Building effective system-wide disability research capacity in Australia

What does it look like and how do we get there?

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Executive summary

This research was commissioned by the National Disability Research Partnership (NDRP) and was designed to examine strategies to develop disability research capacity in Australia.

In order to develop disability research capacity, it is important that there is a shared understanding of what effective research capacity looks like. This project engaged a range of stakeholders (43 in total) to identify what effective Australian disability research capacity could look like and the potential mechanisms in obtaining change and forward advancement.

Most participants agreed there is still significant work to do if Australia is to achieve effective, system-wide disability research capacity. Moreover, most agreed that this will not involve 'quick fixes' but will require changes to practical elements of the system, as well as changes to existing mindsets and power relations. As such, the schedule and direction of reform will need to be a carefully thought-through program of change, which will likely take at least 10 years to realise.

Our data suggests that this program of change, and the realisation of system-wide disability research capacity requires the following:

- **The need for disability inclusive research -** a recurring theme in our study was that quality disability research needs to engage people with disability, and the disability community throughout the research process. Research needs to be designed in a way that is disability inclusive, with engagement and inclusion embedded as the norm in conducting disability research. This is required to address the numerous challenges and barriers identified by our participants (as identified in this report), as well as to demonstrate the value placed on the lived experience knowledge gained by people with disability.
- **The establishment of a Disability Research Agenda -** there is a need for a clear and shared disability research agenda that is co-developed with the disability community to focus on identified areas of need. This agenda would identify priority areas for investment and funding, establish programs of work to deliver on priorities, and support the establishment of relationships and partnerships focused on delivering these programs of work.
- **Funding disability research -** a key enabler for effective system-wide disability research capacity is a range of funding mechanisms to support a broader scope of research than is currently the case across a range of disciplines. This funding needs to align with the Disability Research Agenda and support inclusive disability research.
- **Reform of ethics frameworks and assessments -** system-wide disability research capacity requires appropriate ethical frameworks and assessment processes. This is most likely to involve reform to the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research, with suggestions that the NHMRC could establish guidelines on ethical conduct in research with people with disability, similar to the approach adopted for Indigenous research.

- **Developing research knowledge and skills** – system-wide disability research capacity requires a range of development opportunities to enable a more structured and planned approach to developing research knowledge and skills across the disability field. This includes but is not limited to secondments, internships, mentoring and student placements.
- **Changes to university systems, structures and processes** – facilitating system-wide disability research capacity in Australia requires changes to university structures and processes to address the challenges raised by participants, including ableism and mindsets, accessibility issues, precarious employment, and performance expectations.
- **Longer-term partnerships** – system-wide disability research capacity requires longer- term partnerships across the disability field. These partnerships must ensure engagement of people with disability in all aspects of the research process, including research design, applying for and securing research funding, and knowledge translation.
- **More formal mechanisms to enable networking and information sharing** – system-wide disability research capacity requires people from across the disability field to engage in a more meaningful and deliberate way. For example, through conferences, particularly those that are inclusive of people with disability and through communities of practice.
- **Improved knowledge translation** – system-wide disability research capacity needs effective knowledge translation, with research findings communicated well, in an accessible manner and in a variety of forms.
- **A need for a database or clearinghouse of existing and current research** – system-wide disability research capacity requires a curated database that stores translated research. This may include better utilization of the 'disability research collection' in the Analysis and Policy Observatory (APO) database (see APO, 2022a), a well-established digital repository and open access information platform.
- **The need to link and utilise existing datasets** – system-wide disability research capacity also requires mechanisms to access, link and share de-identified data. A mechanism under development, the National Disability Data Asset (NDDA), was discussed as one example of this.

Building research capacity across all stakeholders involved in disability research will require resources to develop both individual research capacity and wider system change. It will require improved partnerships and information sharing between stakeholders, additional resources, and valuing multiple sources of knowledge and skills. It will also require power sharing and, in some cases, relinquishing power. In this report we have outlined several steps that may be taken to achieve this.

Most of all, building effective system-wide disability research capacity in Australia will require changes in mindsets. Mindsets need to be developed that understand the value that is derived from inclusive disability research and co-design, improving the relevance of disability research to both disability and mainstream communities and improving the quality of research itself. The change in mindsets would involve centring and valuing the knowledge that people with disability contribute to the field based on their lived

experience. It would also involve a willingness to readily engage in the rigor and ethics of inclusive disability research, with the view that authentic co-designed and inclusive disability research can be undertaken when there is genuine commitment and sufficient resources to making it happen. The change also requires mindsets that acknowledge the ownership and sovereignty of disability research by the disability community. Finally, the change in mindsets is necessary to provide opportunities so that more people with disability can become sector leaders, high-level researchers and direct and lead programs of disability research – as the saying goes, 'nothing about us without us'.

Study overview

The National Disability Research Partnership (NDRP) was established in 2019 with seed funding from the Department of Social Services (DSS). The aim of the NDRP is to "facilitate a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice" (NDRP, n.d a). At its core is a focus on building a world-class disability research and policy hub in Australia. To achieve this, the Establishment Phase involves five core deliverables: (1) the development of a national research agenda; (2) designing a governance model to support the NDRP over the long-term; (3) mapping and developing disability research capacity; (4) writing of industry practice guides; and (5) piloting a research funding round (Kavanagh and Bonyhady, n.d). The NDRP is guided by a Working Party, made up of people with disability, academics and independent advisors (NDRP, n.d. b) (see Appendix A for background information on the NDRP).

This research was commissioned by the NDRP to support the third deliverable (developing disability research capacity). To develop disability research capacity, it is important there is a shared understanding of what effective research capacity looks like. This project sought to explore this with a range of stakeholders and provide some preliminary suggestions about how this could be developed. In this study research capacity refers to "individuals, teams, organisations and disciplines having the ability (research expertise, knowledge and skills) to undertake research activities and disseminate research findings, as well as the funding, resources / time, and incentives to undertake and engage in research" (Buick, 2021, p.5; emphasis in original). This definition points towards research capacity as something that is developed and influenced at the individual level and by a combination of contextual factors (see Buick, 2021 for further discussion). Furthermore, focusing on system-wide disability research capacity highlights the need to develop capacity across the range of stakeholders involved in disability research. These stakeholders include people with disability, the disability community, advocacy and representative organisations, Disability People's Organisations (DPOs), service providers, academic institutions, and government. In this report we use the terminology of 'people with disability' in line with the NDRP language guidance but acknowledge that others will use or prefer different nuances ofterminology related to ability.

This study was guided by the following research questions:
• What would effective Australian disability research capacity look like?
• What is currently in place to support research capacity?
• Where are the gaps between what is currently in place and what needs to be in place?
• What are good examples of other systems that have effective research capacity? What can we learn from them?

This report contains a qualitative analysis of stakeholder perspectives on the current landscape, with each section containing suggestions on strategies and pathways for potential capacity building and improvement. It starts with an overview of the study sample, followed by the key themes identified in this research. This includes the need for inclusive disability research, a national Disability Research Agenda, improvements to

funding disability research, reform to ethics frameworks and assessments, mechanisms to develop research knowledge and skills, changes to university systems, structures and processes, longer-term partnerships, opportunities for networking, improved knowledge translation, the need for a database of existing research, and the need to utilize existing datasets.

An ethics review to conduct this research was approved by UNSW Canberra Human Research Ethics Committee (HC210784).

Study Sample overview

To explore the research questions, we undertook semi-structured individual interviews with 28 participants and six group interviews (with 14 participants in total) and received one written submission. A total of 43 participants contributed to this research from different organisations. Our approach to the interviews allowed us to explore similar themes with all stakeholders but was flexible enough to raise issues that were important to different individuals. Group interviews were undertaken when participants were from the same organisation (i.e., from the same government department or service provider organisation), were currently engaged in a research project together, or were mutually engaged in disability advocacy.

Invitations to participate in the study were sent to a range of people the NDRP Working Party identified as being influential in shaping Australia's research capacity in the disability space (in November 2021). Due to the timing of the study, and COVID-19, some who were approached were unable to be involved. The final study sample comprised participants from academia, government, advocacy and representative organisations, disabled people's organisations (DPOs) and service providers. See Table 1 for an overview of study participants.

Stakeholder group	Individual interview	Group interview	Written response	Total
Academics that identify as having a disability	5	1	1	7
Community researcher		1		1
Academic	9	4		13
Government staffer that identifies as having a disability	1			1
Government staff	4	5		9
Staff from advocacy and representative organisations that identify as having a disability	1	1		2
Staff from advocacy and representative organisations	3			3
Disabled People's Organisation staff that identify as having a disability	1			1
Service provider	4	2		6
Total	28	14	1	43

Overarching themes

Many participants expressed the view that while the disability field has come a long way, disability research capacity in Australia varies across the whole disability research landscape. This is due to challenges in the existing context of each stakeholder field (academia, advocacy and representative organisations, Disabled People's Organisations [DPOs] and service providers). Many of those familiar with the field will be aware of these challenges so we have not added these into the main body of the report, rather these are outlined in Appendix B as background information for those less acquainted with these challenges.

Most participants agreed there is significant work to do if Australia is to realise effective system-wide disability research capacity. Moreover, most agreed this will not just involve 'quick fixes'; it will require changes to practical elements of the system, as well as changes to existing mindsets and power relations. As such, reform will require a carefully thought-through program of change, which will likely take at least 10 years to realise with actions from a wide range of different stakeholders. However, this magnitude of change is not unprecedented. In interviews, participants indicated where other areas of research or research systems have managed to build capacity through a series of changes and were there are existing areas of solid capacity. We have drawn on these in setting out recommendations in this report.

The themes presented below are elements participants argued need to be in place to realise effective system-wide disability research capacity; often, these elements address current gaps and barriers in disability research. We have also identified suggested ways forward, developed based on participant ideas, suggestions provided during the broader consultation process (involving the NDRP Working Party, and advocacy and representative organisations), and research team reflections on the data. Due to the range of participants, there were a variety of perspectives evident and, as such, in this report we have attempted to capture as many of these as possible.

Good quality disability research engages people with disability: The need for disability inclusive research

A recurring theme was that quality disability research needs to engage people with disability and the disability community throughout the research process. Participants highlighted the need for all disability research to support the familiar refrain 'nothing about us without us' in terms of legitimising the human rights and social place of people with a disability and the right to their voices and decision-making in research that involves them and their community. Participants argued this is important for empowering people with disability and counteracting the large body of historical research studies in disability that were on and about, rather than with, people with disability, conducted by able-bodied researchers and often ableist.

Participants discussed how the sheer number of research projects on the one population group (people with disability), have led to "disabled people have been researched to death" as participants (Int.16). This is an issue because "…this constant stream of people wanting to look at us on the other side of the sheet of glass, and poke around and then make value judgements about our existence. Very little of that is undertaken by disabled people. Even less is undertaken by trusted folk … People do live with a fair degree of fear and consternation about what will happen if they tell the truth" (Int.16). From the perspective of a community researcher: "There's a lot of people out there that claim to work with people with disabilities, but really they just want to take advantage of us" (Int12/13, community researcher). These approaches to research are underpinned by the devaluation or othering of disability; that is, ableism, which is defined as: "…a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human. Disability then is cast as a diminished state of being human" (Campbell, 2001, p.44).

To address these historical power imbalances and demonstrate the value placed on the lived experience of people with disability, participants considered that engagement and inclusion needs to become embedded as the norm in conducting disability research. This means research needs to be designed in a way that is disability inclusive: "…it needs to be collaborative. I don't think that quite means that it shouldn't embrace the expertise of academics who have deep knowledge that an individual with disability mightn't have. So, I don't think it needs to be exclusive, so I'm all for collaborative work for people with and without disability, but let's keep … empowering up our own is important, not just for those individuals, but symbolically…" (Int.32).

Engagement of people with disability enables research teams to ensure research is undertaken in an ethical, sensitive, and respectful way that meets the expectations of the disability community and provides them with sovereignty and ownership of the research. It was reported that, at present, many gatekeepers in both mainstream systems and within the disability community can prevent this from occurring. Several parallels were noted with the respectful and ethical research and community engagement within Indigenous research: "… we wouldn't consider doing an Indigenous project, or doing Indigenous research., that didn't involve Indigenous people. But … I see it everywhere, that doing research for disability doesn't need to include people with disability" (Int.29). Such observations highlight that disability research is a distinct area that needs to be conducted in particular ways given the historical power imbalances and discrimination that many people with disability have experienced.

The engagement of people with disability can take multiple forms, and could be seen as occurring along a continuum encompassing:
• Full engagement of people with disability that are qualified academically, employed as lead researchers or in a research team and contributing to all aspects of the research process.
• Full engagement of people with disability as community researchers or citizen scientists, who are people with disability involved in research teams who engage in all aspects of the research project. Community researchers and citizen scientists

contribute valued lived experience, community cultural knowledge and other ways of 'knowing' to the research process. The focus here is on contributing lived experience, rather than on academic or research qualifications.

- Inclusion of people with disability on advisory groups or reference groups to a research team throughout the research process.
- Inclusion and engagement of people with disability as consultants (usually via a single interview or focus group).
- Involving people with disability as research participants, who engage in the research during the data collection process.

Several participants referred to the idea of 'co-designed research'. However, it was clear that the same term is currently being used to denote different levels of engagement. Some consider co-design to reflect the full engagement of people with disability as leaders in research teams (either as qualified academic or community researchers), whereas others used the term to denote consultation with the disability community.

Different views regarding engagement highlights the need to clarify what constitutes co-designed research, as distinct from consultation processes, and determine the level of engagement expected for different types of research:

> "
> …one of the things that I'm very strong on is the fact that the ladder of participation that's been articulated around communication, collaboration, co-design … the mistake we make is that we judge each level whereas, in actual fact, there's a time and a place for all of them. We make the mistake that co-design is the impossible dream … the pot of gold at the end of the rainbow … but co-design … is about more than just saying, 'this is co-design'. It's about a sense of connection … but also that people - within the organisations that are working with people with disability - recognise their own power and do something to redress that …you actually have to make steps to relinquish some power" (Int.10).

