



'No Data About Us Without Us'

Community responses to the idea of
a National Disability Data Asset



THE UNIVERSITY OF
SYDNEY

—
Sydney Policy
Lab

October 2022

Acknowledgement of Country

The Sydney Policy Lab acknowledges the Traditional Custodians of Country throughout Australia and recognises their ongoing connections to land, sea and community. Sydney Policy Lab at the University of Sydney is based on the lands of the Gadigal people of the Eora Nation.

We pay our respects to Elders past, present and emerging, and acknowledge the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

About the Sydney Policy Lab

The Sydney Policy Lab (Lab) is a multidisciplinary research institute at the University of Sydney and a nonpartisan space where people from all walks of life can meet and develop plans collectively for the future.

We exist to forge collaborative relationships between researchers, civil society, industry, politicians and policymakers that are capable of creating new knowledge and driving change that would shape an Australia which is more equal, where power is in the hands of everyday people and where more people feel a secure sense of belonging in their own society.

The Lab develops original and far-reaching research projects which unite the grounded wisdom that comes from everyday experience and the perspectives gained from rigorous scholarship.

We work in partnership with institutions who seek to put new ideas into practice. Our unique way of working strengthens the ability of our researchers and partners to collaboratively generate new ideas, transform the ways they work and effect change.

Acknowledgements

The Sydney Policy Lab is indebted to our 40 interview and workshop participants who shared their time, wisdom and experiences with us and the organisations they work for, who supported their participation. We hope that we have accurately captured their divergent and shared views on the potential of the National Disability Data Asset.

We appreciate the NDDA's National Project Team, who entrusted the Lab with this research and who attended the interviews and workshops and joined our learning journey. We are encouraged by the relationships that you built with us and participants, how you elevated their voices and reflected on how the NDDA can best serve them.

We are also grateful to members of the Lab's collaborative research team: Dr Sheelagh Daniel-Mayes for cultural and disability insights from the project's inception, lead interviewer Dr Emma Calgaro, data governance advisors Prof Kimberlee Weatherall and Libby Young, research advisor Dr Leigh-Anne Hepburn, research manager Dr Juliet Bennett, workshop facilitator and learning partner Sarah Hurcombe, project officer Jananie Janarthana, proof-reader Isabelle Napier, copy-editor Vivienne Egan, research assistant Amy Tong, invaluable input from Lisa Fennis and Marj O'Callaghan, brilliant illustrations by Erin Farrugia, graphic design by Lisa-May Pellaschiar, and strategic oversight by Prof Marc Stears and Louise Beehag.

This report represents the views of our research team as informed by the research process.

Acronyms and abbreviations

ACT: Australian Capital Territory
 CaLD: Culturally and Linguistically Diverseⁱ
 COVID-19: coronavirus disease of 2019
 CRPD: Convention on the Rights of Persons with Disabilities
 DDA: Disability Discrimination Act
 DPO: Disabled People’s Organisations
 DRO: Disability Representative Organisations
 NDDA: National Disability Data Asset
 NDIA: National Disability Insurance Agency
 NDIS: National Disability Insurance Scheme
 NPT: National Project Team
 NSW: New South Wales
 QLD: Queensland
 SA: South Australia
 TAS: Tasmania
 VIC: Victoria
 UN: United Nations
 UNCRPD: United Nations Convention on the Rights of Persons with Disabilities
 WA: Western Australia

A note on terminology

In the disability community there are varying preferences for person-first language (for example, “person with disability”) and identity-first language (for example, “disabled person”). We follow the Australia Network on Disability practice of person-first languageⁱⁱ throughout this report, unless participants themselves have used identity-first language, which we retain in their quotes.

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Suggested citation: Calgaro, E, Bennett, J, Daniel-Mayes, S, Hepburn, L, Beehag, L, Tong, A and Stears M, “No Data About Us Without Us’: Community responses to the idea of a National Disability Data Asset,” Sydney Policy Lab, University of Sydney (Oct 2022).

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Foreword

It was a responsibility and a privilege for the Sydney Policy Lab to be selected by the National Disability Data Asset (NDDA) National Project Team to conduct the research with disability organisations contained in this report.

The Sydney Policy Lab exists to create new knowledge and drive change for good by building relationships between people across different backgrounds. We draw our strength from academia, civil society, business, and government, generating new solutions to the challenges that we all face.

The NDDA is a proposal to link existing service data on the experiences of people with disability across states and government agencies. It also aims to improve – and fill gaps in – this data, and make it accessible for disability communities to use. The proposed NDDA could have implications for anyone with disability whose data would be in this linked dataset. Data linking at this scale has not yet been done in Australia. As such, it sets a significant precedent for the use of data in Australia.

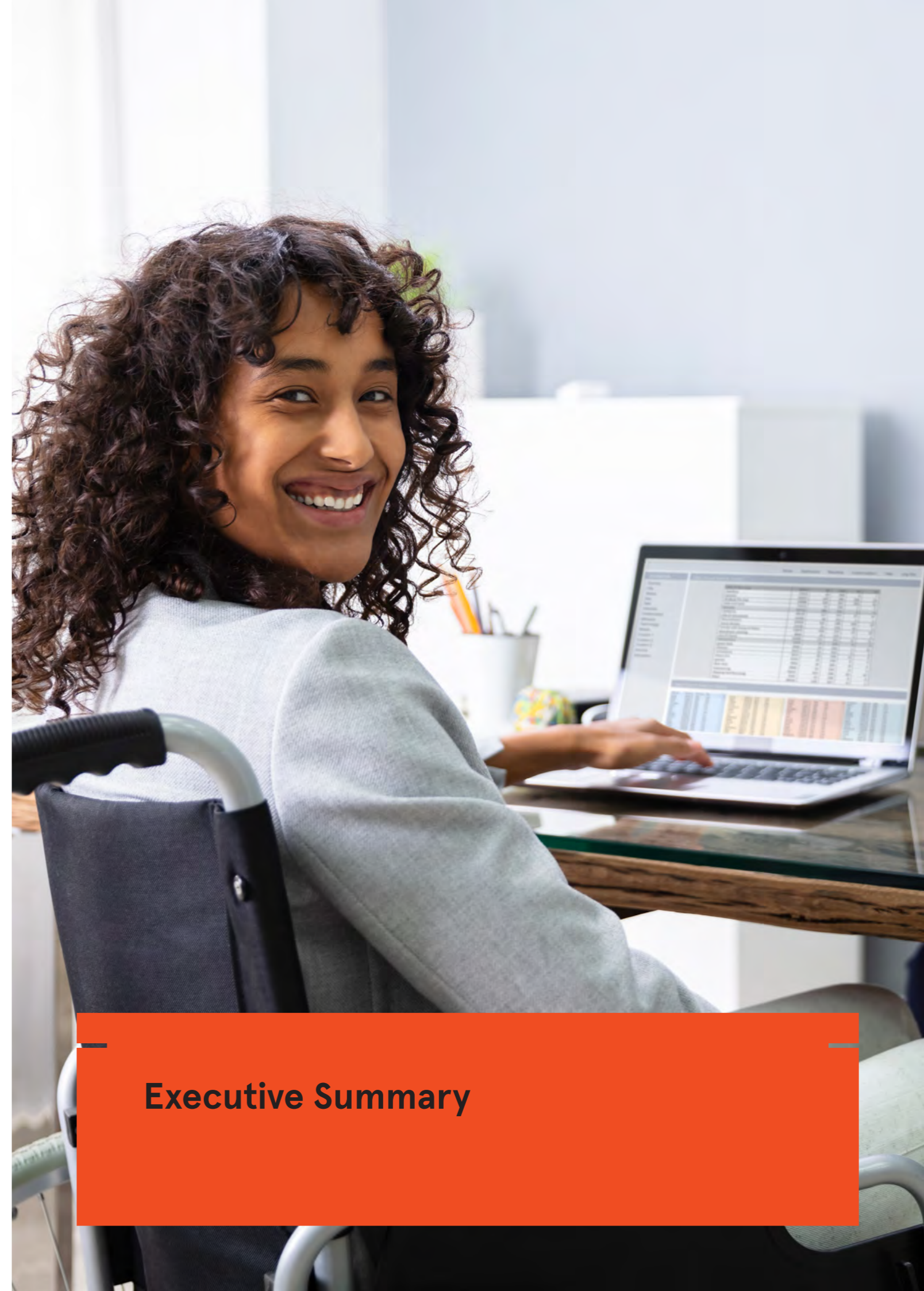
For this research, the Lab brought together experts in disability, law, data governance and social sciences. The Lab team interviewed and facilitated two workshops with 40 participants, seeking to understand their views on the NDDA. Through these engagements, conducted in the second half of 2021, the Lab provided a space for these leaders of disability communities to share their views on specific aspects of the NDDA. Participants chose to have a member of the National Project Team present at the interviews, indicating that they appreciated the chance to connect with government. We sought to acknowledge throughout the project the plurality of ways in which “disability” is understood, and the ways that such definitions exist in specific historical and social contexts.

Questions concerning how data is collected (and not collected), how it is accessed, how it is used and interpreted, and by whom, are complex. Who makes decisions about its usage, interpretation and access, now and into the future – issues of data ownership and data governance – are even more important.

Reflected in the report’s key findings is the enthusiasm of members of the disability community to access better data, addressing the currently dire state of data availability and access. The report underscores the community’s support for the NDDA. However, that support comes with conditions and cautions, with a remedy captured in the title’s adaptation of the famous slogan, “nothing about us without us.” The counterpart to this report, an Easy Read version, reflects our commitment to share back out what has been produced in ways that are accessible to as many members of the disability community as possible.

Our hope is that the Lab has provided a space for those with diverse expertise to come together and participate in inclusive research and policy development. The recommendations, which were co-produced, would position the proposed NDDA to serve the disability community in a way that values what the community values.

Dr Kate Harrison Brennan
Director, Sydney Policy Lab
28 September 2022



Executive Summary

Executive Summary

People and organisations in the disability community could more effectively access and advocate for the things they need, and governments and service providers could better tailor their support, if they had better data. Reliable data on how people experience, and flourish, with disabilities in Australia is lacking.

The ‘National Disability Data Asset’ (NDDA or Asset) takes up this important task.

The NDDA is an ambitious initiative involving federal, state and territory governments that aims to better understand the experiences of people with disability. It intends to do this by linking de-identified data across a range of domains including education, health, justice and employment. Further data collected by communities, researchers and service providers is intended to be linked in later phases. The goal of the NDDA is to meaningfully show how people with disability are served or not served through both government and other service providers, and where needs are being met or not met, to improve service delivery and provide real opportunities for people with disability.

Data and Digital Ministers directed that the NDDA Pilot be delivered in such a way that builds public trust in data and digital initiatives, consistent with the Ministerial Forum. In line with this directive, the NDDA’s National Project Team (NPT) recognised early on that the genuine involvement of the disability community would be critical to the NDDA’s success. Over the course of the pilot in 2020–21, and earlier during the scoping phase in 2019, the NPT has conducted many engagements, forums and consultations with people in Australia’s disability communities. Through these engagements, the NPT sought to understand their hopes and concerns and invite them to influence decisions about their data.

The National Project Team engaged the Sydney Policy Lab (Lab) at The University of Sydney to undertake research with people from disability community organisations to inform decisions about the future of the NDDA beyond its current Pilot phase, which ended in December 2021.

Between June and September 2021, the Lab conducted a series of in-depth interviews and two workshops with 40 people from national and state-based disabled people’s organisations (DPOs) and disability representative and advocacy groups.

