ANZSOG

RESEARCH INSIGHTS

The National Disability Data Asset (NDDA)

THE NATIONAL DISABILITY DATA ASSET (NDDA)

A case study for ANZSOG's project on co-governance and trust in government

12 September 2025
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ΛNZSOG

Acknowledgement of country

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About the Social Policy Research Centre

The Social Policy Research Centre is based in the Faculty of Arts, Design and Architecture at UNSW Sydney. The Social Policy Research Centre makes a positive impact through independent and leading research that tackles critical social issues. For more information see https://www.unsw.edu.au/research/sprc.

About the International Centre for Future Health Systems

The International Centre for Future Health Systems is a cross-faculty research centre based at UNSW Sydney. For more information see https://www.unsw.edu.au/research/icfhs.

CONTENTS

ABBREVIATIONS

ANZSOG	Australian and New Zealand School of Government
DCJ	NSW Department of Communities and Justice
DPC	NSW Department of Premiers and Cabinet (now The Cabinet Office)
DSS	Australian Government Department of Social Services
NDDA	National Disability Data Asset
NDDA Council	Governance group for the enduring NDDA asset
Pilot DAC	Disability Advisory Council for the NDDA Pilot
SPL	Sydney Policy Lab
SPRC	Social Policy Research Centre
TCO	NSW The Cabinet Office
UNSW	University of New South Wales, Sydney

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1. SUMMARY

This is one of three case studies that form a larger project to identify methods to operationalise and implement co-governance arrangements. This project is being undertaken by the Social Policy Research Centre (SPRC), UNSW Sydney, funded by the Australia and New Zealand School of Government (ANZSOG) and the NSW Government.

This case study documents the process of **designing and proposing to establish a co-governance arrangement** for the enduring National Disability Data Asset (NDDA) by the NDDA Pilot Disability Advisory Council (Pilot DAC). The National Disability Data Asset Pilot project that led to the implementation of the NDDA ran from 2019–2021 (see Box 1 for a description of the NDDA). The pilot involved six participating jurisdictions and was delivered by a National Project Team (hosted by the NSW Department of Premier & Cabinet) and a Technical Project Team (hosted by the Australian Institute of Health and Welfare). The Pilot DAC was established in 2020 to advise on the acceptability of the proposed NDDA; however, its scope and the mechanism to deliver this scope, over time grew into a process that had some of the practices that we may expect to see in co-governance arrangements – the key difference being the **membership of the group did not include government representatives and it had been established by Ministers as an advisory council,** hence this is **not co-governance** as defined by this project. The Pilot DAC was tasked to deliver recommendations to government on how the asset should be used and any governance or safeguard arrangements that should be in place to build and maintain public trust in the asset. Much of the work of the Pilot DAC occurred during the second half of 2021; Pilot DAC made its final recommendations to government at the completion of the pilot at the end of 2021.

Box 1: What is the National Disability Data Asset?

The National Disability Data Asset is a new way to connect information about all Australians to improve outcomes for people with disability. In its initial phases, it will bring together de-identified data held by Australian, state and territory government agencies. The disability data asset will provide insights about the needs and outcomes of people with disability that could not be seen previously. This information will help improve programs and services for people with disability.

The National Disability Data Asset was agreed by all Governments and funded by the Australian Government in 2022, was in its build phase at the time of the research was undertaken (2024), and commenced operation during the reporting period (19 December 2024).

The Disability Reform Ministerial Council oversees the National Disability Data Asset project, in which all Australian jurisdictions participate. Implementation of the initiative to build the National Disability Data Asset is led by the Department of Social Services, the Australian Bureau of Statistics, and the Australian Institute of Health and Welfare.

Source: NDDA website ndda.gov.au/faq and study data

The process of establishing the co-governance of the NDDA, through the collaborative work of the Pilot DAC and its recommendations to Ministers, is **included as a case study in this project given the rich insights from the process of designing co-governance and any relevant lessons for practices that may enable co-governance**.

1.1.   Definitions of co-governance

In this study, co-governance and collaborative governance are interchangeable terms that refer to collective decision-making, formal arrangements, deliberative and constructive processes, involving government and other stakeholders, including community members (Smyth & Bates, 2022). This recognises there is a continuum of co-governance arrangements from informal networks to the creation of formal governance entities.

Collaborative governance involves sharing power between the public sector and civil society, recognising that power comes in various forms (such as decision-making, resources, information and knowledge), and participants recognise the process as collaborative governance. However, **the real power often lies in the decision-making around the rules of engagement** rather than on the substance of the decisions themselves.

A review of academic and practice literature identified **four key stages of co-governance** and their key elements:

- Identifying when collaborative governance may be beneficial
- Establishing the collaborative governance arrangement
- Implementing collaborative governance
- Identifying and reporting outcomes from collaborative governance. (Smyth & Bates, 2022)

However, the evidence is largely from the perspective of the public sector rather than civil society. There is an opportunity to provide clearer evidence-based guidance to both the public sector and civil society about what collaborative governance is (and is not), where it is most useful, and to provide insights when negotiating collaborative governance arrangements to ensure they address issues of power imbalance (including information, knowledge and skills), resourcing and trust.

1.2   Purpose and approach

There is a growing interest in collaborative governance as it, in theory, involves all stakeholders affected by an issue coming together to engage in creative problem-solving. The purpose of the case studies is to learn from practice, testing and building on what we know from the academic and practice literature, and identify the enablers to co-governance. Ultimately, this will help develop principles that can be applied by different stakeholders to different contexts.

Each case study aims to build on the key stages identified in the literature to identify how to initiate, develop and implement co-governance arrangements from different perspectives. It is not clear whether universal measures or principles of accountability may apply to all co-governance arrangements, or if they need to be developed on a case-by-case basis.

The overall method for the case study has been approved by the Aboriginal Health and Medical Research Committee Human Research Ethics Committee (HREC) and ratified by UNSW HREC. Each case study is informed by a combination of data (denoted in italics in the report) from document analysis and interviews. A summary of the research method, research participants, and research instruments for this case study are presented in Appendix A and Appendix B.

The NDDA case study focuses on the process of designing the co-governance for the enduring asset during a Pilot phase. Some interview participants were also involved in co-governance arrangement for the enduring asset (the NDDA Council) and provided additional insights for this study by comparing one arrangement with the other.

Each stage in the process starts with a summary of the evidence from the literature. This is followed by observations from the case study and references to data sources (listed in Appendix B). Bold text provides emphasis of the analysis to highlight key points – i.e. is added emphasis.

**Note that fieldwork was completed between May 2024 and September 2024. The data in this report reflects individuals' reflections on a process that occurred up to four years earlier. **

2. IDENTIFYING WHEN COLLABORATIVE GOVERNANCE MAY BE BENEFICIAL

Identifying when collaborative governance may be beneficial → Establishing the collaborative governance arrangement → Implementing collaborative governance → Identifying and reporting outcomes
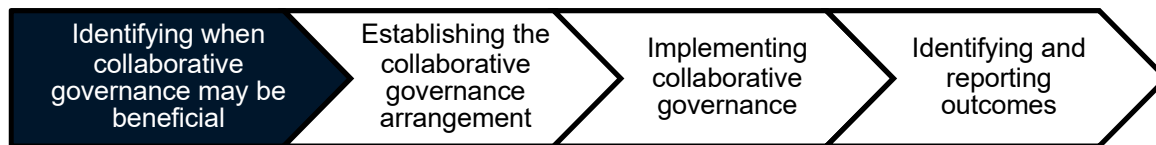
2.1 Evidence from the literature

This first stage of the co-governance process considers when a co-governance arrangement may be beneficial. Factors considered include:

- Who might initiate a co-governance arrangement (who proposed the issue, who were approached at the early stage and who were engaged)

- How was the issue defined/finalised?

- Why a co-governance arrangement might be initiated

    o from an instrumental perspective to address a specific problem and achieve better policy outcomes?

    o from an ethical perspective to ensure communicates have power, resource and information over policy development and implementation

    o or both

- The scope of the co-governance arrangement (aims and objectives, scope)

- What is required to initiate a co-governance arrangement?

    o whether it requires delegated authority or powerful sponsors or champions

    o What was the estimation of resources needed? Was it discussed early on?

- How a co-governance arrangement can be developed.

This section documents each consideration for this case study site based on data collected, including enablers and barriers to their implementation in practice.

2.2 Understanding of co-governance

Participants were asked to describe their understanding of co-governance and how it was enacted through the group. Understandings were overall consistent with the definition of co-governance used in this study:

- 'being one or more groups of people collectively involved in decision making' (#1)

- 'making joint decisions … and having a genuine say … so it's more than just getting people's advice' (#12)

- 'co-leadership' (#13)

- 'when what is agreed through co-governance arrangements is actually done' (#2)

- When power is shared (#3)

- 'shared decision making' and leadership (#4)

- 'shared power, shared decision making, and shared governance' (#5).