This is consistent with arguments by Purple Orange who note in their booklet on co-design with people with disability "consultation is a process whereby relevant stakeholder views are sought but the decisions are made by others. Co-design is a process whereby relevant stakeholder views contribute not only to the thinking but also the making of decisions" (Purple Orange, 2021:3).

Differentiating between types of engagement recognises that full engagement is not always possible within resource and time constraints. However, our participants suggested that at the very least, and preferably more, all disability research should consult with the community on the topic and design of the research. It should also involve full engagement as much as possible and that capacity building efforts should focus on enabling this. However, participants estimated that realising this aim could take some time, perhaps around 10 years, considering the time to train and develop early career researchers and support them to progress through the academic system to levels of senior academics and leadership roles, both within and outside of universities.

Several participants suggested disability research capacity could be enhanced if a similar approach is adopted to that in the Indigenous research sector, where clear guidance is provided by government regarding the requirement to engage Indigenous Australians in research (see Reform of ethics frameworks and national research standards statement and Funding disability research sections for further discussion). This includes the engagement of Aboriginal and Torres Strait Islander peoples in the Principal Committee Indigenous Caucus (PCIC) within the NHMRC. The NHMRC established an internal working committee, the PCIC, to seek advice on Aboriginal and Torres Strait Islander health and health research issues (NHMRC, 2022). It was felt that a similarly constituted caucus should be developed within the NHMRC in relation to disability research.

Regardless of the form of research, it was noted that the historical power imbalances and experiences of discrimination make the disability research space like other groups where it is recognised that inclusion and engagement are core to the research process. As such, ideally, disability research should involve more than just bringing people together and establishing consultation processes. It should involve the establishment of long-term relationships and trust (as discussed in the long-term partnerships section of this report). Also, in research involving people with intellectual disability, it will require planning and active management to provide the support required to optimise engagement.

Many participants highlighted structural issues in undertaking inclusive disability research, due to it potentially being more complex and resource intensive to design and undertake. In particular, some participants highlighted the historical and current exclusion of many people with intellectual disability from research processes, due to perceptions it is too hard or complicated to achieve this. But as one academic highlighted, this may not be due to not wanting to undertaking research with people with intellectual disability per se, but a lack of skills to undertake inclusive research: "...historically if there was engagement with people with disability, it tended not to be people with intellectual disability. It was just assumed that it was too complicated - but from our perspective - [it is] a matter of lack of skills [by academics] in thinking about how to engage with people with intellectual disability in a meaningful way" (Int.26). Some academics provided examples of flexibility and where they had tailored differing ways of undertaking research to enable the valuable contributions of community researchers: "...we just recognise the co-researcher may have a lower degree of literacy, and so [we] adjust the way they undertake their work as a researcher that doesn't weigh too heavily on their need to be able to use literacy skills. It is often about tailoring the research" (Int.6). This may involve not just translating research documents into Easy English, but also providing materials appropriately for visual learners, such as through animation or video. They noted it was a matter of developing ways for community researchers to contribute their unique knowledge and skillsets, which are useful for the research rather than just claiming it is too hard and time consuming.

Participants also noted disability inclusive research needs to recognise the different time demands and requirements faced by different stakeholders: "...governments and universities have timeframes that you set up, and then have to stick to, because there's funding tied to it, and there's reporting tied to it ... but people with intellectual disabilities in

particular, need more time. You need flexibility. I think there's something about being clear about all of that from the start" (Int.10).

Finally, disability inclusive research also requires active efforts to address and overcome existing barriers, including insufficient time and funding for inclusive research, power relations and imbalances, ableism, insufficient capacity and issues with existing university structures, systems and processes. These barriers are discussed further in Appendix C. Our research highlights that these broader systemic and structural issues need to be considered and addressed when striving to enhance system-wide disability research capacity in Australia.

Suggested ways forward:

1. Education of disability and mainstream research communities on the types of engagement involved in disability inclusive research. This could draw on several published materials and guidelines on how to do inclusive research (for example, see RDI, 2020; SCIE, 2015; Strnadová et al., 2020; Purple Orange 2021). These guidelines outline the principles of co-produced and inclusive research and provide suggestions regarding how to undertake it effectively. We note that the NDRP has a piece underway to develop guidelines around inclusive research.

2. Reflect on lessons learnt from past and current projects involving community researchers and citizen scientists. For example, the Dignity Project presented by The Hopkins Centre: Research for Rehabilitation and Resilience, Gold Coast Hospital Collaborative Grant Foundation, and multiple Queensland Government Departments and Offices (The Hopkins Centre, n.d).

3. The NDRP to advocate for the NHMRC and ARC to develop internal working committees on disability inclusive research that mirror the NHMRC's PCIC. These committees would provide expert advice on co-design and disability inclusive research.

4. Review NHMRC and ARC collaborative research guidelines to incorporate principles of disability inclusive research, mirroring indigenous collaboration principles such as Principle 6, 'Recognition of the right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them (NHMRC, ARC and Universities Australia, 2020: iv).

5. Universities to develop training modules and seminars on ableism and how it plays out in everyday interactions in academia and the research context. This training could cover attitudinal barriers that people with disability often encounter which impede their engagement with research. It could also provide practical guidance on how to balance power dynamics, undertake inclusive research and respectfully and actively engage people with disability in research either as academic researchers, community researchers or participants, particularly people with intellectual disability.

6. Ensure universities have current and comprehensive Disability Action Plans, supported by implementation plans, with components that specifically support inclusive research practice.

Focused, quality disability research needs a national disability research agenda

Most participants identified the need for a clear and shared disability research agenda. Consistent with the observations in the last section, participants highlighted this agenda needs to be co-developed with the disability community to focus on identified areas of need:

> " …there's also people with disability and those who are around them saying, 'this is the sort of research we want to see'. They may not be the ones to do the research. They will be though the ones who say, 'this is a problem that's important for us and this is one we would like people to investigate'" (Int12/13).

In 2011 a National Disability Research and Development Agenda was developed (DSS, 2011), with participants noting that its core elements such as the need: (1) to develop co-designed research (with people with disability); (2) for structural changes requiring people with a disability to be key researchers on projects; (3) for increased resourcing; and (4) for more effective knowledge translation. These themes are all evident in our data and presented below. The recurring nature of these themes suggest that many themes from the 2011 agenda have not yet been implemented or, at the very least, implementation has been patchy and not systematic. This may be partially due to the formation of the NDIS in 2013 that virtually eclipsed the achievement of any widescale outcomes from the agenda. The 2014 Audit of Disability Research in Australia that was undertaken by the Centre for Disability Research and Policy at the University of Sydney highlighted further fragmentation of the disability research landscape (see Centre for Disability Research and Policy, 2014). This was again reiterated in the updated audit in 2017 (Centre for Disability Research and Policy, 2017).

Our research suggests this fragmentation has occurred for several reasons. First, the research currently undertaken is often initiated by academics, mostly in response to funding rounds and not always in response to what the disability community is saying it needs: "…researchers …in the past have come up with the problem – and that's not such a bad thing necessarily, but …if the problem hasn't emerged from what the community is interested in, then I think it doesn't have the value that's needed" (Int12/13). Second, many participants noted that the NDIS seems to have become all-consuming in terms of the research agenda with high levels of focus on policy frameworks and service delivery through the scheme. Most participants acknowledged that, while researching the NDIS is important, disability research needs to cover a much broader program focused on improving the lives of people with disability more broadly, as well as blue sky research. Some highlighted that the research agenda also needs greater cohesion across states/ territories and federal governments:

> " …there is a complete paucity remaining in the States and Territories around research with data collection pertaining to disability and education and health systems etc.; and there seems to be huge reliance and pointing to the NDIS for this intelligence, and it is just the tip of the iceberg , and it doesn't help us to get a sense of how nationally both ends of the system can work well; so the NDIS will only be successful if participants can get all of the social and economic community based

> support that they need, and vice versa people will only be able to access those things if they've got the right support through the NDIS if that is the nature of their disability, so there just isn't there cohesion" (Int.14).

Many participants noted there was a real need for a focused approach to funding a disability research program (such as potentially though the NDRP), rather than the haphazard provision of multiple disability grant topics.

Participants identified the requirement for a long-term national research agenda, developed with the disability community, to enable the disability research field to become more focused. This agenda is important because:

1. It signals priority areas for investment and funding.
2. It helps establish programs of work to deliver on identified research priorities, to which individual projects can align. This could help enhance the coherence and integration of disability research, rather than a more fragmented approach driven by the interests of individual academics.
3. Establishing programs of work aids concentration of research activity and helps identify areas of expertise that need to come together.
4. Identifying areas of expertise helps inform where investments in partnerships should be; through knowing what the long-term priorities are, partnerships can be established around key bodies of work that have a long-term orientation and drive collaborations.
5. A long-term orientation towards priority areas could help establish career pathways in these areas.
6. It could inform the research topics for Higher Degree by Research theses.

It should be highlighted that the NDRP is currently developing a new national Disability Research Agenda which will direct its focus for disability research; this is expected to be released in July 2022. The NDRP is well positioned, if funding is ongoing, to drive this agenda forward for the next decade.

Suggested ways forward:

7. NDRP to consider the findings of the National Disability Research and Development Agenda (2011) and the proposed national disability research agenda for the NDRP, 2022 to adopt and promote a broadly themed research agenda that identifies priority areas that are currently significant gaps in disability research.
8. Identify ways to ensure investment occurs in programs identified in the new NDRP research agenda.
9. New National Disability Research Agenda to be used as leverage to increase sustainable research funding by grant bodies.
10. Different stakeholders sign up and commit to the research agenda and use this to underpin funding for research priorities.
11. If funding is ongoing, NDRP to drive new 2022 research agenda forward for the next decade.

Funding disability research

Linked to the topic of the research agenda, it is unsurprising that greater investment and funding for disability research was identified by all participants as being key to building capacity. Several participants noted a shortfall in the overall amount of funding disability research obtains in comparison to highly funded fields such as health and medicine.

Participants noted that a lack of funding in disability research was inhibiting research capacity and improved outcomes for people with disability. Amounts of funding received for disability research were contrasted with other fields that have received significant investment and have achieved improved research capacity and outcomes such as public health. It was noted that disability research attracts minimal philanthropic and Australian Research Council (ARC) funding. Participants did comment that the NDRP funded projects were a good start; however, there was insufficient funding for the range of proposals submitted and, therefore, there will need to be additional funding streams secured from other bodies and/or an increase in NDRP funding specifically.

It was specifically noted that the National Health and Medical Research Council (NHMRC) is considered an effective funding source for many disability researchers; however, this funding is specific to medical and health research and does not necessarily integrate more social science-based disciplines that may be needed for a more rounded exploration of disability-related issues.

These findings suggest that a key enabler for effective system-wide disability research capacity is a range of funding mechanisms to support a broader scope of research across a range of disciplines. These funding sources incorporate the NDRP, Australian Research Council (ARC), NHMRC, philanthropic and other governmental funding sources, including from state and territory governments. This may involve the ARC and NHMRC running more dedicated disability research funding rounds, as they do with Indigenous specific funding schemes. The recent NHMRC targeted funding round for improving the health of people with intellectual disability is one example of this.

Some participants suggested that the funding criteria for ARC and NHMRC grants need to be reviewed. One participant suggested that the NHMRC's consultations with Indigenous people in their working group advising on funding application requirements should be mirrored for disability research funding applications. This approach could also be expanded to the ARC, to ensure funding applications on disability research are only funded if they adhere to inclusive research principles. It is noted that such processes exist in the research councils of several countries; for example, the Economic and Social Research Council (ESRC) in the United Kingdom.

Importantly, picking up an earlier theme, funding also needs to be adequate for supporting inclusive disability research. This means the funding may need to cover a longer timeframe and provides additional resources for co-design methodology, including pre-study disability community consultations, translations to easy-read, and meeting accessibility

requirements (i.e., captioning for data collection). Research teams also need to be adequately funded to enable researchers to use diverse research techniques to 'reach' all in the community and be funded for the additional time and effort required to do inclusive research well. This includes additional resources to employ people with disability as community researchers, and supports for people with disability to be members of advisory and reference groups, and participants:

> "…funding for the participants and the researchers with disability also needs to happen at that early stage, and we need more work to be done listing the actual true cost … of what it means to be completely accessible; the actual cost of alternative formats, or of in person accessibility assistance, or providing accessible spaces for the research and the participants. You know, it takes time to do these things, and that's really important because truly providing access takes extra time, extra people, extra technology, sometimes a guide dog or two as well as extra money" (Int.37).

Further, the requirement to engage Indigenous Australians in research is established in the NHMRC Indigenous Research Excellence Criteria and this should be mirrored in disability research. The Criteria identify the requirement for community engagement, for the research to derive benefits for Indigenous Australians and make broader contributions for, and build capability of, Aboriginal and Torres Strait Islander peoples (see NHMRC, n.d). Similarly, the Health Research Council of New Zealand requires research teams to obtain ethics approval before they fund projects involving Māori participants or projects undertaking research on issues relevant to Māori health. Thus, funding for research is granted only after research teams have demonstrated they have consulted with Māori communities, agreed on the form of community engagement, and indicated the level of involvement of community in the research design, development and implementation of the research (see HRC, n.d.).

It was also suggested that:
- Funding criteria should ensure that applications demonstrate the genuine engagement of academics with disability and/or include community researchers wherever possible, in all disability-related research, and the use of consultative reference groups and advisory boards comprising people with disability.
- Designated funding for people with disability to undertake research, such as a specified number of ARC Discovery Early Career Researcher Awards (DECRA) for researchers with disability per year. This was deemed important for enabling researchers with disability to establish a track record and fast-track their research capability development and increase the number of academics with disability. It was noted that this funding should include reasonable adjustments criteria if required, whereby it is acknowledged that the circumstances of people with disability may mean they require flexible working arrangements or reduced workload requirements (i.e., 0.8 FTE).
- Ensuring funding criteria for mainstream research applications adopt a disability lens, including the need for applications to identify how the research addresses the needs and priorities of people with disability as well as the benefits generated for people with disability.