This report articulates the hopes of these members of the disability community that the NDDA can improve the quality and availability of data about people with disability; that this improved data will be used to create positive change for people with disability; and that people with disability will be empowered through their involvement in these processes.

The importance and urgency of this goal was underscored by a dearth of data that is reliable, or perceived to be reliable, about people with disability in Australia, in a climate in which data is increasingly used to direct services, secure funding and influence policy.

Most participants expressed strong conditional support for the idea of the NDDA. While supportive of the idea of the NDDA, some of our participants wanted more detailed information about the specifics of the Asset before fully endorsing it at this early stage. The condition upon which people’s support depended was the meaningful involvement of people with disability in the Asset’s design, governance and operation. This condition was the clearest single insight to emerge from the entire process.

A major concern among participants was that the NDDA could replicate their recent experiences with the National Disability Insurance Scheme (NDIS). While included in the NDIS from the outset, people with disability have often felt excluded from positions of true influence and from ongoing governance. Participants were adamant that this should not happen again, and that the NDDA must be disability-led in meaningful and enduring ways.

The research findings captured in this report reflect our best effort to share the views of our participants. We recognise that our retelling is a partial representation of the views that we heard, and that the views of our participants cannot be taken as representative of the whole disability community. This has been a learning process for us too as researchers. Our team was guided by Sheelagh Daniel-Mayes, a First Nations scholar who has a vision impairment, and people with lived experience of disability in our network.

We designed our research to complement other NPT engagements, including coordinating early on with Australian National University’s Centre for Social Research and Methods’ research into how Australians with disability feel about the NDDA. Our research would have been enriched by speaking with members of the disability community more broadly, and our findings should be read in conjunction with reports of other such community engagements. Our findings here are dependent on the generosity and insights of our 40 participants, and the broad personal and professional experience with disability that they represent. We hope that our findings will be brought into direct discussion with multiple others including governance experts, data scientists and policymakers.

Guided by our participants, we summarise three key insights from the research and provide a series of suggestions intended to inform decisions about the future of the NDDA. Reflecting the broader application of these insights, we offer a further set of suggestions to analysts, researchers and civil society engaged in any other project about – or for – people with disability.

Key Insights:



1. There is an opportunity for better data on the experiences of people with disability to inform better decision-making.

Our participants from Disabled People’s Organisations (DPOs) and disability representative and advocacy groups made it clear that broader and more reliable data about the life experiences of people with disability in Australia is desperately needed.

The people we spoke to observed that decisions are increasingly being based on data. They were concerned that if data is of poor quality, or doesn’t accurately capture the life experiences of people with disability, it will lead to poor quality decisions. They hoped that better data collected for the NDDA will be used to make better decisions and be available for them to use to influence policy, enable advocacy, and direct services in ways that improve the lives of people with disability.

Our participants also wish for the NDDA to be used to update and ensure consistency in how disability is made visible across datasets and to measure outcomes in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

According to our participants, generating better data involves improving and extending data, guided by people that understand its context. It requires not solely focusing on deficits in abilities, but also on the strengths of people with disability and their communities. Linked to this is participants’ hope that the NDDA will be directed towards people’s aspirations as well as their needs.

2. The prospect of the NDDA raises significant concerns about how to ensure that the use of data directly benefits people with disability.



Our participants were concerned that government could link existing data and use it for government purposes, without properly engaging communities and meeting their needs too.

Participants identified three ‘red lines’ that they believed should not be crossed: anything related to a person’s finances and compliance; anything which created personas or avatars; and commercial mining.

A more complex concern is the way the NDDA’s use might evolve over time, and the prospect of it being used to the long-term detriment, instead of the benefit, of people with disability. Linked to this are questions of power: Who decides and measures what is a benefit or detriment? Who can change the rules about how the NDDA is used?

Disability-led processes and systems of governance were seen as the best way to prevent misinterpretation and misuse and to ensure data is used to benefit the community in the short and long term. This includes people with disability playing leading roles in the NDDA’s governance bodies to shape how it develops, and in understanding and interpreting the data and its applications.

3. The meaningful engagement of people with disability at all levels of the NDDA is the most important safeguard for ensuring its success.



Many of the concerns voiced by participants are best mitigated by deep engagement with people with disability at all levels of the NDDA and in a multitude of ways, including setting up governance institutions, processes, mechanisms for change and ongoing operations.

Participants stressed that engagement cannot be tokenistic. They emphasised the importance of both people with disability who are experts in their fields and those who are experts from lived experience providing ongoing valued input. Effective mechanisms for community-led decision-making were also seen as essential. This sentiment is captured in the report’s title: ‘No data about us without us.’

Meaningful engagement encompasses the full range of disability cultures, First Nations cultures and culturally and linguistically diverse (CaLD) groups. It also includes embedding accessible practices in the platform for disseminating data and in processes relating to the NDDA’s operation and governance.

Practical measures that live up to this objective include employing people with disability in day-to-day operations, sharing power via disability-led governance and a disability-led ethical oversight body, and ongoing community engagement across multiple channels.



Requirements of a successful National Disability Data Asset:

1. Ensure people with disability are in the lead.

A commitment to having people with disability in the lead should be at the heart of the NDDA. One way to embed disability leadership is to ensure that a significant portion, even a majority, of people in governance bodies bring expertise from lived experience with disability in addition to other forms of expertise. Participants also suggested that employing relevant experts with disability in teams responsible for the NDDA’s design and operation would be invaluable.

2. Address the community’s desire for better data.

Participants saw the NDDA and associated conversations as a key opportunity to improve data collection and address data quality and gaps. Even if the NDDA does not go ahead, we recommend that the government consider other ways to support the community’s desire for better data, particularly through community-led initiatives.

3. Develop a user-friendly digital platform to disseminate insights.

Participants saw great benefit in an accessible, user-friendly digital platform providing information to support people with disability in making their own decisions and navigating the supports available to realise their aspirations.

4. Be transparent and rebuild trust with the disability community.

Transparency is foundational to trust. Being transparent about government decision-making processes, about how power will be shared and about processes for selecting people to be on governance bodies, will help to rebuild trust. A relationship of trust will also require honouring community-agreed acceptable and unacceptable uses and not crossing ‘red lines’ that they identify.

5. Set up multiple channels for building and maintaining relationships.

Clear and responsive two-way communication channels will also help build trusting relationships, with government communicating updates about the NDDA and disability communities providing input to improve data and influence the NDDA’s ongoing governance and operations. Recruiting people with disability to design and run community engagement and communications activities would also help to foster trust and build lasting relationships with the disability community.

6. Be a model of accessibility, diversity and inclusion.

The NDDA needs to ‘walk the talk,’ modelling exemplary practices that embed inclusivity and accessibility in all work related to its operation. In this way, the NDDA could be a model that other government services can follow.

7. Advance forms of participatory data stewardship.

The NDDA presents an opportunity for people with disability to participate in the collection and management of their data. Thus, it represents an important shift of broader significance towards involving people represented in datasets or affected by datasets in the governance of that data. This is known as participatory data stewardship, and is part of a global movement.ⁱⁱⁱ

Principles for collaboration: suggestions for analysts, researchers and civil society

1. Recognise the diverse strengths and aspirations of people with disability.

‘Disability’ means different things to different people and within different cultures. In some cultures, the word does not even exist. Beyond medical definitions, there are many ways that cultural and social conditions make it difficult for some people to live what is taken to be a ‘normal’ life.

While having a disability involves impairments of some kind, it also involves a wide range of strengths. Thus, in addition to targeting basic needs, data can shed light on people’s strengths and aspirations and better enable them to achieve their goals.

This reflection can change the ways that research is done and policy designed. It can also change the way people may interact on the street – a shift from pitying another’s deficits, to sparking a curiosity about their differences.

2. If you are doing work for people with disability, it should be done with people with disability.

Any project about or for people with disability should employ people with disability where possible. There is also great value in finding creative ways to listen to the voices of people with diverse and complex disabilities.

We recognise that timeframes set by decision-makers may not allow for such opportunities, which brings us to a final recommendation:

3. Prioritise meaningful relationships, even when under pressure to meet rigid deadlines.

There is a need to reconcile the longer, more flexible timeframes involved in building relationships with institutional cultures that are managed top-down and with rigid key performance indicators and deadlines. This disconnect is often seen when government, academia and business work with diverse communities not usually involved in formal decision-making processes. Here, successful and appropriate engagement and co-design requires significantly more time and flexibility.

Some disability cultures also require particular sensitivities and approaches. For example, building a relationship with someone who is non-verbal and trying to understand and include their perspectives, is not a box to be ticked or an outcome achieved. This speaks to broader opportunities to pioneer shifting institutional practices from project-specific or time-limited engagements towards enduring relational approaches based on mutual learning and sustained dialogue with communities.



Introduction

Introduction

For a lot of areas, we're not recognised as experts, so I'm really pleased to see this study. Everybody else is the expert about our lives without understanding that if you'd actually talk to us, we'll give you a more nuanced response. (Community participant)

The research behind this report set out to learn what people in the disability community think about the idea of a National Disability Data Asset (NDDA or Asset). At that time, the NDDA was in its pilot phase.

The Lab was engaged by the NDDA National Project Team to understand what people in the disability community want the proposed NDDA to do for them, any concerns they have and the ways they see these concerns being addressed. The research also sought participants' opinions on the forms that the NDDA should take to enhance its functionality, accessibility and governance. More detailed insights from community engagement have been provided to the NDDA National Project Team and the Disability Advisory Council for their consideration.

This report shares key insights guided by the critical question: Can the NDDA improve the lives of people with disability, and if so, how?

After articulating our research aims, context and methods, the chapters that follow share our participants' views on the opportunities for the NDDA, their concerns about the NDDA and possible safeguards to address those concerns. The concluding chapter discusses key insights and recommendations including some thoughts on future approaches to policymaking in general. We begin by clarifying our understanding of 'the NDDA' and 'disability.'

What is 'the NDDA'?

The NDDA is a cross-government initiative – Federal, State and Territory – which aims to link de-identified data on the experiences of people with disability. The idea of the NDDA occurred to people who were working on the National Disability Insurance Scheme (NDIS) transition nearly three years ago. The disability community was first engaged about the idea in some forums in 2018. After another full year of further engagement, the NDDA received endorsement from ministers to establish a pilot phase from April 2020 to December 2021. This included setting up a National Project Team to coordinate its development and support all nine governments and establishing the NDDA Disability Advisory Council.

The pilot involved five public policy test cases. For example, one test case linked data to understand the characteristics of people with disability who interact with the criminal justice system, both as offenders and victims. Another test case focused on early childhood support programs for children with developmental delays and disability before entering school. The pilot has also involved convening an NDDA Disability Advisory Council and more than 140 different engagements. This included commissioned research, interviews, workshops and meetings with disability organisations, government officials, academics, service providers and people with lived experience.

At a technical level, the NDDA – if extended beyond its pilot phase – is intended to be an enduring data infrastructure that can be updated and expanded, and overseen by operational and governance bodies. This infrastructure will house linked, de-identified data about the experiences of people with disability from datasets across domains, such as education, health, employment and justice, and jurisdictions.

The NDDA's governance system is envisioned as comprising institutions and groups of people, including operational, technical, ministerial and governing bodies, together managing and monitoring the data and its use within agreed rules. It is also intended to include a range of communication channels, including a platform for sharing insights and ways of interacting with the community.

