Setting an agenda for disability research in Australia: organisation-led and targeted consultation report

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THE UNIVERSITY OF SYDNEY

FOREWORD

By the NDRP Research Agenda Guidance Committee

What is the National Disability Research Partnership (NDRP)?

The National Disability Research Partnership has been funded by the Commonwealth Department of Social Services for two years, 2020-2022 to build the case for large-scale ongoing investment in a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice.

The NDRP is guided by four principles: deliver high quality, collaborative research; recognise the knowledge of people with disability in research; value all forms of knowledge; and build research capacity. More details on these principles can be found at this link: **NDRP Principles.**

A Working Party made up of academics and independent advisors, 46% of whom identify as having a disability, is facilitating the establishment of the NDRP.

At the end of the two year Establishment Phase, the NDRP will have completed:

1. A preliminary NDRP research agenda

2. Proposed a governance model to support the long term NDRP

3. A plan for developing disability research capacity in Australia

4. A practical guide to research funded by the NDRP

5. Piloted a research funding round to build the evidence base and to demonstrate and refine NDRP processes.

This report relates to the first of these deliverables – the NDRP research agenda.

What is the NDRP 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 went through a competitive tender process and appointed a consortium led by the University of Sydney (co-leads Professor Jen Smith-Merry and Associate Professor Mary-Ann O'Donovan) to develop the research agenda. The Consortium included 30 organisations involving six university or academic centres, Disabled People's Representative Organisations, services, and other non-government organisations involved in a range of different activities including advocacy, training, and service provision. People with lived experience of disability were key members of the team.

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 second stage included a survey as well as consultation led by organisations involved in the Consortium. This report is about the consultation results.

What did the consultation involve?

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.

Who engaged in the consultation?

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 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 Australians 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 people in this Phase 2b survey were combined with those in Phase 2a, yielding a sample of 31 Aboriginal and Torres Strait Islander people across both surveys.

What did they find?

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 people wanted to see research on the experiences and needs of Aboriginal and Torres Strait Islander people 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.

What are some of the limitations?

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.

Where to from here?

This is the third of four reports from the Consortium who are conducting the research agenda setting exercise. From the perspective of the NDRP Working Party the consultation findings provide us with information about some of the issues that should be considered in the NDRP research agenda.

The NDRP Research Agenda Guidance Committee (in alphabetical order)

Professor Bruce Bonyhady

Ms Tessa de Vries

Professor Helen Dickinson

Professor Anne Kavanagh

Professor Gwynnyth Llewellyn

Executive summary

This report presents the results of the Phase 2b consultation conducted with 974 individuals from 21 non-government organisations (NGOs), including service providers and disabled peoples' organisations (DPOs), the First Nations-focused National Disability Research Agenda survey and online focus groups and in-depth interviews with people with augmentative and alternative communication needs. It complements the results of the Phase 2a National Survey[1] which surveyed 973 people via an online survey and is part of a multi-component project to inform the development of a disability research agenda in Australia. This research was funded by the National Disability Research Partnership (NDRP) to develop the foundation for an agenda for Australian disability research over the next decade. The research was conducted by a sub-group from our broader Consortium of NGOs, academics and research partners, including people with lived experience of disability and DPOs.

The consultation process and tools were co-designed with a consultation work team of project partners, NGOs and people with lived experience of disability who were part of the overall Consortium. The consultation work team and broader Consortium ensured that the project scope, methodology, and logistics reflected the cultural diversity of Australia and the spirit of Reconciliation between Indigenous and non-Indigenous people.

The organisation-led consultation ran from April 2021 to September 2021 and aimed to gather qualitative data on the following questions:

- What do people with disability and the organisations that support them see as the priority areas where research is needed to improve the lives of people with disability?
- How do people with disability and the organisations that support them currently use research?

Consultation around these topics was undertaken via NGO partners as well as through targeted consultations undertaken by team members on the consortium consultation work team. Targeted consultations included focus groups with and by people with intellectual disability, mental health lived experience research group, people living in boarding houses and children and young people. This brought in over 1000 people through a wide variety of consultation processes. Consequently, because of the wide variety of groups and processes, results were broad ranging and provide responses that go beyond these base questions. There are over 4 million people with disabilities in Australia and a relatively small number of organisations participated in this consultation process. As such this sample should not be considered representative of the full diversity of disability and the priorities that may exist for this population.

Due to delays with ethical approval, the First Nations survey took place in early 2022, and was live from Wednesday 2 February 2022 and concluded Monday 7 March 2022. The survey was distributed via email and advertised online through social media platforms. The online focus groups and interviews with people with alternative and augmentative communication needs, was similarly delayed and ran across March and April 2022. These targeted efforts sought to ensure the perspectives of First Nations people and people with Alternative and Augmentative Communication needs with regard to future disability research priorities were included.

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[1] Smith-Merry, J. J. Plumb, G. Gallego, I. Yen, C. Imms, A. Dew G. Carey, M. O'Donovan, J. Gilroy, S. Darcy, B. Hemsley on behalf of the Research Agenda Consortium (2021) *Setting an agenda for disability research in Australia: Survey results.* Centre for Disability Research and Policy, The University of Sydney: Sydney. ISBN: 978-0-6487544-3-5

Summary of Findings from the consultation

Key findings:

- Participants felt strongly about the need for lived experience of disability to be valued in research. People with disability should be included in all aspects of research design, implementation and dissemination as a priority.
- Research was recommended in the areas of human rights, supports (formal and informal), inclusion (social, employment, education), health and health systems, government and the NDIS.
- Organisations described research in these areas as a way to build evidence to address and overcome current challenges and barriers that exist for people with disability.
- A life course approach to research should be taken with emphasis on changing needs across the life course as well as key transition points, for example, school transition points, transitions to older age.
- Research must be made available and accessible taking into account the diverse communication needs of people with disability.
- First Nations participants emphasised the experiences and needs of Aboriginal and Torres Strait Islander people with disability, mental health needs of people with disability, the personal experiences of people with disability, discrimination and abuse and the rights of people with disability.

Limitations

It is important to highlight that Covid-19 restrictions meant that consultations had to take place predominantly on-line with only a few occurrences of face-to-face consultation possible. In-depth consultation with First Nations groups was not feasible during this time and consultation was via online survey only. Online engagement does not suit all people with disability and not everyone has access to technology and/or support to use technology.

People with disabilities are a population group who confront many barriers to participation in society as well as experience health inequities and multi-morbidity. This was nowhere more evidenced than during the response to CoVID-19 where people with disabilities in Australia were de-prioritised for vaccinations and neglected. Thus, seeking to consult during the pandemic may have been a burden too far for this population and potentially biased participation towards the healthiest people. This may also explain to some extent why people with disabilities only represented 16% of the sample, with the remainder being families, carers, paid supporters and other disability staff. The full diversity of the population of people with disability is not represented completely in these findings.

The sampling frame to reach people was organisation and network based, so it is likely those not linked with service providers and disability/advocacy groups are under-represented. The broad promotion of the online survey which was conducted separately reached people outside of the typical 'disability provider' groups and settings as did the inclusion of the social networking group Kindship. However, reach was still restricted.

Disability community groups are diverse and many, but and only a relatively small number of organisations participated. The consultation does not claim to reflect the views of all organisations or community groups, or all people with disabilities and is therefore limited by its reach and representation.

Some voices that have limited or no representation in this consultation include people with profound disability, LGBTQIA+ people with disabilities, people with disabilities who are culturally and linguistically diverse (CALD), people with disabilities living in institutions (including the justice system), people with mild/borderline disability who may not be connected to services or DPOs and siblings of people with disability.

Further work is needed to ensure a more inclusive process of consultation so that the voices of people with disabilities in all their diversity are elevated. This will require a worthwhile larger investment in time and money to ensure a comprehensive and representative process. Any further consultation will also need to be cognisant of other social and environmental demands on people with disabilities and ensure the range of supports are in place to overcome any barriers to participation.

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Introduction

This is the second report from Phase 2 of the NDRP research agenda consultations. In total, there are four reports from the NDRP funded research agenda project:

1. Mapping Disability Research in Australia 2018 - 2020 (Phase 1 report)
2. Setting an agenda for disability research in Australia: survey results (Phase 2a report)
3. Setting an agenda for disability research in Australia: organisation-led and targeted consultation report (Phase 2b, current report)
4. Setting an agenda for disability research in Australia (Phase 3 report)

Key findings from each stage will be made available in easy read formats developed by the Council for Intellectual Disability (CID) NSW. The reports will be hosted on the NDRP website **https://www.ndrp.org.au/research-agenda**

These reports will be used to inform the Final Report and Recommendations for a research agenda produced by the NDRP.

Structure of this report

This report outlines the aims, process of consultation, thematic findings and implications based on the disability and advocacy organisation-led consultations and targeted consultations conducted by the Consortium consultation work team. Four of the targeted consultations facilitated by consortium members in partnership with organisations, included consultations with and by people with intellectual disability, people living in boarding houses, mental health lived experience research group and children and young people. The findings from these consultations were returned using the same standardised templates as used by organisations and analysed and presented together in this report. The findings from the Aboriginal and Torres Strait Islander survey and the targeted online focus groups and interviews are presented in a separate section of this report.

Findings from the survey-based consultation are reported elsewhere (Smith-Merry et al, 2021[2]). The integration of open text findings between all phases of the consultation (survey, organisation-led and targeted consultations) are presented in the discussion section of this report. The purpose of this is to demonstrate the similarities and differences in issues that arose in the various phases of the consultations and provide opportunity to compare responses from people with disabilities and other participant groups, such as families, and service providers.

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[2] Smith-Merry, J. J. Plumb, G. Gallego, I. Yen, C. Imms, A. Dew G. Carey, M. O'Donovan, J. Gilroy, S. Darcy, B. Hemsley on behalf of the Research Agenda Consortium (2021) *Setting an agenda for disability research in Australia: Survey results.* Centre for Disability Research and Policy, The University of Sydney: Sydney. ISBN: 978-0-6487544-3-5

Method

The complete consultation consisted of four elements – Phase 2a, a National Survey (reported elsewhere), and Phase 2b that included organisation-led consultation, targeted consultations by consortium members, Aboriginal and Torres Strait Islander Consultation, and online focus groups and interviews. This section of the report outlines the approaches underpinning the development of the consultation toolkit and its planning and administration, the adaptation, planning and administration of the Aboriginal and Torres Strait Islander survey, and the online focus groups and interviews.

Research team

From the Research Agenda Consortium, a consultation work team was formed to develop and advise on the consultation process. Consortium members for the project and the consultation work team are listed in Appendix 1. The overall lead for the consultation phase was Mary-Ann O'Donovan, Associate Professor of Disability Studies, from the Centre for Disability Studies (CDS) at the University of Sydney. For the purposes of this report, the work team referred to is the phase 2b work team.

Associate Professor John Gilroy led the development and implementation of the Aboriginal and Torres Strait Islander data collection in consultation with the First Nations advisory group. The process of developing and implementing the survey along with results is described in detail in a separate section of the report.

Professor Bronwyn Hemsley, Professor Simon Darcy and Ms Danielle Manton, with research assistant Barbara Almond, conducted the online focus groups and interviews component of the consultation [UTS Ethics ETH21-6405]. A Co-Creation Panel was set up to provide a 'check' on the processes for the overall consultation project and to advise and guide on process improvements.

The online interviews and focus groups were designed to enable participants to choose to attend at a time that suited them best for a discussion, whether in a focus group or individual interview. In addition, it also enabled the needs of people with communication disability to be met, including those who use augmentative and alternative communication (AAC) and speech or sign language interpreters.