Issues regarding funding also highlight the need for adequate funding for advocacy and representative organisations, DPOs and service providers to engage in the research process. A key issue impeding the engagement of these organisations was their lack of funding for research, as this limits their capacity to actually 'do' any research due to the high demands on their time and resources for undertaking core business functions (these issues are discussed in Appendix B). Additional funding was considered necessary to address these issues and to build their research capacity to avoid their research being minimized and superficially undertaken: "…you do need to resource organisations to build that capacity so they can do it beyond tokenism. You also need to build the capacity of people with lived experience and representative organisations to be able to support that process" (Int.8). It should be highlighted that advocacy organisations are often well positioned to undertake research about advocacy.

Finally, as flagged above, when determining how to establish funding mechanisms that support disability research capacity, consideration should also be provided to funding PhD scholarships, as well as postdoctoral fellowships. As discussed in Appendix B (challenges within academic institutions), many academic positions are short-term contracts for individual research projects, rather than on a long-term program of work in disability research.

Suggested ways forward:

12. ARC and NHMRC to run dedicated disability research funding rounds, including for ARC Discovery Early Career Researcher Awards (DECRA) for researchers with disability

13. ARC and NHMRC to develop clear funding criteria for disability research, like the approaches in Indigenous research and in other countries around disability research, including the requirement to engage people with disability.

14. ARC and NHMRC to establish funding criteria for mainstream research, identifying the requirement to adopt a disability lens wherever possible.

15. ARC, NHMRC and other funding bodies to ensure funding decisions are made in a transparent way, aligned with funding criteria. Funding should, in the main, be clearly aligned with the Disability Research Agenda and identified priority areas.

16. ARC and NHMRC to establish dedicated internal councils to review funding applications related to disability research and to communicate and extend knowledge to these funding bodies of disability research issues and expectations.

17. Obtain increased disability research funding from co-investment with philanthropy, a currently under-utilised avenue of funding.

18. Funding bodies to expand funding parameters and allocations to fully fund all elements of disability inclusive and co-designed research.

19. Government to provide specific funding to foster partnerships and networking between various stakeholders in the disability research field; this would help enable the establishment of long-term relationships and trust.

20. Funding bodies to provide adequate and dedicated funding for knowledge translation.

21. The NDRP, if funded adequately, should seek to play an oversight role to ensure the above is occurring.

Reform of ethics frameworks and assessments

Several participants highlighted the challenges they have faced receiving ethical approval for disability inclusive research. Participants described examples of many universities having paternalistic approaches to ethics, that did not provide opportunities to try and do undertake more inclusive research design methodologies: "the challenge of the whole thing is actually doing something that is actually different to what we're doing now and doing something that actually results in a transformation; we're [not] going to have a really profound change to disability research without making a profound change to the way we do things" (Int.28). This highlights the need for changes to institutional arrangements to address these challenges.

Participants argued that such alterations to institutional arrangements and regulatory change are necessary for clarifying expectations regarding quality disability inclusive research, incentivizing inclusive disability research, and holding researchers to account for ensuring they undertake their research in an inclusive and ethical way. It was posited that, through clarifying expectations and incentivizing desired behaviours, these mechanisms can facilitate the behavioural change required and, over time, a shift in mindsets regarding disability: "…you've got to come in at government, you've got to come in at regulation, you've got to come in at legislation. Because …people are unsure, or they try their best to be inclusive but often they just don't have a blooming clue of what that really means" (Int18/19). Several participants noted that unless there are institutional requirements for inclusive disability research, such as inclusive research guidelines for ethics committees, that change will not happen because "…institutions respond really well to levers. That's the reality, is you change the rankings, you change the calculations for the rankings and all of a sudden, we're now - if you could get it in the excellence research, the ERA calculation, overnight, you would change research disability culture" (Int.7).

Some academic participants noted that there needs to be improved understanding by ethics committees on risk and involvement of people with disability as participants. It was noted that just because a participant cohort were identified as disabled, this did not automatically mean they were a vulnerable group. A key example was provided where a study on leadership and disability had to undergo a high-risk review, even though all participants were high-level professionals (e.g., the disability human rights commissioner), that otherwise would have warranted a low-risk review.

Suggested reform of institutional arrangements included:
- Reform of the National Statement on Ethical Conduct in Human Research: The National Statement on Ethical Conduct in Human Research provides guidelines for researchers, Human Research Ethics Committees (HRECs) and others conducting ethical review of research "…[and] emphasises institutions' responsibilities for the quality, safety and ethical acceptability of research that they sponsor or permit to be carried out under their auspices" (NHMRC, ARC and Universities Australia 2018). Key to participant discussions was the need for clear guidance for researchers and human research ethics committees regarding the requirement to undertake inclusive

disability research and engage people with disability as a core part of research teams (wherever appropriate): "…I'd like to see a code, for example, where you cannot actually undertake disability-related research unless you have a certain proportion of disabled people in the room" (Int.16). Whilst not a new concern, with changes to the National Statement a recommendation of the 2014 Disability Audit (see Appendix D), participants argued these changes are key to establishing inclusive disability research as a core principle and expectation.

- Review assessment processes for ethics applications at university level (by human research ethics committees). Some participants argued that any ethics applications in the disability field that did not involve people with disability on the research team should be rejected by ethics committees and, that at the very least, researchers should demonstrate consultation with the disability communities around any form of disability based research: "…the win will be when we get an [ethics] application that considers disabled people and it's not led by a disabled person, we reject it without looking at it - you have to demonstrate to the Ethics Committee why you haven't included people with lived experience on your research team and organisations that represent most people in your partnership group. Like, nothing without us - nothing about us without us should be embedded" (Int7). However, participants also argued that there could be scope for justifying non-involvement of people with disability with a 'if not, why not?' robust statement: "You have to basically prove why you wouldn't have someone with a disability in the research team if you're doing disability research" (Int.22).

Some participants highlighted the need for the NHMRC to adopt a similar approach to disability research as it does for Indigenous research. In particular, it was highlighted that the NHMRC have developed the Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (NHMRC, 2018). These guidelines stipulate the principles of ethical research, where research teams undertake research that is with, and not about Aboriginal and Torres Strait Islander Peoples:

> "
> It is important that research with Aboriginal and Torres Strait Islander people and communities is led by Aboriginal and Torres Strait Islander people and communities. This can mean that the chief researchers and/or members of the research team are Aboriginal or Torres Strait Islander people. It can also mean that research and its priorities are driven and guided by the Aboriginal and Torres Strait Islander communities with whom the research will take place" (NHMRC, 2018, p.2).

As noted above, the Māori Health Committee of the Health Research Council of New Zealand (HRC) has established guidelines and monitors practice on research involving Māori participants or research issues relevant to the Māori community (see HRC of New Zealand, 2010).

Despite the importance of changing ethics frameworks and assessments, some participants viewed them as insufficient on their own. Some argued these changes to

ethical frameworks and assessments are one component of the broader efforts needed to change research culture: "…something like rules or guidelines doesn't change cultures necessarily, but it ingrains over time a particular way of thinking about it because people are forced to think about it and then ideally, it becomes like a nature. So some of it is about changing the culture of expectations" (FG1). One participant expressed less faith in the impact of changes to ethical frameworks: "I would say the issues around ethics are hurdles that one should get rid of, but fix the ethics and you still don't fix it much" (Int.22). This highlights the need for additional changes to a wider range of institutional arrangements, such as university systems, structures and processes (discussed below), as well as entrenched paternalistic cultures and attitudes.

Suggested ways forward:

22. NHMRC to amend the National Statement on Ethical Conduct in Human Research to establish clear guidance for researchers and human research ethics committees regarding the requirement to undertake inclusive disability research and engage people with disability.

23. The NHMRC to develop an ethical conduct guideline and monitor pathways for research with people with disability for researchers and stakeholders, similar to steps that have been taken for research with Aboriginal and Torres Strait Islander Peoples and communities.

24. NHMRC to develop guidance materials for ethics committees to assist in assessing applications that involve people with disability in research. This could involve developing better practice guides.

25. When the NHMRC / ARC's Disability Inclusive Research Guidelines are developed, ethics committees and panels to draw on them when assessing ethics applications for disability research.

26. The NDRP to influence the NHMRC to establish better practice guidance for ethics committees regarding research with people with disability

27. Group of Eight Board and Team to lead the way with reviewing assessment processes for ethics applications at the university level (by human research ethics committees). This includes the requirement to involve people with disability on the research team and consult with disability communities around any form of disability-based research. This could also include the requirement for research teams to justify non-involvement of people with disability.

28. Once the Group of Eight have reviewed and amended ethical assessment processes, other universities to adopt a similar approach.

29. Universities to provide further education to researchers regarding the ethics process being an ongoing practice across the life of a project, rather than just being a point in time approval process. This highlights the need for researchers to continually monitor their ethical practice, ensuring that participants have an ongoing understanding about their rights, assuring ongoing status of consent, and meeting ongoing accessibility needs. All of these measures can improve the benefit to ratio risk and deepen inclusive practice over time.

30. Some participants suggested the NDRP could be an oversight body for ensuring disability research is ethical. This recognises that research is often undertaken by non-academics, who do not have the infrastructure to ensure research is ethical (i.e., ethics committees, approval processes)

31. University ethics teams and committees to seek training on risk versus vulnerability to improve understanding on involvement of people with disability as participants.

Developing research knowledge and skills

Participants also highlighted the need for strategic thinking with respect to developing research knowledge and skills across the disability research field. This would enable a more structured and planned approach to development instead of the ad hoc and unplanned approach that is currently evident. Such an approach would allow individuals to build the specialist skills required to research in this space through secondments, internships, mentoring and placements.

Secondments: the most common development opportunity identified by participants was secondments. Participants argued that secondments across the different contexts and disciplines of the disability field could help develop both research skills and broader understanding of the disability field and how research is undertaken in different contexts and disciplines.

> " … I think for people to have the opportunity to learn how government works is really valuable, and likewise for government officials, to have the opportunity to learn how it works in a disability advocacy organisation or in a university, how research is done, or a service provider. It's trying to bridge that gap between the two worlds, that would be a really huge step forward in my view" (Int.15).

Internships: One participant identified that disability internships, such as those run in the AIHW, could help build disability research capacity: "… as an organisation [AIHW] we participate in the disability internships that we do run, affirmative measures, recruitment exercises" (Int.20), identifying the importance of "sponsoring some of those sorts of opportunities" (Int.28). This would be a good way to build data literacy and analytic capacity. It is also noted that the Australian Network on Disability runs an internship program for people with disability, which facilitates internship opportunities across multiple organisations (see Australian Network on Disability, n.d).

Student placements: Other participants identified student placements as a way to build research capacity. They reflected on how placements were already happening across advocacy organisations, but how these could be better coordinated to focus on priority issues if there was more resourcing.

> " in a survey of the advocacy organisations some years ago, I just asked - lots of them, or quite a few of them, [if they] host students every year …[some] host law students, and then others have students who are doing master's of social work …all kinds of things - some of them have local TAFE students …students at all different levels, and I had the idea that …maybe we could harness the combined energies of the students that were doing these placements, to get them to look at something …what were the potential two or three things that we could get those students to look at across the next couple of years or whatever. We had no resourcing to do [that]" (Int.5).

Mentoring: The need for more mentoring was highlighted by some participants, who particularly noted that researchers with disability require effective and supportive mentoring. However, the lack of disability representation at senior levels led to participants questioning who they could be mentored by. Also, some concerns were raised about how this would be managed: "… I don't know how I feel about mentoring, because people always want to mentor disabled people, but then they don't give them paid work. And even in the mentoring role, that relinquishment of the power structure of the mentor and the sibling, the younger, it should be more a guiding role, but not so much a top down objectively supporting the person with the disability. They have their own power in the interaction" (Int.31). This highlights the need for careful management of the mentoring program, careful selection of mentors and adequate training for the mentors to undertake this role in an inclusive and appropriate way. It may also point to the importance of going beyond mentoring and thinking about the role that sponsorship can also play in supporting people with disability. Mentoring could also be undertaken between academics, bringing experienced disability researchers together with those who are less experienced to develop knowledge and skills. In the health space an example is Hot North where collaborations have been formed to build local capacity for research around target theme areas (see Hot North, n.d.).

Development opportunities for advocates and service providers to understand and undertake research: Participants highlighted the need for more structured professional development for advocates and service providers, particularly in understanding research and data:

> "
> …understanding reading graphs and charts and making sense of them" (Int.5).
>
> "…how to interpret research when they read it. It's going back to that terminology, how to interpret a journal article so that then I can say, 'here's the evidence, how do then I translate it into practice or how do I convey or how do I advocate for young people and how do I read research effectively so that I can advocate for young people well?'. That's the capacity building that's not in an academic world, it's around lay people interpreting the data because as we all know, it can be alienating. I think that's important" (Int.24).

A key area of development identified by one participant is an understanding of research ethics. Given that advocacy organisations and service providers do not have formal ethics committees, like universities do, they deemed it is important for building knowledge regarding research ethics: "…one of the barriers …[to] undertaking our own research and supporting that is building capacity …[is] how do we conduct our ethical research without a formal ethics process. One, yes, we can establish partnerships and approach universities to approve projects, but building the capacity about developing what does it mean to conduct ethical research?" (Int.24). This would also help improve understanding of what good research is and what comprises good evidence.