If it goes ahead, the NDDA will become a mechanism for certain people to access, analyse and use data about disability, facilitating research and measurement of outcomes of people with disability as a community. Governments and researchers will therefore use the NDDA to draw conclusions and make decisions that impact the experiences and opportunities of people with disability in Australia. The NDDA could be a powerful tool and therefore it is critical to understand the hopes and concerns of the people at the centre of this idea: people with disability.

How do we understand 'disability'?

Not all people with disability consider the same terms appropriate. To illustrate, consider this: there is no word for disability in Aboriginal languages.^{iv}

Dr Scott Avery, a First Nations scholar with disability and a member of the NDDA Disability Advisory Council, explains using the example of the Anangu people in the Northern Territory. The Anangu language has words to describe impairments "such as blind (*kuru pati*), deaf (*pina pati*), to hobble around (*lurpani*) or to have back pain (*witapijara*)." Yet these words are not used pejoratively: they are "factual references to a person's functioning capacity within a community in which there is an acceptance of diversity and difference."^v

In this research, we adopt what academics call a social model of disability. This model challenges 'deficit' views of disability, which depict people with disability as 'less than' in some way and in need of special treatment or care. A deficit view of disability is linked to low societal expectations of capabilities and can lead to people losing independence, choice and control in their lives.^{vi}

In contrast, we view people with disability as dis-abled by social structures and culture.^{vii} The problem, therefore, lies with society and not the individual. From this perspective, disability is a normal human variation, and discriminatory and exclusionary laws, institutions, infrastructures and politicised practices 'dis-able' people with attributes that fall outside a medically determined spectrum of 'normal functioning.'^{viii}

We also share a human rights perspective anchored in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This perspective grants additional attention to the multi-faceted individual and a set of moral principles and values underpinning transformative disability policy and processes. The recognition of the inherent dignity and self-worth of people with disability and their entitlement to the same respect and rights as others is central.^{ix}



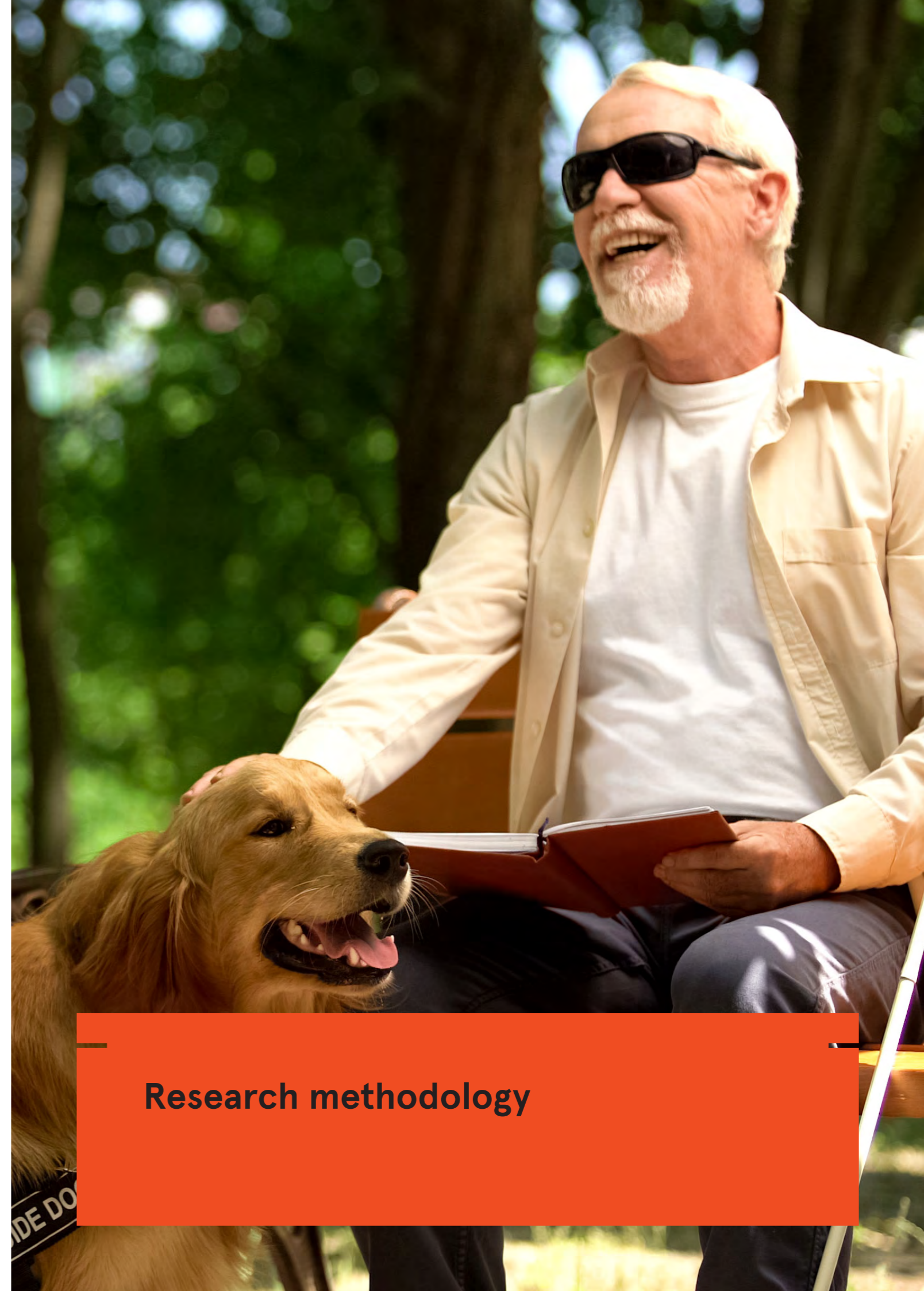
The disability community in Australia

Participants' recent experiences with the National Disability Insurance Scheme (NDIS) were an important backdrop to our engagements. Introduced in 2013, the NDIS significantly reformed the way that funding and supports are provided to people with disability in Australia. A major point of contention for our participants is the absence of people with disability on the board of the National Disability Insurance Agency (NDIA) that governs the NDIS. While people with disability are part of the NDIS Independent Advisory Council (IAC), the IAC does not have governance powers.^x

A debate over the use of "Independent Assessments" in the operation of the NDIS took place at the same time as our research engagement. Associated with the Independent Assessments proposal was the prospect of using data to create a set of avatars or personas of people with a disability, applied as a baseline or starting point for determining the supports to which people are entitled. Some call this approach to categorisation and automation 'Robo-planning.' This remains a concern for many people with disability and many participants in our research.^{xi}

Participants identified such approaches as reminiscent of 'Robodebt,' which involved the highly inappropriate use of data analysis to identify people alleged to owe money to the Commonwealth and the automatic distribution of debt notices. The government agreed a settlement with those affected by Robodebt in 2020. Our research also took place in the context of COVID-19 monitoring data apparently being accessed by police for unrelated criminal investigations, which some of our participants brought up in relation to the data being used for purposes other than those agreed.^{xii}

The inclusion of people with disability in the design, development and implementation of the NDDA was recognised by the NDDA National Project Team as a critical component of its success. This also follows disability conventions including Article 33 of the UNCRPD, to which Australia is a signatory. It mandates that people with disability be routinely included in government processes that specifically concern them.



Research methodology

Research methodology

Method, approach and limitations

The Sydney Policy Lab employs a relational approach to research, working from the assumption that insights and outcomes are strongest when they are underpinned by genuine connections between all of those involved in the research process. Through this process we create and hold spaces for people to connect across difference, creating powerful new ideas and building relationships for change.

Our approach draws on a diverse range of practices, influences and ideas, including co-design and participatory action research, which recognise the dynamic relationship between researcher and participants. We do not see our role as extracting information and providing answers, but as enabling meaningful conversations, then sharing what we have heard.

Our research team consisted of Sheelagh Daniel-Mayes, a First Nations scholar who has a vision impairment, as well as Emma Calgareo, Louise Beehag, Marc Stears, Kimberlee Weatherall, Libby Young, Sarah Hurcombe, Leigh-Anne Hepburn, Jananie Janarthana and Juliet Bennett. We are aware that not everyone in our team has lived experience of disability and recognise the benefits that would have come from having more researchers with disability on our team.

Research design

Our research design – including the questions we asked, how we asked them and how we analysed and interpreted the answers and reflections we received – was informed by recent scholarship on disability and by community-based participatory approaches to qualitative research.

Between June and September 2021, our research team conducted a series of open-ended interviews and reflective workshops with 40 representatives from national and state-based disabled people’s organisations (DPOs), disability representative and advocacy groups and select service providers. We recognise a limitation that additional outreach to people with disability who do not have jobs in these organisations was not part of our project. We designed our research to complement other NPT engagements, including coordinating early on with Australian National University’s Centre for Social Research and Methods’ research into how Australians with disability feel about the NDDA.

In designing our research, we sought to engage deeply, inviting the same participants to three engagements rather than engaging a larger number of people in a single conversation. Our intention was to create a trusting space for building relationships between participants and government representatives from the National Project Team. While beyond the scope of this engagement, our findings would have been enriched by speaking with members of the general disability community more broadly.

Interviews and workshops

The open-ended interviews were used to garner detailed answers to and insights stemming from the following questions:

- How do you feel about the aims of the proposed NDDA?
- How would you like the NDDA to be used? How could it help the organisation or community you represent? Are there certain things it should not be used for?
- Who do you think should have access to the NDDA and why?
- How would you like to see disability community stakeholders engaged in decision-making about how the NDDA is used over time?

An indicative list of open-ended questions that were asked are included in Appendix A. Interview participants were also invited to take part in Workshops 1 and 2. A list of participating organisations is included in Appendix B.

Workshop 1 focused on the sharing of insights gathered from the open-ended interviews. Participants reflected on the interview responses, delving deeper into the main themes to promote shared learning, identify gaps in the knowledge and work through challenges that they see in relation to the design and use of the NDDA.

Workshop 2 was designed based on participant feedback on the issues they most wanted to explore. It opened with a short session of ‘sense-making’ where the project’s preliminary findings were presented, followed by detailed discussions on engagement mechanisms, inclusive governance and acceptable safeguards.

The participating organisations were selected to represent the spectrum of disabilities experienced by people living in Australia, notably long-term physical, mental, intellectual or sensory disabilities as per the UNCRPD. They were identified by the NDDA’s Disability Advisory Council, comprising of disability-focused academics, professionals working in the disability space and people with lived experiences of disability. They were also identified by the NDDA National Project Team, the Lab’s research team and by members of the disability community through the process of “community nomination.”^{xiii}

All interviews were conducted by Lab researchers. Participants were asked by the Sydney Policy Lab team if they wished for a representative from the National Project Team to attend to hear feedback directly and to provide information and technical content. All participants chose to include the National Project Team, welcomed by participants as an opportunity to communicate directly with government and build valued relationships. With one exception, each interview had a member of the National Project Team in attendance.

All interviews and workshops were undertaken on the virtual meeting platform Zoom, which is supported by the University. All participants provided explicit consent for all interviews and workshop content to be recorded using Zoom’s record function to ensure that the gathered information was correct. Participants who were volunteers, self-representing or where costs would otherwise be a barrier to participation for themselves or their organisations were offered a voucher of \$100 per interview and workshop session. We concealed the identities of individual participants in the write-up of the research results and outputs, following the University of Sydney’s Human Ethics requirements. The Ethics Committee provided detailed advice and input into all of the research design.