Description of Disability

Throughout the project the Consortium has used the United Nations (UN) Convention on the Rights of Persons with Disability (CRPD) Article 1 description of disability: "Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[3]

Consultation aims

The aims of the Phase 2b consultation were to:

- Acquire in-depth information from disability organisations to complement the Phase 1 survey data;

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[3] United Nation Convention on the Rights of Persons with Disability (2006) **Convention on the Rights of Persons with Disability (CRPD) | United Nations Enable**

- Enhance participation in the project, and promote the voice of, a broad range of people with disability and/or their supporters across Australia, including Aboriginal and Torres Strait Islander people;
- Provide means of engagement that are responsive and appropriate to the communication needs of people with disability, including people with intellectual disability and augmentative and alternative communication needs;
- Engage organisations in collaboratively consulting with their own constituents and supporting and providing guidance to organisations on sound methods of engagement;
- Engage typically hard to reach populations such as people living in boarding houses; and
- Engage young people with disability and their families, to ensure the voice of children and adolescents with disability are represented.

It should be noted that some voices have limited or no representation in this consultation. For example, people with profound disability, LGBTQIA+ people with disabilities, people with disabilities who are culturally and linguistically diverse (CALD), people with disabilities living in institutions (including the justice system), people with mild/borderline disability who may not be connected to services or DPOs and siblings of people with disability.

Overall consultation approach

The three main principles underpinning the consultation were inclusion, flexibility and self-determination. These principles are linked to those underpinning the NDRP, such as valuing the inclusion of the diversity of the voices of people with disabilities and the importance of research by and with people with disabilities.

These interlinked principles underpinned the choices of research methods and their application. Potential barriers to participation in the consultation were reduced as much as possible and this demanded flexibility in the approaches used, including provision of templates and resources that supported participants by enabling their communication and information access according to their individual preferences. However, acknowledging the restrictions on face-to-face engagement due to CoVID-19.

Rather than imposing one approach to consultation, the consortium recognised that DPOs and advocacy organisations have the most detailed knowledge of how to consult with their members. Therefore, a consultation toolkit was co-designed to enable organisations to run their own tailored consultations, with resourcing or research support from the Consortium as needed. Similarly, for the targeted consultations which were undertaken by members of the consortium, with people living in boarding houses, children and young people, people with intellectual disability, mental health lived experience research group, there was flexibility in the method of consultation based on the needs of the group based on the in-depth knowledge and experience of the consortium members who worked with these populations.

The final approach to these consultations was determined by each organisation based on their understanding of their members' communication preferences and styles, using relevant aspects of the consultation toolkit. The organisations retained the primary data, which was not shared with the Consortium members. Having adapted the consultation methodology for their constituents, organisations then reported summary data to the consultation work team using a standardised reporting template. Although the approach of engagement was flexible the reporting mechanism back to the consortium was standardised. This was to ensure confidentiality and anonymity of participant information, while also ensuring consistency in reporting style.

The overall process was developed in discussion between the consultation work team for Phase 2b and the University of Sydney Ethics Office. The consultation templates are available in Appendix 2. In the context of the Covid-19 pandemic through 2021, the consultation was adapted to social distancing restrictions and conducted online. The participating organisations were geographically spread across Australia so that local consultations could proceed in person where possible as States had different levels of Covid-19 restrictions in place and at different times.

Consultation toolkit

The consultation work team for Phase 2b convened and met on a regular basis from October 2020 to January 2021 to develop, design, review and finalise the consultation toolkit with input from the consortium. Where possible the resources were adapted from existing co-developed resources (Disabled People's Organisations Australia, 2019; Jenkin et al, 2017). Beyond the consultation work team, draft resources were reviewed internally by four organisations (Council for Intellectual Disability, Inclusion Melbourne, Deaf Victoria, People with Disability Australia) in addition to review by the consortium's Co-Creation Panel. A Co-Creation Panel led by Professor Bronwyn Hemsley was set up to provide a 'check' on the processes for the overall consultation project and to advise and guide on process improvements. The final consultation toolkit (see Appendix 3) included the following resources:

- Easy Read information leaflet about the aim and purpose of the consultation;
- Guidance on how to complete an interview and a focus group, including preparation and facilitation and example questions;
- Resource tip sheet for organisations requiring additional information to support consultation (e.g., information on consent and supported decision making);
- Accessible surveys for different audiences, including video supplementation using Auslan to provide context for the consultation and content and purpose of the consultation;
- A 'HOW' template to be completed by organisations/individuals detailing how the consultation took place, what consultation method was used, and who was included, so that the depth and breadth of the consultation could be characterised. This also indicated the extent to which people with disability participated in and facilitated the consultations; and
- A 'WHAT' template to be completed and returned by organisations/individuals collating the findings from each consultation, to inform the prioritisation task of Phase 3.

Online Focus Groups and Interviews

Online focus groups and interviews conducted through UTS were designed to meet the needs of people with communication disability, including those who need or use augmentative and alternative communication (AAC). This was done in recognition that other data collection methods may not necessarily have specifically included people with complex communication needs. This data collection involved both focus groups (n=3 groups) and in-depth interviews (n=8) conducted online to suit the time and communication support needs of participants. In total, 20 people took part in this part of the project, including 12 adults with disability (people with cerebral palsy, deaf, deafblind, autism, intellectual disability, mental health condition) and 8 people who provided support as a family member or direct support worker. Sign language and tactile communication interpreters were used to support communication in three in-depth interviews. Participants were asked to discuss priority areas for them in relation to disability research, without being asked to rank individual areas of research. There was no aim to reach consensus but rather to allow exploration of

individuals' views and give the groups the opportunity to discuss and consider the issues from their own perspectives and many different angles.

Ethics

Ethical approval was granted by the Human Research Ethics Committee of the University of Sydney (Approval number 2021/318) for the consultations conducted by the Inclusive Research Network (IRN) members of the Centre for Disability Studies and with participants in boarding houses led by Dr Kathy Ellem at the University of Queensland. The Human Research Ethics Committees of The Royal Children's Hospital (HREC 78018) granted ethics for the child and youth component. Ethics approval for the consultation with the mental health lived experience research group at ANU was provided by Australian National University (ANU). As advised by the ethics office at the University of Sydney, consultation by NGOs with their members did not require ethics approval as no primary or individual identifiable data were provided to the project team.

Ethics approval for the online focus groups and interviews was obtained from the University of Sydney Human Research Ethics Committee (approval number 2021/318) and the University of Technology Sydney [UTS Ethics ETH21-6405] from February to April 2022.

Organisation and participant recruitment

The consultation was promoted by Consortium members directly to their networks across Australia, through representative umbrella organisations, peak bodies, advocacy agencies, service providers and through social media posts. The organisation-led consultation ran from April 2021 to September 2021 with targeted consultations extending to April 2022 (mainly due to delays in obtaining ethics).

Organisations varied in how they approached the consultations, adapting the methods to suit the needs of their members. The methodology was designed to allow for this. In total, 21 organisations submitted information responding to the consultation questions or the summarising templates provided for this purpose. One organisation submitted a report on a research priority area, but it was not possible to align the content with the 'HOW' and 'WHAT' Templates for analytical purposes. Thus, their information was not included and responses only from the 20 organisations are presented in Table 1. Four of the targeted consultations facilitated by consortium members in partnership with organisations, were the consultations with and by people with intellectual disability, people living in boarding houses, mental health lived experience research group and children and young people. The findings from these consultations were returned using the same standardised templates as used by organisations, and as such are included in the analysis in this section. The findings from the Aboriginal and Torres Strait Islander survey and the targeted online focus groups and interviews are presented later in this report.

Table 1: Characteristics of participating organisations

State jurisdiction (n=20)	Number
All regions of Australia	5
New South Wales	5
Queensland	3
Victoria, New South Wales, the ACT and Queensland	2
Victoria	2
Did not provide information	2
New South Wales and Queensland	1

The majority of consultations were conducted online, which was a result of the impact of Covid-19. Nine organisations used online team-meeting software, including collaborative whiteboards. One organisation used an online interaction app to enable voting and to allow members to prioritise research areas.

Only three organisations reported they had met their clients or members in person while six organisations stated they had used both online and in-person approaches. One organisation also held a follow up event to present the results of their online focus groups to their members to ensure that the results were endorsed by those members who had not attended the initial focus groups. Another organisation sent a summary of findings back to each individual consulted (either in focus group or interview), and to all those consulted collectively, seeking amendments, additions or clarifications.

As shown in Table 2, 974 persons were recorded as participating in the consultation conducted by 20 organisations who submitted completed result templates[4]. However, actual participation numbers are higher as several organisations did not report final numbers. One organisation did not use the templates, instead using a survey approach to gather their data and ascertain their research priorities. In another the organisation reported that they have 18 different organisations as full members and a further 8 as associate members, and all were invited to participate in focus groups. However, the final number of participants who took part was not provided.

One of the main aims of our consultation approaches was to ensure the inclusion of the voices of people with disability. Organisations were asked to report on the number of people with disability who participated. In total, 149 people with disability (across a diverse range of disability groups) were reported as participants. Most participants were family members of people with disability (n=498), then staff members or people with a designated (professional and paid) role in one of the participating organisations (n=349). The low number of people with disability included in the organisation-led consultations is a limitation of this consultation and is described in greater detail in the Limitations section of the report.

One part of the standardised data return template was the 'HOW' template which provided the opportunity for organisations to report age, gender, cultural backgrounds, and LGBTIQ+ status of the groups consulted. However, there was limited information returned in this regard. Settlement Services International (SSI) conducted an in-person consultation and reported that all 27 participants, including 7 people with disability, were from culturally and linguistically diverse (CALD) backgrounds. Another 3 organisations mentioned including people from culturally diverse backgrounds, but specific numbers of participants were not provided. Nine organisations specified that their consultation participants gave their age or life stage as an important characteristic, and four organisations mentioned gender. The Phase 2a[5] survey captured participant profile data to a

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[4] This number deviates by 12 from the number calculated when organisations reported the numbers of people who were involved in the consultation. This difference could be explained by the fact that some organisations also reported the views of their staff, who were involved in facilitating the consultation, as participants. Other organisations might have excluded these persons from their calculations. However, deviance of 12 by a total number of 996 participants is considered as small.

[5] Smith-Merry, J. J. Plumb, G. Gallego, I. Yen, C. Imms, A. Dew G. Carey, M. O'Donovan, J. Gilroy, S. Darcy, B. Hemsley on behalf of the Research Agenda Consortium (2021) *Setting an agenda for disability research in Australia: Survey results.* Centre for Disability Research and Policy, The University of Sydney: Sydney. ISBN: 978-0-6487544-3-5

much greater extent than the organisation-led consultations of Phase 2b, which tended to report broad group level descriptions. This is therefore a limitation of the information reported in Table 2.

Table 2 Participating organisation and consultation groups

Organisation	Total number of people who took part in the consultation[1]	People with disability	Family Members	Staff or service providers
Achieve Australia	20	0	0	20
AFDO	*No information on consulted people/groups provided*			
ARUMA[1]	9	7	0	9
Boarding Houses	15	15	0	0
Centre for Disability Studies	15	5	4	11
Community Resource Unit	30	0	25	5
Continence Foundation Australia	2	0	0	2
Council for Intellectual Disability	11	11	0	0
Deaf Victoria	43	40	2	1
Inclusion Australia	7[2]	7	0	0
Inclusive Research Network	8	5	4	0
Kindship	212	0	212	0
Lived experience research group, ANU	11	✓[3]	✓	✓
Mobility and Accessibility for Children in Australia (MACA)	464	0	195	269
Murdoch Children's Research Institute	50	16	34	0
NDCO	25	11	6	21
PwD Australia	4	4	0	0
QDN	26	26	0	0
SSI	27	7	20	0
Ticket to work	No consultation held. Research report submitted.			
Vision Australia[4]	2	2	0	0
Total	981	156	502	345

[1]All lines with red shade indicate that the total numbers of people who took part in the consultation are not in line with the respective numbers reported for each sub-group. This is because people fell within different groups.