- 'shared responsibility' and 'a culture of accountability' (document NDDA governance meeting)

However, the reality of co-governance with government was also recognised and was still evolving:

- 'I think it's really difficult to do. What we might all idealistically call pure co-governance because there's still hierarchical things. There's still the responsibilities towards the ministers' (#4)

- 'I understand it to mean is that effectively power is shared. You know I think that's probably the simplest description of it. I mean it it's never, power is never quite shared let me say. But it's an attempt to share the power' (#3)

- 'There's always going to have to be a direct administrative control of whatever it is, there always has to be' (#2)

- 'There's a question about whether co-governance is moving beyond into a more shared decision-making space, or whether you would have the view that co-governance represents some groups being part of an advisory group advising a decision' (#1)

- 'For government to accept absolute co-governance is probably significant step' (#10)

- 'The concept of consulting with affected communities has existed for a long time… so it's in that context that co-governance has arisen. And I think it's probably the case that we're still working out how to do it. … co-governance and co-decision making, they're not exactly the same thing' (#11).

One participant suggested that co-governance is useful when there are 'vexed **issues that are cross system, cross agency, across the government responsibility**, that no one agency or system can do it, and you have to bring them together in a collaborative way to get it done' (#2). Another added co-governance was beneficial to address a '**long-term and enduring**' issue 'from the perspective of **embedding and creating this sort of shared ownership**', particularly 'where there is quite strong shared ownership' (#5).

2.3   Why was co-governance needed?

This research considered extensive documentation about developing the Pilot and about the history of the NDDA and why co-governance was needed – in particular, about the 'high stakes, low trust environment' in which the NDDA Pilot operated (#14). The proposed NDDA addressed a need for better data and better linked data to inform policy and do research that the community identifies as a priority that improves outcomes for people with disability – something that is difficult given the multiple approval processes to access and link data. The initial development of the NDDA coincided with the Democratising Disability Data Initiative, which pre-dated the original consideration of scoping an NDDA in 2018 (#3).[1] This would 'give a more complete picture of how people with disability live their lives, including in the areas of education, jobs, health, safety, and disability supports' (Pilot DAC July 2020). This would require data to be linked beyond the purpose for which it was collected to deliver benefits 'bringing together relevant data to inform policy decisions' (#11).

> The rewards from getting this right could be enormous. Improving data collection and linkages between different data sources, combined with insights from lived experience, can be a powerful way of empowering citizens, advocacy groups, service providers and governments with information that can help provide services and resources that better meet the needs of people with a disability, their families, carers and support networks. (Sydney Policy Lab (SPL) Proposal – NDDA Final)

While the need for such an asset was clear, the disability community[2] had significant concerns about the misuse of data 'against people with disability' (SPL report). This was in the **broader context of mistrust in government** due to RoboDebt (#2, #14), NDIS independent assessments (#2), a perceived lack of transparency around data related

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[1] See also, https://disability.unimelb.edu.au/news-and-events/democratising-disability-data#:~:text=Democratising%20Disability%20Data%3A%20Achieving%20safe%20and%20secure%20access,of%20Australians%20with%20disability%2C%20their%20families%20and%20carers (accessed 6 November 2024).
[2] Note that while the term 'disability community' or 'community' is used throughout the report suggests a singular group, the disability community is highly diverse in terms of types of impairment, sex and gender, culture, age, support needs, and other social identities and life experiences.

to COVID (document review), and the lack of community participation in the NDIA Board (SPL report). There was a **need to be accountable** 'back to the community … not just as a vibe, but as a requirement and as a responsibility all the way through'. (#4)

The proposed NDDA is a 'tool, and a powerful one, that could, without appropriate governance, be used in unexpected ways', requiring the community to have 'direct power (1) in deciding and framing research uses of the asset… and (2) in interpreting insights drawn from the NDDA' (SPL expert advice).

Public servants recognised that a different kind of community engagement was required. Specifically, it **required an ongoing 'social licence' and 'trust' to operate** (#2) – importantly ensuring it did 'not destroy its social licence' (#14) – to build trust and credibility in the disability community and to provide safeguards through an institution to involve people with disability in decisions about the the use of the data asset (Workshop report). As explained in advice provided later during the pilot:

> Our usual methods for holding governments accountable for their actions do not necessarily work in the 'in-between' space of incremental policies and policies that are targeted in their drafting or application to small subsets of the population. … The likely ineffectiveness of our usual governance and accountability mechanisms makes the involvement of affected communities in ongoing monitoring and oversight - and in operations of the system - even more important than it would otherwise be. (SPL expert advice)

A **co-governance mechanism**, with people with disability in key leadership roles, came to be seen during the operation of the Pilot DAC and the NDDA's Pilot phase as a mechanism to deliver this, and '**the only way it is going to work**' (#2), and be compliant with article 33 of the UN CRPD. As one stakeholder explained, this provided an accountability mechanism for government to be held to:

> What's been proposed with the NDDA is so far left of field of what [government] are used to, but when you bring along the community and promise, it becomes harder to not meet the community expectations than it is just to dismiss another government agency that is making representations to the Commonwealth. (#2)

2.4 What was the proposed scope?

The Pilot Disability Advisory Council (Pilot DAC) was **established, among other things, to develop recommendations for a future mechanism to involve people with disability in the NDDA**. One report described the complementary nature of the asset and the governance mechanism:

> Visions of the NDDA were generally complementary and reconciled in the project's stages:
>
> 1. Design for a core – "linking data sets to improve the quality of decisions, examining if these are connected to outcomes or not and whether we are missing people."
>
> 2. Governance for the future – "setting up an institution that supports multiplicity in the future - something that can be adapted properly with genuine community involvement - and has social license." (Pilot DAC Workshop report)

Given the feedback from the disability community and the Pilot DAC during the first half of the Pilot about the need to involve people with disability in more than advisory roles (encompassed in the principle of "nothing about us, without us"), the Pilot DAC was asked in May 2021 to 'over the next 6 months, [provide] pretty clear recommendations about what governance of the Asset is desired and what different phases of the asset's development should look like' with a view to making recommendations in September and December 2021 (Pilot DAC Workshop report).

Some interviewees suggested that in effect, while the Pilot DAC was a collaborative process, there were many similarities with co-governance (except for the absence of government members) and the Pilot DAC recommended an ongoing co-governance model (#15).

2.5 Who instigated the Pilot DAC and the development of the co-governance arrangement?

Part of the establishment of the Pilot was to initiate the appointment of the Pilot DAC, as part of broader work to build trust and gain social licence and to advise on how trust could be built and maintained for the enduring NDDA. The need for a co-governance arrangement to oversee the asset was originally identified during conversations between the Chair of the Pilot DAC, a member, and a member of the secretariat, who shared examples from Closing the Gap contexts where shared decision-making had been incorporated into governance arrangements (#1_correspondence).

Public servants drew learnings from other collaborative processes key staff had been involved in, such as the development of the National Mental Health Services Planning Framework (#2):

> From the outset, the involvement of people with disability in co-governance was absolutely critical, and that was never ever ever going to be diminished. (#2)

Community involvement started prior to the proposal for an NDDA and Pilot DAC's consideration of potential governance models, such as through the Democratising Disability Data Initiative, and helped advocate for the asset to be developed.

> It was those non-government players from representative organisations that did a lot of the important work. [Government partners] set the groundwork of, this is how we think it should be structured; we sold it to them and they took it and ran with it, making representation to other ministers. (#2)

They added:

> It's really important that you get those champions [advocating for the development of the NDDA are] embedded within the project, so that if the key person falls over or moves on, there are those champions at the side, and those non-government ones are the most important. Because governments will be governments, and if anything, that's what I think we need to promote in these co-governance arrangements how much value that our community members can have in driving things to change for the better. (#2)

2.6 Summary of practice: Identifying the need for co-governance

Objective	Consideration	NDDA Case study
Why	How was the need for co-governance identified and defined?	The need for the NDDA was clear, but the asset needed community trust (also referred to as a social licence) to operate. The Pilot DAC identified co-governance and ongoing engagement with the disability community as a mechanism to develop how community trust could be built and maintained.
Who	Who instigated the co-governance arrangement? What was required to initiate the arrangement?	The idea that co-governance could be a way to build community trust in the implementation of the NDDA was proposed by a member of the Pilot DAC as part of the group's discussions in mid-2021 and was subsequently supported by community groups and experts involved in arms-length testing of the co-governance proposals. The establishment of the Pilot DAC and the NDDA pilot project, required a mandate from the Digital Ministerial Council (later the Digital and Data Ministerial Council) and the Disability Ministerial Reform Council.
What	What is the aim/scope/ timeframe? Were stakeholders involved in defining the scope?	The initial pilot phase, including the Pilot DAC, was to last two years. It is unclear the extent to which stakeholders were involved in defining the scope of the Pilot DAC. NSW and SA public servants consulted the disability community in the pre-pilot stage and a community advisory

		council was included as part of Ministerial Council agreement to the Pilot.

3. ESTABLISHING THE COLLABORATIVE GOVERNANCE ARRANGEMENT

Identifying when collaborative governance may be beneficial	Establishing the collaborative governance arrangement	Implementing collaborative governance	Identifying and reporting outcomes

3.1 Evidence from the literature

The second stage in the co-governance process considers how to establish the co-governance arrangement in terms of institutional design, composition and leadership. Factors considered include:

- The system context and the collaboration dynamics

- Whether/how the group was granted the authority to act, and whether there is senior and middle management support

- Whether there is a formal (visible), credible and independent governance mechanism – with clear and transparent roles, processes, tools and structures around decision-making (how was this mechanism decided, based on what principles and what was the decision-making process?)