Development opportunities for government officials and academics to write in plain English and Easy Read: A commonly discussed area where development is desperately required is the ability to translate research for it to be understood beyond an academic

audience. Participants highlighted the need for public servants and academics to undertake training on how to write in plain English, with some recognising the need to develop the ability to communicate research in an accessible way: "…that that is a skill in itself and that not all researchers are experts in KT [knowledge transfer]" (int.30). One participant from government suggested that training in Easy Read format would be helpful, particularly due to the time delays associated with outsourcing this activity: "So my team are doing training and Easy Read because we now have to do it all the time and we've figured that three weeks is basically not workable most of the time. At least if we can try to do it ourselves, or have a crack at it, it might be slightly better than producing inaccessible documents. They might not be perfect and as good as the professional people but it's better than nothing" (Int.15). However, this view was not widely shared, with some participants claiming Easy Read is a technical skill that should be undertaken by professionals. Some people with disability are also visual learners and therefore may require translation not just into written formats, but also video or animation forms of communication.

Suggested ways forward:

32. NDRP to facilitate discussions with government, advocacy and representative organisations, DPOs, service providers and universities to consider and sponsor the suggested mechanisms for development.

33. Government to fund capacity for increased secondment opportunities across different disciplines and in academia, government, advocacy and representative organisations, DPOs and service provider organisations.

34. Universities to work with advocacy and representative organisations, DPOs and service providers to establish disability-focused work-integrated learning into undergraduate and postgraduate programs. This would enable student placements as well as enhanced collaboration across the disability research field.

35. Universities to establish cross-university mentoring programs for researchers with disability. This program will need to be developed carefully and sensitively, including the careful selection of mentors and adequate training and development for the mentors to undertake this role in an inclusive and appropriate way.

36. Government to fund capacity for more structured professional development for advocates and service providers, particularly in understanding research, ethics and data.

37. Public servants and academics to undertake training on how to write in plain English and Easy Read.

38. Universities to implement training modules for academics regarding how to engage people with disability, particularly people with intellectual disability, in a respectful and culturally appropriate way.

Changes to university systems, structures and processes

Facilitating system-wide disability research capacity in Australia requires changes to university structures and processes to address the challenges raised by participants, including ableism, accessibility issues, precarious employment, and performance expectations (see Appendix B for more information).

Changes to university structures and processes include:
- The need for senior champions and sponsors within universities, who advocate, and provide opportunities, for people with disability. For example, appointing a Pro or Deputy Vice-Chancellor (PVC), Disability in universities, responsible for overseeing the education and engagement of people with disability (similar to the appointment of PVC Indigenous). It is advisable that these senior champions also demonstrate an inclusive mindset and behaviours, signalling to others what is expected.
- People with disability appointed to leadership positions, such as the recent RMIT University Vice-Chancellor who has a visible disability, which may encourage others to feel comfortable disclosing their disability.
- The need for greater disability representation in leadership roles, particularly to help address inherent power imbalances (discussed above): "…where is the power in research? Well, it's not just a matter of paying people with disability for their time. The power is in the professorial positions and the staff, that is the truth – we need [people with] disability to be in those positions" (Int.32). However, in proposing this, it is also noted that participants raised issues with people with disability being unprepared or unwilling to disclose disability due to historical and current discrimination against people with disability in university (also identified in Mellifont et al. 2019).
- The need for greater accessibility, including physical accessibility to buildings and workstations; IT accessibility (i.e., screen readers, captioning, accessible websites and databases, ability to participate in seminars, tutorials, meetings, on zoom/ teams); and other reasonable adjustments to enable performance.
- The need for psychological safety for students and researchers with disability. Psychological safety is "the sense of being able to show and employ one's self without fear of negative consequences to self-image, status, or career (employees are safe to speak without being rejected or punished)" (Kalargyrou, 2014, p.124). In this context, psychological safety would be evident if there is a safe environment to disclose disability in the first place: "I think it's really important that universities prioritise students who identify themselves as wanting to go into those fields from undergraduate level onwards – I think there's one or two every year for a student who identifies as autistic and wants to go into autism research, and it encourages them to have the opportunity to disclose in a safe context, in a strengths based context, here's what I'm bringing to the table, here's what I can offer. And they're then empowered both through funding and support at the centre, to develop their careers as researchers" (Int.38).
- The need for affirmative action measures, such as quotas: "Strong policy with affirmative action measures (i.e., quotas) could ensure that more researchers with disability are: a) recruited, b) retained – through the availability of accommodations

and environments that encourage safe disclosure; and c) given opportunities to advance their research careers and attain leadership roles (opportunities that are currently granted far more frequently to non-disabled scholars)" (Int.23).

- The need for dialogue regarding ableism in universities and how it manifests, such as in performance expectations regarding funding and publications, collegial attitudes and perceptions of research quality: "… more of an understanding around ableism …because that's something we talk a lot about in the disability community and it's something that disabled people …so discrimination is an outcome, abuse in an outcome, harm is an outcome, but what's underneath that? Ableism. So my thought is that there's this real disconnect between researchers who have made a career out of research with people with disability, but they don't get that ableism aspect" (Int.31).

- The need to facilitate "crip time" for researchers with disability: this involves accepting and supporting researchers with disability to operate within the limits of what their minds and body can do (for insight into crip time, see Raghavan, 2020; Samuels, 2017): "…It's a shame that academia is so unstable and it doesn't allow anyone to work on what I call crip time … when you have a disability you have to operate within the limits and the constraints of what your body can do, which is crip time, it doesn't necessarily match up with abled bodied time expectations – especially within academia. It's really difficult because you're supposed to have however many publications done for example in order to get funding opportunity and to be able to be promoted and stuff like that. And so that means, instead of elevating people with lived experience who are professionals, who do have academic knowledge, it lowers them in positions to casual positions. So that's the thing, the way that we assess the quality of someone's work is based on able time, not crip time" (Int31); and "…how to factor in supporting those people with fluctuating conditions … so there might be times when they can engage and then they can't, so how to support that. There's a barrier, I guess, for expectations – they may not be able to commit to one, a six-month long project, but if they want to then it's how to support them if they do have to dip in and dip out" (Int.28). This may include flexible working options and making reasonable adjustments with research deadlines and milestones (so they are more achievable) and performance expectations. This will enable academia to benefit from the immense knowledge and insight of people with disability, without risking burnout for individuals (see Appendix B for issues faced by researchers with disability meeting performance expectations).

- The need for more disability specific PhD scholarships and postdoctoral fellowships, with top-ups available if required, to provide sufficient time to complete research (i.e., 3-5 years).

- The need for universities to introduce all students (and not only those undertaking studies relating to disability topics) to content relating to disability and what it means to take a disability lens.

- The need for unconventional / non-traditional career pathways that enable people with disability to enter, and remain in, academia. This would enable more representation of people with disability in research teams: "… in my view, no department, no academic department in a university across the country dealing with disability should be content unless they've got people with disability on their research staff, but we're a long, long way from that at the moment" (Int.32).

Another consideration raised by participants is the location of disability research in academic disciplines. It is well understood that 'disability research' is highly interdisciplinary, with theoretical underpinnings in sociology, philosophy, medicine, design, community services and intersections with the arts and humanities, engineering, IT, education and employment.

Typically, disability studies is located within medical and health faculties. A small number of participants, however, debated whether disability studies should be located within humanities or political science disciplines, particularly given the medicalised-model history of disability, where disability is predominantly viewed through the deficit model, with a focus on how to eradicate or reduce certain disabilities: "…in the US you'll see a lot of disability studies are taking on that critical theory edge, more looking at ableism … that more humanities approach to disability" (Int.32).

In addition, the need for "inclusion of disability as a standard operating procedure" (FG1) was emphasised, with the view that a disability lens should be integrated into all mainstream disciplines. This is particularly important as nearly one in five (18%) of Australians identify as having a disability (ABS 2020). These discussions focused on the need to integrate disability into the teaching curriculum across all disciplines, as well as disability researchers working in multi-disciplinary, collaborative teams to apply a disability lens and incorporating a disability lens into mainstream research: " …mainstream research to actually feature the experiences of people with a disability, and then how do you deal with research that is specific to the needs of people with disabilities and addresses the issues that matter and that impact on their lives" (Int.14). This included universities holding industry days to encourage collaboration across different disciplines to establish disability research projects, with seed funding available to support the establishment and initial stages of these projects.

These discussions included the location of intersectional research; for example, how research can be undertaken that crosses both the Indigenous and disability fields, and questions of where this research is located in terms of theoretical underpinnings, but also in terms of access to that knowledge.

Suggested ways forward:

39. Universities to appoint a Pro or Deputy Vice-Chancellor (PVC), Disability in universities, responsible for overseeing the education and engagement of people with disability. A key responsibility of this role would be to champion, sponsor and advocate for people with disability and disability research.

40. The need for greater disability representation in leadership roles, particularly to help address inherent power imbalances.

41. The need to address ableism, collegial power imbalances and attitudinal barriers experienced by people with disability in university settings with training provided for all university staff.

42. The need for greater accessibility, including physical accessibility to buildings and workstations; IT accessibility (i.e., screen readers, captioning, accessible websites and databases, ability to participate in seminars, tutorials, meetings, on zoom/teams); and other reasonable adjustments to enable performance.

43. Universities have a dedicated funding pool for meet IT access requirements.

44. The need for psychological safety for students and researchers with disability, including a safe environment to disclose disability in the first place.

45. The need for affirmative action measures, such as quotas.

46. The need to facilitate "crip time" for researchers with disability: this involves accepting and supporting researchers with disability to operate within the limits of what their minds and body can do

47. The need for more disability specific PhD scholarships and postdoctoral fellowships, with top-ups available to provide sufficient time to complete research

48. The need for unconventional / non-traditional career pathways that enable people with disability to enter, and remain in, academia.

49. Universities to develop disability material for interdisciplinary curricula that exposes all students to related disability content.

50. Universities to fund interdisciplinary research days offering seed funding to research teams initiating research that positive impact the disability field.

51. NDRP to have a Charter that members sign up to that commit them to advancing capacity across all disciplines to recognise people with disability should be considered in all areas of knowledge advancement.

52. Government to sponsor opportunities for universities to come together to consider strategies to positively support people with disability's career development, particularly in research.

53. Invest in the training and development of early career researchers with disability.

54. Support and advocate for the employment and career development of early career researchers with disability

55. Government to create incentives for universities to create scholarships and specific grants to address the lack of adequate representation of people with disability in research careers

Long-term partnerships

Many participants highlighted the need for long-term partnerships across the disability community, academic institutions, advocacy organisations, Disabled People Organisation's, service providers and government. Currently, one-off research projects are funded, and thus incentivised, rather than broader programmes of work and deeper engagements across organisations.

Participants discussed the importance of having long-term partnerships for establishing the basis for effective disability research that engages people with disability. As discussed above, funding limitations sometimes mean there are insufficient resources and time to co-develop research aims and questions and inclusive approaches in the research design, thus undermining the relevance and impact of research. Some participants considered long-term partnerships as a way to mitigate this, or engaging people with disability in more informal ways. When reflecting on the value of long-term relationships and partnerships, one participant commented: "They get to know [one another] - rather than - I'm trying to stop this sort of - the academics just approaching people they don't know, in a careless way, with poor language and poor understanding of disability" (Int.16). Other participants discussed the need for long-term relationships to establish trust and ensuring that the voices of people with disability are captured, both during formal research and informal processes:

> " I have lots of conversations where I'm thinking about my work, but I'm having conversations with that community around the Disability Royal Commission, or research, or anything like that. And you know, there's no way that they're going to participate in research with someone at a university in [place] that they've never heard of. They don't want to feel like they're studied. And they're like, why would I do that anyway, what's in it for me? Because a lot of research is voluntary as well, … so I think there's hurdles there to capturing some of the more marginalised voices in the less informal… less formal ways, the more informal ways. Sit around and have a yarn and capture the stories. I think universities usually do a really formal call out via social networks or through organisations, and it's not always accessible to people as well" (int.27).

Other participants framed the importance of partnerships in terms of funding. These discussions focused on how partnerships can put research teams in a better position to secure funding:

> " … we were very well positioned to play that game and it would have been very difficult to do, before, very difficult to do otherwise with new partners or anything like that, it was only because we had those established relationships. Every one of those people on the team, I have worked with at least four or five other projects and most of them have worked - all together, not - the whole team hasn't worked together but everybody's worked somewhere with somebody else on something" (Int.7).

Participants also discussed the importance of partnerships to enable capitalising on the research expertise of academics, as a significant level of research capacity typically exists within universities. They argued that this facilitates knowledge sharing to generate new ideas and the dissemination and translation of research more effectively:

> " So, for us it's actually just easier if everyone works together … We get more information, we get more research, we get more ideas and, also, I think the dissemination of research is more effective as well, if everybody is disseminating that research" (Int.15).

Some participants who were disability advocates identified these partnerships as being important to their ability to establish capacity and engage in research processes. When reflecting on how equipped the advocacy sector is to undertake research, one participant said: "I think it varies markedly from very poorly to pretty well - I think university partnerships is perhaps part of it - the mutual learning within the advocacy sector" (Int.26). Some participants who were service providers discussed how they have established a long-term partnership with particular universities or research groups, which have developed over time. They deemed these partnerships as useful for undertaking quality research, as well as enhancing the perceived legitimacy and credibility of that research:

> " …a CEO of a large disability service provider formed a partnership with two universities, one with [uni name] [and] one a conjoint appointment - because I could see that if you are a service provider conducting research, there may be a perceived or actual conflict of interest - and then not sufficient independence in the research and …I knew that, {and that} we could attract alternate forms of funding through that partnership" (Int.2).

In highlighting the importance of partnerships, it was clear from participant accounts that partner selection is also important. For those who had established long-term partnerships, core to their success was the establishment of trust and relationships. As one participant said:

> " I can think of a lot of good examples where we've always partnered with [organisation] …I guess being in there on the ground floor …finding the partner that suits …[who] ask the question that we have. So that's tended to be how it's been when working with [organisation] and finding – and so establishing those relationships …that's really quite critical … You've got to have the relationship to have the trust to know that … both parties are on the same page … philosophically, values wise, ethically and with an understanding of the problem that you're looking at" (Int.35).