[2]Inclusion Australia did not provide a 'HOW' template but informed in their document that they conducted two focus groups with a total number of seven participants with intellectual disability and both groups included a co-facilitator with intellectual disability

[3]The group included people with disability, family and providers and provided their information as shown above. Numbers for each category were not recorded.

[4]N=2 refers to number of participants in the Vision Australia focus group co-hosted with CDS. Note that Vision Australia also sent the Phase 2a online survey to all their members (N=13,000) and stated they included people with disability, family members and staff or service providers. Survey responses are reported within the Phase 2a survey report.

None of the organisations reported the inclusion of Aboriginal or Torres Strait Islander people in the Phase 2b consultation. The online focus groups and interviews ran from February to April 2022 with 20 people in total taking part, including 12 adults with disability and 8 people who provide support as a family member or direct support worker. Participants were aged from 25 to 63 years of age. Similarly, to the organisation-led consultation, none identified as being of Aboriginal or Torres Strait Islander background. The parallel survey with First Nations people is designed to ensure inclusion of First Nations people.

Approaches to prioritisation

The participating organisations were tasked with identifying priorities for disability research during the consultation sessions. In total, 15 consulted organisations reported some prioritisation taking place, but not all organisation-led groups discussed research priorities or were able to reach a consensus about priorities, and so provided more general responses. Prioritisation was approached differently by different organisations, with some organisations using individual priority setting during an interview. Four organisations stated that paid staff had performed the prioritisation process and typically used a thematic approach.

The 'SLIDO' app was used by one organisation, and this enabled participants to articulate their opinions through voting on certain issues. Two organisations presented their participants with a list of topics discussed in the consultation (a summary), and the participants then agreed on a ranking of priorities. Another organisation used a whiteboard to present themes from the focus groups, for participants to discuss and agree on a prioritisation.

Most organisations reported that they aimed to work with participants to identify priorities from the research areas discussed, but some were unable to achieve this due to time constraints, or all issues were deemed important and therefore could not be prioritised.

Participating organisations were asked to rate how well their consultations had worked. The majority (n=14) stated the consultation process had worked very well, and four reported it worked well. Two organisations did not provide an answer to this question, and none responded that the consultation had worked poorly or very poorly[6]. Similar findings were provided for engagement of participants. Sixteen organisations stated their participants had been very interested in participating in the project and two that their members were at least somewhat interested. Two organisations did not answer this question.

Data analysis

The data were completed and returned using the WHAT and HOW templates. One organisation did not conduct a consultation but provided two reports highlighting areas of research from a previous piece of work the organisation had completed. Two other organisations did not use the templates and instead provided reports guided by the template but omitting some HOW questions.

Data from all documents were then loaded into data analysis software (MAXQDA Version 11.2.5 by Verbi GmbH, Berlin) and analysed by a member of the University of Sydney's research team. Initial results reported back to the Consortium Core Project Team (see Figure 1) so that critical feedback

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[6] The results of this analysis were collated by analysing a provided "How" template that entailed information on how the consultation worked. While 20 of the 21 participating organisations returned a How-template, one organisation only provided additional information about their organisation that was somehow related to the project but no information with regard to an actual consultation of their members and thus no information about how well or poorly that consultation went.

could be given before another round of analysis started. Summary descriptive statistics and a content analysis approach were used for demographic and descriptive questions on the HOW template. A qualitative deductive-inductive approach was then used to identify themes. Examples of themes identified are human rights, support, participation and engagement (see Figure 1 for full list of themes and sub-themes). Themes and their component categories of meaning are areas for future research proposed through the consultations and identified through the analysis.

Participants were then asked to provide more information on the top three issues that had been identified in the consultations and also to identify one thing that they would like the research agenda to achieve (see Appendix 2). The analysis for these questions was completed by looking at the absolute values of the issues given by the participants or the organisations. No weighting was assigned during the analysis. Some organisation-led consultations named more than three issues or areas and noted that time constraints did not allow prioritisation of individual areas. In other cases, fewer than three areas for future research were named. In the end, a broad picture of research areas emerged as priorities for future research. The analysis showed that these research priority areas aligned well with the areas of life in Australia which the participants in the organisations felt needed improvement (these are not reported here in detail). A general introduction is provided to each thematic area which provides context for the research themes identified and insight into the areas of life that were deemed important to the participants. Within each thematic area a box is provided outlining the specific research questions identified through the consultation process, expressed in the returned templates or constructed by the consultation working team in the process of analysis and review.

Data from the online focus groups and interviews were analysed separately after being collected late in the project in March-April 2022. An inductive content analysis was conducted by three members of the research team at UTS (Hemsley, Almond and Bobyreff) experienced in qualitative data analysis and who had also transcribed the data.

Section 2: Findings

There was one overarching theme and seven thematic areas raised by the organisations as areas where research was needed that could inform work to improve the lives of people with disability. These are presented in Figure 1.
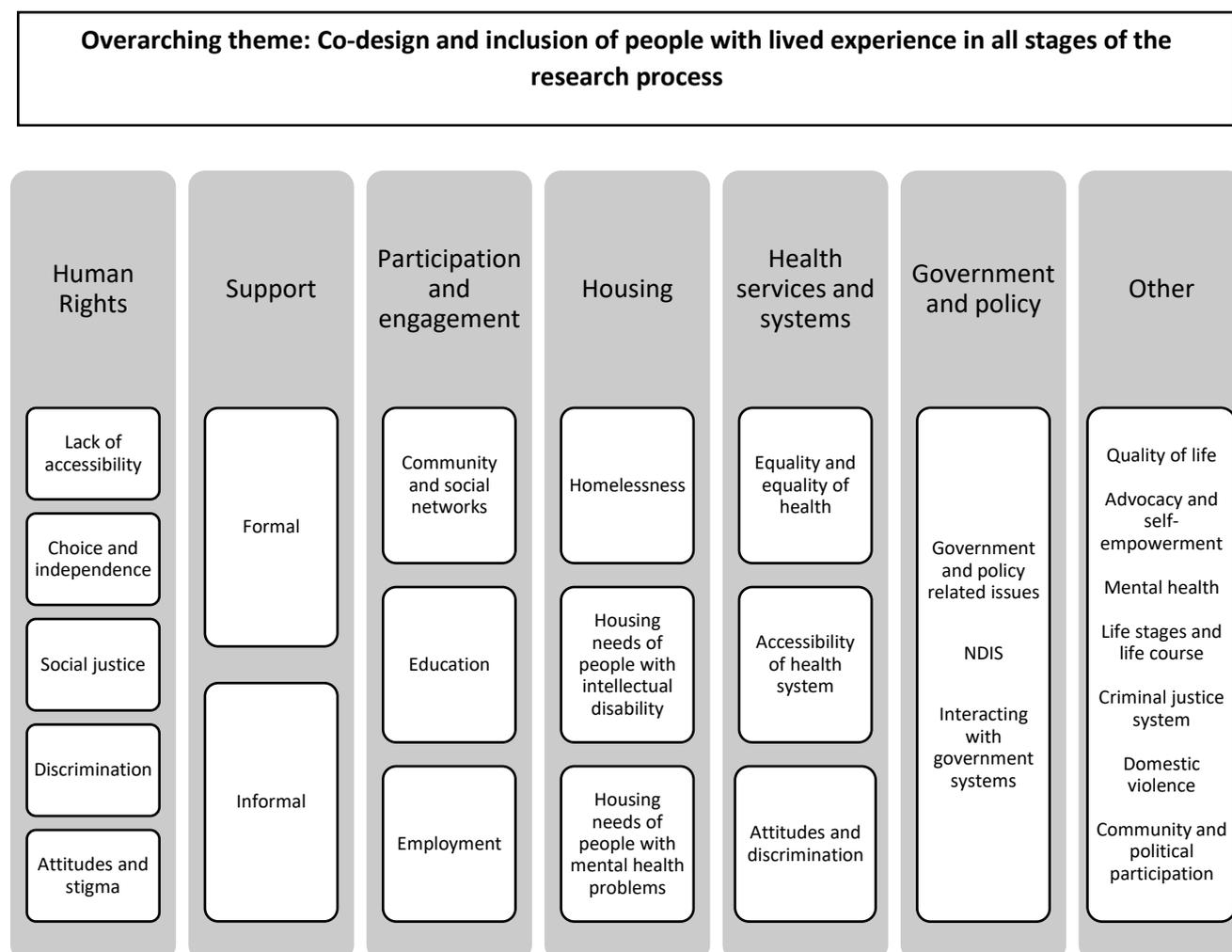
Overarching theme: Co-design and inclusion of people with lived experience in all stages of the research process

Human Rights	Support	Participation and engagement	Housing	Health services and systems	Government and policy	Other
Lack of accessibility	Formal	Community and social networks	Homelessness	Equality and equality of health	Government and policy related issues	Quality of life
Choice and independence		Education	Housing needs of people with intellectual disability	Accessibility of health system	NDIS	Advocacy and self-empowerment
Social justice	Informal	Employment	Housing needs of people with mental health problems	Attitudes and discrimination	Interacting with government systems	Mental health
Discrimination						Life stages and life course
Attitudes and stigma						Criminal justice system
						Domestic violence
						Community and political participation

Figure 1 Thematic findings from organisation led consultations

The focus of this report is the specific issues that are amenable to research and identified through the consultation exercise. A brief introduction to each thematic area is provided based on the broad issues raised in the consultations and which participants indicated as important in their lives and lives of people with disability. A range of the specific research questions or areas for future research are presented in boxes that accompany each section. As noted, some voices are not well represented in this consultation while others are well represented and had high responses. Thus, the questions are examples of those that arose and are important to the groups who participated but by no means represent the full list of potential research areas and no one research question should be considered more important than another.

Overarching theme – inclusive research, co-design and valuing lived experience

The consistent, overarching theme from the consultations was a demand for greater **co-design** and **inclusive research** with a focus on and appreciation of the **lived experience** of disability. This was the dominant research priority identified by all the consultations and linked all the other themes.

Lack of inclusivity was consistently raised by the organisations as a problem with current research. Even though many people with disability indicated they participate in research as subjects, the extent of "true" participation and agency as well as poor dissemination of research findings to participants, has resulted in a sense of exclusion from research. In addition, inclusive research should better reflect the diversity of the disability population, with a specific call to ensure that those groups who are further marginalised by society (such as homeless people with disability or people with disability in the criminal justice system) are also included.

There was demand for more **disability-led research**, consultation and co-design. Organisation-led consultations emphasised the importance of including people with disabilities at every stage of research, including the decision-making processes and leading research projects. Future work should also focus on the 'how' of doing inclusive research.

There was demand for more research focused on the lived experience of people with disability. Participants considered that if the government knew about the everyday lives of people with disability via lived experience and story-telling research, the challenges described in the consultations and experienced by people with disability and their families could be more effectively addressed.

The following quotations illustrate some specific comments relating to inclusive research and co-design:

> *"People with intellectual disability said they want to be listened to in a real way and see action come from what they say."*

> *"Co-design should be a guiding principle in all disability research, with representatives of the relevant population cohort and disability type being involved at all stages including planning, design, collection, and implementation."*

> *"People with disability and their families need to be consulted and included in the research and the design of systems otherwise changes may not be helpful. The National Disability Research Agenda needs to have meaningful co-design."*

> *"Talk to us about how it can be fixed and consult with us better because we're the ones that know about our disability and, yeah, not think that they can just do what they like and say yeah as a token value thing, shut us up."*

> *"The NDRP has a unique opportunity to build capacity in lived experience researchers."*

Box 1: Inclusive research

Inclusive research should:
- Focus on the lived experience of disability.
- Be truly inclusive: more research is needed on methods to increase inclusivity.
- Reflect the diversity of disability.
- Be co-designed with people with disability.