- Whether the arrangement includes actors from civil society affected by the initiative in the governance – alongside other organisational actors

- Whether there was an appointment of a clear, independent and skilled leader that instils trust and supports contributions, facilitating collaboration (and how this was achieved)

- The mechanisms needed to enable the group to have the capacity to act, through procedural and institutional arrangements, leadership, knowledge and resources

- Whether there is a realistic timeframe to establish and implement the arrangement.

This section documents each consideration for this case study site based on data collected, including enablers and barriers to their implementation in practice.

3.2 Context

In late 2018, the Australian Digital Council had agreed to a scoping exercise for a data asset focused on disability (#1_correspondence). In October 2019, the **Data and Digital Ministers and the Disability Reform Ministers**[3] agreed to establish an enduring, longitudinal National Disability Data Asset (NDDA) – this was to commence with a pilot phase (document review).[4] The preliminary work on the NDDA coincided with the start of the COVID-19 pandemic, NDIS independent assessments, RoboDebt, and later during a period where there was a perceived lack of transparency around pandemic vaccination statistics for the disability community. This 'could not have been a worse time to get a committee to say trust us in government'; however, it 'really sharpened everyone's minds' (#1).

The **initial pilot was for 2 years** (up to December 2021), was supported by $15m (from the Australian Government) and a dedicated National Project team and a Technical Project team (employed by NSW DPC and

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[3] One participant highlighted that while there were lots of representative organisations, 'there's no one overarching structure for how they feed into the DRM [Disability Reform Minister] council business' (#2).

[4] The Democratising Disability Data initiative from Melbourne University demonstrated to government there was potential support for the asset in the community (#1, additional correspondence).

AIHW), and involved six of the nine jurisdictions (#1). Within government, the NDDA pilot included multiple entities in relation to disability and data, and human services more broadly (#1).

> For the NDDA Pilot, a proportion of the budget was allocated to engagement with the disability community, including the appointment of the Disability Advisory Council, engagement with the community across the course of the pilot … and towards the end of the pilot, engagement of academic centres to test social licence further. (#1_correspondence)

This recognised that making decisions about data should 'remain with the people whose data is included' and 'thus, the authority to make decisions about personal data here is necessarily shared' (document review).

In terms of the context at the time, 'the origins of the project in the data/digital context, where Building Community Trust principles were adopted nationally and influential in NSW activities during the relevant period, was a key factor' (#1_correspondence). The involvement of the NSW Government (which during the relevant period had a significant focus on digital and data, and building community trust) was instrumental in 'driving this from within government as well as community members from outside of government for these kinds of arrangements' (#5). It was recognised that there was:

> … a lot of anxiety from some governments or some officials about the consequences of this type of arrangement. There wasn't a precedent really, other than closing the gap. … [there was] nervousness about proposing to spend more money than we've ever spent before, to link more data than we've ever linked before, in a context where when your minister asked for it to be used, you have to say to them absolutely Minister, subject to these elaborate governance process that will involve people with disability. And that I think has felt confusing and for some government people uncomfortable. (#1)

The timeline of the establishment of the NDDA is presented in the table below.

Table 1 Timeline of the NDDA

Scoping Phase & agreement to Pilot	Pilot phase	Ministerial consideration and inter-jurisdictional negotiations	Implementation phase
September 2018-October 2019	April 2020 - December 2021[5]	2022-2023	2024 onwards
	Pilot Disability Advisory Council (Pilot DAC)	Ministerial councils consider recommendations, Government departments set up to deliver	NDDA Council established[6]

Source: document review and information provided by participants during interviews.

3.3   Institutional design (governance mechanism)

The Pilot DAC was established in early 2020 as part of the formal structure for delivering the NDDA Pilot phase approved by the Disability Reform Ministerial Council and Data and Digital Ministerial Council (#2). The Pilot DAC **aimed to ensure 'the wishes and needs of people with disability [were] considered in the design of the NDDA'** and to '**build community awareness, support and confidence in the NDDA**' (Pilot DAC July 2020). The Pilot DAC would 'provide guidance to the NDDA project team and give **advice on how to design and operate the [enduring] asset'** (Pilot DAC July 2020). See Box 1.

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[5] Most work to design co-governance April-December 2021. (#1, correspondence)
[6] Delayed implementation while Commonwealth agencies responsible for delivery set themselves up and agree detailed with states and territories. (#1, correspondence)

The Pilot DAC had a committee structure and formal agenda, and members were 'there ostensibly to represent the communities' (#15). It was recognised that the governance model of the enduring asset would require a different model to manage the 'power, risks and benefits of data' (document review).

Box 1 The terms of reference for the Pilot Disability Advisory Council (Pilot DAC) role of the NDDA Council

Overview

The Australian Data and Digital Council and Disability Reform Council agreed to develop the National Disability Data Asset, a nation-wide cross-domain data asset to improve services delivered and outcomes for people with disability.

The pilot phase that brings together data from select Commonwealth agencies, including the National Disability Insurance Agency, and from New South Wales, Victoria, South Australia and Queensland to establish the asset and support 5 high priority test cases. The pilot will focus on demonstrating government use of the asset and laying the foundations for use of data-driven insights by people with disability, researchers and the wider community.

Objectives

The [Pilot] Disability Advisory Council [Pilot DAC] will provide recommendations to the NDDA Senior Executive Steering Committee and Senior Oversight Group on the development and use of the Asset, including priority areas of research; researcher data access; public reporting and data platforms for people with disability; policy priorities and key uses for the asset.

The [Pilot DAC] will drive the building of trust in the Asset amongst people with disability, the broader community and the sector. It will drive the design of how people with disability will be involved in designing the use of the enduring data asset and in its ongoing operation and development.

The NDDA National Project Team will support and report to the [DAC Council] on the Social Licence and Building Trust workstream, as well as provide it with oversight of the pilot's implementation.

Decision- making

The [Pilot DAC] will have no formal decision-making role. It will instead provide recommendations to the Senior Executive Steering Committee and the Senior Oversight Group, with the Steering Committee to provide reasons for any recommendations it does not adopt.

Direct reporting will be to the Steering Committee. In practice it would be preferable that developed recommendations are provided to the Senior Oversight Group to consider and allow refinement before going to the Steering Committee.

Chair

The NDDA Disability Advisory Council [the Pilot DAC] will be chaired by Dr Ben Gauntlett.

Membership

Core membership will comprise:

● Ten members appointed at the outset of the pilot, with the option to add up to an additional two four members during the pilot if necessary, to ensure the correct mix of expertise

● A minimum of three members will have data and digital literacy skills to inform the direction of the NDDA

● The remaining members will represent different cohorts and stakeholders within the disability sector and/or have experience in the broader human services sphere

● A minimum of one representative from the ATSI, CALD and regional and rural communities (one member may represent one or more of these cohorts)

Source: member of the former National Project Team.

3.4 Governance structure and leadership

The Pilot **DAC was chaired by the then Disability Discrimination Commissioner – Dr Ben Gauntlet** – and was supported by a **secretariat provided by the National Project Team**. Strong leadership was noted as key to the functioning of the group (#3).

3.5 Composition of the group

Membership of the Pilot DAC was by invitation rather than application (#1, #2, #3, #7) and was based on a long list assembled by disability and data officials in early 2020 that was ultimately provided to the Australian Government Minister responsible for Disability to appoint individuals to the Pilot DAC (#1_correspondence).One interviewee suggested this included individuals who had 'say the loudest voices' who were expected to 'challenge' the thinking, and 'trusted experts' who were considered 'allies' to the community; having a 'voice of reason sometimes can take the emotion out of certain debates' (#10).

While the mixed membership provided 'multiple perspectives' (#13), many participants interviewed expressed **concerns about how the membership came about** (document review, #1, #6, #15).

> We have mutual friends and [they] approached me. (#10)

> [I was approached] 'mainly through reputation. (#13)

There were also concerns about the **level of representation of the disability community** (#6), and the **burden** placed on the same people, while also recognising the difficulty in achieving representation of the community of groups likely to have 'very different views' (#11, #12, #13).