A small number of participants also discussed the need for stronger coalitions across multiple universities, government, advocacy organisations and service providers. These coalitions would involve members working together in a complementary way, and with the disability community, prioritising needed advocacy to influence government where reform is needed: "…often that you're expected to achieve that impact, but the funding stops when

you've finished the actual research. You aren't funded to do the advocacy that's desirable to maximise impact from your research - our formal partnership between advocacy and researchers are built into that - it will be an ongoing core capacity to push translation into action" (Int.26).

Certainly, there is a role for 'boundary spanning', where people from different contexts gain experience in other contexts to broaden expertise and knowledge, as boundary spanners can create linkages between government, academia, advocacy and representative organisations, DPOs and service providers. For example, academics working in the advocacy space, and advocates and service providers engaging in and using research. Establishing these coalitions could also aid the development of research skills among advocates and service providers:

> "I think that's where we've got to think about the coalitions of academia and community-based organisations advocacy groups, DPOs and so forth, and how they work together. It's not necessarily that all the research occurs in the university, but the academics can have a really important role in helping or supporting community organisations to do research as well" (Int 17).

> "…Yeah, well sometimes you've just got to live with the fact you don't have the academic research but have academics who are willing to stick their necks out on positions and what we quite often do is have open letters in support of our campaigns signed by a whole lot of luminaries from various backgrounds including research … the fact that even researchers see the wisdom of what we feel in our gut carries some weight" (Int.26).

Some participants also argued that partnerships and coalitions can contribute to improved research and, ultimately, improve the outcomes for people with disability:

> "…I think that if we get better at collaboration we will do 'something' in terms of bettering the lives of people with disability, and the leveraging of that… so doing better research and leveraging those research results just through collaboration; Yes, more money is needed but collaboration will at least help us make progress" (Int.15).

It was clear from our interviews that collaboration is already occurring across the disability field, but the range and capacity for partnerships and collaboration to occur varies quite dramatically. For example, various advocacy organisations and universities had longstanding research partnerships that had been in existence for over decades, whereas other advocacy/service providers had no real affiliation with universities and were not able to drive any research agenda. Often these providers were approached by universities simply to access their cohort of participants and that was as far as the research partnership went. This highlights the need for a central entity to undertake a brokerage role to help foster connections:

> "
> …for some new organisations or people in [an] organisation unfamiliar in the field or don't have those partnerships with universities [they] wouldn't even know where to start, I think a brokerage is a great approach" (Int.3/4).
>
> "…brokering would be good, I think, to help … smaller organisations who don't have a research agenda or culture just because they don't have the funding for it to support that. It's kind of critical" (Int.24)

Key considerations mentioned by participants included:
- The need for partnerships and coalitions to remain independent from government: "… establishing ways of collaborating and working together on things (possibly through new platform) that doesn't involve pre-emptively editing choices on what gets researched, who gets to see that data, how methodologies are chosen and those sorts of things. There's still going to be a degree of independence in some of this stuff…" (FG2).
- The need for partnerships and coalitions to focus on improving the lives of people with disability: "…first and foremost, [partnerships] must be centered and driven by what is important to people with a disability" (Int.2).
- The need to work through the challenges identified in this report, including the lack of resources for advocacy and service provider organisations; how to encourage collaboration when operating in a competitive/market-based system of service providers, and when some advocacy organisations are competing for funding. A challenge is the lack of time of advocacy organisations and service providers, who need to focus on core business: "…I haven't had time. Every single time one of their two-hour meetings crops up, which is a few times a year, there's always something that is a critical, core business thing that I have to be doing" (Int.5)
- The potential challenges with establishing partnerships where there is a history of conflict, yet the need to recognise these conflicts while also putting them to the side and focusing on working together: "I do know of really bad extremes where people have literally rung people up the day before and said will you write a letter supporting this? - just atrocious behaviour. But I think if we really want to move forward, we've sort of got to let bygones be bygones a bit and say unless we do this together, unless we demand together that research has to be with and by people with disability, it's not going to happen" (Int.18/19).
- How to establish sustainable arrangements that do not just rely on individuals; this is important due to turnover being an impediment to progress: "…you spend hours building relationships and then they go, then the people leave. You know, I've been doing this longitudinal study since 2009 and regularly the organisations lose their CEO, they lose their other senior people and they forget, they have no corporate knowledge that they're actually part of the study. So, you have to start all over again" (Int.35).

Networking

In addition to more formalised partnerships, participants highlighted the need for more formal mechanisms to enable networking and information sharing. This would provide ways for people from different parts of the disability research field to engage in a more meaningful and deliberate way. Participants argued these opportunities are important for maintaining an understanding of what is going on, how people are operating and the kind of pressure points, and what is happening. This includes providing informal opportunities for those with common interests to interact:

> "…so you can talk to the people involved, send them an email. People with interests – common interests - can start to connect in a room to collaborate … find out what other people are doing … that sort of very wonderfully messy informal space where people can start bumping into each other as they sort of browse that space and connect" (Int.6).

A commonly discussed networking opportunity is conferences, particularly those that are inclusive of people with disability. Some participants argued that conferences are important for facilitating research and knowledge translation: " …as a national advocacy peak, we would bring in academics and researchers, invite them to come and present at the conference on topics related to …the work that advocates were doing …we were entitled to get access to some of their time and energy and expertise, and for them to help us find what it was we were looking for at that time or talk it through or explain it to us - the knowledge translation bit that you need" (Int.5).

Participants also highlighted the need for inclusive conferences, rather than just academic conferences, that actively engage people with disability. It was identified that there has been some development in this space, but that there is still considerable room for improvement.

> "…the recent ASID conference had an easy read program, and it had … two members of my team from [organisation] with intellectual disability who presented, and there were other speakers with intellectual disability there. There were still many sessions that were not accessible … the audience was other academics … [so we] still have such a long way to go, in terms of being as inclusive as it needs to be. It's still about people, not with people, and as the old adage goes, nothing about us without us" (Int.10).

In the past, National Disability Services (NDS) have run networking conferences for service providers. This enabled the information sharing necessary to build capacity and supporting service providers through transition and change as a result of the NDIS.

However, some stakeholders also highlighted that conferences are expensive to run: "…we used to have an annual national advocacy conference, ran over about maybe eight years. The last year was in 2013, which was the year before I came to the organisation, and it lost money. We haven't had one since, because they're too expensive, and we'll probably

look at doing an online one next year" (Int.5). Therefore, depleted resources (as well as COVID-19) have meant that conferences have been more difficult to run.

Communities of practice

Participants also identified communities of practice as being a key mechanism for networking and knowledge sharing. This would include continuing with, and building on, the community of practice recently established by the NDRP, which participants supported:

> "…the community of practice …It's the start of getting to know other people doing work in this area, so that's been a good thing" (Int.12/13).
>
> "…having communities of practice, that type of thing. Where whatever research is being - new knowledge is being developed, that is sort of widely shared and there's kind of a universal place where people go to tap into that work…So, I think bringing together different - people together in - around the different topics. To sort of I guess maximise the sum of the parts, rather than us all doing sort of our own thing" (Int.3/4).

Participants noted that the NDRP community of practice provided the opportunity and space to discuss what constitutes research and what best practice research is, in terms of inclusive research, working with community, and working with people with disability. It is also a good opportunity to discuss research methodologies and research practice. As well as providing an opportunity to share knowledge, a community of practice also facilitates a sense of community, shared purpose and professional development, particularly for community researchers.

It was also noted that some community researchers and citizen scientists need professional research development, which can be supported by being engaged in a community of practice: "…we've got eight community researchers across our discipline here working on different projects in different levels of depth. We're looking at bringing together a community of practice for them now so that they're not working in disparate ways across different projects. So, they get some better sort of sense of community and shared community and some professional development. But it would really help for them to have some professional development activities and some sense of being part of a larger project" (Int.28). However, as this quote suggests, although the community of practice is a good start, and one example of how to develop the research capabilities of community researchers, additional initiatives are required to realise system-wide disability research capacity.

Suggested ways forward:
56.   Government to provide adequate resourcing and funding for advocacy and representative organisations, DPOs and service providers to participate in research partnerships.
57.   Government to provide funding provided to advocacy and representative organisations and DPOs to build in time for reflection and learning, building and engaging in partnerships, and creating the space for shared learning.
58.   Academics, advocacy and representative organisations, DPOs and service providers should be encouraged to establish formal partnerships, established around research projects or through Memorandum of Understanding.
59.   Universities and the NDRP to stablish mechanisms for advocates to be able to identify specialist researchers in subject areas of interest to their advocacy focus.
60.   NDRP to facilitate opportunities for networking and for communities of practice.
61.   NDRP to provide funding to establish a database to match the interests of academic researchers with advocacy and service provider organisations.
62.   NDRP to facilitate webinars and other forums that bring academics, advocacy and representative organisations, DPOs and service providers together to discuss potential areas of partnership.
63.   Universities consider waiving some research on-costs or provide more in-kind contributions (in terms of wages for tenured academics) to allow advocacy and representative organisations and DPOs to work with academics, even if they have limited amounts of research funding.

Knowledge translation

Participants highlighted that effective system-wide disability research capacity requires improved knowledge translation. This means that research findings are communicated well, in an accessible manner and in a variety of forms appropriate to their purpose, so they can be implemented in practice. If effective capacity was evident, there would be more incentives to translate knowledge and use research in practice. Providing additional funding for these activities could encourage research teams to communicate their research in a variety of formats. This would include short, practice-oriented pieces targeted at advocacy and service delivery organisations, to aid research translation, application / use of findings and impact. Some participants expressed the need for funded research to require a broader dissemination strategy:

> "…every piece of funded research should have that kind of output. Like in the same way that people put at the front of an article you know a kind of plain English statement about what this adds to what we already know. It should be just a default that researchers spit out a plain English thing that is suitable for workers and managers in the industry. Who may not have tertiary qualifications and may not come from an English-speaking background, to understand what this thing means to me. That would save us having to do it ourselves" (Int.3/4).

All participants felt that research translation is a clear gap and that more time and resources are required to enable effective research translation. This would include research teams asking themselves: "...what does that look like for this audience? What does it look like for the CEO of an organisation? What does it look like for the frontline workers? What does it look like for the person with disability? What does it look like for families?" (Int.10).

One of the common issues raised was the difficulties with accessing and understanding academic research, which is often published in journals that could not be accessed by advocacy organisations and service providers:

> "...when research results are developed, not just having them sitting in an academic space behind a paywall, having them accessible in some ways and not just accessible in the academic forms" (Int. 20/21).
>
> "...industry reporting, it's more layman's terms, it's more digestible, it's more usable within the industry and unfortunately academic journals they're not easily digestible, they're not usable, they're not practical, and I think when you're doing valuable research that's playing into this industry, it needs to be digestible. So, whether you were doing a supplement to that paper ... ultimately, we need to go, 'well we're writing this to make a change to this, so we need a translational method of getting that into practice'" (Int.29).

Participants argued that effective research translation also includes translating research into plain English for the general population and easy read language and formats for people with intellectual disability:

> "...reading academic literature can be ...as [much] an access problem for a person with a disability as is a no ramp for someone who's using a wheelchair and wanting to access a building. It is very - there's a barrier there, definitely. I think that if you could actually help people to understand the language, but also offer an alternative where there's a - easier to read kind of and interpret the data and the articles" (Int.24).

Some participants suggested that consideration could be devoted to how Australia could adopt initiatives established in other countries to aid research translation. For example:

- The What Works Networks in the United Kingdom (UK) (see Gov.UK, 2019): "The UK have developed the What Work Networks in the UK. They have a website that you can go into on any kind of subject, and it will tell you whether there's good evidence around those sorts of interventions on a scale, and what some of the findings are in a basic way, and then you click back into that, and you can kind of find some of the studies that are done, and you can click back into some of the data, depending on how sophisticated you are, there's levels in those sorts of ways. It's accessible to a range of different stakeholders if you need to" (Int.20/21).
- The 1:3:25 principle, developed by the Canadian Health Services Research Foundation (see BetterEvaluation, 2014), but attributed by Participant 28 to UK public policy: "...to just have that one page sitting on the front of your reports and things for

accessibility and make that as easy read …we actually do our initial report in Easy Read and then we go on and write the academic article after the actual project … because you should have a responsibility to report back to the people who you've done the research for comprehensively" (Int.28).The UK Social Care Institute of Excellence (SCIE) (SCIE, 2022), who: "… did a 14-week program of supporting people to undertake action research - and everyone said that that program and the research that came out – a fabulous partnership; How could you adopt that model and apply it more broadly? It seemed to be really successful" (Int.2). This would involve establishing a disability research centre of excellence that focuses on research translation, involving "…a partnership between people with intellectual disability and their advocates, disability health professionals and health academics" (Int.26).

Suggested ways forward:
64.   NHMRC, ARC and NDRP to include the need for a broader dissemination strategy in funding criteria, supported by additional funding provided to achieve this. For example, funding for additional time to develop short summaries of research and better practice guides in Plain English, to cover costs associated with outsourcing the translation of summary pieces to Easy read format, and funding to cover expenses to make journal articles available via Open Access. 65.   Funding bodies to consider adopting a similar approach to the Economic and Social Research Council (ESRC) that requires research teams to demonstrate impact with and in communities. 66.   Funding bodies could also provide guidance to research teams on how to optimize impact; similar to, for example, the ESRC's Impact toolkit for economic and social sciences (see ESRC, n.d). 67.   Build on, and expand, existing mechanisms that facilitate good research translation. For example, the Australasian Society for Intellectual Disability (ASID) journals: "…ASID publishes two journals that have very good reputations. One's a practice journal, one's an academic journal. In the field of intellectual disability, we're publishing those, we write, we have commentaries in them. You know, it plays a very significant role … [it needs] some funding to do some of the dissemination and some of the sort of translation work" (Int.35). 68.   Research teams to develop practice guides to aid research translation and use by service providers and advocacy organisations.