Human rights was one area prioritised for future research by many consultation responses. Issues related to human rights included accessibility, social justice, inclusion and lack of inclusion, bullying and discrimination (and protection), and choice and independence. Each of these is discussed further below. The issue of voting was mentioned by one organisation only, and the focus of this was on enhancing participation of young people with disabilities in voting and the accessibility of voting stations to support participation.

A **lack of accessibility** was reported for many areas of everyday life. The need for and availability of reasonable adjustments across all aspects of life was emphasised. Assistive technology was predicted to become increasingly important for people with disability, either as individuals' need for assistive technology change or to improve accessibility of public spaces. Lack of accessible information was a persisting barrier to navigating the health system, transport, education, and leisure spaces. The issue of accessible information and appropriate formats was raised specifically by and for people with intellectual disability, people in the Deaf community, and people with vision impairment or low vision. Access to information in a person's preferred language was highlighted by CALD groups. Accessible (and safe) transport, including in rural and remote areas, was a particular concern for participants in the 18-30 age group.

Having choice, access, and control over one's life was mentioned frequently, followed by being able to pursue a typical life trajectory with opportunities and sense of purpose. The lack of **social justice** for people with disability was reported by four different organisations, with one suggesting that greater social justice for people with disability could be achieved by integrating representatives of marginalised groups as full members and leaders.

Three groups in the consultation raised **discrimination** as an urgent issue. Discrimination was seen as linked to negative attitudes and prejudice about people with disability, and associated stigma. Thus, it was recommended that myths and assumptions about disability need to be effectively debunked and replaced by an improved understanding and a greater awareness of people with disability. This was, for example, raised for people with intellectual disability, 'invisible' disability, mental health issues, and for people with disability in the tertiary education sector. One consultation group pointed out that a greater understanding of the abilities and contribution of people with disability to the community, and less focus on deficits, would improve perceptions. In addition, there was a call for a review of and research into the Disability Discrimination Act (1992), particularly in relation to how legislation affects Deaf, hard of hearing and deafblind people, with regard to access to information and communication.

Box 2: Research gaps and priorities in the area of human rights

Human rights-focused research should:

- Examine the structures for people with disability in the legal and justice system and whether there are contradictions between international conventions and Australian laws and policies.
- Investigate the consequences of negative experiences in the legal and justice system for people with intellectual disability.
- Highlight discrimination experienced by people with disability that intersects with ageing, or First Nations or LGBTQI identity.
- Inform support of people with disability to make decisions, and specifically to empower younger people with disability in the 10-17 years age group.
- Gather evidence on the role of place and geography in the experience of disability.
- Examine perceptions of disability in the community and in health care.
- Explore how to shift community attitudes towards acceptance and inclusion.

Within the thematic area of human rights, participants wanted more scrutiny of the ways to improve accessibility across all life domains and of services and equipment to adapt the environment for people with disability, through research that:

- Addresses inaccessible communications in the community.
- Focuses on communication needs of people with disability.
- Understands the existing capacities and demands on Auslan interpreters, in order to meet the needs of everyone who needs interpreters.
- Compares the cost of retrofitting design to starting with Universal Design planning and principles.
- Focuses on improving innovation in assistive technology and making it more affordable.
- Investigates motor vehicle restraint options use of harnesses for the transport of children with disability.

Support

Formal and paid

Support was identified as a priority in the lives of people with disability. This generated a need for research to improve formal and paid supports available to people with disability, with an emphasis on support free from abuse and harm. Some organisations also highlighted safety and consistency of supports across the life course and changing life stages or environments; freedom from abuse, harm and bullying; and support person capacity and relationships. The treatment of young people with disability in foster care was specifically mentioned as an area needing more research.

Box 3: Research gaps and priorities in support related areas

Organisations recommended research on formal support to:

- Examine whether government funding for reasonable adjustments granted to students with disability have a positive effect on the access, participation, retention and success of these students.
- Characterize differences between urban and regional support needs.
- Examine the impact of ageing on support needs and provision for people with disability.
- Look to other countries for best practice that might be transferred to the Australian context.
- Identify the support needs of people with disability who are in the criminal justice system or users of illegal drugs, to ensure they receive needed supports while still being able to make decisions for themselves.
- Investigate the effectiveness of community-based supports and services for people with disability that take a holistic approach.
- Explore the dissonance between support need and support received, and implications for the self-determination of people with disability.
- Understand and challenge systemic issues that enable harm and abuse to occur in support settings/relationships.
- Understand experiences of young people with disability in foster care.

Informal and family carers

Parents and family carers suggested better access to respite services is essential for their needs. Consultation participants also spoke of the financial, health and other stressors that accompanied caring for a family member with disability. The impact on siblings and siblings' carers was also discussed. Potential future research areas related to informal caring are presented in box 4.

Box 4: Research gaps and priorities in caring, carers, and informal supports

Organisations recommended research on family care and informal support to:

- Identify services and interventions that help carers and other family members such as siblings.
- Track long term health and financial impacts of caring on carers, including between generations and on sibling carers.
- Understand the impact of disability on the mental health of carers and other family members, including impact on siblings.
- Examine the financial security of families living with disability, with research particularly needed on financial stress of ageing carers and women carers.

Participation and engagement

Community and social networks

Evidence about social inclusion, that is the inclusion of people with disability in all their diversity as full members of the community, was identified as a research gap. Having meaning and purpose in a group or community, with social networks, friendships, and other personal connections for people with disability, were highlighted as important elements of inclusion. The connection between community inclusion, social networks and community attitudes and stigma was discussed as well as

the need to make people with disability more visible in communities to challenge negative attitudes. Related to these issues, areas for research suggested in the consultation are outlined in box 5.

Box 5: Research gaps and priorities in the area of community and social networks

One specific research question identified in this thematic area was research that:

- Measures the socio-economic costs and benefits of social inclusion.

The human rights themed research already outlined, and research to enhance inclusion in education and employment detailed below, also contribute to this area of research on community and social networks.

Education

Education emerged as an important area in the consultation and was elaborated on by seven different organisations. First, participants commented that people with disability still have limited access to education. The need for equitable access, as well as supports at transition points, were highlighted.

Participants of organisations operating in this sector suggested a need for more peer support on university campuses to improve the experience for students with disability, especially helping to navigate the physical space on campus. It was stated that many university lecturers lacked teaching qualifications to deal with special needs and reasonable adjustments in the classroom. It was felt that there was a need for more equitable forms of assessment.

For better educational outcomes, participants also suggested that disability needs to be demystified and the potential of people with disability to continue to higher education be promoted.

Although there was a strong emphasis on technical and further education was strongly represented, the issues of having sufficient support during primary and high school and enhancing development of independence in early years learning was also raised.

Box 6: Research gaps and priorities in the area of education

Research in the area of education was proposed to:

- Benchmark current practices and identify the gaps and omissions in existing government policies.
- Focus on identifying and removing ableism in schools, colleges and universities.
- Understand long-term graduate outcomes for graduates with disability.
- Examine the nature and extent of supports required at various transition points in education, including transition from education to employment.
- Focus on the impacts of Aboriginality and cultural diversity on the transition to and participation in tertiary education of people with disability.
- Focus on variety of disability among the student population and include the voices of students with disability and storytelling of lived experiences in disability research about the tertiary sector to better cater for their needs.
- Investigate reasonable adjustments in the education sector to see if they are fit for purpose and achieve the intended outcomes, and the costs and benefits of flexible supports.
- Assess current teaching practices, including existing supports, and differentiate between universities and TAFE institutions.

- Identify the prevalence and success of specialised University or TAFE career supports for students and graduates with disability.
- Develop more equitable assessment practices.
- Understand whether the NDIS makes a positive difference for students with disability at post-secondary level.
- Identify models of universally accessible support for tertiary education and how this enhances inclusion of students with disability.
- Identify how teachers can promote independence in many areas of life.
- Understand why the education system is failing people with disability, including the failure to provide education that facilitates access to further training and education.

Employment

Most participants considered having a meaningful job or occupation as vital. Some organisations mentioned that people with disability consider employment a way to contribute to their communities and thus as a mechanism for inclusion and participation. It was emphasised that people with disability need to have equal opportunity in employment and Australia has performed very poorly in this area. As the unemployment rate of people with disability (and especially people with intellectual disability) is still high compared to people without disability, research should focus on how people with intellectual disability can get jobs, and how an occupation can develop into a successful career for people with disability.

Box 7: Research gaps and priorities in employment

Research in the area of employment was proposed to:

- Understand the barriers to employment in the general community faced by people with disability and what processes can be put in place to remove them.
- Understand how employers can be encouraged to see the value that employees with disability provide.
- Challenge workplace attitudes to present barriers to employing people with disability.
- Build the evidence base for inclusive employment practices and examine how to engage with employers to make the workplace more inclusive.
- Examine supports and systems to help people with intellectual disability to find and keep jobs.
- Develop an evidence base for the outcomes of inclusion in employment.
- Compare the extent to which people with disability can progress in their careers and hold leadership positions, with non-disabled peers.

Housing

Participants talked of the importance of **housing**, and of having a place to live that is safe and free from violence. The housing market for people with disability was deemed not fit for purpose. Current housing solutions were considered mostly insufficient or unsuitable, especially for people with intellectual disability. Becoming homeless (which includes being placed in inadequate, insecure and unstable housing as well as rough sleeping) with a disability was identified as involving increased risks. Organisations noted that people with disability who are homeless are highly dependent on availability of public housing. The attitudes of staff in the public housing sector were described as unhelpful because they often take away choice and control from homeless people with intellectual disability. Furthermore, staff in public housing were not capable of determining the needs of people

with disability experiencing domestic violence and trying to access emergency housing, as there is limited knowledge of people with intellectual disability.

It was noted that animals can hold an important place in people with disability's lives, providing companionship and helping to avoid isolation as well as acting as service animals; but pets are often not allowed in certain housing arrangements.

Box 8: Research gaps and priorities in housing

Housing research was noted in the human rights sector under the right to housing. Organisations recommended specific housing focused research to:

- Understand housing needs of people with mental health issues and intellectual disability, including how to cater for people who are seen as hard-to-reach populations, such as homeless people with psycho-social disability, or how to engage with people who choose not to be in contact with formal services. These populations are frequently either directly or indirectly excluded from participation in research.
- Explore issues of housing security and affordability.
- Examine the experiences, pathways, and solutions to homelessness among people with disability.
- Improve access to safe and secure homes and develop and trial support models in housing that promote inclusion for people with mental health issues.
- Understand the knowledge, skills and attitudes of public housing staff working with and supporting people with disability, including people with intellectual disability.
- Examine the right of people to stay in their own homes.
- Examine housing market factors and models of housing.
- Track outcomes of different housing models for people with disability such as semi-institutional, Supported Independent Living (SIL), and customised options such as Individualised Living Options (ILO).

Government and policy related issues including NDIS

The NDIS garnered a lot of discussion across the consultations. Some organisations reported their participants praising the NDIS as helpful or noting that it reduced isolation for Australians with disability. However, there was also a view that the NDIS is a fragile system at risk of break down.

There was a consensus that NDIS supports must be sufficient and sustainable; fear that current supports and funding may be discontinued, and recognition of a need for supports to relieve the caring duties of ageing carers. One organisation reported a wish for a seamless and functioning interface between service systems, where the NDIS supports, health services and educational supports collaborate effectively with each other. The bureaucracy related to NDIS applications was described by some parents as complicated, difficult to navigate and an impediment to accessing funding and services. The process of annual re-assessments was also considered unsatisfactory.

Participants noted that any research agenda must align with the future recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The effectiveness and efficiency with which government money is spent is another future research focus.