> Everyone in the room is exhausted (document review)

> I was on 17 or so different government committees. (#9)

> I can't quite remember what phrase he used, but [said] 'I'm getting on, you're going to need a whole bunch of people and you can't keep using the same 10 people who happen to know about data and disability, and potentially are people with lived experience'. (#1)

> Small organisations in many cases [had] a lot of demands on their time. (#15)

There was reported **tension between representativeness and inclusiveness** and involvement in terms of what the Pilot DAC was trying to achieve (document review). Comments from participants included:

> You probably need to have a clear idea of what skill sets and opinions are essential for the task and work backwards', having ' transparency and a process that is really clear for everybody' and identifying and resolving any gaps in capabilities. (#13)

> The way you create effective boards is to make sure its skills based … so the first mistake that's been made here is this is not a skills based board, it's a representative board, council. (#3)

> Somewhat challenging that [disability representative organisations] weren't included from the start because our organisations are at the policy coal face the whole time and need evidence and data to help us with our policy and advocacy. (#9)

> There's about 30 national representative organisations and you can't have all of them involved all of the time. … how can you build advisory structures that bring the voice of people with different disabilities? (#9)

Findings from community engagement said:

> The disability sector is very white and ableist even in the advocacy sector [4,10,16]. Participants emphasised that **representation must be inclusive of subsets of the disability community that often miss out** [1,4,8,10,12,17,18,20,22,23,26,29,32,33,A,B]. This includes a diversity of disabilities, genders, cultures, a spectrum of ages, those with complex needs (and potentially their families and carers), those who are non-verbal, those with intellectual disabilities, Deafblind Australians, and people with lived experiences of disability that are not white and middle-class [1,2,6,7,8,9,10,12,16,17,18,20,23,24,26,29,30,34,A,B]. (SPL report)

Further, in both documentation and interviews, issues were raised about capability of members of the group, while also recognising different members brought different knowledge and expertise (#2). As one participant highlighted:

> The Pilot discussions generated the insight that the knowledge and experience relevant to the NDDA project was very broad, crossing multiple disability, data, digital and other areas of knowledge. This prompted the Pilot delivery team to seek advice from an academic on the capability development that could support co-governance. (#1_correspondence)

An assessment of capability development needs of an NDDA included:

> Prior to embarking on any capability development program for the NDDA, it is essential to first establish baseline capability levels across data innovation and disability domains. Even beyond capability development, however, baselining is critical for productive governance. Mistaken expectations and assumptions around a shared understanding of core concepts is dangerous indeed – leading to potential for miscommunication, misinterpretation, governance inefficiency and a preponderance of talking past each other. (document review)

Interviewees identified this dynamic was particularly visible between the Pilot DAC during the pilot phase, and the NDDA Council during the implementation phase, where foundational knowledge was lost as the governance form and membership transitioned from the pilot phase to the implementation phase – creating a 'disconnect' (#13). This highlighted that **continuity was an enabler**.

The membership of the group is summarised in

Box 2 below. Membership changed over time as some people resigned and additional people were invited to the Pilot DAC – again by invitation (rather than application) due to the short timeframe involved (#3). This change was managed by providing an update to the group with the new members about what had been achieved so far (document review). Note that some members of the group had multiple affiliations, and their key affiliation is noted here. With multiple affiliations came multiple interests and potentially conflicts of interest. One participant highlighted it was 'absolutely crucial to have people capable of working in these spaces that are not academics and that are representing the community in a very different way' (#1).

Many of the original members 'did know each other beforehand' which resulted in 'a lot of trust in the first council [Pilot DAC]' (#3). Many considered the chair instrumental in being the 'bridge between government and the disability community' (#1).

Box 2 Membership of the Pilot Disability Advisory Council (noting not all members were members for the entire Pilot period)

Membership
Chair: Dr **Ben Gauntlett**, the then Disability Discrimination Commissioner at the Australian Human Rights Commission
Dr Scott Avery, Senior Lecturer, School of Social Sciences, Western Sydney University
Professor Bruce Bonyhady AM, Executive Chair & Director, Melbourne Disability Institute, previous Chairman of the National Disability Insurance Agency (NDIA) Board
Professor Gemma Carey, Centre for Social Impact, UNSW
Professor Anne Kavanagh, Chair of Disability and Health, Head of the Disability and Health Unit in the Centre for Health Equity, Co-Director, NHMRC Centre of Research Excellence in Disability and Health, University of Melbourne
Professor Gwynnyth Llewellyn, Director of Family and Disability Studies, University of Sydney, Head, WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems, Co-Director, NHMRC Centre of Research Excellence in Disability and Health, Disability and Inequity Stream Leader, Centre for Disability Research and Policy
Dr Steven McEachern, Director, Australian Data Archive, Australian National University
Professor Julian Trollor, Head of **Development Disability Department**, University of New South Wales
John Walsh AM, Adjunct Professor, The University of Sydney. NDIS Board of Directors.
Belinda Drew, the then CEO, Community Services Industry Australia, Chair, Social Enterprise Finance Australia
Damian Griffis CEO First People's Disability Network
Mary Mallet, the then CEO of the **Disability Advocacy Network Australia**, the peak body for disability advocacy organisations.
Mary Sayers, then CEO, **Children and Young People with Disability Australia**
Kevin Stone, CEO, Victorian Advocacy League for Individuals with Disability, Chair, **Inclusion Australia** (National Council on Intellectual Disability) **– replaced by Catherine McAlpine**, CEO **Inclusion Australia**
Leah Van Poppel, CEO, Women with Disabilities Victoria

The Pilot DAC and the subsequent NDDA Council for the enduring asset were two distinct groups, one having an advisory function the other having a co-governance function, each having different membership, appointment structures, and chair arrangements. The Pilot DAC's recommendations about the appointment process for the NDDA Council were considered by Disability Reform Ministers.

3.6   Resourcing

Engagement in the Pilot DAC came at a cost to participants who were not paid for their time to participate. *Australia's Disability Strategy Good Practice Guidelines on Engaging with People with Disability (2023)* [7] promotes what has been good practice in disability research for many years but had yet to become standard practice in government when the Pilot DAC was appointed. The Guidelines recommend considering time and costs, and planning and budgeting for the time, money and other resources needed to ensure an activity will be fully accessible to people with disability – recognising this will be unique to each activity. One participant highlighted that this was not always the case (#6).

For the Pilot **DAC, members 'were not paid to be on the Advisory Council [Pilot DAC]'** which, while illustrative of broader government practice at the time, was recognised as 'absolutely the wrong thing to do' (#1). This has

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[7] See the Good Practice Guidelines in different formats, including Easy Read, available here https://www.disabilitygateway.gov.au/good-practice-guidelines.

been resolved in the new NDDA Council where everyone except government members are paid and the support required for individuals to attend has been discussed (#1), recognising the work required before and after meetings (#4, #6). This cost was considered to be minimal relative to the benefits of building community trust (#1).

Resourcing was also discussed in terms of the **informational resources and support** required to engage in decision making on complex issues. In the future, this was suggested by an academic expert to require a 'foundational capability development program … [to] ensure that all participants in the ongoing stewardship of the program speak the same language and can meaningfully grapple with the risks, complexities and opportunities that will emerge across its design, governance and delivery' (document review). Interviewees also recognised 'you actually need to pay people to learn about the specifics that you're thinking about before you can expect them to co-design and co-govern things, to even be meaningful parties in a dialogue about what to do' (#1).

Irrespective of resourcing, **the representative role often fell to senior staff** in organisations with limited recurrent funding (#6) **who had long-term knowledge across issues**. With extensive requests, there was often little time to 'really prepare very well … plus manage your staffing, plus manage other priorities, … [and not] having enough staff to actually help you prepare for meetings'; this was in contrast to government representatives who 'will have an officer who will prepare a briefing for them, for example, they would read the papers and say these are the important issues' (#9). This highlighted the 'uneven playing field with government because you don't have those structures underneath you to help' (#9).

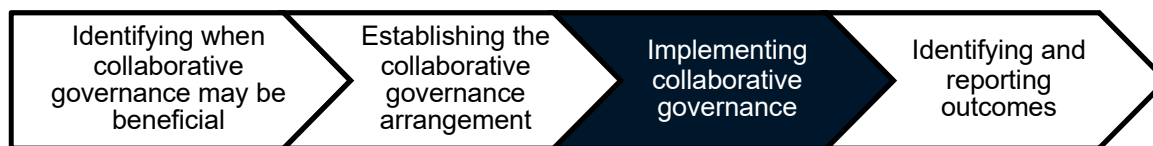At the end of the Pilot DAC's life, the Chair made the following statement:

> The Chair, Ben Gauntlett thanks the Council [Pilot DAC] members for **voluntarily contributing their time and expertise** to create a framework to potentially develop an important asset for the disability community. The Council's contribution, which included numerous out-of-session informal meetings, highlights the fundamental ongoing importance of listening to the disability community and **has depended on Council members willingness to work collaboratively and find ways to listen and understand each other's perspectives** during the challenges created by the Covid-19 pandemic. (emphasis added, Pilot DAC November 2021)

3.7   Summary of practice: Establishing co-governance

Objective	Consideration	NDDA case study
Context (including dynamics)	Is the system and context defined? Are collaboration dynamics understood?	The Pilot DAC was established to guide the pilot of the NDDA and inform the development and use of the enduring asset, including the design of an ongoing governance mechanism. Collaboration at the Pilot DAC largely involved people with disability, academics and community group representatives. However, the Pilot DAC operated within the broader Pilot, which was delivered with a significant program of government-driven work engaging the disability community – the evidence developed through this work was used by the Pilot DAC to inform its recommendations and by public servants to validate those recommendations. In this way, the Pilot DAC performed its function within what became a broader collaborative process. Ultimately, Ministers were the decision makers empowered to decide whether to accept the recommendations from this collaboration process.
Institutional design	What formal arrangement is needed?	The Ministerial Council established the terms of reference for the Pilot DAC and the resources to support it.
	What provides the group the authority to act? Does it have senior and middle management support?	The secretariat was led by a senior NSW public servant, who was Head of the NDDA Pilot National Project Team, with the secretariat provided by public servants employed by that team (rather than, for example, a secretariat employed by or appointed by the Chair).