1. Opportunities: The need for better data



1. Opportunities: The need for better data

If you don't have the data, you're invisible... the decision follows the data so if you don't have the data, you won't get the funding. We feel quite visible in our daily life and what we're doing, who we talk with and stuff, but it's quite scary when you get up to that top level of those people making decisions in a very short amount of time. They don't live in our world, they don't know the way we see things, and so we don't exist, and so therefore we don't end up on the table. (Community participant)

People's lives are increasingly affected by the use of data. Data is used to direct services, allocate funding and influence policy directions. Yet a key insight from our research is that there are major gaps when it comes to data on the life experiences of people with disability.

Community stakeholders cited a range of weaknesses in existing data. These include: a lack of correspondence between data and outcomes; inconsistencies in indicators, categories and definitions of disability; lack of integration with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); insufficient intersectional data, for example linking data across different disability cultures, other cultural identities and between different sectors like education, justice, health; and underutilisation of stories from lived experience paired with data.

All our participants saw the NDDA as a critical opportunity to fix data gaps, improve data quality and rethink the way data is collected, including making categories and definitions consistent and appropriate across datasets. As one participant remarked, "It definitely addresses a gap... it's just screaming out for it." Another put it this way: "We need to have the evidence behind us. Mostly, with disability... there's simply a dearth of data in Australia."

The NDDA was also seen as an opportunity to empower people with disability through their involvement in the NDDA's governance and operations. This involvement was seen as the most important safeguard to ensuring the data is used to the benefit and not the detriment of people with disability. (Safeguards are discussed in greater depth in Chapter Three.)

Here we discuss participants' priorities for the use of the NDDA in three categories:



- Collecting better data and using it to provide a more complete picture of the experiences of people with disability.



- Developing a platform that draws from the data to support decision-making by, with and for people with disability.



- Using the NDDA to update definitions and measure outcomes for people with disability.



Opportunity 1: A clearer picture of the experiences of people with disability and services to support them

According to our participants, datasets on the needs, wants, experiences and aspirations of people with disability in Australia are either incomplete, wrong or wholly missing. All our participants emphasised the importance of community involvement in collecting better data. Many participants also emphasised a need to more adequately display the range of services available to people with disability and to link services with stories of people who have used those services to achieve their goals.

Several participants cited the Census as an example of limited data, with the inclusion of only five questions on disability described as “bleak” and “appalling.” One participant concluded, “I mean, really, I don’t get counted [as having a disability] in the census... and yet I can’t walk. If you look at the data from the last census, 6.5 percent of the population had a disability, 13.5 percent were carers and the questions are flawed.”

Another participant observed, “So we’ve got aged care systems, we’ve got NDIS systems, we’ve got some state systems, etc. that we supply a heck of a lot of data to... and don’t get much back that actually provides us value.”

Data gaps were thought to be especially pronounced among culturally and linguistically diverse (CaLD) groups, First Nations people, those with complex disabilities, children and youth who are in care and people in less stable employment circumstances, such as casual and gig economy work. Consequently, it is very difficult for advocacy and service organisations to know with clarity what to focus on. These data gaps also make it difficult for them to provide quantitative evidence to support government submissions or requests for targeted funding. This is in part due to which questions are asked, how they are asked and phrased and which questions are missed altogether.

Some people recalled spending a lot of time searching complex datasets to obtain basic statistics that are often incorrect. For example, participants would like to know “How many people with disability are put in our detention systems?” And: “How many children of CaLD background are attending special schools across the country?” And: “How many children with disability are in residential care in Victoria each night?” Participants would like to be able to track such trends over time. Another participant stated their hope that:

this Asset [will] be used to give a really clear picture of what’s happening for people. So for those children who receive early intervention, [they] enter primary school education then secondary, when are they exiting? Why are they exiting? What are their employment options? During secondary school, have they received that early transition to work focus that you absolutely have to have with children with disability?

Participants stressed the need for high quality intersectional data, which could underpin better understandings of the connections between health, injury, the justice system and disability. Participants stated that the interlinkages are often well known by organisations, but the evidence is largely anecdotal, which hampers effective interventions. As one participant reiterated: “The data that has been collected has been really good at obscuring the reality of the situation.” Another participant observed that “visibility shifts the landscapes. So, to capture that data is a huge way to change and to adhere to the National Disability Strategy.”

In our conversations, the central appeal of the NDDA was the opportunity it offers to improve the way that data is collected and thereby produce a more complete picture of people with disability, the services available or unavailable to them and stories about people’s experiences. One participant explained:

We need somebody to go in and actually say, ‘Well, what has been wrong with the way we’ve collected data in the last few years? Why have we only gotten this?’ Not only the how, but the why. Then, there has to be a commitment about the way we will actually collect data in the future, which will remedy the mistakes made in the past. I really think there needs to be a bit of soul searching.

Several participants believed that an underlying reason for skewed and unhelpful data is that current methods of collecting data are based on a deficit model of disability. They emphasised the benefits of using the NDDA to capture and showcase the strengths of communities, rather than simply perceived impairments:

It’s about gathering the good about what a community has. I call it the Sesame Street model: who are the people in your neighbourhood? So, we’re not just collecting, ‘there’s 25 people with a brain injury’, we should also be collecting, ‘how many older adults are working at a Men’s Shed, and helping support the community?’ So, we actually look at not just a deficit-based collection of information, but the strengths that are within that community.

At the same time, a significant number of participants expressed that the data should not be relied on as the only source of truth and that it must be paired with qualitative insights and stories to build a more holistic understanding of the diversity of lived experiences. One participant remarked: “We still think the gold standard of science is to do surveys, but the richest data we can get is from that qualitative stuff and then we can actually design what people need.” Another participant observed that “numbers are not the narrative but inform the narrative.”

However, one participant had reservations about the incorporation of qualitative data, believing that it could be easily “hijacked” to highlight a particular story to privilege a chosen narrative over others: “Who’s in control of telling that story? Understanding how that story is synthesised is a really key part of the transparency [of the NDDA] for me.”

Community-led data collection across cultures and abilities

The NDDA was seen by some as an opportunity to ask the right questions, including adjusting these questions and modes of data collection to peoples' differing abilities and cultures. One participant stated:

For me, there's a real missed opportunity to genuinely think differently about the questions asked and to give that person a go and give them a chance... And no, their answer wouldn't be as broad as if you asked the carer, or it wouldn't be as detailed or deep or whatever, but it would be their voice and it would be stronger than if you'd asked everybody else... You could ask really simple questions: Who are your friends? How often do you see your family? Do you see your family? Who do you see that you don't pay?

Another participant observed: "First and foremost, for us, is culture. Culture plays such a vital role. So, you know, that needs to be embedded in whatever is developing across those platforms...and that will look different in every jurisdiction too... how do you collect those other stories?"

This is particularly important for building trust with communities such as First Nations people, as one participant observed: "It can take at least two years to build a trustful relationship of yarning about everything else except the topic. Then when you finally get to the topic, it's about giving people agency... [For indigenous communities] having a pathway to having a voice to contribute is critically important."

Another participant raised the potential opportunity to and challenge of building the capacity of Indigenous researchers who are working in remote communities:

The capacity to have that honest truth [in the data] is going to be really challenging, so it is about supporting traditional owners as researchers, giving them increased skills and capability, encouraging them that anecdotal evidence is really, really important and assisting them in ways to de-identify that, so those narratives can be shared... If we're basing services on non-Indigenous datasets, we're always going to miss the target.



Opportunity 2: Support decision-making by, with and for people with disability

All our participants wanted people with disability themselves, their families and communities to have access to the NDDA. This was conceived by some participants as access to data about the life experiences of de-identified people with disability and by other participants as access to data on services and opportunities for people with disability.

This desire accompanied an overarching hope that the NDDA will give people with disability more "choice and control" over their lives. As a participant who works in disability advocacy put it:

I want people with disability to access it, because some of our most amazing advocates and people who are shining a light and speaking up, don't have any paid role or honorary position at a university. But they are incredibly important in terms of being able to really unpack what is happening and their personal passion for this and their capacity to see what the data is really saying, I think would be really important.

Elaborating how this could work, some participants envisioned a user-friendly interface to support decision-making by and for people with disability. One participant suggested a platform that "takes you through a checklist [for example, of aspirations] and then gives you some options" for services and support. A few participants suggested this would ideally also track the quality of service-providers by linking it to a user forum where people can share their experiences.

Some participants articulated a desire that data be available in multiple formats, including pre-analysed trends and underlying raw data, to enable different actors to search for more detailed and specific data that suits their needs. A representative from a peak national body said: "The more interactive, the better... I see two things: there would be a dashboard and I think that's for general use by everybody, then – one that probably would take a bit more skill – is a report builder like ABS's data cubes. So, you can say, 'Okay, I want to look at these types of fields and apply filters.' Then what would be produced is a high-level thing like an extracted CSV file."

In addition to people with disability accessing the data, many participants thought the NDDA should be broadly accessible in principle, reflecting a commitment to giving everyone a better understanding of people with disability. One participant noted:

If you're going to make it accessible, you have to make it accessible to everybody... You know, whether it's a member of the general public, whether it's an advocacy organisation, DPO, or service provider, or government agencies, you just have to make it available to everyone.

But there were also strong views that access needs to be limited to help protect the NDDA and people with disability from unapproved and non-consensual use.

All participants agreed that decisions about who gets access and at what level must be regulated in some way that is transparent. Crucially, they wanted people with disability to have a say in, if not control of, deciding who gets access.

Most participants saw an opportunity for the data to be used in developing targeted and responsive governmental, non-governmental and service sector programs, projects and services that are evidence-based and meet diverse needs. This includes in all social services, as well as services specifically for people with disability.

People working for advocacy organisations saw an opportunity to use the NDDA to anchor and strengthen systemic advocacy for people with disability. They hoped the data could support better policy submissions and Senate enquiry presentations, which would inform policymaking. They also wanted to use the data in individual advocacy to see "what's happening with cases... key themes and trends that are coming through in advocacy."

People working for service providers wanted to use the NDDA to improve their services. They hoped to learn about "the sort of options that need to be developed and put forward" to better address the needs and life goals of people with disability. One participant explained that socially aware investors are looking to invest in projects and activities that lead to impact and transformation, but that there is often no data to help underpin this. As they put it: "The innovation and design process stem from the why: why does this problem happen? But often, you can't get to the why, because we need the who. The who has to tell you the why and if we had the data, it would help feed into the why."

Several participants brought up an opportunity to use the NDDA better to inform and support measurable benchmarking linked to the UNCRPD articles and global datasets and assist efforts to:

- i. gauge outcomes, or how people with disability in Australia are progressing over their lifetime;
- ii. chart use and successes and outcomes from the NDIS over time from the local level to the federal level over time; and
- iii. assess Australia's progress in meeting its obligations to the UNCRPD.

One participant observed: "the fact that we don't hold governments and businesses to account to [the UNCRPD] speaks to the fact that everyone, myself included, is guilty on a day-to-day basis of just treating it as a reference document instead of a guiding set of principles."



Opportunity 3: Update indicators and measure outcomes for people with disability

Several participants see the NDDA as an opportunity to create consistency in the ways that disability is identified across datasets, as well as categories of certain subsets of the population, including children, youth and CaLD groups. For example, one participant pointed out that the Disability Discrimination Act (DDA) was written in 1992 and has 11 categories of disability, all of which differ from the definition used by the Australian Human Rights Commission.