Box 9: Research priorities and gaps related to government and policy

Research priorities in government and policy-related themes, and specifically NDIS, were suggested to:

- Understand the social impacts of the NDIS.
- Understand the positive and negative impacts of the NDIS on individuals with disability.
- Monitor the impact of NDIS independent assessments.
- Understand the expectations of people with disability prior to the NDIS and the reality they experience now that the NDIS is operating throughout Australia.
- Identify the persistent barriers to community participation when people have access to funding through the NDIS.
- Evaluate how equitable the NDIS is and whether groups with greater advocacy fare better in this system.
- Examine the experiences of people with psychosocial disability in accessing and managing NDIS supports.
- Examine the experiences of people with disability for whom English is a second language with the NDIS.
- Examine if adequate supports help to avoid hospitalisations of people with disability.
- Examine the social and economic costs and benefits of securing support through the NDIS.
- Examine the interactions of the NDIS, health and education systems.
- Examine the sustainability of the NDIS.
- Examine the effectiveness and efficiency of how government money is spent, and in particular how those people with disability who are most marginalised are impacted by government funding choices.
- Examine the decision making around government motivation for funding of support services more broadly.
- Understand the role of the NDIS in supporting people with disability in tertiary education.

Health services and systems

The intersection of disability and health, and consequently **health services and systems,** was discussed across the consultation. Organisations highlighted that people with disability still lack equal access to mainstream health services and this was therefore an important area for future research. In some cases, this inequity was because people with disability live in remote geographic areas where mainstream health services are scattered, under pressure, or simply do not exist outside of the hospital system. Furthermore, bureaucracy can exacerbate barriers to some services. Some participants noted that GPs and medical specialists communicate by speaking to carers or support workers rather than directly to the person with disability.

Services seldom distinguished between vision impaired people and people with low vision – although both conditions have distinct support needs. This is exemplary of a need for better understanding of the specific needs of people with particular impairments and more specialist knowledge on requirements of people with disability in health services. The consultations highlighted the need for more peer-support workers with lived experience of disability and suggested that the voices of people with disability are included when services are restructured. A greater focus on health needs of people with mental ill health and psycho-social problems and intellectual disability was also recommended.

> **Box 10: Research gaps and priorities in health services and systems**
>
> It was recommended that health system research should:
>
> - Capture data on interactions of people with disability with the health system to identify what needs to be improved.
> - Examine the experience of people with disability of the Covid-19 vaccine roll-out.
> - Examine the interplay of mental health, intellectual disability and access to health services and supports.
> - Examine the interplay of mental health and physical disability for younger adults.
> - Determine any specialist disciplines and supports that may be required for people with disability within the health system. [One example was the lack of specialist mental health and intellectual disability nurses in the health (hospital) system].
> - Determine how to remove barriers to mainstream health services to ensure equality and equity of access for people with disability.

Life course perspective

A life course approach to research, which examines experiences and events across a person's life span, was frequently highlighted as important in the consultations. The lack of life-stage specific research was also raised in relation to person-centredness. Supports and information should be targeted to age groups, with a particular focus on children with disability and related early childhood interventions but also on ageing and disability. Two organisations suggested concentrating on whole-person approaches (taking account of physical, emotional, social, behavioural and spiritual aspects of the person, for example) and on pathways for people with disability, for example in employment, or for children or other specific age groups. Gaps in research in the area of life-stages and the need for future research here are presented in Box 11.

> **Box 11: Life course and life stage research**
>
> Research that addresses the life course and life stages could include:
>
> - Transition to adulthood and to investigate ways to improve the understanding of sexuality in this life stage.
> - Providing tailored services across life stages.
> - Gaps in service provision for older people and fighting ageism.

Other areas of importance and suggested research gaps and priorities

Some topics were less frequently mentioned in discussions but are nevertheless important. These included:

Quality of life such as "having fun", "love", "just being a kid"; or more complex issues relating to quality of life, such as "wellbeing, stability and security of the whole family" or "use social valorisation processes to help for a better life".

Advocacy and Self-empowerment with parents especially mentioning that though they are their child's best advocate, they need access to information and support to know what is available in relation to their children's needs to enable optimal advocacy, and to have the stamina to fight for their child's and family's rights under current arrangements.

Similarly, the **Political sphere, Interacting with government systems, the Criminal justice system, and Domestic violence**, were named as areas in need of improvement but were not developed further in the consultation discussions.

Some specific areas for future research raised in the consultations but not yet covered in Boxes 1-11 are presented in Box 12.

Box 12: Additional research gaps and priorities

Additional research proposed to:

- Examine the role and impact of incontinence in the lives of people with disability.
- Raise awareness of the transport needs of children with disability.
- Examine hate-crime experienced by people with disability.
- Explore the effects of climate change on people with disability.
- Understand and explore leadership and disability and identify mechanisms to support people in leadership positions.
- Understand the experiences of people with disability for whom English is a second language.
- Quantify the number of disability support workers and their economic contribution to the community.
- Examine intersectionality of disability including but not limited to experiences of people with disability who are Aboriginal and Torres Strait Islanders, LGBTIQ+ people, young people, older people, women in domestic violence situations, and people in the justice system.

Organisational perspectives on research gaps and priorities

Organisations that undertook consultations were asked what they themselves rated as the top five areas for research, based on the responses from members in their consultation approach, rather than priorities the organisations may hold independent to member responses. Five organisations did not complete this section and did not name any areas as a priority.

The research priorities listed by the remaining 15 organisations aligned with the priorities identified by the consultation participants. Inclusion and inclusive research were the highest priority areas reported by the organisations. There was an emphasis on doing more inclusive research, valuing lived experience and using the NDRP as an opportunity to build capacity in lived experience research. One organisation recommended filling the existing data gap about Deaf, hard of hearing and deafblind people through inclusive research.

Organisations also gave the broader area of social inclusion as a general research priority as well as providing evidence to support efforts towards greater inclusion in and access to education in particular, tertiary education and employment.

Research into community attitudes was identified by six organisations as a top priority area, specifically ways to change attitudes, target social norms and beliefs about people with disabilities by enabling their stories to be told, tackle stigmatising attitudes and discriminatory behaviours, and raise awareness among professionals about people with disability.

In terms of healthcare and support systems priority should be given to research to improve medical care for people with disability, and research on service and system issues, family and person-centred practices across the healthcare system, and staff competency in the mental health system.

Some areas were only prioritised by one organisation and unsurprisingly these were often related to the mission and purpose of the organisation. They included early intervention for children with a disability, ageing and disability, and trauma-informed parent wellbeing initiatives.

One organisation also identified the need to tackle existing unconscious bias against people with disability by ensuring research narratives do not consider disability as solely negative.

Access, use and impact of research

Organisations consulted with their members on their access to and use of research, and their perspectives on current and desired impact of research. The findings below are based on data in the consolidated templates submitted by organisations following consultations with members and thus reflect the perspectives of participants in the consultation.

Access

Six of the organisations reported members using **search engines** such as Google or social media outlets to identify research relevant for their needs. Being a member of an organisation, for example a disability support organisation, was also given as a common way to acquire research articles. Informal networks such as peers or carers were another way to find research of interest. Two organisation led consultations mentioned that they would get their research and information through health professionals and GPs.

Some participants had no access to research literature as it **is mostly hidden behind paywalls** and with most of the organisations operating outside of the academic field, they do not benefit from university library subscriptions to research journals or databases. One organisation reported that although it can be a requirement to reference research in applications to the NDIS, many allied health professionals lack access to current research because it is not openly accessible.

The use of academic jargon was another frequently mentioned barrier, especially for people with intellectual disability. The professional language typically used by research publications makes it extremely difficult for people with intellectual disability to understand the meaning of the words and sentences. Thus, some participants suggested providing easy read summaries for those research pieces that specifically dealt with topics of concern to people with intellectual disability.

One participant group noted that people cannot access research as Auslan is their first language and English (the main language used in research articles) their second. A similar challenge was reported by another organisation in that publications are not accessible to blind or visually impaired people who often use assistive technology to access research outputs. Particularly for elderly people with disability, the digital technology gap was named as another barrier that hinders access to research outputs, which are now mostly digitalised.

Another challenge reported by participants was the difficulty to **find and determine high-quality research**. The criteria used to assess the quality of research are not always available and transparent to people working outside academia. Thus, it can be difficult for them to make this judgement.

Participants emphasised the **dissemination of research results** as critical. Participants of research were seldom informed about the research they were involved in or related outcomes from the research. One response suggested that knowledge could be shared between organisations. As noted above, the communication needs of people with disability should inform the format of research dissemination materials. Organisations also suggested broader distribution of research findings through information shared on TV, across media platforms or even through MyGov.

Use

Participants had used research evidence to inform practice as well as decision and policymaking. Research was also used to become informed about a topic and/or to stay up-to-date about a condition and related developments. Individual and organisations reported using research to improve the lives of people with intellectual disability, their families, and their carers, especially co-designed and co-delivered research. Research was being applied by one organisation to develop a mental health toolkit, an example of how evidence is used to support practice. Research about people with disability should be data-driven, that is, the research question should be based on existing data and the research itself should aim to gather more data. The availability of reliable data was seen as important.

Funding

Funding for disability research was considered a scarce resource. It was felt that in general the government does not provide sufficient funding for disability research and that this was especially true for research with Deaf and deaf-blind populations. It was recommended that funders focus on quality, methodology and scientific appropriateness of research. The potential for research translation and impact in the field of practice was suggested as another criterion by which to judge research and evaluate research effectiveness and thus inform future funding.

Impact

Implementing and evaluating research findings and exploring the potential to scale-up for greater impact and benefit for people with disability was recommended.

One organisation-led consultation group highlighted that clinical practice in Australia often lags far behind the latest research from overseas. They further emphasised that doing research about disability is often dependent on researchers with postgraduate degrees, which typically excludes people with intellectual disability.

Issues of importance to online the focus group and interview participants for future research to improve the lives of people with disability

Analysis of the individual interviews and online (focus group) discussions of research priorities identified 12 main themes, along with one category of 'other' content, which appeared to a lesser degree in the focus group and interview data transcripts. The purpose of this part of the consultation was not to facilitate comparison across methodologies but to include an often-excluded group and realise commonalities in findings and representing a different voice.

In alphabetical order, these interconnected (and not mutually exclusive) categories were:

- Accommodation, Advocacy, Attitudes & Awareness, Communication Access, Education, Employment, Health services, Mental Health, NDIS, Support Workers, Transitions, Safety, and Other (less frequently mentioned issues of inclusion/exclusion; gender; starting a family; transport; technology).
- Transitions and **support services,** together with the NDIS, connected several themes impacting the lives of people with disability participating. Discussions about **transition** included issues related to **ageing** and **health**, and transition from **educational** to **employment** settings.
- Participants frequently mentioned the problems encountered when leaving school and facing adulthood with much fewer supports available and few options in terms of accommodation, employment or education. Indeed, **transitions** and **support services,** along together with the NDIS, connected several themes impacting the lives of people with disability who took part in the online interviews or focus group discussions participating.
- Another strong connecting theme was research to address **community attitudes** and to generate greater **awareness** of disability in both health services and the general community.
- A recurrent theme concerned the multiple impacts of disability culminating in **increased risk of mental health** conditions for people with disability and their supporters, particularly family members providing support across the lifespan.

The intersection of these themes meant that no one priority could be addressed in isolation, without addressing multiple areas of need for greater knowledge that can inform strategies to remove barriers and enhance facilitators to inclusion. The need for **accessible health services** and **better ways to engage with the NDIS** and associated support services, along with improvements in the preparation and support of the disability support workforce, was emphasised repeatedly. Many of the participants had a communication disability, but the majority did not rely on assistive communication systems or interpreters to get their message across. Nonetheless, communication access issues were raised as impacting multiple areas of life, because mainstream community services have negative attitudes towards people with communication difficulties and are not aware of how to implement communication accommodations or strategies, disempowering the person with disability and potentially reducing safety. Connected with this theme was a focus on **legal and advocacy** issues for people with disability, particularly the need to develop self-advocacy and exercise self-determination and decision-making.