Objective	Consideration	NDDA case study
	Is there sufficient time to establish the arrangement?	The work of the group was time limited and operated during the context of the COVID pandemic. The deliverables were achieved within the time period, noting that the original 18-month timeframe for the Pilot was extended by agreement through the relevant Ministerial Councils to December 2021 (approximately 2 years).
Governance and leadership	Is leadership clearly defined? How was leadership established? Are the roles, processes, tools and structures for decision-making documented? How do chairs support contributions and enable collaboration?	The chair of the group was clearly defined as part of the appointment process. The work of the group was documented. The chair ensured each member of the Pilot DAC was heard and valued.
Composition	Is membership representative? Does membership include civil society? Is power distributed equally?	The group improved in representation over time. The process of establishing the group and its composition were questioned by members of the Pilot DAC. The group included some civil society – this increased over time. It also included some individuals with disability and experience of data and its use in disability contexts, who were not representing any organisation (nor were they researchers). Power appeared to be distributed.
Resourcing	Is the group able to act through institutional arrangements, leadership, knowledge and resources?	The group was able to act through its institutional arrangements. Some of these arrangements evolved over time.

4. LEARNINGS FROM THE OPERATION OF THE DAC

Identifying when collaborative governance may be beneficial	Establishing the collaborative governance arrangement	Implementing collaborative governance	Identifying and reporting outcomes

4.1 Evidence from the literature

While the Pilot DAC was not co-governance as defined in this study as it did not contain any government representatives and was set up by Ministers as an advisory council, the Pilot DAC offers many lessons in the implementation of collaborative arrangements because it worked collaboratively with the public servants tasked with providing its secretariat and delivering the Pilot NDDA. This evidence is therefore included in this report.

The third stage in the co-governance process considers the implementation of the co-governance arrangement at both the strategic and operational level to ensure it is implemented and effective. Factors considered at the strategic level include:

- Ensuring there is a joint understanding and commitment to the goals and scope (including accountability and desired outcomes)

- Developing mutual understanding, respect and trust (accepting trust may vary)

- Identifying strategies to build trust, including by learning, sharing information and resources, and being transparent

- Ensuring there is a joint understanding of commonalities and differences between collaborators, including different organisational cultures

- Reflecting on the strengths and weaknesses of arrangement and adapting to changes in the operating environment to sustain the arrangement over the long-term

- Supporting the arrangement to deliver and sustain collective action.

At the operational level (in terms of diagnosis, design, implementation and assessment), this involves:

- Developing a theory of change. This involves a process of discovery, definition, deliberation and determination – leading to a shared theory of change/action or strategy (including measures of success) – fed by, and leading to, trust, understanding, legitimacy and commitment

- Having repeated, face-to-face dialogue and communication, leading to trust-building, commitment to process, and a shared understanding

- Having support from an intermediary (backbone support organisation), which is able to coordinate reinforcing activities across organisations

- Developing additional processes, such as co-creation, to drive innovative outcomes

- Establishing an accountable evaluation system that tracks inputs, processes and outcomes, and provides assurance back to bureaucracies

- Communicating accomplishments as early as possible.

This section documents each consideration for this case study site based on data collected, including enablers and barriers to their implementation in practice.

4.2   Strategic implementation

4.2.1 Agreed objectives, priorities and timeframe

When agreeing to the pilot in late 2019, the Disability Reform Ministerial Council directed 'that it be implemented consistent with the building trust principles around community engagement, including working with an NDDA Disability Advisory Council [Pilot DAC]' (document review). The **Pilot DAC for the NDDA met between February 2020 and November 2021 with a view to making recommendations to the Disability Reform Ministers**. The status of the group was perceived by interviewees to have changed from the first meeting after **concerns were expressed over the advisory status and the extent the group would be heard** (#15).

From mid-2021, the Pilot DAC set out to design the governance structure, the terms of reference for the subsequent NDDA Council as the key co-governance mechanism, and develop a draft charter (what the NDDA could and could not be used for; #2) **for the enduring NDDA**. This included what shared decision-making would look like and recommendations about the purpose and use of the enduring asset (#1). One participant reflected that the first purpose of the Pilot DAC was to develop ways to ensure the NDDA 'does no harm' and to ensure 'appropriate protections are in place' and that 'the asset is used in transparent and contestable ways' with 'co-governance [being] one way of ensuring that' (#3). The policy domains that were the focus of five analytical test cases for the NDDA came were recommended to Ministers by government agencies rather than through a formal process engaging with the disability community. As one participant reflected, 'it's fair to say that the Council [Pilot DAC] came too late in the pilot to really inform the selection of the pilot study areas, but they became involved in the direction of those studies' (#12).

One interview participant suggested that, in many ways, the Pilot DAC was an **attempt to pilot collaborative governance** with governments on data sharing (#12) **at the same time designing how to co-govern the NDDA in the longer-term**.

4.2.2 Understanding commonalities and differences

The membership of the Pilot DAC was diverse, with each member bringing distinct expertise to the group. However, this did not necessarily mean members understood each other. This was captured in one project document which set out a desirable state for capability development for this kind of initiative in future:

> Being transparent is not the same as being understood. The risks, techniques and language swirling around data innovation are new, complex and seldom intuitive, particularly for non- specialists. … Moreover, where data innovation expertise does exist, it is unlikely that such capability is complemented by a genuine understanding of the disability space. (Document review)

This required the secretariat to work with Pilot DAC members to bridge gaps in knowledge.

4.3   Operational implementation

The Pilot DAC **met periodically**, and more frequently as needed, had set agendas that were accompanied by extensive reading papers; in addition, outside of session, people were consulted to give their feedback (#10). The secretariat ensured that **members could provide feedback in or out of session** (#10). Most meetings were held **online** due to the COVID-19 pandemic which reduced time commitments required (#10); this raised concerns for some participants who felt that online meetings were 'transactional' and should have been in person when they could be (#3), #10). People needed to come together to strengthen connections (#6) and the place that people met was important (#1). However, when the group did come together in person, this was when 'some of the conflict came out' (#10).

Given the different expertise each member brought to the group, the chair highlighted the **complexity in working out how to pitch discussions** at, and what underlying knowledge could be assumed. Effort was made to 'bring those people who didn't have the background up out of session rather than dropping to the lowest knowledge base'

(#10). The pilots running in parallel also provided a realistic focal point to discuss some of the broader issues associated with the asset (NDDA) (#10).

> I think one of the understandings I'm coming to is for all the understanding of limitations of the process is there's no perfect process for do it. (#13)

As noted earlier, there were frustrations about the formation and scope of the group, particularly around the lack of transparency (#13). However, in terms of meetings, 'the prioritisation was given to the community voice, because that was the point of the committee itself … really trying to bring the lived experience to the fore' (#15). Information was provided to members of the Pilot DAC to make informed decisions about recommendations to the Ministers. As one participant said, 'I never got the sense that people were struggling with the content' (#3).

The Pilot DAC also required a strong chair. As one participant commented:

> This was also a pretty bolshy council [the Pilot DAC], right? It wasn't an easy council. It was technically strong, but it was a very opinionated and outspoken council. People did not hold back. Managing the diversity of views, managing the strength of the views, took quite a lot. (#3)

Ultimately, operation of the Pilot DAC came down 'somewhat to the personalities of the individuals concerned' (#5). Co-governance 'is harder, it requires deliberate effort, it requires investment in time, money and energy' (#5). They added:

> It would have been probably [good] to have brought everyone together, not for any decision making, but just for getting to know one another as a precursor. Because what we found in the early period was that effectively we had to have two bites at every cherry to get to decision-making. And I think that's completely fair enough and not really surprising in hindsight. But I think that investment in individuals and common understanding, the baseline and in relationships I think could have perhaps meant that we landed things in a single meeting on those things, maybe, maybe not, but we'll, but that's my reflection. (#5)

4.3.1 Continual engagement

The Pilot DAC had **12 formal meetings** during the pilot. The NDDA partners also had additional discussions with individual members of the Pilot DAC or as small working groups on specific topics (document review).

4.3.2 Decision making

Decision-making for recommendations made to the Disability Reform Ministers was by consensus. Government partners committed to pass on the recommendations directly to ministers, recognising officials can provide ministers with their own advice as to whether to accept recommendations (#1). This arrangement of recommendations being provided directly to Ministers, without the mediation of officials deciding whether or not they reached Ministers, was formalised as part of Pilot DAC's recommendations for how the subsequent NDDA Council should operate.