A need for a database or clearinghouse of existing and current research

Most participants spoke of the need of a curated database, a connection point or a portal where they could find previous research related to disability research policy and practice. They expressed the desire for both past and current research, including recent research that has been funded and is currently underway, so that research is not duplicated. This was particularly cited by participants from advocacy organisations, who explained they were often approached to engage in research that had previously been undertaken; in these cases, the researchers themselves were unaware of the research, or were trying to source literature and knowledge that was not behind a journal paywall. Further, many participants were unaware of NDRP's 2018-2021 research mapping exercise (Smith-Merry et al., 2021), and the extensive 2014 and updated 2017 Audits on Disability Research (Centre for Disability Research and Policy, 2017) (see Appendix D).

Increased awareness of future research was viewed as important to know who is doing what research, to facilitate collaboration and partnerships across different actors. One participant felt it could contain a 'future research' section where people could nominate and post their interest in various areas to support research collaboration processes "…the NDRP could become …a way of people flying the flag and saying look, we're really wanting to do - we're doing this project. Is anyone interested? …it's really important that we build coalitions by reaching out as well' (Int.18/19).

The development of any database will need to address this lack of access to academic knowledge and information by researchers outside of academia, such as advocacy and service provider researchers (possibly through academic translation work), and also incorporate researchers outside of the field who may not know their research is impacting on people with disability, such as IT or robotics. The database would need to extend to the curation of intersectional research. It may also extend to including individual stories and narratives of living with disability.

Some participants mentioned the Analysis and Policy Observatory (APO) database (see APO, 2022a), the now well-established digital repository and open access information platform, as a source of research information. The APO holds collections of grey literature across various public policy issues, including a 'disability research collection'. Since 2020, the NDRP has had a role in facilitating information within the disability research collection (see APO, 2022b). Information on the APO platform is usually sourced from a wide range of organisations such as government, agencies, regulators, research institutes, non-for-profits and think tanks. However, only a few participants seemed to know about the APO disability research collection and, of those participants that did, they noted that it is not curated and that it is sometimes difficult to navigate: "…the APO - I mean, that's actually adding to the confusion about what research is and isn't - because it's just collecting more and more reports - it doesn't collect the peer-reviewed literature and curate that, it just creates, just collects reports" (Int.35).

Participants who were service providers expressed the need for a database that contains research translation pieces that they could use in practice to support evidence-based service delivery:

> "So really producing intelligence for the field - [for example], for a scheme the size of the NDIS, so much [is] at stake - and for a scheme that is actually predicated on you know a kind of return on investment that's supposed to come from providing effective interventions … it wouldn't be that hard a case to make to put money aside for that kind of service [a database of translated research] for a kind of intelligence for the sector …because how else do you learn what works? How do you know what - how our service is different from the one down the road? Unless your customers tell you or your families tell you or your staff tells you. There's no obvious place to go" (Int.3/4).

Participants who were service providers also expressed a desire for the curation of industry best practice guides to enable service quality improvements. Participants noted they were too time-poor to plough through disorganised digital repositories: "…there is no body in Australia that either does practice guidelines, if you're talking about practice, or does the stuff that the Social Care Institute for Excellence used to do in the UK. There's not even a clearing house" (Int.35).

Further, participants who were service providers also identified the need for a centralized repository for the multi-disciplinary research that characterizes the disability field. This is particularly important due to the tendency for academics to publish research in discipline-specific journals, which are not that accessible for service providers.

> "…it also has to cover …within academic fields the multiple disciplines …to do this properly, you'd have to be part of networks or make connections across [various] academic areas …that might be geographers or social work, psychology, but also the various therapy fields, very different …each of those, they all have a closed area where they discuss among themselves, and they have their own journals, and they have their own jargons …so they don't all necessarily talk to each other, and we have to be able to pick little useful bits out of all of them" (Int.5).

Overwhelmingly, participants indicated that the development of any database would need to be well curated, with the ability to do keyword searches and with as much open access to information as possible. A participant noted the quality of legal databases with effective search filters and capacity and listed legislation, and another participant noted government reports should be on any database with a well-structured framework, given the amounts of research work across multiple levels of government and various state-based and then local governments. Participants also highlighted that the key aims of any database would be to enable research and knowledge translation, be a central location of all disability research, to support networking and minimize duplication of research. As one participant stated: "…it's about community control and ownership of the data - [and] facilitat[ing] a sector conversation and participation in research" (Int.3/4).

Utilisation of existing datasets

A final area discussed by participants is the need for existing data to be utilised, with government agencies supporting its use. This would help address the issue of disability research by advocacy organisations, that is often local and qualitative, being difficult to find and often repeated.

The field could benefit from improved capacity to access, link, translate and share de-identified data. Government participants discussed an existing mechanism in its development stage 2020-2021 – the National Disability Data Asset (NDDA) (see DSS, n.d.). They argued the key benefit of an enduring NDDA would be the ability "…to bring [data] together – otherwise you're stuck with 87 different data sets to find the answer" (FG2). Further, "in linking them together, we'll be able to do things we haven't done before, but before we can link it, a degree of curation is needed, and a degree of data improvement is needed to address some of these issues" (FG2). They also noted that the effective utilisation of an enduring NDDA would require data literacy across the entire disability field to use it in a meaningful way: "if it's not actually able to be translated, then we won't have won there" (FG2). However, they also claimed that the knowledge and skills required to effectively use the outputs from these datasets is currently lacking in the disability field. For example, the skills required to critically analyse and make sense of the data findings to yield new insights, as well as the data literacy required to understand research outputs and limitations with administrative data.

> "…the government's just invested $40 million in the National Disability Data Asset - a linked data asset. We don't really have that many people around the country who can interrogate that in a really thoughtful way; what's going to happen, if we're not careful, is the only people who'll use it is government, and we can't necessarily … trust government to do that in the interests of people with disabilities. So, I think what we want is - and that's a really important skill to build in researchers - any analysis done there needed to be done with the interests of people with disabilities. So, that's why we need their involvement from the get-go, to ensure it's not used against, rather than to promote their interests" (Int.17).

The need for a variety of improved data skills recognises the importance of different knowledge bases and thus the collaborative effort required to undertake analyses that yield new insights. Insightful analyses requires both expertise with analytical techniques and the ability to contextualise data to make sense of what it means and why it is important. But these skills are insufficient in themselves and require effective governance mechanisms and the willingness of the Board charged with overseeing the NDDA to support analyses of these datasets to answer questions that people with disability determine as important.

Suggested ways forward:

70. Government to identify and fund ways to build data literacy broadly in the disability research field.
71. Government to identify and fund ways to build analytical capacity outside of government to analyse NDDA data.
72. Government or NDRP to design and implement training in analytical techniques and make this available to people from across the disability research field.
73. Government or NDRP to develop a data dashboard containing cleaned and linked datasets that are ready to use, including with a neutral explanation of what the data is saying. An example to draw on is the data dashboard at NDS which contains the longitudinal data for the Annual Market Survey and Workforce Census. Establishing this dashboard will enable access to advocates and others without journal access open access to information in a ready to use format.

Conclusion: The way forward

In this report we have identified the key elements of system-wide disability research capacity, as identified by our participants. These include: the need for disability inclusive research; the establishment of a Disability Research Agenda; a range of funding mechanisms for disability research; reform of ethics frameworks and assessments; developing research knowledge and skills; changes to university system, structures and processes; long-term partnerships; more formal mechanisms to enable networking and information sharing; improved knowledge translation; a need for a database or clearinghouse of existing and current research; and the need to link and utilise existing datasets.

From our analysis, it is clear that building system-wide disability research capacity will require action to develop the research knowledge and skills of individuals, alongside wider system change. These changes will need commitment and resourcing for at least 10 years to realise effective system-wide disability research capacity.

Importantly, the full realisation of effective system-wide disability research capacity will rely on a change in mindsets, both within and outside of the disability field. It will require an attitudinal change towards people with disability, with value placed on the immensely valuable knowledge people with disability have gained through their lived experiences. This knowledge helps improve the questions asked in research studies and the quality, relevance and impact of disability research. Making this shift will also require willingness to share and, in some cases, relinquish the power status currently accorded to researchers. Its achievement will require clear statements that establish expectations and mechanisms to incentivise desired behaviours; this will need to be complemented by changes to structures and accountability mechanisms with clear rewards and consequences to reinforce desired behaviours.

Appendix A: NDRP

The establishment phase of the NDRP (June 2020 to June 2022) saw the development of four guiding principles that would drive the NDRP, that aligned with the principles with the UN Convention on the Rights of Persons with Disabilities (CRPD). These principles are:

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

Recognise the knowledge of people with disability in research
- Research 'by' and 'with' people with disability
- Research that addresses the priorities of people with disability as outlined in the national disability research agenda.

Research which specifically addresses people with disability who:
- Require support to express their will and preference, and to implement their decisions
- experience intersectional disadvantage
- Genuine, paid for, co-design with people with disability

Value all forms of knowledge
- Value knowledge creation from many different sources
- Knowledge that is accessible to the community: including journal articles, podcasts, videos and easy read summaries

Australian policy will be informed by research and evidence
- Build research capability
- Build a vibrant, connected and thriving disability research ecosystem
- Create career pathways and targeted support for researchers with disability
- Build capacity of the disability sector to create and use (NDRP n.d. d)

In December 2021, the release of the most recent National Disability Strategy 2021-2031 committed further forward funding to the NDRP of $12.5million over the next 2 years NDRP (n.d. e). This will enable the NDRP to continue its work to develop disability research capacity.

Appendix B: Key challenges in academic institutions, advocacy organisations and service providers

Academic institutions

In discussions about what system-wide disability research would look like, participants argued that a key part of this is: "…disabled academics in disability research. There's no doubt about it. It's really important" (Int.17). This is because researchers identifying as people with disability bring valuable lived experience and subjective understandings of people with disability into research. However, academic participants with disability reflected on the deeply embedded ableism that underpins decision-making, structures and processes within the disability research sector, particularly in universities. This can lead to structures and processes being discriminatory.

The experiences expressed by participants with disability who are as researchers within academia are fraught with challenges. The challenges faced by people with disability in academia have been documented elsewhere (for an excellent overview, see Mellifont et al., 2019), and are reflected in our data. Of the participants that were people with a disability employed in research roles (mostly PhD candidates, and early-mid career researchers), most described power and mindset challenges of colleagues as problematic. Barriers included the mindset of their colleagues, citing ableism as a key barrier to inclusive disability research: "…being inclusive of researchers with lived experience is not difficult. Diversity is natural and the inclusion of researchers with disability in studies about disability should be something that is normal and natural. Such natural inclusion is only made difficult by closed minds and the bigotry and discrimination that closely follows" (Int.23). These attitudes were cited as being an impediment to researchers establishing legitimacy, with participants stating:

> "…so there's this whole attitude thing. I think there's a big thing about oh well, people have a disability, then how could they possibly be eminent researchers? … there's lots of barriers …largely attitudinal but a lot about getting into the system … getting into the system is hard for early career researchers generally …you can't get on grants because you haven't got track record or you need to be linked to some eminent researcher to even get a start …so that requires some real change within universities …what I said about structure, we have to understand what are those structures that allow that capacity to be [prepared]" (Int18/19).
>
> "…sometimes that being taken seriously as a younger academic with disability working in disability and being treated as if it's a hobby of yours because quote you're afflicted with that, therefore, you would be interested in it, wouldn't you? A kind of humouring and not taking them seriously as other researchers are" (FG1).

Other challenges faced by researchers with disability who participated in our research were:
- Difficulties with physical accessibility to buildings and workstations.
- Difficulties with accessibility to IT, including screen readers, captioning, accessible websites and databases. Lack of supportive and accessible technology led to participants being unable to complete research in adequate time.
- Employment precarity: Not having a disability studies discipline to teach into is often a problem in securing fixed employment positions within the university -unless the individual had capacity to teach into another field such as health, or social work or geography related to their PhD/ research work, they often had difficulty securing fixed term work at a university.
- Performance expectations regarding community / service / engagement / leadership: participants discussed the expectation they would be involved in disability politics and advocacy within the university and in the community more broadly: "…you do all this silent capacity building as a person with a disability - stuff like I was doing a whole lot of unpaid advocacy when I was working in academia with all sorts of people, the tech people - I had done all of this background advocacy where I tried to get the university to make sure that when we're rolling out online we are proactive about accessibility and making sure that we have resources and a standard around captioning. So I was doing all of this for weeks in advance. And it took six, seven, eight meetings and a lot of work, and all of that stuff doesn't get counted, and yet it is work that I have to do as a person with a disability in academia - I was trying to do it at a systemic level within the institution that I was in, but it took so much time …now I think about it, I was doing a whole lot of stuff that a non-disabled PhD student would not have to do" (Int.31).
- Meeting performance expectations generally, with some participants with disability stating they will leave academia due to the personal toll of the required workload and limited opportunities: "…[we need] a complete overhaul of the whole academic system, isn't it, and expectations regarding performance and all that sort of stuff, so it goes back to those cultural things as well, but in a different kind of way, where it's become so deeply embedded within academic institutions, and the expectation is that we will be everything. We'll be a fantastic teacher and we'll get perfect teaching scores. We're going to publish research in high impact journals, we're going to have a community engagement and we're going to be a good community player, and we're going to supervise PhDs" (Int.38).

Advocacy and representative organisations and Disabled People's Organisations [DPOs]

Within the disability research field in Australia, Disabled People's Organisations [DPOs] and advocacy and representative organisations undertake research. Although University's undertake the bulk of the research (along with government and service providers), DPOs and advocacy and representative organisations do undertake research themselves.

The disability advocacy sector is mostly funded by Department of Social Services (DSS) through the National Disability Advocacy Program (NDAP), with DSS contributing

to funding for 60 of the approximately 80 DPOs and advocacy and representative organisations in Australia. All remaining funding derives from the state and territory governments, with minor philanthropic funding.