First Nations survey

Associate Professor John Gilroy, who is a Yuin man from the NSW South Coast, led the development and implementation of the Aboriginal and Torres Strait Islander survey in consultation with the First Nations advisory group. This group included Aboriginal (Elizabeth McEntre, Danielle Manton, and Ninti One researchers) and non-Aboriginal (Jen Smith-Merry) disability scholars. The Ninti One team and the University of Sydney project team worked collaboratively to build key research survey

questions for an online survey to be constructed and distributed to a broad range of sample participants.

The First Nations engagement was led by Associate Professor John Gilroy working with a First Nations advisory group, which consisted of First Nations people and non-Indigenous people and were conducted in partnership with Ninti One[7]. Ninti One, an Aboriginal owned professional services company building opportunities with and for Aboriginal and Torres Strait Islander people through research, innovation and engagement, were engaged prior to the initial tender in order to collaboratively develop the project. Ninti One has a history of doing First Nations owned and led disability research during the launching the NDIS in remote and rural communities. Their role was to work with Associate Professor Gilroy to engage and connect with First Nations people with disability, organisations, and First Nations owned peak bodies in the health, disability, and community service sectors who have insight and expertise in a culturally respectful manner. Having Ninti One on the team ensured the research proposal and implementation was co-develop and led by First Nations researchers and fit within the overall project methodology. In the planning stages of the project we reached out to key First Nations disability organisations and academics to join the project. Some were able to do so but others did not have the capacity to be involved. The Ninti One Project Team who undertook this research were: Adriana Schembri (Arrernte/Gurindji) – Project Manager/Research Officer and Tammy Abbott (Lurtija/Pintupi) – Senior Research Officer.

It was decided initially that the approach to First Nations data collection within the consultations would involve a survey and focus groups. However, due to the increase in Covid-19 during the period of data collection and the toll of this on the communities that Ninti One wished to connect with, the focus groups could not proceed in a timely fashion (that would meet the needs of the overall project to be completed for the funder). As a result, it was decided to proceed with the survey on its own and combine findings from the First Nations data within the national survey in order to create a greater, pooled data source. During phase one, the group discussed the importance of First Nations voices in designing the Research Agenda. Associate Professor John Gilroy and other First Nations advisory group members utilised national contacts to garner input into drafting the survey, including having discussions during Government hosted Aboriginal and Torres Strait Islander advisory group meetings.

The First Nations data collection was approved by both the Aboriginal Health and Medical Research Council (AH&MRC) Human Research Ethics Committee (approval number 1858/21) and the University of Sydney Human Research Ethics Committee (approval number 2021/636).

The First Nations-focused National Disability Research Agenda survey was live from Wednesday 2 February 2022 and concluded Monday 7 March 2022. The survey was distributed via email to Ninti One's networks, then advertised online through social media platforms. Members of the Advisory Group also distributed the survey via their networks to ensure a good, managed, spread of the survey. Data analysis was completed by the Aboriginal researchers working within Ninti One.

First Nations data analysis of the Phase 2a survey was completed by the Aboriginal researchers working within Ninti One. Ninti One researchers brought together descriptive statistics from the closed response survey items and undertook a thematic analysis of open text responses. This analysis is brought together with the overall analysis from the consultation in the discussion section of this report.

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[7] Ninti One **https://www.nintione.com.au/**

Results

Across the phase 2a survey and the First Nations survey in phase 2b 31 Aboriginal and Torres Strait Islander people were included. 38% of First Nations participants were from urban locations, 31% from regional, 21% from rural and 10% from remote locations.

The most frequently prioritised areas across all surveys were the **experiences and needs of Aboriginal and Torres Strait Islander people with disability, mental health needs of people with disability, the personal experiences of people with disability, discrimination and abuse** and t**he rights of people with disability**. The most frequently prioritised areas are listed in table 3, below.

Table 3 Most frequently prioritised areas by Aboriginal and Torres Strait Islander participants.

Topic area	Number of participants indicating choice
Experiences and needs of Aboriginal and Torres Strait Islander people with disability	17
Mental health needs of people with disability	15
The personal experiences of people with disability (e.g. of accessing and receiving support, participating in education, employment etc.)	12
Discrimination and abuse	10
The rights of people with disability	9
Housing	8
Communication technology (e.g., speech generating devices) and communication needs related to technology (e.g. using telephones, computers)	8
Disability workforce-related issues	8
Self-advocacy of people with disability	7
Public attitudes to people with disability	7
Early childhood intervention services and supports	7
Supports for daily living	7
Disability-related adjustments or accommodations (e.g. accommodations that assist someone with disability to participate in education, employment, live independently)	7
The design and operation of the NDIS	7
Experiences and needs of people with disability from Cultural and Linguistically Diverse communities	6
Criminal justice	6
Health literacy (accessing, understanding and using health information)	6
People with complex needs	6
Experiences of unpaid carers, supporters, family members and/ or allies	5
Communication access	5
Technology development and access	5

Selections were made based on the personal experiences of participants from their own lived experience of disability, supporting people with disability, or working in the sector.

There was a strong demand for **easily accessible disability information** and **correct training provided on the information.** There are not enough resources available to support their clients' needs and not enough support available for themselves, the carers or those with a disability.

The information that is currently available is not always suitable because it is not free, it is hard to find and it doesn't consider the diversity of needs of people with disability. It is not being presented in user friendly ways: Plain English, Braille, Auslan or different Aboriginal and/or Torres Strait Islander language groups, and there is no thought put into access of information for remote communities or the delivery of information in remote communities along with considering additional barriers Aboriginal and/or Torres Strait Islander people face through intergenerational trauma and systemic racism.

When delivering training or information to Aboriginal and/or Torres Strait Islander people it needs to be delivered with culture in mind, training needs to be presented on the ground in remote communities and facilitated by Aboriginal and/or Torres Strait Islander people. Within Aboriginal and/or Torres Strait Islander people the term 'Care' or 'Support' is essentially different to what many other Australians refer to it as. Aboriginal and/or Torres Strait Islander people take it upon themselves to care for their family members with disability rather than externalising the role of caring. This is due to a lack of services within remote communities and incorrect information being provided not in a culturally appropriate way. This type of care is something that is embedded into Aboriginal and/or Torres Strait Islander peoples culture. To make effective changes there needs to be switch in perception towards Aboriginal and/or Torres Strait Islander caring and cultural practices in relation to disability research aims and results.

Participants also spoke about research needing to take an intersectional view:

> "Intersectionality of disability with other identity markers such as Aboriginality, gender"

> "We need to realise we are not just disabled but female/male, old/young, etc. Our intersectionalities impact how we are in this world."

Participants strongly endorsed the need for more inclusive and community-controlled research and research outputs:

> "Research needs to focus more on disabled voices and stop centering non-disabled voices, regardless of their relationship with actually disabled people."

> "Research still fails to meaningfully engage in co-design most of the time. It is a responsibility of non-disabled disability researchers to be engaging in co-design, and ultimately, building up the next generation of disabled researchers."

There was also a need to conduct research with 'harder-to-reach' groups which would take more time but would stop those people's voices from being continually missed from disability research. This includes "criminalised women and sex workers" and "Aboriginal people that live in regional, rural, remote [areas] of Australia".

Participants also spoke about the ways that research could be conducted that would make it more useful for people with disability and their families. In these responses there was a strong interest in reciprocity, for example "when the research is conducted, a follow up for the families. The aftermath of the interviews can leave scarring and reopen wounds."

Section 3: Discussion

This discussion brings together the findings from Phase 2a (online survey) and 2b (organisation-led consultation, First Nations survey, online focus groups and interviews).

The dominant theme in the organisation-led consultation was a demand for greater emphasis to be placed on the lived experience of people with disability in research, with more inclusion of people with disability across all aspects of the research process and co-design. This raises questions of capacity building for disability-led research, both in disciplinary areas where disability research has historically taken place but also in disciplinary, interdisciplinary and transdisciplinary areas where such research is still uncommon. There is a need to support lived-experience research careers, and to include a diverse range of people with different experiences of disability, including intersectional experiences.

One approach suggested is to create adequately funded scholarships and prizes for disability research to help create and advance existing scholarly careers. It is vital to include First Nations communities in these schemes, given the limited number of First Nations scholars including those who live with disability, and the limited academic attention given to this population. The First Nations consultation highlighted greater need for research that includes the voice of and is led by Aboriginal and Torres Strait Islander people with disability.

Research was also seen as a way to identify, highlight, and address human rights issues. A range of research gaps in accessibility, assistive technology, attitudes, discrimination, choice, stigma, and rights to housing were noted. The need for research in these areas was further supported in the First Nations survey and online focus groups and interviews. In particular, research on communication needs, access to mainstream services, and rights and advocacy were prioritised. Consulted groups also proposed specific research directions under the thematic areas of support (formal and informal), education, employment, participation and engagement, housing, health services and systems, and government policy such as the NDIS.

The consultation data also indicated that there is an inverse relationship between the highest support needs and lower participation level across all areas of citizenship. It is the most "disabled" who have least access to participation. People in rural and remote locations, including in remote First Nations communities, are also disproportionately excluded for society, supports and services. For First Nations participants, family capacity to provide support over the longer term is connected to availability of formal supports that are presented in culturally relevant ways. Less frequently raised areas of future research included quality of life, advocacy, incontinence, transport, domestic violence, and the criminal justice system.

The survey of Aboriginal and Torres Strait Islander peoples with disability indicated a need for research into violence and trauma. Both the organisation-led consultation and the online focus groups and interviews recommended taking a life course approach to research, with specific questions on transition points suggested. Considering intersectionality in research practices and topics was also strongly promoted in the First Nations results.

These responses from phase 2b consultations align with the results from the National Survey reported in Phase 2a. In that survey, there was notable emphasis on the need for greater inclusion of people with disability and their lived experience in research, service design and policy. Like participants in the Phase 2b consultations, survey respondents stated that research would be more useful if it involved people with lived experience of disability, their families, allies, and supporters

through a partnership with researchers at all stages of research including agenda setting, development and framing of research questions, design and governance. Phase 2a survey respondents also mentioned the importance of inclusion so that people with disability guide research priorities and the research undertaken. Furthermore, disability services and policies should be guided by the interests and needs of people with disability. Research findings should be distributed in forms that people can use in their lives and work.

Not all the topics were raised by all organisation consultation exercises in this phase of the project, with some (quality of life, advocacy, and self-empowerment) mentioned by a small number and others (political sphere, interacting with government systems, the criminal justice system, and domestic violence) by just one.

These findings from the organisational consultation are in line with the Phase 2a survey responses showing differences by participant-reported role. For example, the 'rights of people with disability' was a higher priority for people with disability, their families, allies and supporters, First Nations respondents and advocacy/peak organisations, when compared with people in paid provider roles, academics and government employees. There was a somewhat similar pattern for 'public attitudes to people with disability'. Government employees' top priorities were also different from those of participants (only four of this group's top 10 priorities were among the top 10 priorities overall). 'Integrated care across systems' was ranked first by government employees, while for people with disability it ranked lower at 16th than for any other role-based group.

Both the Phase 2b consultations and the Phase 2a survey highlighted the importance of translation and dissemination of research in accessible formats and ensuring open access of research. Having open (free) availability of research articles (not behind a paywall) and easy to understand summaries of research that outline the main research points would make research more accessible. They also needed to be translated into culturally accessible formats and resources for First Nations people.

Areas for future research that had been expected but were not raised in the organisation-led consultation included transition to retirement, civic engagement and voting (one organisation raised voting), young people with disability in the youth justice system, as well as health system issues related to responsibility for health of people with disability at state versus national levels and its impact on service provision.

Overall, the issues of importance in the lives of people with disability and that should form the focus of future research were closely aligned between the Phase 2a survey respondents the Phase 2b organisation-led consultations and the First Nations data.

