverts to a medicalised and diagnostic approach. For example, terms such as “mental health problems”; “mental health issues”; “vulnerable” are outdated concepts that not only reflect a medical approach, but also imply a deficit in the individual.’ WWDA submission

Some respondents to the feedback form also noted the **importance of language, and specific cohorts of people with disability should be more prominent and more carefully considered** in the work the NDRP is doing. It was suggested the current framework is ableist and ethnocentric and does not deal

with intersectional issues at all, and users of Auslan and other signed languages are completely ignored or only considered in broad terms. The need for a stronger focus on, and involvement, of people who use sign languages was highlighted, including First Nations people and deaf people from migrant and refugee backgrounds. The importance of ensuring research is focused on the needs and experiences of people with disability experiencing poverty or living in rural and remote communities was also highlighted.

'The most marginalised and poorest amongst us feel excluded and ignored by your research agenda.'
Respondent to feedback form

Making the agenda flexible to account for changes and new information

Stakeholders and people with disability identified it would be important for any research agenda to remain flexible to reprioritise and adapt as new evidence and information is found.

Currently, major reviews and inquiries are underway which could present new findings and significant systems reform. Examples include the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the NDIS Review which are both expected to release final reports and findings later this year. For the NDRP to meet its vision of building evidence for developing policy and practice decisions, the agenda will need to be agile and responsive to these ongoing reforms.

In the QDN workshop participants suggested the agenda needs to be flexible enough to actively support novel and innovative research that has not been anticipated. They advised care needs to be taken in the way research topics are specified and categorised to ensure potential research is not discounted or overlooked because it does not 'fit into the boxes'.

Recommendations

The following recommendations are to assist in drafting the next version of the NDRP research agenda based on the insights in this report.

Setting context up front

Context about the consultation process to develop the preliminary research agenda should be replaced with strong statements about how the NDRP research agenda will align with and take account of the key conventions and policies this research should be aiming to contribute to, or lead change within.

These include, but may not be limited to:

- UN Convention on the Rights of Persons with Disabilities (CRPD)
- Australia's Disability Strategy
- Gender equity strategy

- National Disability Data Asset
- Nothing about us, without us
- Closing the Gap and other strategies for strengthening Indigenous research capability

Better demonstrating its links to Australia’s obligations under the UNCRPD and aligning with other human rights frameworks

The NDRP research agenda could be better positioned within the context of existing human rights frameworks and international obligations. Research that focuses on upholding rights was a priority across the engaged groups and for most people who responded to the feedback form.

Based on the feedback, upholding the human rights of people with disability could be featured as a stronger, underpinning principle of why research is important – put in an upfront section of the agenda with a strong statement about upholding rights and addressing discrimination applied to each research area.

‘For example, Priority Area 6 as currently stated in the draft Research Agenda is “Upholding and promoting rights of people with disability”. Given that the NDRP is framed by and within the CRPD and the ADS, the ‘Upholding and promoting rights of people with disability’ should be embedded in any/all of the research priority areas of the research agenda.’ WWDA submission

In addition to the context setting, it would be important to demonstrate how the NDRP research agenda will be monitored to show progress against these frameworks.

Adding research topics based on what people said is missing

The NDRP Working Party could consider adding research topics that people identified as missing, noting there are many which could be combined and/or may require additional context if being included.

Given the amount of additional or variation to research topics suggested in this report, and the specific workshop and feedback form reports, the agenda could be structured to allow for inclusion of sub-topics (perhaps as a longer, more detailed version).

Make sure language is right

- Undertake a full edit and review of language across all research topics and questions presented.
- Build in time for disability representative organisations to review language, ensuring there’s a coordinated and efficient process to do this.
- Consider testing the next version of the research agenda with a group of people with disability
- Create a readable Easy Read summary version of the research agenda.

Prioritise research

The NDRP Working Party needs to set some guidance for how NDRP research agenda topics would be prioritised over the short, medium and longer terms.

Based on the findings of these targeted consultations, and considering information available in the more extensive research agenda consultations undertaken over two years, we suggest:

Communicating all topics that are important

Reiterating all topics are important and could be considered 'in scope' for NDRP research – either funded or by commission. Encourage departments (federal and state) and social/health/employment/other sectors and corporate stakeholders who have an interest in particular research areas, to explore the types of topics people with disability said are important. Encourage others to continue to define what adds value to them either as funders, or as people impacted by systems and policy design.

Rather than a written document, a research section of the NDRP website could have a navigable and searchable function where stakeholders can explore what sorts of research topics people said was important under different categories.

Short term

Identify **8 priority categories** for short term research with:

- **1 category about intersectional research:** a more open range of topics but research must strongly demonstrate how it will help to address barriers impacting intersectionality
- **7 other categories with a priority focus under each of the outcome areas of Australia's Disability Strategy:** This would help to align the research agenda to the ADS and ensure short term priorities link to identified action areas.

Medium-term

This could be areas that will need to be actioned based on current reviews and major investigations. For example:

- **safety and rights** – acknowledging this was one of the most important research areas to people, be ready to respond to outcomes of Disability Royal Commission
- **NDIS implementation** – following the review
- **human rights** – following work into a Human Rights Act for Australia
- **research with First Nations people** – leveraging any changes and opportunities

Longer term

Group together topics that **require system changes. For example more data sources**, linking this with the work and outcomes of the NDDA.

Suggest longitudinal studies or similar approaches for some topic areas where research is unlikely to show results without **longer term trends**.

Consider updating structure

The current structure of the preliminary research agenda aligns all research topics and questions to the seven outcome areas of Australia's Disability Strategy. Because these outcome areas are broad, there is too much content for people to navigate through, especially if more topics are added.

While it makes sense for some framing to be in line with the ADS, there is risk that simply grouping topics of research by the seven ADS outcome areas will:

- not clearly articulate any priorities for research
- duplicate measurement strategies for the ADS (e.g. research that measures progress or targets within the ADS Outcomes framework)
- dilute the independent nature of the NDRP.

In relation to the '12 research areas' in the engagement paper, the submission from WWDA noted *'they maintain the policy and funding framework status quo, rather than engaging in the transformation, based on evidence, that needs to occur to fulfil CRPD obligations.'*

Because the NDRP research agenda will be framed by and within the ADS and CRPD, it may not be necessary for the structure of research topics to follow its outcome areas. The upfront context of the research agenda could clearly and strongly explain each of the research topics to be featured and prioritised within the NDRP research agenda would link back to those seven outcome areas (reversing how that is presented). For example, tagging each topic with outcome areas, similar to a Sustainable Development Goals process, may be a more appropriate way to demonstrate those links.

Possible structure: The Working Party could consider:

- maintaining up to 12 areas (or a similar number) to reduce the number of topics and questions under these areas could be more relevant to a person's life stages or factors and they could be called categories.
- adding sub-topics to better demonstrate specific topics of research for intersectionality and priority groups
- applying tags to each topic to link them back to the seven ADS outcome areas.