They explained that consistent and contemporary indicators of disability would make it easier to see trends in achievements, gaps in service provision and benchmark against milestones over time. They recognised that addressing this will be a complex and challenging undertaking.

A lack of consistent indicators of disability can produce data which understates the number of people with disability in Australia and poorly captures their needs. It also means that some people may miss out on the supports they need because they do not fit into a given category. Illustrating this point, one participant told the story of a young autistic man who has a range of primary and secondary disabilities:

He has issues with co-morbidity, depression... anxiety. [There is no way] without scaffolded support that taps into his true potential and his strengths and his aspirations, [that he] is going to find employment. But he is still not disabled enough to receive any supports and services, nor his family. His mum drops him off at 7.30 every morning, because he's not eligible for Headspace. There are no services that will actually take this young man. And so, he has a range of diagnoses. And I'm just using this as an example. It's where the system is falling short.

It is also important to acknowledge that some people choose not to identify as having a disability. To address this, one participant emphasised using flexible language and framing to ensure "people are able to make the initial entry through the front door."

A few participants stressed that indicators must also be culturally sensitive to be relevant. As one participant remarked: "there is no word for disability in Aboriginal languages...disability is white man's word. It's a balanda word." In Aboriginal cultures, this participant explained, disability is "defined by Dreamtime story" and can be held differently in different stories.

A resounding message was that community input will be important, both for context and to ensure that any known problems with the data are addressed during the development of the NDDA and over the full course of its usage.



2. Concerns: How the data is used and by whom

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There is an anxiety within the disability community around collection of information and breaches of our privacy, particularly since Robodebt... Could [the sharing of data across government agencies] ultimately leave me vulnerable financially? Could they cut off my DSP [Disability Support Payment]? Could they cut off my JobKeeper? Could they decide that they'll use this as part of my NDIS assessment?... We just don't know what they're going to do with that. (Community participant)

While all but one of our participants were positive about the overall idea of the NDDA and its potential, they also raised multiple concerns. We heard anxieties about whether this linked dataset could be used to remove support for people with disability, pigeonhole them or marginalise them further. Participants identified certain potential misuses of the NDDA or insights drawn from the NDDA that could have troubling consequences: commercial datamining and marketing; analysis to construct avatars or types of people with disability; use of personas for National Disability Insurance Scheme (NDIS) budgeting or individual plans; use of data for political purposes such as "doorknocking campaigns"; analysis for compliance purposes, such as identifying characteristics of individuals most likely to engage in non-compliant behaviour; and the use of re-identified data. In this chapter, we share participants' key concerns including:



- A distrust of government linked to recent experiences with the NDIS and the use of data for government purposes without the ongoing involvement and leadership of people with disability.



- Three 'red lines' that should not be crossed: anything related to a person's finances and compliance; creating personas or avatars; and commercial mining.



- Poor data that is used poorly, including by linking existing data without improving existing data or collecting new data, which could result in misleading analysis and interpretation.



Concern 1: Distrust in government and sidelining of people with disability

The biggest anxiety expressed by participants is that the disability community could be sidelined in the process or be included in a tokenistic and disingenuous way.

This anxiety was amplified by their disappointment with aspects of the NDIS and a resulting distrust of government. As one participant recalled:

We've done this before and it was taken out of control, and people with disability were completely shafted in that. And I really feel that we could be shafted in this one as well. I wouldn't be here unless I wanted to avoid that happening. And I absolutely get the benefit of data handled properly and with good, intelligent usage and ownership, ethical ownership.

Another participants stated that "people with disability are surveilled a lot and governments have a history of using that data against them. So, I think people with disability have a good reason to be suspicious of the collection of data and the use of that data."

A related concern is that the NDDA would be used to meet government priorities without meeting the needs and priorities of the disability community. For example, government could link data without improving the data and without providing an accessible, user-friendly platform to access the data. One participant worried:

I have absolutely no faith and trust in governments introducing this stuff, because ultimately, it will be for their own end and they will devise governance systems and everything else, which will mean that a two-dimensional impairment-based dataset will be set up around people with disability... It is very likely that this data is not going to be used necessarily for the benefit of people with disability. It's going to be used for the management of people with disability by governments, and that seems to me to be the way it's been set up.

Some participants wanted more detailed information about the specifics of the NDDA before fully endorsing it at this early stage. For example, one participant who works in the disability sector and is a parent to a child with a disability felt a tension between professional and private connections to people with disability. On a professional level, the benefit of the NDDA and access to the data was clear, but on a personal level, this person was concerned about how the data could be used against their child. They observed: "The data that we hold on people with disability is incredibly sensitive and incredibly personal and [...] you have to trust governments to use that data wisely."



Concern 2: Red lines and misuses

Disability community members raised three distinct 'red lines' that could not be crossed with relation to usage.

First, participants stressed that it is unacceptable for the NDDA to be used in relation to people's personal budgets, taxation levels, Centrelink, NDIS or financial support. In particular, participants stated that it would be unacceptable to use the data to justify a cut in funds or access to certain services. For example:

[Say] a person that's lived in their own home for 10 years, has a degenerative condition, they're at the end of their life, and being told, 'You can't be supported, you need to move into a group home, we're not going to fund [it].' [If the data] is being used to support these kinds of decisions, I don't think that's helpful. It's got to have integrity around it... That's got to come from the community as well, not just top down.

One participant recounted the government using a person's health data "to say that they wouldn't fund an assistance animal for her, because the reports contained prior histories of self-harm." There were also some concerns that data could be re-identified, which would enable government to "actually pin it to you individually."

Second, it is unacceptable for the data to be used to create avatars or personas from the data for people with disability. As one interviewee explained:

That was what was one of the major concerns with independent assessments: they were coming up with a base of 400 avatars, your disability would be aligned to this particular avatar and then this is how much funding you're going to receive. I mean, that was a really big concern.

Third, some participants did not want the data to be available to for-profit entities who could mine the data for commercial purposes, and were concerned about how to prevent the data from being shared without a person's approval: "What would stop that [the data] from being leaked to banks and all that?... So, you've opened it up a bit more, but then some other people, you know a home loan guy says 'yeah ok what can I find? What can I mine out of this?'"

However, other participants hoped that some commercial uses would be acceptable. A participant working for a service provider pointed out that using the data to "innovate and to come up with things... could be really good and could be really helpful" for people with disability. Another participant noted:



There could be a commercial organisation that is actually doing something to really make a big difference to people's lives and this data could be really important to inform that... What we really want to do is ensure that people's rights are protected and that the way that the data is used minimises risk to misrepresent the people with a disability.

These sorts of nuances were pointed to as examples of why people with disability should be centrally involved in decision-making at every step along the way, including both governance and day-to-day operations.

Concern 3: Poor data and data used poorly

Getting the data right and ensuring data quality was a basic and critical consideration for all participants. As one participant put it:

Data used well can be an asset... inadequate data, two-dimensional data is also damaging... In other words, if you're going part of the way, you'll end up with poor data, and then you use that for decision-making purposes and you make situations worse.

One issue repeatedly raised by participants was the importance of context when it comes to disability data. Context can determine whether someone appears, or is willing to appear, in the data identified as a person with disability. Context can also influence the kinds of information that are not collected, including because it is not deemed relevant to the reasons for collection, because is hard to collect, or because it was simply not thought of in the design of data collection processes.

One participant gave the example of students with a disability who are suspended from school, noting "you cannot access what the [suspension and expulsion] statistics were for the last school year. It's not broken down by disability." Even when some detailed statistics are released, "informal suspensions," referring to situations in which teachers ask a parent to pick up their child or suggest they only come for "two hours a day," are reported as "parent choice." The data on the impact of disability on school engagement thereby creates a misleading picture. Such examples reinforce the need for ongoing community input on the data used in the NDDA.

Data collection that is poorly resourced or undertaken for purposes unrelated to people with disability can have harmful effects when used to make broader decisions. One participant highlighted:

Frontline workers will just quickly go through stuff because they've got to fill out databases and forms. So right at the coal-face, the quality, the reliability, validity of the data and then you get kind of poor quality data that can then accelerate through the system... and we'll be making decisions on poor quality data.

Data experts in our research team suggest that information about the input data, the reasons for its collection and possible weaknesses of collection processes should be considered as part of the NDDA.

This will enable a critical understanding of weaknesses in data throughout the process, including when presenting analysis and drawing conclusions. One participant remarked that analysts using the NDDA will need to ask: "Is the data good enough to draw the conclusions, or lead to the consequences, that I propose?" Community engagement can provide such information, helping to ensure that known problems with the data are addressed during the development and use of the NDDA.

Taking these matters into account, another participant shared their fear that there is simply too much involved:

I'm terrified that when people realise how big the job is to redesign those existing datasets to get the right questions, it will be delayed [or] called off. We will still be stuck in the same situation where we're allocating scarce Australian resources to the wrong thing, because it's led by incorrect numbers, rather than the wisdom of individuals, their communities, their cities, their towns, about what it is that they need.

Ultimately, participants want the NDDA to be used to improve the lives of and outcomes for people with disability and not to be used to their detriment. They pointed out that "if we're talking about what truly community needs, what truly government should be funding, then the power belongs to asking the people, 'Tell me what it is you need.'" This reiterates the importance involving people from inception in initiatives that are intended to help them. Participants felt that having people with disability in decision-making positions is the most important safeguard against poor data and data used poorly and that this will also help foster positive social change in an ethical, fair and safe way.





3. Safeguards: 'No data about us without us'

3. Safeguards: 'No data about us without us'

You've got a jewel here. And it needs to be looked after well, needs to be protected well. You need to ensure who you share it with, that they're doing the right thing with it... It will change people's lives. That's how powerful this thing is. But in the wrong hands, the wrong people involved, it can destroy people's lives. (Community participant)

A clear message from our participants was that the greatest safeguard to address their concerns is to set up institutions and processes that embed people with disability in all aspects of the NDDA's design, governance and operation. One participant stressed: "it's about working with people with disabilities, rather than for." Participants offered many suggestions as to what this could look like in practice, including:



- Employing people with disability in day-to-day operations.



- Being a model of diversity and inclusion.



- Disability-led governance.



- An ethical oversight body.



- Government transparency and ongoing community engagement.



Safeguard 1: Employing people with disability in day-to-day operations

Participants stressed that it is not enough to involve people with disability in the development of principles and rules alone. People with disability need to be involved in the implementation, contestation and improvement of principles and rules through day-to-day operations and decisions on the ground. One participant stated:

I think that we can do a really good job with a governance structure, and I think that we can do a really good job, in terms of setting up really good rules, but the devil is always in the detail. And the devil is always in the day-to-day approvals that might be made.

It is critically important to the people we spoke to that people with lived experience of disability are meaningfully employed in the NDDA. One participant stated: "anybody who's working in the space where people with disabilities are involved should be employing people with disabilities." Another participant explained:

Undoubtedly, there'll also be a bureaucracy level to this as well, where there'll be a department, or a section of a department, that will end up being in control of what I would call the operational guidelines of the asset... I generally find that when you've got a council, and then you've got a government department, it's the interaction between those two where things can possibly go pear-shaped.

There was a strong sense of "combining lived experience with learned experience." Many participants stressed that involvement of people with disability cannot be tokenistic but involves drawing on existing skills and aptitudes that already exist in the disability community. There are many people with disability who are highly skilled in governance and who have expertise in data. A participant pointed out:

There are some anthropologists in the room who have disabilities, for example, who are really, really knowledgeable about data, and we have other people from other walks of life who have an interest and an expertise in governance. So, I think that that should be at the focus of what we do.