The aim of Phase 3, the next phase of the NDRA project, is to identify potential focus areas to inform the development of a national disability research agenda. To meet this aim, evidence from Phases 1 and 2 of the NDRA project will be consolidated to develop an online survey, to capture a diversity of concerns and interests of people with disability as well as of other stakeholders including families, providers of disability and mainstream services, researchers, and policy makers, to refine and identify future research focus areas aims to synthesise the findings from Phases 1 and 2 and will present these via an online survey to a range of stakeholders who will be asked to confirm the relative importance of a range of proposed research agenda themes towards the development of a refined and consolidated Australian disability research agenda.

Section 4: Limitations

Overall, several limitations to Phase 2b of the project should be noted:

A key limitation is the ***proportion of people with disability*** who took part. Although participant numbers overall were high there were fewer people with disability than anticipated, with greater number of family and paid supporters contributing. The sampling frame to reach people was organisation and network based, and social media advertising was also used to try to reach more broadly. It was hoped that the broad promotion of the survey would reach some people outside of the typical 'disability provider' groups and settings. Nevertheless, it is likely that those not linked with service providers and disability/advocacy groups, such as people with disability in prison, hospitals, and other institutional settings, are under-represented or excluded. Invitations were extended to many disability community groups, including disabled people's organisations (DPOs) and disability representative organisations (DROs), but not all of these were able to respond. Small organisations may not have the resources or capacity to lead consultations; for others, research may not be seen as important and they may have chosen not to take part.

This phase of the consultation is therefore unlikely to have sampled the views of all organisations or community groups, or all people with disability. Nevertheless this consultation is a starting point for identifying a range of future research areas for consideration and highlights the value placed on research by participants as a mechanism to provide evidence needed to address barriers and challenges faced by people with disabilities in Australia. The process also offered an opportunity for learning in methodological approaches for national consultations which can be developed for future work.

Other, limitations include:

- Covid-19 restrictions meant that consultations had to take place predominantly online with only a few face-to-face consultations possible. Online engagement does not suit all people with disability, and not everyone has access to the required technology and/or support to use it. This restriction, unavoidable at the time, will have excluded some disabled participants.
- For the First Nations consultation conflicting priorities such as the Covid-19 pandemic, bushfires, mice plague, floods, and the strain and expectation to participate in the Royal Commission into Disability Abuse, Neglect, and Exploitation, and the Royal Commission into Aged Care, all combined to restrict the capacity of First Nation people with disability to take part. This, combined with the necessary time-limits placed on us by the funder, meant that we could not proceed with the originally planned focus groups.
- The ethics application process proved difficult and delayed the roll out of the First Nations survey. Ethics approval for some groups conventionally assumed to have special vulnerabilities (e.g. children, people with intellectual disability, people with disability living in boarding houses) was delayed. The time between submission to the University of Sydney Human Research Ethics Committee (HREC) to final approval was 65 days. Further approval from the Aboriginal Health & Medical Research Council (AHMRC) was subsequently, and this took an additional 88 days.
- Some organisations found the task of prioritising future research areas, as well as seeking consensus where prioritisation was achieved, challenging due both to the nature of the topic and time constraints of the process.
- The Online focus groups and interviews was a relatively small qualitative study providing individual interview and small group perspectives. In group discussions, individual views are aired, and interaction with other people with disability generates new ideas; this generative

process is not available in one-to-one interviews. However, some participants preferred individual interviews and this meant that these people could take part in a way that would not have been possible if only one method (group discussion) had been offered.

Appendix 1: Consultation working group members

Members of the Consortium and those working on phase 2

Consortium partners: whole of project
University of Sydney (project lead)
Ability First
Australian Association of Special Education
Australian Federation of Disability Organisations
Australian National University Lived Research Unit
Autism Awareness Australia
Centre for Social Impact National (including University of NSW, Swinburne University, University of Western Australia)
Children and young people research group (including Murdoch Children's Research Institute, Monash University, Australian Catholic University)
Community Resource Unit
Council of Regional Disability Organisations
Deaf Victoria Inc. (and Expression Australia)
Deakin University
Disability Advocacy Network Australia
Disability Research Network, The University of Technology Sydney
Family Advocacy
Inclusion Australia
Inclusion Melbourne
Kindship
Nossal Institute for Global Health, The University of Melbourne
Mobility and Accessibility for Children in Australia Inc.
Motor Neurone Disease Australia
National Disability Services
Neurodevelopment Australia
Ninti One
NSW Council for Intellectual Disability
Onemda Research and Innovation Centre
Queenslanders with Disability Network
Settlement Services International
University of Melbourne
University of Queensland
Vision Australia
Academic advisers: Elizabeth McEntyre, Priscilla Ferazzi, Gerard Goggin.

Consortium partners active in Phase 2
Non-government organisations and representatives: Inclusion Melbourne (Nathan Despott; Marita Dunphy); Inclusion Australia (Catherine McAlpine; Becky Rowe); Settlement Services International (Tadgh McMahon); Australian Association of Special Education (AASE) (Rahul Ganguly); Autism Awareness Australia (Nicole Rogerson); Council for Intellectual Disability (CID) (Rachel Spencer); Disability Advocacy Network Australia (DANA) (Mary Mallett); National Disability Services (David Moody; Philippa Angley); Family Advocacy (Cecile Elder); Onemda (Janice O'Connor); Deaf Victoria (Maxine Buxton); Mobility and Accessibility for Children in Australia Inc. (MACA) (Helen Lindner); Michael Bink (AbilityFirst) Academic research team members: Kate Anderson, Michelle Banfield, Gemma Carey, Angela Dew, Simon Darcy, Kathy Ellem, Gisselle Gallego, John Gilroy, Adam Guastella, Bronwyn Hemsley, Christine Imms, Manjula Marella, Keith McVilly, Mary-Ann O'Donovan, Jenny Plumb, Jen Smith-Merry, Ivy Yen.

Appendix 2: How and what templates

HOW template

About your consultation This form is about your consultation process – what you did, how it happened and who was involved. It is important to fill in this form, so that we can know how the information was collected and who it came from.	

About your organisation This section is about your organisation and where you provide services.	1. What is the name of your organisation? [____] 2. Do you give permission for the name of your organisation to be included in the final NDRP report, as part of a list of organisations who helped with the consultation? □ Yes □ No 3. What areas do you service? □ Urban/metro □ Regional □ Remote 4. What states or territories do you provide services in? □ NSW □ ACT □ VIC □ QLD □ WA □ SA □ NT □ TAS
How did you consult? This section is about what you did in your consultation, how you asked people for information.	5. Were the consultation/s done: □ In person □ Online □ Combination of in person and online □ Other (please tell us what you did) [____] 6. What type of consultation/s did you run? Please tick each type of consultation you ran and fill in the details. □ **Interviews** How many interviews did you run? [____] □ **Survey** How many people did you send the survey to? [____] □ **Focus group** How many focus groups did you run? [____] How many people were in each focus group? [____] □ **Workshop (including Online Café)** How many workshops did you run? [____]

	How many people were in each workshop? ☐ **Other (please tell us what you did)**
	7. Which parts of the NDRP toolkit did you use? (Tick all you need to) ☐ Interview template ☐ Focus group template ☐ Information leaflet (Easy read) ☐ Resource tip sheet ☐ None 8. In your own words, please tell us a little about what happened in your consultation/s.
Who ran the consultation? This section is about the people who asked the questions.	9. How many people were involved in running the consultation/s (e.g. asking the questions in an interview or focus group, writing the questions in a survey)? 10. How many of these were: ☐ People with disability? ☐ Indigenous? 11. Were interpreters used in the consultation/s? ☐ Yes – language interpreters ☐ Yes – Auslan interpreters ☐ No 12. Were supporters involved to assist people to take part (e.g. support workers, advocates)? ☐ Yes ☐ No
Who took part in the consultation? This section is about the participants – the people who answered the questions.	13. Overall, how many people took part in your consultation/s? (Please include only people who took part in their own right. We have asked about interpreters, support workers and advocates separately). 14. How many of the people who took part where: **Note:** Where you know someone can fit into more than one answer option below (e.g. person with disability who is also a service provider, person with disability who is also the parent of a child with disability), please count them in both. ☐ People with disability ☐ Family members (e.g. parents/siblings/spouses etc of people with disability) ☐ Staff or service providers ☐ Others 15. In your own words, please tell us about what people mentioned during the consultation/s as important **identities** or **characteristics** about themselves? For example: - Did they mention being **Indigenous** or their **cultural background**? - Did they mention **gender**?

	- Did they mention being **LGBTIQ**? - Did they mention their **age** or **life-stage**? - Did they mention their **type of disability**?
What do you think about what happened? This section is about your thoughts and reflections on what happened in your consultation.	16. How well would you say your consultation process worked? □ Very well □ Well □ Poorly □ Very poorly 17. How interested were the people who took part in research? □ Very interested □ Somewhat interested □ Not at all interested 18. How was the prioritisation process done? 19. Did people reach a consensus on priorities? 20. Do you have any other comments about what happened in your consultation/s?

WHAT template

Consultation Questions Using an approach to consultation that suits the needs of your organisation and its members, and/or people you work with please answer the following questions. The answers should reflect the opinions of your members as discussed during the consultation. The resource pack includes guidance on how to conduct focus groups, interviews and surveys. You may wish to use these or other approaches that suit your members better. You may ask a range of questions but it is important for the consultation process that the following template is completed.

What is important and what do we need to know more about? • During the consultation, what did the people report as things we needed to know more about so that Australia could become a better place for people with disability and their families to live;	

- things that were important to them or the people they support in their lives? - what more do we need to know to make things better for people with disability?	
The role and use of research - During the consultation, what did the people report with regard to - How they use ideas or resources developed by research as part of your work or everyday life - What is research used for? - How is it used? - What features make research useful?	
Things to improve During the consultation, what did people propose in response to the question: 'If the National Research Agenda could achieve one thing to make the life of people with disability better what would it be?' *If more than one thing was reported please record more than one recommendation*	
Research priorities Based on the consultation, what are the top five changes people would like to	

see for people with disability in Australia?	
Additional reflections Is there anything else that came up during the consultation that people with disability and/or families/supporters would like to feedback to help form a 10-year National Disability Research plan/agenda?	

Thank you for your time and contributions today.
The answers from today sessions will contribute to a report that outlines the priority areas for disability research in Australia over the next 10 years.

Please answer the following questions from an organisational perspective	
Having heard about the issues that are important to your members, what is the organisations opinion on what are the top 5 priority areas for research?	
What do you as an organisation hope to do with this information?	

WHAT template – family/children sessions

Each organisation/group will choose and use consultation processes that suit the needs of the organisation and their members or the people they work with. The information collected in this template should reflect the opinions of members/individuals who took part in the consultation.

This template is designed to support organisations/groups who wish to consult with parents and families for their perspectives on the NDRA, and in doing so, also seek the ideas and goals of children and youth. When consulting with parents/families who have a child or young person with a disability, please consider the following:

- To obtain the answers to the topics in the table below (Table 1 or 2), questions can be asked in a variety of ways, for example, using a survey, in a focus group or interview, or in an online chat forum or web-based repository.
- If it is not possible for organisations/groups to directly engage with children, please consider the following:

- o   Prior to the consultation it is recommended that family members are told that we are interested in their perspectives, as well as those of their children and youth.
- o   For that reason, we ask family members to speak directly with their child/youth – to the extent possible depending on age and capacity – to ask what they think, and to report the child/youth perspectives to the consultation.
- o   With parent/guardian permission, children/youth may wish to submit photos, images, stories or statements to explain what is important to them.
- o   Parents/guardians will need to decide whether their dependent young person is able to understand and contribute their ideas.
- Family members are also welcomed to share their own perspectives about the disability research agenda.
- Not all questions need to be answered by every person consulted – children/youth may not have responses to all questions.
- If it is possible to reach children and youth directly, the questions in table 2 can be used

Consultation Questions: For parents/guardians or other family members. In thinking about the questions below, you may wish to consider your own needs as a parent or family member supporting a child with a disability, as well as your child/youth's needs	
1. What is important As a parent or family member with a child with disability, what is important to you in your life? *(Link to the information sheet that identifies areas that might be most important to talk about)*	
What is important to your child in their life?	
2. What helps you achieve the important things What supports, services or other things help you, your family and child do the important things in life?	
3. What makes it hard What makes it hard for you and your family to do the important things in life?	
4. What needs to be improved What problems exist for children and youth with disability, and their families, that you feel need solving?	
5. Looking to the future What are your hopes and dreams for you and your family in the future?	