The Pilot DAC was supported by the secretariat who worked with Pilot DAC members to develop recommendations for the group to consider. For example, to consider 'what recommendations it may choose to make on the proposed decision-making body overseeing strategic decisions on how the NDDA is used and developed' (document review). The scope of recommendations required included:

- Objectives and strategic governance role
- Decision making scope
- Membership – size, composition, appointment
- Meeting frequency
- Support, operations and resources,
- Relationship between the NDDA Council and Data Linkage Infrastructure Board and any other bodies established, and
- Reporting lines to ministers. (document review)

As one participant reflected:

> There was a lot of trying to scope. What the National data asset should be to whom? What it could be and how. It was about thinking … What's the most that this could be, which I think is quite unusual in those kind of discussions. Like the ambition was really broad and exciting as well. (#7)

Another added:

> These are incredibly complex things you are governing, they evolve overtime, there's layers of understanding, how do we get to inform decision making about those sorts of things, it's really challenging. (#1)

The **group aimed to reach consensus in making recommendations**. One participant highlighted the risk of not reaching consensus:

> You can see with the Disability Royal Commission what happens when you can't build consensus right. It completely undermines the recommendations. … With any of these things you've got to maintain unity otherwise you lose all effectiveness. (#3)

They also talked about the how to achieve consensus through good governance.

> I find this governance, the mechanics of it as opposed to the science of it, misses the most important point which is **the art of good governance**. I'm a big believer in if you give people the same information, that's the foundation of building consensus. I think the second thing is **robust debate**. And that then goes to the culture of the council. The culture is one of, we want the best idea to win, right. … You got to talk through how you are going to deal with difficult issues before the difficult issues arise. (#3)

The Pilot DAC 'had a very large part in saying you can go ahead but only on this basis… under these conditions' (#1). It was also recognised that this required a 'group of people who were prepared to say yes to something of which there was obviously risk attached' involving a new governance mechanism for a new type of data asset; 'the breadth of design work that needed to occur for people to say yes was pretty striking' and 'if there was a gap in information.. it was greeted with cynicism and a lack of trust' (#1).

> The disability community were absolutely right to nail down the details. Had they not drafted the terms of reference, drafted the charter, and put an incredible amount of detail, it would not have transpired as that all of that was agreed. (#1)

This extended also to providing the reasons behind recommendations – an approach considered to help explain the success of this process (#1).

Some participants reflected on this new 'grey space', and about whether it was decision making or 'guiding the work that different levels of government do' particularly when public funds are being used, 'there are accountable authorities and ministers have responsibilities … so there always needs to be the right sort of balance' (#11). They also reflected that there were some 'extreme views that you're never going to be able to fully engage with, but you need to respectfully hear them and understanding where you're going' (#11). Decisions were never 'going to make everyone happy' but co-governance helped with 'execution and implementation, and helped you understand if one issue might be more important than another' (#11).

Some members highlighted the benefit of '**genuine engagement**' (#14) and '**genuine discussion**', and bringing people in at the 'right time and on the right issues in a genuine way' (#12).

> Most of the engagements I've had with governments around governance have been very much present a model. What do you think? Whereas from the start it felt like the team that were involved in this were far more open to wanting to think about what members of the disability community wanted. (#14)

However, others who joined the Pilot DAC later had different experiences, although noted it was 'very respectful' (#9):

> Most of the decisions have been made by the time that [some disability representative organisations] came on board, so we felt too late and with no disrespect at all to the Academy or to academics, representative organisations and disabled persons organisations have been advocating for policy change for a long, long time and know the policy relevant questions. (#9)

Another participant questioned the visibility of conversations that occurred outside of meetings, where issues raised in a meeting were smoothed out and resolved by the next meeting (#13).

> It sometimes leaves me wondering what's happened there and has the issue really been resolved or is there a risk that pressure is put on, particularly in the context of when there's you know power differential. (#13)

On the subject of transparency, one participant added:

> There's some things that are still not very transparent to me. However, every time I ask for things to be explained or asked for transparency, or ask to meet someone, that request is always granted. (#4)

There were also questions about how co-design and coproduction feature as part of co-governance (#1). The process of decision making, and the group overall, was considered to vary over time. As one participant explained:

> The group started well, wobbled in the middle, and finished well with a lot of shared understanding and excitement about the final and advice and model and I thought there was a great degree of agreement. (#13)

Ultimately, the group helped put staff in government departments 'on notice' (#12), and held government to account to fulfil its commitments to the disability community. The group was instrumental in establishing safeguarding mechanisms for the development and use of the asset – such as through the terms of reference for the subsequent NDDA Council and the NDDA Charter about how the asset should and should not be used – reported in Section 5.2 below.

4.3.3 Understanding organisational differences

The Pilot DAC comprised members with backgrounds as academics, individual people with disability with relevant professional experience, and community representatives – supported by the National Project Team staffed by public servants. There were **differences in expertise, experience and language** between these groups, and efforts were made to conduct business at a level that most people in the room could understand. Several learnings were observed about these differences, **why these differences were also important**, but also what was needed to **manage these differences**.

- 'There were a large number of academics on the council [DAC Pilot], which led to academics talking to each other in academic jargon' (#6).

- There was an underlying tension as to whether 'someone had the dominant stake in this? We've kept coming back to the fundamentals that this is about people with disability primarily and that those voices should really be heard.' (#13).

In addition, in more general terms, participants highlighted:

- '**Government understands government** really well' (#4) and the involvement of public servants is useful in terms of how to navigate government.

- Due to turnover in government departments (#1, #14), the **community representatives 'have an ongoing role in having to educate the public servants** about what it really means' (#1). The continual movement of government staff can impact 'on the trust, on the relationships, on the longevity of certain things' (#14)

There were some changes to organisations and representatives at the Pilot DAC. As one participant highlighted, 'we've seen new people come on board, you can see that people take quite some time to understand' what the NDDA is (#1).

4.3.4 Representation and engagement with the community during the pilot

Alongside the work of the Pilot DAC, there were more than '140 engagements with the disability community, government agencies, academic researchers, and service providers'; engagements tested data needs, enablers and barriers to an NDDA, and technical and trust-building elements of the design, 'including the conditional social licence that exists currently' (document review). The design was also reviewed by external experts to ensure it incorporated good practice, is 'privacy informed' and 'will build trust by the many stakeholders in disability use' (document review). Engagements sought to understand community perspectives of and seek support for the NDDA both in the preparation phase and the pilot phase (#1, #2) (see Table 2).

The active engagement outside of the Pilot DAC was built into the design (and funding) of the Pilot within the Building Community Trust framework. The Pilot involve three key components: the appointment of the Pilot DAC, engagement with representative organisations and service providers (through both direct interviews with the National Project Team and commissioned research), and engagement with people with lived experience (the latter through a variety of means, including involving in designing a data insights platform by a specialist provider and via commissioned focus groups). This was seen as important to compliment the work of the Pilot DAC and inform their work (#1).

In many ways, this approach helped to overcome the **challenges of 'carrying the community along'** (#13), particularly given 'the lack of visibility for the community on what's happening and what some of the controversy or emerging issues are, and there being no clear mechanism for providing broader input into those' (#13). While representation on the Pilot DAC may be expected the include both 'representing the diversity of views in your community, and reporting back to the community', the view from some is that the reality is 'people don't' (#4). Engagement therefore needed to be ongoing:

> This is a very big best and there's lots of opportunity, you need to check in all of the time so that you are sure you still have the mandate that people with disability gave you at the outset. … And that you're actually doing what you said that you were going to do. (#2).

The project team commissioned **Sydney Policy Lab (SPL)** to independently test the previous community engagements, and test the governance proposals emerging from the Pilot DAC with various organisations and individuals from the disability community, as well as support Pilot DAC workshops and engage academic experts to critically review the proposed co-governance design. As part of this work:

> The [Pilot] DAC requested we gather for a workshop and the National Project Team commissioned the **Sydney Policy Lab (SPL) to convene that workshop**, as well as do some independent testing of what we'd taken from our engagements with the disability community over the 2 years prior. (#1)

Participants at the SPL workshops emphasised the need for two tiers of governance – an oversight group with rotating membership, and 'sub-groups and reference groups' that were able to include 'multiple voices and a provide dynamic platform for deeper engagement' (SPL report). Specifically:

> Sustained **engagement and co-design must happen at multiple levels** … . Participation cannot just be a tokenistic tick-box exercise. … This is imperative for building trust and ensuring that the Asset is fit for purpose and remains ethical throughout its lifecycle. (SPL report)

This also required 'appointments being made through a rigorous, transparent and accessible application process' and community engagement 'undertaken by people with disabilities' (SPL Report 2021).

The project team also contracted the **Centre for Social Research and Methods at the Australian National University** to investigate the attitudes of people living with disability about the sharing and integration of their

personal data for the development of the NDDA. Consultations were performed by **JFA Purple Orange** who conducted a series of focus groups with people living with disability that were run throughout October 2021. The consultations targeted different cohorts including people with specific diagnoses (psychosocial disability and autism; intellectual disability), age (18-30), and a cultural backgrounds (Bhutanese). The consultations highlighted the need for people with disability to have oversight and decision-making powers in relation to the NDDA (JFA Purple Orange Report 2021).

The NDDA project team also undertook 'about **140 interviews** with people from across the spectrum of disability, community and providers, over the course of those two years' and brought the insights to the Pilot DAC (#1). It was also acknowledged that 'the Advisory Council [Pilot DAC] themselves had spent decades talking to people' (#1).