Employing people with disability has multiple benefits including providing a project with insights unique to those with lived experience, increasing trust through relationship building and providing employment to people who are often under-employed. By modelling diversity and inclusion, as another participant put it, the community can "see that government is walking the walk and talking the talk."

A model of accessibility, inclusivity and diversity



A recurring theme in our conversations was the need to build inclusivity and accessibility into all aspects of the NDDA to represent and meet diverse needs and cultures within the disability community.

This includes ensuring accessibility in all aspects of the NDDA. One participant stated: "We need [application processes] to meet the needs of anybody who's going to apply, so that we don't disadvantage those who have, say, for example, acquired brain injury, or perhaps who have an intellectual disability, or who are dyslexic."

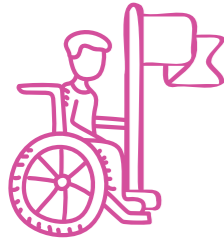
It also includes engaging diverse cultures found in the broader population, the range of disability cultures and cultures of government.

An example of this cultural difference expressed by a participant is the need to shift from approaching disability and services in an "individual way" focused on "the individual outcome" to a "more of a family- or community-centred" approach. As they articulated: "For a lot of Aboriginal people, it's about family... decision-making is often not [with] the individual, but it's broader."

Participants also emphasised that the formats and platforms through which the NDDA is accessed will need to be easy to use and tailored to different needs: "There's no one-size-fits-all." For example: "You have to think about, what will the website look like? And how will people who are blind or vision impaired use it? Or, you know, how will a deaf person use it? Or a person with intellectual disability? How are you going to explain concepts simply and clearly?"

These considerations must be front of mind in the development of communication channels, application processes for accessing data and for roles on committees and jobs in operations, and the platform and formats for disseminating the data. All aspects of the NDDA must take various forms to appeal to different people and be accessible "whatever their needs."





Safeguard 2: Disability-led governance and sharing power

All participants raised the involvement of people with diverse disabilities in ongoing governance mechanisms as a critical safeguard and emphasised the need to get this right at the outset.

There was a strong view among participants that power must be shared directly with people with disability. It is insufficient to include only those working for disability representative bodies who are not disabled themselves. In other words, people with disability should have seats at the table where decisions are being made throughout the lifecycle of the NDDA. Some went further to suggest that there should “be a majority or at least half of the people within that structure or within the decision-making framework, who are people... with disability.”

Representation also requires attentiveness to diversity of disabilities, genders, cultures, a spectrum of ages, those with complex needs and their families and carers, those who are non-verbal, those with intellectual disabilities, Deafblind Australians and people with lived experiences of disability who are not white and middle-class. One participant remarked: “With the governance around the dataset... the makeup of it should be relatively equitable and inclusive, across many different forms of disabilities, and people of colour and all that sort of demographic stuff, cohort representation.”

However, participants reiterated that diversity considerations should not be tokenistic. As one participant put it: “It’s not just ‘we’ll get our token blind person’. It’s about acknowledging that diversity and making sure that diversity is embedded in our system.” For example, it was seen as unsatisfactory for a person with disability to be part of an advisory group or board otherwise populated by those without a disability, as their advice may not be listened to or prioritised. One participant explained: “It’s assumed that if you have a disability and you’re on a board that you’re there as the token person with disabilities. It doesn’t recognise our skills and abilities as equal citizens.” Another participant added: “The first person on any board with a disability will always be seen as token. It’s actually the second, the third, the fourth person where you start to actually make your real runs on the board.”

While there is an awareness that it is impossible to include all disabilities at the decision-making table, effort needs to be given to capacity-building to include people who are often excluded, such as those with complex disabilities including intellectual and psychosocial disabilities. One participant emphasised the importance of bringing in “missing voices” to counteract the dominant voices of those in privileged positions:

We often have people who are well-articulated, with lived experience of disability and without lived experience of disability, but we’re not getting to the person who is in prison, who has a brain injury, who is reoffending... Whether it’s by colour, by gender, or by disability, we’ve got to have people who aren’t in the positions be able to do the Zoom and have other ways of engagement.

Suggestions to support involvement include different modes of participation such as a mentoring buddy system, adapting meeting formats and materials to differing needs and offering a developmental program designed to support interested individuals to develop the skills and confidence they need to participate. One participant noted: “For some people that would take concerted effort, it would take time, it would take intentional teaching, but I think it’s totally worth it.” Another participant added to this the value of including “informal family carers to ensure that the voices and needs of little ones can be heard.”

The idea of a multi-level governance structure emerged from our early interviews:

I would suggest two stages. You have the DPOs [Disabled People’s Organisations] and the DROs [Disability Representative Organisations] in some sort of panel capacity, but then also having a network that goes right down through into the community... But then, you’ve got a secondary mechanism where you’re doing authentic engagement and authentic consultation on the ground: going out, testing ideas and concepts in focus groups. It’s about going into the peer engagement space and saying: ‘What do you really think?’

In subsequent interviews and at our workshops, participants expressed support for and elaborated on this idea. They suggested an overarching entity with a rotating membership that would oversee the NDDA. Members would include representatives from government departments, peak national disability representative bodies, representative bodies for service providers, key strategic disability advocacy groups, disability academics and other influential people with disability.

In addition to the overarching body, subgroups and reference groups would represent different communities clustered according to disability type, culture, remote, regional and urban geographies, state and territory jurisdictions, age groups, or interests and areas of expertise aligning with NDDA priorities, such as health, education or gender. These subgroups and reference groups would foster the inclusion of multiple voices and provide dynamic platforms for deeper engagement.

Other ideas for governance mechanisms included a citizens’ jury, an ethics committee and a three-layered system of governance comprising a formal structure such as an advisory council, disability representative organisations, and grassroots organisations with deep connections to community.

There was no consensus as to the specific composition of the membership for the various governance structures proposed, and participants agreed that any composition would inevitably leave some people out. Regardless of the governance structure, its guiding principle should be the central involvement of a diversity of people with lived experience of disability and intersectional identities in ongoing decision-making at a strategic as well as operational and day-to-day level. This reflects a participatory approach to data management.

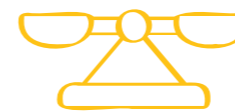
Participatory approaches to data and its management

There is increasing evidence that involving people in data governance can help address social and economic inequality, imbalances of power and increase confidence the use of data,^{xiv} and lead to better policymaking.^{xv} This supports the aspiration of ‘nothing about us without us,’ and the goals of policymakers who recognise that “people are experts in their own lives; policy should be designed by people with relevant lived experience.”^{xvi} Involving people in data governance raises complex questions, for instance:

- What level of participation should people have? There is a spectrum of modes of participation with increasing power through informing, consulting, involving, collaborating and empowering people.^{xvii}
- How should people participate? Directly as individuals through representation such as a data trust, or collaboratively through structures like data cooperatives?^{xviii}
- Which parts of data processes should people be involved in? Should people participate in decisions about the collection of data, its analysis, who can access it, or how it can be used?

Some examples of participatory data include trans and non-binary people collecting data about themselves in New Zealand^{xix} and Indigenous peoples seeking sovereignty over how data about them is collected and used.^{xx} The European Union-funded DEcentralised Citizen Owned Data Ecosystem (DECODE) project is another example, which experimented with putting “people in control of their personal data,” piloted in Barcelona and Amsterdam.^{xxi}

We recognise this may be politically and ethically complex. Having the capacity to try things that might not work, or “safe spaces to fail,” can help public managers to experiment with participatory data practices like these.^{xxii}



Safeguard 3: Ethical oversight body

Many participants emphasised the importance of an ethical oversight body with purview over a wide range of aspects of the NDDA, including processes of application and appointment to governing bodies, the type of data the NDDA holds, and protocol for data access and use.

Once again strong representation of people with disability was central to the discussion and seen as critical to the integrity of any ethics body. As one participant put it: “we need an ethics committee for every stage. And it needs to be populated by people with disabilities who have the skills and expertise.” Another participant remarked:

If data is going to be used [it should be put] before a board of people with disabilities from diverse backgrounds and intersections of the community. A proposal needs to be submitted to explain what that data is going to be used for, and the benefit is going to be for people with disabilities.

Other community representatives stressed the need for both legislative and regulatory mechanisms, such as an enforceable ‘Code of Conduct’ and ‘User Code’ and a risk management plan, all with strong legislative parameters. The User Code would ensure that the NDDA was used in an ethical way. The Code of Conduct would ensure that decisions made by the ethical oversight body are taken in a transparent manner and in accordance with the changing needs, wishes and aspirations of the disability community. Such legally enforceable mechanisms would provide any governance and ethical oversight bodies with ‘teeth’ and institutionalise accountability.

However, some participants cautioned against the risk that too many levels of bureaucratic governance could unintentionally slow down critical decision-making and create “unnecessary red tape” for service providers looking to use the data asset to understand their market and create innovative solutions addressing gaps in provision.

One participant observed: “There’s possibly a way that if there’s too much red tape... if it becomes too difficult, it might just make the data impossible to access and therefore impossible to use for the benefits that it’s initially set up for, if it’s too difficult.” In sum, when designing institutions and processes involved in ethical oversight and governance these should be weighed against the significance of the value they offer and protections they provide.



Safeguard 4: Transparency and ongoing community engagement

Participants expressed that government transparency across a number of aspects of the NDDA would be highly valued by the disability community.

Transparency is facilitated by building relationships through enduring engagement with the community and making it clear what the NDDA can and cannot achieve at what stage.

When it comes to the distribution of power across different governing bodies and “to state, to departments, across governments,” one participant wanted to know: “How much influencing power does [this governing body] have with developing and building or influencing social policy? If it does, or if does not?” They continued:

...whether it's the Department of Agriculture and Lands, or whether it's the Department of Treasury, whether it's the Department of Education or Health? How much power can you have to say, 'We would like you to collect data x, y, z. We would like to also in return, have unidentified data on x, y, z.'

Many participants emphasised that application and appointment processes should be transparent and meet different accessibility needs. Appointments that are not representative of the disability community or are made unilaterally by the government will be seen by the disability community as simply an extension of the ‘arm of the government’ and could undermine trust in the NDDA itself.

Participants also suggested that their trust in government could be repaired if government demonstrated prioritised disability voices in leading the ongoing design and operation of the NDDA. One participant noted: “If you're talking about how we engender trust, it's got to start from an authentic position of really wanting this to be of benefit to people with disability on their terms.”

Some participants suggested that people with disability should be employed to do the community engagement work:

Community engagement must be undertaken by people with disabilities: people with disabilities talking to people with disabilities and using their expertise... We have some really great people with disabilities who are terrific facilitators and are able to bring other people with disabilities along. That actually creates a spirit of trust, so that everybody in the room knows that it's not some bureaucrat or some academic talking about us.

Employing people with disability to involve communities in the future development of the NDDA will not only enable people with disability to engage their peers directly, but will also continue to build capacity, confidence and trust. This approach harnesses the benefits of what one participant described as the “I get you factor”: “We have genuine conversations, because of that ‘I get you factor’, we all identify as people with disability and there is that relationship, there is that trust and so the conversations are much deeper, and more genuine.”