6. The research focus What do we need to *know more about* so that people, services and governments can better address the needs of young people with a disability and their families? *(In thinking about this question, it might help to consider examples of where research has changed something in the everyday life of people with a disability, or where you think there are gaps)*	
7. The type of research Is there anything you would like to tell us about *how research is done* that would improve its usefulness for families and children/youth with disability?	
8. The impact of research Is there anything you would like to tell us about how you (or your child/youth) are able to *find and use* disability research?	
9. Most important things to change As a parent/family member of a person with disability, if implementing the National Disability Research Agenda could change one or two things in your life, what would they be? *What are the priorities from your perspective?*	
10. Anything else we should know Is there anything else you, or your child/young person, would like to tell us about the disability research agenda?	
Thank you for your time and contributions today. *The answers you have provided will contribute to a report that outlines the priority areas for disability research in Australia over the next 10 years.*	

Consultation Questions: for children and youth

To tell us what you think, you might like to write things down, or share a photo/image, or do a drawing.

1. What is important to you? *You might like to think about what you like to do, what you would miss if you could not do it. This might be things like friendships, school, sport, music, being with your family.* *(Link to ideas/images that show different life situations/activities that might be important)*	
2. What helps you do the things that are important to you? *Things that help could be people, places, activities, equipment, technology, time, transport, or there might be things about yourself (eg your personality or skills) that help you*	
3. What makes it hard to do the important things? *Things that make it hard could be other people, places, activities, equipment, technology, time, transport, or it might be things about your health or disability.*	
4. The research focus What would you *like to tell* the government or the Australian community about what could be done better for young people with disability?	
What would you *like to know more* about disability or services for people with disability?	
5. The type of research Do you have ideas *about how research might be done* to make it more useful to young people with disability?	
6. Most important things to change What is the most important thing that you would like to see change in your life?	

7. Anything else we should know Is there anything else you would like to tell us about the disability research agenda?	
Thank you for your time and contributions today. *The answers you have provided will contribute to a report that outlines the priority areas for disability research in Australia over the next 10 years.*	

Please answer the following questions from an organisational perspective	
Having heard about the issues that are important to your members, what is the organisations opinion on what are the top five priority areas for research?	
What do you as an organisation hope to do with this information?	

Focus group template

FOCUS GROUPS

Organisations may wish to facilitate focus groups to gain feedback relating to the aim of the consultation which is to develop priority areas of disability research for the next ten years. You may utilise existing forums, such as peer support networks, organisational boards, current members or users of services, project advisory groups.

An overview of focus group principles and guidance on how to run a group is provided. There is also an example session plan, with questions to promote discussion on the topic.

Please note good things and challenges that have happened in peoples' lives. Try to prioritise things that people would like to change or have as focus for future research.

Some of the discussion in the group may be sensitive or upsetting for individuals, so we encourage you to ensure support or referral is provided during and after the session.

A focus group is a small group discussion run by a facilitator to learn about issues, ideas and opinions on a topic or topics. It complements other data collection methods such as surveys.

A summary of findings from the audit (included in the resource pack) should be shared with participants before the focus group. You can share the questions or themes to be covered prior to the focus group so they have time to prepare and think about their answers.

Planning

- Number of people: minimum 4, maximum 10.
- Who to invite: people with disability, families, supporters, advocates, staff.
- Room: accessible, private space, with breakout space; or online platform like Zoom.

- Time: 1.5 hours is sufficient 2-3 hours will mean more gets covered. A break will be needed. Online sessions may need to be shorter.
- Equipment: whiteboard, flip chart, or online tools like Mural, Zoom whiteboard.
- Refreshments: cup of tea on arrival and during session.
- Follow up: thanks and summary within 1 week and share report and outcomes later in the year when available.

Roles

Facilitator; to lead the session, manage participants, encourage everyone to have their say and ask further questions to get deeper responses.

Co-facilitator; person with disability (if lead facilitator is not).

Note taker; vital to record key points and quotes, particularly if not recording session. If you decide to record the session full informed and voluntary consent from each participant would be required, with a clear data storage policy in place and explained.

FOCUS GROUP PLAN

This is a guide to run a focus group for the National Disability Research Agenda consultation. Build your session around this plan, be responsive to the people attending and stay focused on the overall goal of the session. Discussions can be in one group or small groups.

Topic	Content
Intro 15 mins	Welcome, acknowledgment, purpose and overview of focus group. Introductions and icebreaker; name and one good thing in your life. This helps people feel comfortable and willing to contribute. Group agreement; set rules including respect, confidentiality, stay on topic. Car Park to record off topic issues and questions for follow up. Research; explain what it is and why it is important.
Discuss 25 mins	Open questions adapted from interview guide: **What do we need to *know more about* so that Australia can become a better place for people with a disability and their families to live?** Follow up prompts (if needed): • What is important in your life? What could be better in your life? • What helps you to achieve what is important in your life? • What could be better in your life? • What are the most important things people can research about disability and the lives of people with disability?
Break 10 mins	
Discuss 25 mins	Open questions:

	Do you ever use ideas or resources developed by research as part of your work or everyday life? Follow up: • What do you use research for? How do you use it? What features make research useful? **If the National Research Agenda could achieve one thing to make the life of people with disability better what would it be?** **Is there anything else you want to tell us that would help form a 10-year National Disability Research plan?**
Wrap Up 15 mins	**Summarise key points and work to put issues in order of importance:** Final comments; Ask participants to name the most important and least important issue. Or, the top three change you would like to see? **Thanks:** thank people for their time and input that will contribute to a report outlining priority areas for disability research in Australia over next 10 years.

Source: this template was adapted from DPOA's consultation guide for UNCRPD Review, 2019

National Disability Research Agenda (NDRA)

Consultation

	The NDRA is a project looking at research for people with disability.
	We want people with disability to take part in a **consultation.** You can talk to us on your own, with support or in a group. We also have a survey you can fill in.
	You will talk about issues you face and ideas you have to make things better. We want to find out what research should be done for people with disability.

	We want to hear from • People with disability • Family members • Carers or informal supports • Staff and service providers
	We want to include • Children with disability • Young people with disability • First Nations people with disability • People from different cultures
	Being involved Contact David Taylor or Greta Westermann at CDS for more information. **david.h.taylor@sydney.edu.au** or **greta.westermann@sydney.edu.au**

	If you would like more information about the NDRA you can go to **www.ndrp.org.au**

Consent Form:

National Disability Research Agenda project

Please read everything on the participant information sheet first.

Then read the information on this form. If you are happy to be in the study please sign your name on the last page.

You can ask someone you know and trust about this form before you sign it.
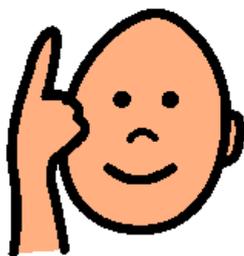
✓ I know what the study is about.

✓ I know what you will ask me to do.

✓ I have talked to someone about the study.

✓ I have received answers for all my questions.
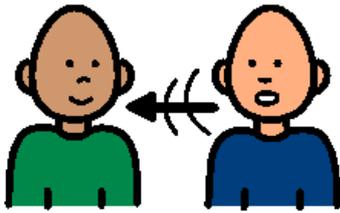
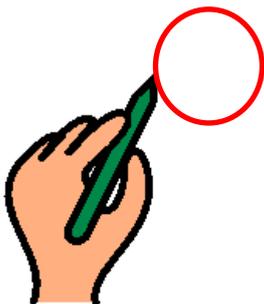✓ I know that I don't have to be in the study if it doesn't suit me or if I don't want to.

✓ I know that I can stop being in the study if I don't want to do it anymore.

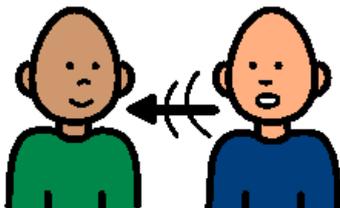✓ I know that I don't have to answer any questions if I don't want to.

✓ I know that the researchers won't tell anyone what I say, unless I tell them about being hurt by someone or hurting myself or someone else.

Please circle Yes or No:

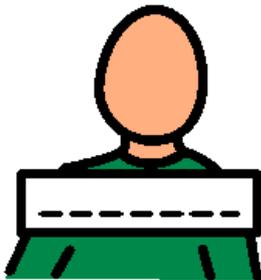**Do you say yes to the information in this form?**

Yes

No

Do you want us to tell you about the findings of the whole study?

Yes

No

My name:

_____

My contact details:

Home phone: _____

Mobile phone: _____

Email Address: _____

My signature:

_____

Interview template

SEMI-STRUCTURED INTERVIEW GUIDE

These interviews should be conducted one on one. It may be useful to include a note taker (if the person being interviewed agrees, and conditions around confidentiality are established). By having a note taker, the interviewer will be better able to focus on the discussion. The interviewee may also have support requirements to be taken into account.

The template contains six questions. Each question has a suggested prompt question to help you enquire for more information.

The interview should take about 20-30 mins maximum.

The purpose of the interview and a summary of findings from the audit (included in the resource pack) should be shared before the interview

You may wish to share the questions or themes to be covered with participants prior to the interview so that they may have time to prepare and think about their answers.

We ask that the interviewer or note taker record the key points of the discussion for each section, rather than transcribe the entire conversation. This should ideally be a summary of approximately 150 words per section. Key points should be checked with the interviewee to make sure that everything they feel is important has been captured. We also ask that quotes be included that highlight an issue being discussed. Please note good things that have happened in peoples' lives as well as challenges. Please try to prioritise (put in order of importance) the things that people would like to change or have as focus for future research.

Some of the discussion may be sensitive or upsetting for individuals, so we encourage organisations to ensure that support or referral is provided after the interview if required.

Introduction

This interview is the opportunity for you to talk about what research is needed to give information on how to make Australia a good place for people with disability to live.

You might want to think about things you have noticed impacting on people with disability that could be fixed.

The answers you give will contribute to a report that outlines the priority areas for disability research in Australia over the next 10 years.

If you don't want to answer anything, you can skip it or you can come back to it later.

If you are talking about something that is upsetting and you want to take a break, let me know.

Source: this template was adapted from DPOA's consultation guide for UNCRPD Review, 2019

Questions

1. **Tell us a bit about yourself and why you want to contribute to this consultation.**
2. **What do we need to know more about so that Australia can become a better place for people with a disability and their families to live?**

Follow up (if needed): What is important in your life? What could be better in your life? What more do we need to know to make these things better for you and also for others?

3. **Do you ever use ideas or resources developed by research as part of your work or everyday life?**

Follow up: what do you use research for? How do you use it? What features make research useful?

4. **If the National Research Agenda could achieve one thing to make the life of people with disability better what would it be?**
5. **What are the top five changes you would like to see for people with disability in Australia?**
6. **Is there anything else you want to tell us that would help form a 10-year National Disability Research plan/agenda?**

Wrap up

Thank you for your time and contributions today. Your answers will contribute to a report that outlines the priority areas for disability research in Australia over the next 10 years.