The consultations through the National Project Team occurred across the 2 years of the Pilot, and those through the Sydney Policy Lab and ANU engagements occurred towards the end of the pilot phase of the project (#14). The Sydney Policy Lab engagements were considered to have involved genuine engagement by participants; low drop outs provided 'a sense that this is important and that what people are contributing to is important, and something would be done with it'. Participants were provided an option from someone from the NDDA team within government to sit in on interviews and workshops – all said yes, and all but one was able to be organised. However, not every aspect of these engagements was considered successful; one was felt to have 'been wasting people's time and that reduced the level of engagement for a period' (#15).

Members of the Pilot DAC were also asked whether to develop **communiques from the meetings** to share on the **NDDA website**. The Pilot DAC produced summaries of meetings, shared as a 'Message from the Council' [Pilot DAC], summarising topics discussed, decisions made, as well as attendees. Summaries were made public on the NDDA website on 17 July 2020 (for meetings on 4 June and 9 July 2020), 6 August 2020, 17 September 2020, 27 October 2020 (27 October meeting), 3 February 2021, 3 December 2021 (for 26 Nov Meeting). This ensured information about the pilot and the work of the Pilot DAC was available to the broader community.

During the period where the case was being made to government to establish the NDDA as an enduring asset, the Pilot DAC, the National Disability Research Partnership Working Party, and Disability Representative Organisations, service providers and disability advocates, were engaged with and consulted on various co-governance arrangements, including the panel and the mechanism for recruitment (#5).

Table 2 Timeline of consultations for the NDDA

Preliminary work	Pilot phase, leading up to Ministerial consideration	Engagement on detail of NDDA implementation
Up to October 2019	April 2020 - December 2021	2022-2023
Engagement with disability organisations and people with disability in the scoping phase.	October 2021 JFA Purple Orange 'attitudes' consultations Sydney Policy Lab consultations and workshops Project team 140 interviews with people with disability Communiques from the Pilot DAC	Consultations with and involvement of: Members of the Pilot DAC (noting the Pilot DAC ceased to operate at the end of the Pilot) National Disability Research Partnership Working Party Disability Representative Organisations

One member of the Pilot DAC said the project did 'try and put quite a bit of effort into gaining trust of the wider community – I don't think we did it particularly well' (#3). The SPL report suggested the need for community engagement to be undertaken by people with disability (SPL report).

4.3.5 Operational support and evaluation

The Pilot DAC was supported by the National Project Team (public servants funded by the Australian Government and employed by the NSW Government) who provided a secretariat to the group. The secretariat helped facilitate design by the group and 'the council [Pilot DAC] had to come to an agreement themselves to recommend that to the ministers' (#1). During the pilot, there was no formal capacity building, but the **secretariat encouraged knowledge sharing between members to build capacity across the Pilot DAC to build the understanding required to make informed decisions** (#1).

> It was a **two-way sharing of knowledge and that built out capacity enormously**. … the disability community consistently knew more about the data than governments hold, so it was absolutely two way this kind of knowledge sharing. (#1).

The support of the secretariat was recognised by all participants (e.g. 'they did all the work', 'did a remarkable job' (#3), 'amazing' (#4)), and the secretariat members themselves also recognised having the right people in these roles was critical. The secretariats (for both the pilot and the enduring asset) both recognised it was critical to have content knowledge (data and disability) and to build relationships with each of the individual members of the Councils (the Pilot DAC and the subsequent NDDA Council) which 'makes a huge difference to the quality of a secretariat function' (#5).
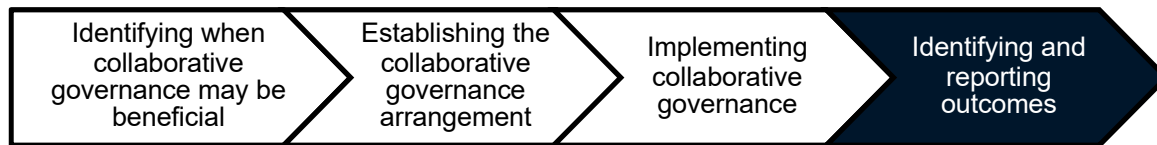
One participant suggested that more broadly in co-governance it was possibly 'useful to have a government [based] secretariat because they understand the mechanisms of government, but once it's set up and running, that ownership could be transferred to the community to take it forward' (#1). Although this may depend on what a group was co-governing (#1). For the enduring asset, the secretariat now sits in DSS; 'you've got to have a really close relationship with ABS and AIHW who are building the asset, so for me it makes more sense to have the secretariat in government' (#3).

4.4 Summary of practice: Learnings from the operation of the Pilot DAC

Objective	Consideration	NDDA Case study
Strategic implementation	What are the agreed objectives, priorities, timeframe? Is there a joint understanding of and commitment to the objectives? What are the mechanisms to develop understanding, respect and trust, including transparency, sharing information and resources?	The Pilot DAC had agreed objectives, priorities and timeframe. The advisory status was challenged and resolved by making decisions on recommendations that went to the Ministerial Council. There was a joint understanding and commitment to the objectives. The secretariat, and the members themselves, facilitated the development of understanding. Respect and trust was managed in the support and leadership of the group. Transparency was questioned and some improvements were made over time.
	Is there understanding of the commonalities and differences between collaborators, including cultural?	Different members had different strengths and knowledge and this was understood. Rather than being considered strengths/deficits, the group and the secretariat focused on different strengths. Language of business was difficult at first, with a large group of academics using academic language, but this was resolved over time.
	Is the group responsive to change in need?	The secretariat and the group appeared to be responsive across the period of operation.
	Is the group sustainable long-term?	The group was established for a fixed term. However, the recommendations were to establish a co-governance group closer to the ministers in the longer term.
Operational implementation	Is there a program logic?	No program logic.

Objective	Consideration	NDDA Case study
	Is there an ongoing engagement process? Are organisational differences understood?	Ongoing engagement through meetings. Organisational differences understood over time – organisational differences were seen as an asset.
	How are decisions made? How is collective action facilitated?	Decisions were made by consensus. The work of the group was facilitated by the secretariat.
	Are stakeholders represented?	Questioned whether stakeholders were adequately represented. This improved over time. It was recognised stakeholders could never truly be represented.
	Are stakeholders given the opportunity to engage?	Pilot DAC members could engage in decision-making for recommendations made. Other community members were engaged through broader active engagement initiatives.
Operational support	What operational support is required?	The Pilot DAC was supported by a well-resourced secretariat which was highly motivated to support the success of the Pilot DAC. The secretariat had expertise in disability and data.

ANZSOG

5. IDENTIFYING AND REPORTING OUTCOMES OF THE PILOT DAC

Identifying when collaborative governance may be beneficial	Establishing the collaborative governance arrangement	Implementing collaborative governance	Identifying and reporting outcomes

5.1 Evidence from the literature

As stated previously, while the Pilot DAC was not co-governance as defined in this study as it did not contain any government representatives, the Pilot DAC offers many lessons in the implementation of collaborative arrangements. This evidence is therefore included in this report.

The final stage in the co-governance process considers how to identify and report outcomes from the co-governance arrangement. The potential outcomes of collaborative governance can be varied, intentional, unintentional, measurable, unmeasurable, positive, negative, short-term and long-term. Ultimately, the test of whether collaborative governance is successful and increases public value is whether it achieves better policies or programs than would have been the case if decisions had been made by government on its own – reported as outcomes. Co-governance can also have other outcomes related to the *process* of collaboration.

Outcomes from specific actions include:

- Strategic plans and theories of change/action

- Short, medium and long-term outcomes 'on the ground' that have occurred due to the collaborative arrangement (intentional or otherwise).

Outcomes from the process of co-governance may include:

- Redressed power, information and resource imbalances

- Improved relationships, understanding and accountability

- Increased trust in government or service system

- Willingness to engage in future co-governance arrangements.

The absence of outcomes, or reporting of outcomes, may affect continuity of the arrangement.

This section documents each consideration for this case study site based on data collected, including enablers and barriers to their implementation in practice.

5.2 Direct outcomes and outcomes

This section describes both the **outputs** from the collaborative process (terms of reference for the new NDDA Council, the draft Charter) as well as **outcomes** from delivering specific priority actions (test cases).

5.2.1 Outputs

The Pilot DAC was asked to provide recommendations and advice to government on the development and use of the NDDA. The specific parameters included policy priorities and key uses for the asset (demonstrated through test projects), trust building in the asset with the disability community and sector (delivered through extensive consultations), and the design of how people with disability will be involved in designing the use of the enduring asset and its ongoing operation and development (document review).

The Pilot DAC identified six key themes in relation to the NDDA in its recommendations to Ministers:

- Shared decision making between people with disability and their representatives, researchers and government representatives. This should involve people with disability in the highest decision-making body
- NDDA Charter between people with disability and their representatives, researchers and government
- Ethical oversight over NDDA uses; other organisations can voluntarily engage the NDDA ethical oversight mechanism
- Program of input from people with lived experience and the disability community to support effective decision-making by the proposed NDDA Council
- Capability and capacity building support to enable informed and effective input by the disability community
- Transparency over uses and data to build trust and maintain social licence. (NDDA website, Message from the Council [the Pilot DAC] November, published 3 December 2021)

Key outputs included:

- The **Terms of Reference** for the NDDA Council, including composition of the NDDA Council and the appointment process.
- A safeguard mechanism through a **draft Charter** for the Asset (to be finalised after consulting with representatives from the disability community) that set out what the asset can and cannot be used for. (NDDA website)
- A set of **recommendations and reasons** for those recommendations.