Participants highlighted the importance of ongoing communication mechanisms that provide “clear channels for people to be heard,” including on issues of improving the quality of existing data in the near term. Such mechanisms support the NDDA to evolve alongside the people it exists to serve. For one participant, the key is to “get creative to [reach] people that you never hear from” or see in the data and to “give [them] an opportunity to tell their story.” One participant explained:

Not everyone has internet, not everyone has IT. And there's a lot of hurdles that people have to jump. Not a lot of people can travel for lots of reasons... [So] how do we support people to have that really important voice at the table?

Participants' suggestions included:

- A soft, flexible approach that supports conversations and relationship building within an open timeframe and in varied forms, from an occasional phone call to years of patient engagement.
- Partnerships with existing networks, grassroots organisations, advocacy groups and peak bodies which already have the hard-earned trust of and deep reach into their communities.
- Greater use of social media and digital platforms such as Twitter and closed groups on Facebook. Many people with disability are active online, as one participant highlighted: “You know, if you look in the Twitterverse and the disability community is actually very active on Twitter, because you know, a lot of people are home-bound and bed-bound.”
- A broader spectrum of approaches to hard-to-reach populations who might not be digitally literate, such as engagement through mainstream television and public service announcements and local networks of people distributing ‘low-tech information’ on supermarket noticeboards or on USBs.

Finally, some participants expressed concern that engagement with the NDDA will place undue burdens on people who are already time poor. Resources must be allocated to support sustained engagement. At minimum, stipends should be provided to those sitting on councils or sub-councils, with enough operational budget to cover interpreters, helpers, materials and interfaces that cater for different accessibility needs.



Conclusion and recommendations

Conclusion and recommendations

Across a series of engagements, our research team listened to the views of people from disability community organisations about the idea of the NDDA. Data is central to influencing policy, distributing funding and directing services, and the ways in which it is collected, stored, accessed, used and updated therefore greatly impacts the lives of people with disability. The NDDA seeks to link de-identified data on the experiences of people with disability across Australian jurisdictions and a range of policy domains, serving the overarching goal of improving service delivery and real opportunities for people with disability. Community support and vision is at the heart of the NDDA and its potential futures.

Over the course of interviews and workshops, we built an understanding of our participants' hopes for the NDDA and their concerns, which we have done our best to share in this report.

The key question for our research team was: Can the NDDA improve the lives of people with disability, and if so, how? From our participants we heard a resounding message: The NDDA can improve lives of people with disability, so long as people with disability are in the lead.

Most participants expressed strong conditional support for the idea of the NDDA, embracing it as a critical opportunity to fix data gaps and data quality. The condition upon which people's support depended was the meaningful involvement of people with disability in the Asset's design, governance and operation. The imperative of enduring involvement of people with disability was the clearest single insight to emerge from the entire process. It underpins participants' hopes for the NDDA to fulfil the potential they identified and is seen as the only way to alleviate their concerns.

Participants were clear that the NDDA could make a tangible difference to the lives of people with disability, not only through responsible, transparent and creative use of reliable data but through the shape of the NDDA's operations and institutional processes. We heard a strong, shared conviction that the positive potential of the NDDA will be realised only if people with disability play key roles in the NDDA's ongoing design, governance and operation. One participant concluded:

It's all about really living the 'nothing about us without us' and I feel that... this project will really support people with disability to be the major decision makers, to be well informed and to actually be at the centre.

This primary insight, reflected in our report title "No Data About Us Without Us" is reiterated in participants' perspectives in each chapter. Further key insights include:

1. There is an opportunity for better data on the experiences of people with disability to inform better decision-making.

In Chapter One, we heard a call for better data on the experiences of people with disability. Our participants saw the NDDA as a critical opportunity to fix data gaps, improve data quality and rethink the way data is collected. Beyond the fundamental importance of linking existing data, participants emphasised that existing data needs to be improved. This data collection must be informed by the contextual understandings held by people with disability and their communities.

The people we spoke to observed that decisions are increasingly being based on data. They were concerned that if data is of poor quality, or doesn't accurately capture the life experiences of people with disability, it will lead to poor quality decisions. They hoped that better data collected for the NDDA will be used to make better decisions and be available for them to use to influence policy, enable advocacy and direct services in ways that improve the lives of people with disability.

Our participants also hope that the NDDA will be used to measure outcomes in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and update and ensure consistency in how disability is made visible across datasets. Reflected in this is an understanding of the ways that people are dis-abled by culture and society. Thus, participants identified a need for data collection, analysis and interpretation to be underpinned by an appreciation of the strengths of people with disabilities and their communities rather than by perceived impairments. Participants hope that the NDDA will be directed towards people's aspirations as well as their needs.



2. The prospect of the NDDA raises significant concerns about how to ensure that the use of data directly benefits people with disability.

In Chapter Two, participants emphasised the risks of data linkage and shared their concerns about how to ensure the NDDA is used to benefit people with disability. People had concerns that the data would be used for compliance, the creation of personas or be re-identified. They also worried that people with disability would be sidelined in the process, engaged superficially, or tokenised. They stressed the value of combining lived and learned experience, employing people with disability in all aspects of the NDDA and ensuring enough people with disability are at the table so that they are genuinely heard and power is shared.

The people we spoke to believed that if the NDDA connects existing data without collecting better data, it will worsen the situations for people with disability because decisions will be made based on inaccurate data. Community-led data collection to improve and expand the data connected was identified as crucial.

Participants' experiences with the National Disability Insurance Scheme (NDIS) have eroded trust in government in this part of the disability community. Participants hoped that the NDDA will take up the task of rebuilding trust by empowering people with disability as leaders and experts employed in and advising the project.

Disability-led processes and systems of governance were seen as the best way to prevent misinterpretation and misuse and to ensure data is used to benefit the community in the short and long term. This includes people with disability playing leading roles in the NDDA's governance bodies to shape how it develops, and in understanding and interpreting the data and its applications.



3. The meaningful engagement of people with disability at all levels of the NDDA is the most important safeguard for ensuring its success.

Participants identified multiple ways to safeguard data collection, access and use, as articulated in Chapter Three. Once again, we heard that data will be best protected and most responsibly used if people with disability are centrally included in the design, ongoing governance and day-to-day operations of the NDDA. Participants underscored that engagement cannot be tokenistic. There are diversely skilled people with disabilities who should be appropriately engaged in the work of the NDDA. There is also a need for multiple clear channels for two-way engagement with the community on the NDDA and improving data collection. This could be done now.

Looking ahead, engagement of the disability community could be taken a step further along the spectrum of participatory research and design methods, moving from consulting the community to involving, collaborating with and empowering the community in these engagement processes.^{xxiii} Applying co-design practices from the earliest possible stage and creating a space for participatory policymaking holds promise for better public policy outcomes. Although genuine co-design necessarily involves ceding some control and increasing the complexity of a project, it has many benefits including better suited and more innovative outcomes and facilitating community investment and trust through the design process itself.^{xxiv} Successful co-design also involves being upfront about the difficulties of navigating cultures of government, academia and communities and experimenting with shared solutions that can inform a broader participatory and community-led approach to policy and practice in the future.

Guided by our participants, we provide a series of suggestions intended to inform the NDDA’s ongoing design, governance and operation. Many insights from our research process are relevant not only to the NDDA, but to any other project about or for people with disability. Accordingly, we offer a further set of suggestions to analysts, researchers and civil society engaged in this space.

We hope that the findings of this report will be brought into direct discussion with data scientists, governance experts and policymakers, and with further research led by people with disability.

Requirements of a successful National Disability Data Asset:

1. Ensure people with disability are in the lead.

A commitment to having people with disability in the lead should be at the heart of the NDDA. One way to embed disability leadership is to ensure that a significant portion, even a majority, of people in governance bodies bring expertise from lived experience with disability in addition to other forms of expertise. Participants also suggested that employing relevant experts with disability in design and operations teams would be invaluable.

2. Address the community’s desire for better data.

The NDDA and associated conversations are an opportunity to improve data collection and address data quality and gaps more broadly, as outlined by participants. Even if the NDDA does not go ahead, we recommend that the government consider other ways to support the community’s desire for better data, particularly through community-led initiatives.

3. Develop a user-friendly digital platform to disseminate insights.

Participants saw great benefit in an accessible user-friendly digital platform that will provide information to support people with disability to make their own decisions and navigate the services and supports available to realise their aspirations.

4. Be transparent and rebuild trust with the disability community.

Transparency is foundational to trust. Being transparent about government decision-making processes, about how power will be shared and about processes for selecting people to be on governance bodies, will help to rebuild trust. A relationship of trust will also require honouring community-agreed acceptable and unacceptable uses, and not crossing ‘red lines’ that they identify.

5. Set up multiple channels for building and maintaining relationships.

Clear and responsive two-way communication channels will also help build trusting relationships, with government communicating updates about the NDDA and disability communities providing input to improve data and influence the NDDA’s ongoing governance and operations. Recruiting people with disability to design and run community engagement and communications activities would also help to foster trust and build lasting relationships with the disability community.

6. Be a model of accessibility, diversity and inclusion.

The NDDA needs to ‘walk the talk’, modelling exemplary practices that embed inclusivity and accessibility in all work related to its governance and operations. In this way, the NDDA may be a model that other government services can follow.

7. Advance forms of participatory data stewardship.

The NDDA presents an opportunity for greater participatory data stewardship, enabling people with disability to make decisions about and for themselves. It also represents an important shift of broader significance towards involving people affected by data in the governance of that data. As such, this work is part of a global movement to advance participatory and deliberative institutional forms of data stewardship.^{xxv}

Principles for collaboration: suggestions for analysts, researchers and civil society

1. Recognise the diverse strengths and aspirations of people with disability.

'Disability' means different things to different people and within different cultures. In some cultures, the word does not even exist. Beyond medical definitions, there are many ways that cultural and social conditions make it difficult for some people to live what is taken to be a 'normal' life.

While having a disability involves impairments of some kind, it also involves a wide range of strengths. Thus, in addition to targeting basic needs, data can shed light on people's strengths and aspirations and better enable them to achieve their goals.

This reflection can change the way that research is done and policy designed. It also can change the way people may interact on the street – a shift from pitying another's deficits, to sparking a curiosity about their differences.

2. If you are doing work for people with disability, it should be done with people with disability.

Any project about or for people with disability should employ people with disability where possible. There is also great value in finding creative ways to listen to the voices of people with diverse and complex disabilities. We recognise that timeframes set by decision-makers may not allow for such opportunities, which brings us to a final recommendation:

3. Prioritise meaningful relationships, even when under pressure to meet rigid deadlines.

There is a need to reconcile the longer, more flexible timeframes involved in building relationships with institutional cultures that are managed top-down and with rigid key performance indicators and deadlines. How can cultures which call for flexible and longer timeframes to build relationships be reconciled with institutional cultures, managed top-down, with rigid key performance indicators and deadlines?

This disconnect is often seen when government, academia and business work with diverse communities not usually involved in formal decision-making processes. Here, successful and appropriate engagement and co-design requires significantly more time and flexibility.

Some disability cultures also require particular sensitivities and approaches. For example, building a relationship with someone who is non-verbal and trying to understand and include their perspectives, is not a box to be ticked or an outcome achieved. This speaks to broader opportunities to pioneer shifts in institutional practices from project-specific or time-limited engagements to enduring relational approaches based on mutual-learning and dialogue with communities through time.