The problems with funding for advocacy and representative organisations are well-known. Each state or territory runs their own advocacy funding, however the lack of liaison between the Commonwealth and the states/territories means that most advocacy organisations scramble to apply for and receive funding in order to obtain adequate resources and, ultimately, survive as an organisation. In addition, in 2021, three states put their funding up for tender, forcing a competitive process where advocacy organisations were bidding against each other. Finally, DSS are also just about to announce that they are getting the Commonwealth-funded advocacy organisations to reapply for their funding through a 'direct selection' process rather that a competitive process.

Given this landscape, it is unsurprising that the most common theme from the interviews with DPOs and advocacy and representative organisations was the severe lack of resources and funding, and low levels of secure recurrent funding available. Participants from DPOs and advocacy and representative organisations explained that they are mostly micro-organisations of less than three staff, with medium to large organisations comprising six staff, and described the high demands they face due to increasing NDIS appeals and the Royal Commission. Most participants from these organisations described being in a state of survival and just trying to get through the next 12 months.

> "…disability representative organisations, they're just underfunded at the moment. There's this extraordinary avalanche of policy submissions and enquiries that they're being expected to respond to, all without any additional funding. They're pulled all over the place … they sustain themselves through a series of projects where they get this project or that project. They then employ people through it. But again, it's all really hand to mouth" (Int.22).
>
> "…we're small organisations. We're tiny organisations. Tiny. Micro organisations, and we're expected to have the capacity to turn up and input into these. There's no structure about it, which means, we don't have the capacity to plan what the demands of government will be, in our responses - and then, suddenly, we've got our schedule - our plan, our strategic plan - for the next three to five years. We know what the research is that we need to undertake. We know what the policy imperatives are. We know what needs to happen to support those policy imperatives in the way of evidence gathering, and yet, suddenly, whoo-poo, hijacked by some study wants to look at this. No extra funding, and you have to find time, when you're already overworked and underpaid, to find some energy to contribute to this" (Int.16).

Consequently, most participants from DPOs and advocacy and representative organisations reflected they had no resources for capacity building, or even capacity (time and resources) to reflect on what is needed to build capacity. Although they understand research is an important element of disability advocacy, their daily advocacy caseload

meant they lacked the time to undertake research activities. Another issue was that it is often the same organisations who are approached to engage or assist with research. "…we've been down in this black hole of virtually no funding for a number of years, it's actually very difficult, really, really difficult, for us to switch our brains around and try and think, what would it look like and where would these people be, whether we have the capacity to employ them ourselves or they were located somewhere else" (Int.5).

Participants from DPOs and advocacy and representative organisations debated as to who is responsible for undertaking research within the disability research sector. The lack of resourcing and funding certainly seemed to play on their minds, leading some to question whether advocates should be undertaking research at all. However, advocates often play a central brokerage role, connecting academic researchers with participants and undertake aspects of the research. Some participants also argued that advocacy and representative organisations and DPOs are best placed to undertake research on advocacy in the disability ecosystem. A challenge with undertaking this research role, however, is lack of remuneration for the extensive work undertaken and ensuring that research is rigorous:

> "
> …I would like to be able to do some of that research rather than passing it back to universities. Because I feel like they are very removed when say come to us, 'you do this, this and this' in terms of running the focus groups, doing the interviews, talking to people with disability, dah, dah, 'then you report back to us and we'll take it from there'. I feel like they then have this task of analysing but they do it without people on the ground, and so I don't think that's a very credible process" (Int.31).
>
> "A lot of the advocacy sector - they're often expected to provide their time and their knowledge and energy for free - that's one of the key things that just needs to change. That needs to be valued. It needs to be budgeted by the universities into the research design – [including] the organisations, their management, plus the participants themselves need to be adequately funded and it needs to be a significant amount of money for the valuable knowledge that they're putting into the research. Not just a $30 voucher for participants. No, there's the management organising things as well, there's time and effort, there's pre-meetings like you said, there's Easy English things that need to be done. That has to be valued in the research process and funded" (Int.26).
>
> "The membership organisations like the DPOs and then often the advocacy organisations have - they know the people …crudely, they have access to them, but it doesn't mean that those people are interested in taking part in a research opportunity anyway" (Int.35).

Participants also expressed a desire to engage in genuine co-designed research, where advocates and academics co-identify research problems and areas, design the research, and collect and analyse data together. However, the reality of resourcing means that the ability to engage in co-designed research is severely limited:

> "For the advocacy organisation partnering with unis – problem -for what they're funded for, the bulk of the funding, usually 90%, is for individual advocacy, and they have people sitting on waiting lists waiting for them to help them – so conducting research/research engagement not a main priority" (Int.5).

Instead, what seems to happen, is that DPOs and advocacy and representative organisations receive ad hoc and last-minute requests from academic research teams seeking funding for disability research. These efforts were perceived to be tokenistic, as the last-minute requests were often in response to funding criteria that require engagement with advocacy and representative organisations and DPOs. This is opposed to a genuine desire to partner with these organisations to improve the research process and outcomes. Reflecting on participant commentary, it is clear that this approach is not conducive to research capacity; instead, it places further demands on these organisations, creating tensions and issues. These participants reflected on their conflicting feelings, as they felt torn between the desire to engage in research and the reality of limited time to do so. Some identified difficulties discerning between research opportunities to identify what they should engage in.

> "...it happened before the recent funding round from the NDRP, where, suddenly, out of the blue, advocacy orgs and DPOs …would receive requests to be part of the research. so, some academic …they approach the advocacy orgs to say, can we put you as a research partner? so, we get this influx of requests that'll happen periodically, whenever there's a big funding round on …now, the actual organisations, the front line organisations, both advocacy and DPO, might already be putting in their own applications for these processes, for these funding buckets …yet, we got people we've never heard of, who take no interest in our work at any other time, who suddenly turn up and say, can we partner with you on this research? Even more offensively is that often those people have no idea of disability. So, they're deciding to study something, but they're actually, what can only be described as part of the patronising bastard crew …they don't know the language, so they use highly offensive language to speak to us. They might even have the temerity to tell us how we should speak about ourselves, which is really good of them" (Int.16).

> "…at the moment, [some] advocates don't have the knowledge or the skills to do research and … they should be partnering with respectable academics, but they don't know to tell one academic from another, which comes back to the capacity issue about understanding the landscape of research. They think somebody's got a PhD, therefore they must know everything about research" (int.35).

> "…the job then is for an individual advocate to help the person find the solution to whatever the system they're arguing into at that time, and to understand the legislation and the rules that apply around that particular thing and get them legal assistance … we need to quickly be able to find the current latest information about the numbers of people with disability who live in a house by themselves, for instance, or whatever. It could be any one of multiple things, because that information may be

> needed to argue back against the NDIA, who are insisting that the person has to live in a four-bed group home instead of by themselves - so being able to find the most up-to-date data and then the research - there's different layers to that - and being able to find where that is, even understanding that as a struggle we have had for years … which is to do with the lack of funding and the lack of capacity" (Int.5).

Further challenges regarding research capacity experienced by the advocacy sector were disconnects between academic demands and what is required on the ground. One issue that participants cited was the lack of practical application of some academic research:

> "
> …some academic research is fascinating, but you look at it and you think, 'well, as an advocate, how can I use this to change the world or improve lives? Whereas, other research is, you know, well-equipped to do that" (Int.26).

Other challenges exist due to the different timeframes driving government and the advocacy sector, versus academic timeframes: "…one of the things that I discovered in that time, as I tried to talk to some researchers and make contact, the timeframes that academics have are so different from the timeframes that we think - to apply for funding to do some research and then for the researchers to decide which topic or which research question or whatever" (Int.5).

Other challenges faced by DPOs and advocacy and representative organisations was trying to access and implement research when academic research outputs are behind paywalls of journals. They also identified that they were so strained for time that they would not have the time to search through journals, even if they did have access to them, because they were inundated with advocacy client work. Other participants noted that sometimes the research just wasn't there to be found and identified significant gaps in advocacy research for people with a disability.

> "
> …the fact that so much research sits behind a pay wall and it's often the case, people see stuff on Twitter or social media and there's some kind of interesting study around something, and then they find that they can't access that. About whether there's a possibility that there can be a repository that brings that together and allows you to physically access it, but also have it in different versions so that you can understand it as well" (Int.27).

This led into a key discussion on the need for more effective research translation. In some cases, organisations had devoted some resources to undertaking the translation function. However, chronic underfunding meant their ability to do this effectively was limited. Those from peak bodies argued that they should be able to translate research for individual organisations; however, had insufficient resourcing to do so:

> "
> …as a peak, our role should be to be looking at a whole range of recent research papers and then filtering them to the appropriate advocacy organisations on the ground … broadly, to all of them, but some of them that we know are working on

particular issues … with very brief summaries, they're extremely busy, so they're only going to have time to read the two or three dot points that'll make them think, 'ah, yes, I should look into that further. I'd like to know more about that', or 'no, it's not of interest to me now or whatever' - but you have to have the time … to turn that [article] further into something directly that would speak to what the advocacy organisations want, if you know what I mean. They're not even going to be bothered reading through the full article" (Int.5).

Service providers

It is difficult to determine the exact number of disability service providers in Australia. The National Disability Services (NDS) are the peak body for service providers in Australia. They have a membership of over 1100 members (NDS, 2022). However, many other disability service providers sit outside of this membership. There is also a distinction between NDIS approved/registered service provider organisations and general mainstream service providers that people from the NDIS may purchase services through with their plan. According to a report by the Joint Standing Committee on the National Disability Insurance Scheme (2018:47-48), the number of NDIS registered service providers in June 2018 was 16 755 nationally, however, only 50% of these registered providers were active at June 2018, with 44% of these being sole traders (i.e., the market is clearly dominated by large providers). They note that 30 June 2018, 80 to 90 percent of payments made by the NDIA were received by 25 percent of providers. In this report, McKinsey & Company (2018:48) note that 70% of NDIS payments are to providers that cater to 100 or more participants each

In the current landscape, service provider organisations are under increasing financial pressure due to the way the NDIS are structuring their funding. As such, similar to DPOs and advocacy and representative organisations, service providers are struggling with a lack of resources, along with difficulties with policy implementation, workforce stability and/or availability and service delivery quality (NDS, 2021)). Consequently, there is limited capacity to undertake research or engage in other research activities, such as reading research reports: "I think it's fair to say that providers, since the move to individualised funding in the NDIS, have much less capacity to be involved in research. They have less flexibility within their own funding mechanisms to be able to be involved in research, but they were really key partners" (Int.10).

Lack of staff capacity for undertaking research activities was noted as a significant issue, with heavy reliance on individuals:

> "We are ourselves with our all of one person on staff who has research credentials and is - as part of their job description. They are trawling literature to then write short notes that are suitable for us to give to a workforce primarily born overseas and from non-English speaking backgrounds. About what that research says about their practice in group homes. Or what it says about what we should do about cancer screening for our customers or whatever ..So we're literally just taking research material ourselves and writing a note" (Int.3/4)

This is with the exception of one large disability service provider that has extensive capacity; they have undertaken their own research around improvement of service delivery and workforce capacity, and engagement with the NDIS. This is a rare occurrence in the disability service provider space, with most research being conducted with universities who access clients or their workforce.

Despite the lack of resources, service provider participants overwhelmingly supported the need for research. They claimed research is needed to contribute to "continuous quality improvement" (Int.2) and to improve their evidence-based practice: "…service providers are under huge pressure to think about their practice and to be more evidence-based, and they want to be, they want to know how to do it. So they're searching and they sort of search in all sorts of funny places because they don't know how to navigate that sort of landscape" (Int.5). Some also advocated for more positive research into the NDIS: "In my ideal world it would be great to be able to deliver research that shows with quality, positive outcomes assessments …looking at the achievements of people, looking at the goals they've attained, by having an NDIS plan. You provide some really good feedback on why the NDIS is the right thing to be doing" (Int.1).

Government

Another key actor in the disability research field is the government. Australia was established as a federation, comprising three levels of government: Commonwealth, State / Territory and Local government (see APSC, 2003; Hughes, 1998; Johnston, 2000). Due to the small size of this study and that funding for both service provision (through the NDIS) and the majority of advocacy funding is provided through the Australian Public Service (Commonwealth government), this study focused on representatives from key departments and agencies at this level. This included representatives from the Department of Social Services (DSS), the Department of Health, the Australian Institute for Health and Welfare (AIHW), the National Disability Insurance Agency (NDIA), the NDIS Quality and Safeguarding Commission and the National Health and Medical Council (NHMRC).

It is worth noting that all but the NDIS Quality and Safeguarding Commission had internal research groups and budgets. Research capacity within the NDIS seems particularly evident, with a Research and Evaluation Branch that focuses on a range of research activities . The NDIA participant stated that research is undertaken for a variety of reasons: "…Sometimes [questions] might come from participants …It might be that there's a policy question that needs to be answered. It might be that there's a service design question that needs to be answered. A range of reasons why we might embark on a piece of work" (Int.30). The NDIA and NDIS Quality and Safeguarding Commission draw on national datasets and work with the Australian Institute of Health and Welfare (AIHW) to use disability-related data in research; this contrasts with a historical focus on comparing datasets from each state and territory. In some departments, however, most research is outsourced to external providers. For example, the Department of Health have panels they outsource research to: "… there are panels and we have to go to the panel

and we have to put out a grant opportunity, advertise it, get the applicants, evaluate the applicants - sometimes they're open, but mostly they go to a panel and on those panels are universities, consulting firms, some other bespoke things. We can give money directly to the AIHW if they are the only ones that can do it. But normally they would collaborate with somebody else" (Int.15).

Most government sector participants identified that good quality disability research requires engagement with the disability community itself, including people with lived experience of disability themselves, their families, advocates and service providers. When engaged directly in research processes, participants discussed how they made considerable efforts to ensure co-design and community engagement was a part of their research, as this was important for aiding their understanding of experiences and needs. Engagement efforts included examples of preparing easy-read versions of key documents (and presenting these early to advocacy groups to allow for facilitation of pre-event discussion), arranging Auslan interpreters and captioning, engagement with their specific department disability advisory groups, translating research finding reports into easy-read and plain language formats and efforts to ensure that public web-based information released online, such as best practice documents, quarterly reports and research findings reports, were made available in various accessible formats. However, they also identified that the ability to do this effectively takes additional time and resources:

> "So, it takes a lot of time to put thought into how we would do that, how we would run it, and even just producing Easy Reads, it's a three week turn around. We don't have agenda papers for meetings done three weeks before ever, so that amount of time and the amount of time it takes for people to do that work is not acknowledged - it needs to be acknowledged that it is, in fact, different to doing a national research agenda on diabetes, for example. It takes more time, more resources, more liaison, more networking, all that kind of stuff" (Int.15).

When outsourcing research, participants discussed how they put mechanisms in place to ensure academics and consultants engage the disability community: "… we always make a point of ensuring that the voice of people with disability is included - we require outreach to people with their disability as a part of an interview process or whatever it may be, either authentic voice or testing of things that are coming up through research with people" (Int.14).

Although value was placed on engaging the disability community in research, it appeared that this was largely isolated to consultation. Government participants discussed the mechanisms through which they consult with the disability community: "We've got a team within the agency who focus on engagement with [NDIS] participants, so they help us to – in a range of ways - to engage with participants in focus groups or as partners in our research to help us understand the issues from a participant perspective" (Int.30); and "We have our own consultative committees which includes a specific consultative committee around this sector which is separate to industry; so we don't combine those; we want to hear the voice of people with disability through their representative bodies but from them directly" (Int.14). However, some participants from outside government questioned the

effectiveness and value of these: "I continue to sit on several reference groups and panels and, whatever, and you know, every time they come and go 'can you tell us about blah de blah'. All right. Off you go, you trot along and you give them a spiel about this and that. It's still so rare that you really see evidence that what you've said is taken into policy. Of course, it's not a straight line. It's not a linear line of influence. But I think it's much more consultation than co-design. Yeah, is what I see. I'm questioning more and more the value of those interactions" (Int.28).

Non-government participants also highlighted issues with a lack of value placed on quality research, informed by the disability community by government: "…Agency attitudes towards research is go and hire a bunch of consultants who will come back with a report and if they don't like it, they'll bury it. If they think they can use it, they'll use it" (Int.1). Although, participants from government argued that they commission research according to its focus; therefore, who undertakes it is appropriate to that: "there's places where government needs to be able to commission research for particular needs, and there's times when we commission research and we want independent researchers doing things and we want the answers, whatever they are. There's times when we commission consultants to do things, where we want slightly arm's length, but we are curating the answers we're looking for and the types of things we're considering" (FG2). However, those from outside government argued that commissioning research to consultants is problematic both due to the costs associated with commissioning research that may not be used, as well as its lack of effectiveness due to outsourcing research activities to consultants, rather than the disability community:

Issues also exist with governments commissioning research from academics, whose own knowledge is limited: "… you've got a lot of academics who undertake research …they wouldn't even know a policy if they fell over it; trying to get academics to engage in policy-relevant research I think is a real challenge. Part of it is because they don't understand policy. Part of it is because they don't have relationships with people in government, so they never talk to policymakers" (Int.22). This further emphasizes the need for collaborative research, with the importance of developing "… relationships with our other government partners and with researchers" (Int.30) emphasized. When engaging in these partnerships, however, some participants also highlighted the need to recognise that the needs of government may differ to those of academia and the disability community: "We may not have the same views on what the research priorities are, so there's got to be room for that - there's also got to be room for getting research that you don't want the answers to and getting answers you don't want - in both directions. Government will ask difficult questions, and it may not be where the sector wants to go" (FG2).

Participants identified additional challenges with the role of government in disability research. A key challenge is confusion regarding size of government, as well as the fragmentation caused by different levels of government. Participants reflected on the silos evident within government: " … organisations and agencies typically work in silos and I think that makes it challenging in terms of – people may have different agendas. They may have different priorities - It may be a resource issue some of the time. Some of the

time … partners may want to work together, but it's just a resource issue. It may be that we don't understand the issue enough. There's a whole range of reasons why it can be hard" (Int.30). They also reflected on how the Commonwealth government has its own disability policy and programmes, particularly regarding the NDIS and employment, and this meant that: "… the states are really struggling to adjust to the fact that they don't have control over the pointy end disability supports - and there is a complete paucity remaining in the States and Territories around research with data collection pertaining to disability education and health systems etc. - it doesn't help us to get a sense of how nationally both ends of the system can work well; so the NDIS will only be successful if participants can get all of the social and economic community based support that they need, and vice versa - people will only be able to access those things if they've got the right support through the NDIS - there just isn't there cohesion and it was always just a hotchpotch … at the moment it's a dog's breakfast" (Int.14).

A final issue concerning the government's role in disability research, raised by participants, is that the risk aversion of government impacting funding decisions. In particular, concerns that funding could be cut if research identifies issues with current programs or services: "… people are personally invested in whatever we're doing and whatever we're delivering – [but] they need the risk appetite to engage with that - so the people aren't just scared of losing their funding if the evidence doesn't come out the way we thought it was – [people] willing to test things, willing to actually put hypotheses out there and see what happens and actually pilot pilots or whatever it might be and do more of that. We did this, we left it long enough to see what happened, we collected the data, we did the research, we analysed it, and we found this. Therefore, we're feeding that back in and doing something else. It's not just all or nothing" (FG2).

Participants from government also identified the need for improved research translation: "… clearly stated findings are really useful - we need the bottom line upfront, and to some extent, we will verify things; you've got to be able to easily pick up the key findings without having to wade through the entire 100-page research report … we ran this experiment, we did this set of interviews, we did whatever, and this is what we found, you need that bit in the middle, not all that how we got there; we've got to be able to trust that and leave to us the 'what are we going to do about it'" (FG2).

Appendix C: Existing barriers to disability inclusive research

Participants discussed existing barriers to fully inclusive disability research at present, including:

Funding and time

Insufficient funding and time allocated to enable engagement of people with disability was cited as a barrier to disability inclusive research. For example, funding that allows for time to develop relationships and trust, for project materials to be developed in easy-to-read formats, and to enable adequate time for consultation, particularly with people with intellectual disability.

Power imbalances

Participants also discussed how inherent power imbalances currently act as barriers to inclusiveness and the full participation of people with disability. These include power imbalances between government officials, academic researchers, community researchers, people with disability as participants and members of the disability community, with these operationalized as poor attitudes or lack of awareness towards people with disability engaged in research: "…disability as a concept is all about an imbalance of power. If you look at theories of what disability is about - I think that's the essence of the meaning of disability. It's about the way in which power imbalances continually reduce the involvement of people with disability in their own future" (Int.32). Existing power imbalances need to be addressed when undertaking co-design, between both junior and senior researchers, disabled and able-bodied people, and where there is intersectionality (i.e., gender, race, diversity, disability): "…the power imbalances are really deeply intersectional power imbalances. It's not as simple as 'I'm an early career researcher and you're senior, I'm disabled and you're abled'. I think it's context specific, so we need to be mindful of how structural inequality works, and how structural violence operates. What are the cultural and institutional structures in place that disempower a disabled person in a relationship with a research team? Because it's one thing to be on the research team, it's one thing to be recognised, but is that culture conducive to a healthy working environment? There's the intersectionality of gender and disability status, and being younger and being earlier in your career, and race and ethnicity also would play into that in different contexts. So, I think, like we need huge cultural change in this area, which is why it's not as simple as let's bring in a policy in the same way we have a patriarchy, there's also a neuroarchy, and our society is ruled by a hierarchy of neurotypes, and neurotypicality is privilege, and historical, neurotypical has meant cis, het, white, male, upper class, European and abled" (Int38).

These power imbalances are particularly evident when there is representation of a single person with a disability in a group, as they would often not be heard, and their opinions easily dismissed. Participants spoke of the need for multiple people with disability to be engaged in research and in meetings to ensure their voice is heard and that there is appropriate representation of issues: "…then suddenly there was this other research

assistant who also identified as someone with disability and she backed me up, and it wasn't until two of us said that they went 'oh, OK, I guess we should include it'. But if I'd been there on my own, they wouldn't have said it - it was so, this is ableism right here in this meeting!" (Int.31).

Mindsets and ableism

A key barrier to disability inclusive research is mindsets and ableism. For example, there were suggestions by some in the academic community that community researchers, despite valued lived-experience knowledge, do not have the breadth of skills and research knowledge to fully conduct all elements of a research project to the required standard. Rather than considering how these knowledge and skills could be developed, some focused on current skillsets getting in the way of disability inclusive research. In addition, it was apparent that deeply engrained mindsets and ableism in academia underpin both structural and systemic elements (i.e., university recruitment and selection, ethics etc. rules), as well as presumptions that academic engagement and research is actually wanted by the disability community. This was highlighted in the example where multiple forms of research around employment of disability had just been duplicated over many decades without many outcomes or results, and questions from the advocacy sector as to why researchers were requesting research about a topic yet again. Finally, some participants also expressed the view that researchers with disability will struggle, be over fatigued and/or not "survive" an academic career, due to current performance expectations and workloads. This negates any discourse on reasonable adjustments and the potential capacity of a person with a disability to at least have the dignity of risk to try and undertake academic roles.

Insufficient number of disability academic researchers and community researchers
At present there seems to be an insufficient number of disability academic researchers for co-designed research to be a mandatory requirement for ALL disability research. There is a risk that if this becomes a requirement, that demand will be placed on the same core group of researchers to be involved in almost all research projects, leading to burnout for these individuals. One participant who is an academic with disability reflected on the demands they face on an ongoing basis and the personal toll this was taking: "… I looked at what the week ahead [holds] - so it was 10 o'clock and I had a splitting headache and absolutely exhausted by Monday. I can see people are going, 'I want this, I want this, I want this'. People who said no to funding in the past, 'I need this by, I need this by', and I just go, 'I've just got to get through'. Just the only way you can get through it is to own the struggle" (Int.11).

Participants also noted that there is a lack of people with disability in academia due to:
- Inflexible and narrow entry pathways into higher degree by research degrees for people with disability pursuing an academic career.
- Significant lack of equity and disability scholarships at masters, PhD and post-doctoral fellowship levels to drive the capacity and support people with disability through their academic career.
- Employment precarity in academia for people with disability. Many participants who were academics reflected on how academics with disability often end up in casual

research and teaching positions, which limits employment to short-term, ad hoc and limited contracts (i.e., 1-2 days per week; rather than tenured or longer-term appointments). This was particularly apparent for those in the disability studies discipline, as the lack of teaching opportunities in this discipline often means people with disability are restricted to research roles in other disciplines only.

Another barrier to disability inclusive research, as identified by participants, are difficulties employing community researchers in universities, due to lengthy and onerous recruitment, selection and onboarding processes, as they often require community researchers to undertake and navigate compliance modules and training. While considered to be an essential part of onboarding in the university system community researchers may end up spending a disproportionate amount of energy and time navigating them, rather than engaging in the research itself. This can act as a deterrent to employment. Participants also noted that the employment of community researchers, and/or vouchers for participants, could have an adverse impact on income levels related to receipt of disability support pensions. Finally, participants also noted issues with not adequately remunerating or compensating community-researchers for contributing their valuable expertise and time.

Appendix D: Audits of Disability Research in Australia

The 2014 Audit of Disability Research in Australia was undertaken by the Centre for Disability Research and Policy at the University of Sydney in collaboration with University of Melbourne, People with Disabilities Australia, and National Disability Services (2014). It aimed to create better understanding of the state of disability research in Australia and used a human rights and social equity approaches in reviewing and mapping both scientific and grey literature from 2000 to 2013 in Australia. As it states, 'the goals of the work were to identify gaps in the research base and evaluate the evidence frameworks typically used in disability research'. The Audit found that research 'was fragmented and short-term, lacking a strategic coherence and investment in long-term approaches to building an evidence base' (Llewellyn, 2014).

In 2017, the initial audit was updated, using the same methods (with minor modifications to align with the Centre for Applied Disability Research (CADR) Clearing House protocol), using publications and information between mid-2013-2017 (Centre for Disability Research and Policy, 2017).

Since then, the NDRP has funded Mapping Disability Research 2018-2020 (Smith-Merry et al., 2021). Run by a consortium, the Consortium conducted 'a rigorous process to identify the amount and extent of research related to disability in Australia that had been published in academic journals as well as government and community reports' (Smith-Merry et al., 2021, p.2). The findings provided solid insights for NDRP and will contribute to the development of a National Disability Research Agenda.

The report describes their findings in detail, with notable findings of:
- Only 50 of the publications mentioned lived experience as central to their approach.
- There is a dearth of research that looks at the experiences of people with disability from Culturally and Linguistically Diverse backgrounds
- There has been an increase in the number of publications about Aboriginal and Torres Strait Islander people with disability, some authored by Aboriginal and Torres Strait Islander researchers.
- Only one percent of studies concentrated on people over 65 years indicating a major gap in research on disability and ageing
- Health and wellbeing (19%) and education (10%) were the most common topics of research articles and service development (16%), health and wellbeing (14%), and policy (13%) were the most common among research reports
- Like the current research mapping exercise, 2014 and 2017 audits found that health and wellbeing and education were common topics however the methods to organise topics were different - the current audit coded outputs across 29 topics while the previous audits coded outputs across eight life domains
- Nearly half (47%) of the publications mentioned one or more funding sources with nationally competitive grants (ARC, NHMRC) comprising 30% of all funding sources and government funding such as contracts making up 21% of all funding sources reported. Of note, investments in programs of research (e.g., NHMRC Centre of

Research Excellence Scheme; fellowship funding (ARC, NHMRC) and projects that are conducted in partnership (e.g., ARC Linkage) were productive in terms of research outputs (Smith-Merry et al., 2021, pp.2-3).

Of most consequence to NDRP was that few participants, and the disability community more broadly, seemed to be aware of the extensive of this amount of work being done in the last decade on mapping disability research. The existence of the APO platform and Disability Research Collection also appeared to be minimal.

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