Notes

- i. The decision not to capitalise the 'a' in CaLD is guided by recommendations of the National Ethnic Disability Alliance (NEDA) which argues that there is a marked difference between culturally and linguistically diverse groups. Treating them as one homogeneous group is misleading and creates incorrect assumptions and data.
- ii. Australia Network on Disability, "Inclusive Language' language," <https://www.and.org.au/pages/inclusive-language.html> [Accessed 25 Sept 2021].
- iii. Ada Lovelace Institute, "Participatory data stewardship: A framework for involving people in the use of data," Ada Lovelace Institute (Sept 2021) <https://www.adalovelaceinstitute.org/report/participatory-data-stewardship/> [Accessed 25 Sep 2021].
- iv. Scott Avery, *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*, (Sydney: First Peoples Disability Network, 2018), 2.
- v. Avery, *Culture is inclusion*, 4.
- vi. Marno Retief and Rantoa Letšosa, "Models of disability: A brief overview," *Theological Studies* 74 (2018).
- vii. Colin Barnes, "Understanding the social model of disability: Past, present and future," in *Routledge Handbook of Disability Studies*, ed. Simo Vehmas and Nick Watson, (Oxon: Routledge, 2020).
- viii. Theresia Degener, "Disability in a human rights context," *Laws* 5 (2016).
- ix. Frederick Douglass, "Speech at the New England Woman Suffrage Association (May 24, 1886)," in *The Essential Douglass: Selected Writings & Speeches*, ed. Nicholas Buccola (Indianapolis: Hackett Publishing Company, 2016 [1886]); John Thrasher, "Self-ownership as personal sovereignty," *Social Philosophy & Policy* 36 (2019): 116–33; Timothy Hinton, "Equality, self-ownership, and individual sovereignty," *The Philosophical Forum* 44 (2013): 165–78.
- x. At the time the research was conducted, the last person with disability on the NDIA board had just stood down. NDIS, "Council – The voice of participants," <https://www.ndis.gov.au/about-us/governance/iac> [Accessed 29 Aug 2021]. Encouragingly, since this time five people with disability were recruited to the board including paralympian Kurt Fearnley as chair." Also see Rashida Yosufzai, "People with disability say their trust in government has been damaged over NDIS assessments controversy," *SBS News*, 2021, <https://www.sbs.com.au/news/people-with-disability-say-their-trust-in-government-has-been-damaged-over-ndis-assessments-controversy/f76e341f-7ef1-499c-8815-48a3419243d5> [Accessed 29 Aug 2021].
- xi. Nas Campanella and Celina Edmonds, "Former NDIS chairman slams changes to support scheme as 'robo-planning' and 'a disgrace'," *ABC*, 23 Apr 2021, <https://www.abc.net.au/news/2021-04-23/former-ndis-chairman-slams-changes-to-support-scheme/100091348> [Accessed 29 Aug 2021].

- xii. Graham Greenleaf and Katharine Kemp, "Police access to COVID check-in data is an affront to our privacy. We need stronger and more consistent rules in place," *The Conversation*, 7 Sept 2021 <https://theconversation.com/police-access-to-covid-check-in-data-is-an-affront-to-our-privacy-we-need-stronger-and-more-consistent-rules-in-place-167360> [Accessed 25 Sept 2021].
- xiii. Sheelagh Daniels-Mayes, "Researcher or student? Knowing when not to know in community-led indigenous research," in *Community-led research: Walking many pathways together*, ed. Victoria Rawlings, James Flexner and Lynette Riley (Sydney: Sydney University Press, 2021).
- xiv. Ada Lovelace Institute, "Participatory data stewardship."
- xv. Emma Blomkamp, "The promise of co-design for public policy," *Australian Journal of Public Administration* 77, no. 4 (2018): 729–74, 732.
- xvi. Blomkamp, "The promise of co-design for public policy," 732.
- xvii. Ada Lovelace Institute, "Participatory data stewardship."
- xviii. Ada Lovelace Institute and AI Council, "Exploring legal mechanisms for data stewardship," Ada Lovelace Institute (Mar 2021) <https://www.adalovelaceinstitute.org/report/legal-mechanisms-data-stewardship/> [Accessed 25 Sep 21], 6–7.
- xix. Counting Ourselves, "Counting Ourselves: The health and wellbeing of trans and non-binary people in Aotearoa New Zealand," Counting Ourselves New Zealand (2019) <https://countingourselves.nz/2018-survey-report/> [Accessed 26/9/22]
- xx. Maggie Walter, et al., *Indigenous Data Sovereignty and Policy* (Oxon: Routledge, 2020).
- xxi. DECODE, "Pilots," <https://decodeproject.eu/pilots.html> [Accessed 2/11/21].
- xxii. ANZSOG, "Using innovation to encourage public managers to embrace risk," (2019) <https://anzsog.edu.au/research-insights-and-resources/research/using-innovation-to-encourage-public-managers-to-embrace-risk/> [Accessed 26/9/22].
- xxiii. Ada Lovelace Institute, "Participatory data stewardship."
- xxiv. Blomkamp, "The promise of co-design for public policy," 735–737. For a summary see Maria Katsonis, "The promise of co-design for public policy," ANZSOG (2020) <https://www.anzsog.edu.au/resource-library/research/the-promise-of-co-design-for-public-policy> [Accessed 14 Jul 2021].
- xxv. Ada Lovelace Institute, "Participatory data stewardship."

Appendix A. List of open-ended interview questions

Opening questions about data and experiences with data in their organisation

1. How important is data to your organisation?
2. How do you currently use data?

Questions about the Asset in its proposed form

1. How do you feel about the aims of the proposed Asset?
 - a. Do you like what you see?
 - b. Do you have any concerns with the asset in its proposed form?
 - c. Are there elements/components that are missing/inappropriate/unsettling?
 - d. If so, what are these? What needs to be changed?
 - e. What can the NDDA team do to overcome or alleviate your concerns?
2. Use: How would you like the Asset to be used? How could it help the organisation/community you represent?
 - a. What do you see at the potential benefits of having an Asset that links data?
 - b. What is most important to your organisation and what is not as important?
 - c. What are you hoping the Asset will do and achieve?
 - d. How would you like to see priorities for the Asset's use being set? What would you nominate if you had the chance?
 - e. Are there certain things that the Asset and its data should not be used for – no-go's for use?
 - f. If so, what are these?
3. Access: Who do you think should have access to the Asset and why?
 - a. Do you want specific access to the Asset?
 - b. If so, for what purpose?
 - c. If so, how would you like to access the Asset?
 - d. Who else should have access to the Asset and why?
 - e. Who do you trust to access the Asset?
 - f. Who don't you trust to access the Asset?
 - g. What can the National Disability Data Asset team do (if anything) to improve your trust levels?
4. Governance: How would you like to see disability community stakeholders engage in decision-making of the uses of the Asset over time?
 - a. What are your thoughts on this proposal?
 - b. Should anything be changed and if so, what would these changes look like?
 - c. Or should it look completely different? If so, what should it look like?
 - d. How is the best way for disability community stakeholders and advocates to engage in the management and decision-making of the Asset over time?
 - e. From your perspective, what mechanisms/systems/platforms need to be in place to foster true engagement?
 - f. What can the NDDA team do to improve engagement?

5. Is there any information that is important/missing currently/unclearly communicated that you or the people/community/organisation you represent need to/would like to know?
6. Would you like further information about the Asset on an ongoing basis?
 - a. If so, what would you like to know more about and how would you like to receive this information (email, webinar, meeting with National Project Team, communique from the Council)?
 - b. Would representative bodies like yourselves be a good way of sharing information about the Asset?
 - c. If so, how can the NDDA support peaks to share information about the Asset?

Any final reflections from the participant on the Asset or the interview process?

Explain what the two workshops are and ask them if they are willing to participate.

Appendix B. List of participating organisations

- Accessible Arts Australia
- AMAZE
- Arts Accessible Australia
- Assoc. Children with a Disability
- Assoc. Children with a Disability (VIC)
- Australian Federation of Disability Organisations
- Autism QLD
- Brain Injury Australia
- Disability Council NSW
- City of Sydney Inclusion Advisory Panel
- Community Mental Health Australia
- Council for Intellectual disability
- Council of Regional Disability Services (servicing regional and remote WA)
- Deaf Australia
- Disability Advocacy Network Australia
- Diversity and Disability Alliance
- Down Syndrome Australia
- Family Planning NSW
- First Peoples Disability Network Australia
- Health Justice Australia
- HireUp
- Inclusion Moves
- Independent Consultant
- Life without Barriers
- Melbourne Disability Institute
- National Disability Services
- National Ethnic Disability Alliance
- NorthCott
- People with Disability Australia
- Physical Disability Australia
- Purple Orange
- Queenslanders with Disability Network
- Rights & Inclusion Australia
- Synapse
- Vision Australia
- Whitecoat
- Women with Disabilities Australia
- YouthWorX NT

Appendix C. Pre-workshop Two: Handout for participants

Thank you for taking the time to share your views on the design of the proposed National Disability Data Asset (NDDA). During the interviews and first workshop, two things people said they wanted to discuss further were safeguards, governance and how to ensure delivery of the NDDA benefits for people with disability. Our next workshop on Friday 3 September 2021 will focus on these topics. Below are questions we will talk through at the second workshop, which you might want to think about in advance.

Questions to think about:

1. What are the critical things that need to be part of the NDDA for the community to support it? What would be the deal-breakers – things about the NDDA, or use of it, that would mean you couldn't support it?

Governance

2. We've heard people say 'nothing about us without us.' What does that mean in practice for the NDDA? What is needed for the community to trust processes and outcomes over time, in an enduring way?
3. If there were a Council or Committee involving people with disability, who should decide who is part of this group, and what should this process involve? Who from the disability community should be represented at the Council level and other levels of governance?
4. In our system of government, ministers are the ultimate decision makers. What would you want to see from ministers if they did not take on board recommendations from the Council? Would you still support an NDDA if this were a potential outcome?

Rules and Safeguards

5. A Council might not be involved every time NDDA data is used: it might instead be involved in setting the rules so people managing the asset can apply them. What rules do you think there need to be about:
 - a. Who gets access to NDDA data?
 - b. What the priorities are for the NDDA?
 - c. What questions people can ask using NDDA data?
 - d. How results of any research using NDDA data are interpreted or used?

Questions about live test cases

In this phase, the idea of an NDDA has been developed using test cases, described at NDDA Public Policy Test Cases

Are the test cases good examples of potential uses of the NDDA?

If you heard NDDA data was being used for these purposes, what would you think? What would you want to know?

"What if" questions for the future

The NDDA will not be allowed to be used for some things. But rules, or how rules are interpreted, often evolve over time. How should people with disability be involved in decisions about how those rules change? Here are two "what if" questions on this.

"What if" 1

The NDDA is being developed with limits on its use, through rules as well as its design. This means NDDA data can't be used to adjust individual NDIS packages, to assess eligibility for government support, or for compliance purposes.

- How should these limits be enforced?
- Do these limits need to be put in 'hard' regulation, even if that means the NDDA will be very challenging to establish (given all nine jurisdictions will have to make legislative changes)? Or would other options that ensure no government can unilaterally make changes to the settings of the NDDA be just as effective?
- If a government wanted to remove these limits in the future, who should decide if that is OK?

"What if" 2

NDDA data won't be accessed for commercial use, for example, for businesses to promote their products. But in the first workshop, and in interviews, we heard different views on if commercial use of the data could be OK.

- Do you think it might be OK for a start-up to use the data to identify a gap in the market and work with people with disability to identify solutions?
- Who should decide if that is OK?
- What kinds of conditions of use should apply?

Get in touch

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