Each recommendation is documented and is publicly available on the NDDA website and are therefore not repeated here.

Notably the new co-governance NDDA Council is the overall strategic decision-making body rather than a separate advisory group. In addition, the Pilot DAC recommended a disability informed ethical oversight mechanism, data development priorities, and direction on case studies (document review). The terms of reference included a requirement that should recommendations not be adopted, written reasons should be provided back to the NDDA Council providing the reasons (document review). The **recommendations were made at the end of 2021** and the task of the Pilot DAC was considered complete. As noted in Table 2 in Section 4 above, the members of the Pilot DAC were subsequently consulted and engaged with during the transition stage to implementing the enduring asset. The **NDDA Council for the enduring NDDA was up and running in early 2024**.

There were concerns expressed at the start of the Pilot DAC as to the extent their recommendations or advice would be acted upon (#15). The recommendations were supported in principle by the NDDA Senior Executive Steering Committee on 3 November 2021, and all but the 50:50 composition of the NDDA Council were agreed to by the Ministerial Reform Council. The new NDDA Council consisted of 12 members: six from government, three non-government disability experts, and three from the disability community. Members included people with lived experience of disability (including carers and family members); people with specialist knowledge and experience in disability policy, data and management; and people from a wide range of cultures, backgrounds, genders and locations (NDDA Council Factsheet). There is also 'no funded work under the capability building' (#1).

When asked whether the NDDA was better because of the Pilot DAC, one government stakeholder said, 'without a doubt' … 'it was part of the conversation right from the start which I think was wholly appropriate' (#11).

5.2.2 Outcomes

The five **policy test cases** provided an opportunity to provide a 'proof of concept in handling data' and 'the tests cases did their job' (#9). The test cases were designed to demonstrate the extent to which data would be shared, insights into sharing and linking data, and new insights that could drive policy and service improvement. The test cases linked 51 national and state/territory datasets (NDDA website). The test cases received some input and direction from the Pilot DAC.

The test cases provided insights to government departments they had never had before. As one participant explained:

> Some of the insights that we got, you know the justice one, the Bureau of Crime Statistics and research, the experts in justice field forever, they were overwhelmed by some of the insights that they could get that they had never had before. And then you put that in a way that people can use that… So the education one, early childhood education one, some of the insights that we could give teachers and schools and parents about kids with disability and in schools that was just great. (#2)

There were however concerns that there was little reference to the learnings or understanding from the test cases and that knowledge did not appear to be carried forward (#13).

During the pilot, the Pilot DAC also provided an '**opportunity for genuine sharing of knowledge and experience … [with] beneficial effects for all participants**'; for government about community perspectives, and for community, how government and decision making works (#5). This allowed the group to 'codevelop solutions that might not have otherwise transpired in a traditional' context (#5).

In addition to specific structures related to the NDDA, the asset comprises data **foundations that could support multiple data assets** (document review), with a front end that can be tailored to the social licence and information needs of the relevant community (#1). Therefore, the **learnings of this pilot, both the asset and the governance, has the potential to benefit other policy areas**.

'The quality of the process itself – that matters for people who participate in it', as well as the 'ability to make substantive decisions and recommendations', and the desire and support to continue, are all key measures of success (#1).

5.3   Indirect outcomes including trust

In addition to delivering recommendations, there were several indirect outcomes from the process, including demonstrating greater compliance with the UN CRPD (document review), and transferring lessons learning from the recommendations around governance elsewhere (#12). Some participants found it difficult to specify this additional value (#6), while others were more specific.

5.3.1 Relationships and trust

The development of the NDDA occurred in a low trust environment – both in terms of disability but also more broadly ('the way the public sector now interacts with people … emails from nameless inboxes… people want to interact with other human beings'#6).

> The success or otherwise of the pilot and the establishment of the enduring asset depends significantly on the trust of those involved in the system that the data will be used in ways consistent with their interests. (document review).

Yet there was a 'willingness of Council [Pilot DAC] members to work collaboratively and find ways to listen and understand each other's perspectives during the challenges created by COVID-19' (document review).

> You may not want to do this in every single policy environment, but there are contexts in which relationship building is an important part of any policy going forward. … But remember that the particular project we're talking about here related to the context of people with a disability, the context of everything that's going on around the NDIS, and the use of data in that, and everything that's going on around RoboDebt, and so on. So you are working in a kind of high stakes, low trust environment and maybe it's more worthwhile there. (#14)

The consultations delivered by the Sydney Policy Lab, occurring in the final third of the pilot period, identified ongoing distrust in government and concerns about 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. (SPL report)

The co-governance mechanism proposed by the Pilot DAC for the enduring asset was used to address some of this mistrust – but could not necessarily resolve it.

I think that the trust was built through relationships and there was a positive trust relationship between state and territory governments, and the disability organisations that they engaged with. There wasn't the trust with the Commonwealth from an NDIA perspective, from people's experience with DSS overtime, and the robodebt was just really high on people's minds when this was in its formative stages. So there was no trust of the Commonwealth at that particular stage, so that was a big hurdle that we actually had to get people over and it was forged through relationships. … So long as you can maintain those elements of the design that are trust building, then that builds their trust in the Commonwealth and the co-governance arrangement that's been put in place. (#2)

I think that there is merit in some form of co-governance arrangements that again builds a kind of community trust in what you're doing, provides the opportunity for really important co-creation activities. (#5)

The Pilot DAC had a '**dual role of trust and accountability**; trying to build trust for the community but holding government to account … helping government not lose trust by behaving properly' (#4). The fact that 'the recommendations ended up being quite specific', reflected 'the low trust context' (#1).

I think inherently there will be scepticism in any co-governance arrangement until it's sort of proven otherwise. (#5)

In this sense, if done well, one participant highlighted that 'might give other marginalised groups confidence to participate in a similar process' (#3).

Ultimately, the NDDA obtained the social licence to operate in difficult circumstances (#10) – a social licence that needs to be maintained. Without this support from the disability community, 'the NDDA would not have been approved and funded' (#1).

And so ultimately, if you see that as a proxy for trusting that this design was going to be implemented and that it was worthwhile going ahead, I think there was trust. But I think, there's a lovely phrase from the Russian Secret Service, 'trust but verify'. I think that's where community is and possibly rightly is which is I'll trust you to go ahead with this, but I need to be there to verify every step of the way that you're doing what you agreed. (#1)

It is hoped that co-governance 'increases community trust in the asset' and 'enables ongoing improvement over time' (#5). The acceptance of almost all the recommendations will go some way in building the relationship with the community and starting to build trust in this process, although the new NDDA Council was described as being 'towards co-governance and it's getting better' (#4). However, there were **some concerns expressed at the long delay between the completion of the Pilot DAC's work and the establishment of the new NDDA Council**, and the **lack of continuity in its members** ('I thought I was getting back on the same train, except its not the same train, the crew is all different, and its not clear to me that we're heading in the same direction' (#3)).

Realistically, there are 'limits of what governments will allow decisions to be made about. And I think that's the frustration that I've certainly seen in the disability sector … [for example,] where they call [something] codesign but they've pre-selected which elements they will codesign on there's a whole lot of really important things they won't codesign' (#6). This concern, of a process being co-opted and diluted, was shared by others (#8).

One participant reflected on trust:

Before I started this project I would say, you participate in co-governance because you don't trust the other person. So it's not about trust, it's about saying I am there to influence decision-making so I don't have to

trust, I can influence. It is kind of less requirement to have blind trust in another party because you're a party to the actual decision making. (#1)

5.3.2 Power

Ultimately, power to act on recommendations made by the Pilot DAC rested with government ministers.

> I wouldn't say that there was equal sharing of power or decisions in the national disability data asset; it was about being there to provide a service to government and advice to government. I don't think anybody felt like they were going to have any kind of say in the end product. … But that also came with data access and some case studies playing around with things that we wouldn't normally get to do. So it was give-take relationship. (#7)

> I'm aware of the lack of power that we have there because we're mainly talking about existing data sets and influencing existing data sets, which are where the data custodians are government. So I don't really feel like the NDDA Council has got a lot of power sometimes. (#4)

Within the Pilot DAC, **power within the group needed to be carefully managed** to ensure the voices of people with disabilities could not be derailed (document review). During meetings, the Pilot DAC 'very clearly demonstrated that everybody's input was valued and there was not some more valued than others' (#13).

What occurred outside of meetings was not clear, with views being shifted behind the scenes leading to participants to wonder how issues were resolved:

> There's a risk that pressure is put on particularly in the context of when there's a power differential. (#13)

5.3.3 Willingness to continue and apply lessons learned elsewhere

The **government agreed to have an NDDA Council with people with disability in key decision-making roles, supported by both a secretariat and funding, to govern the development and use of the NDDA** (#1).

> I think the main reason that the NDAA has kept its legs is because of the community expectation that has been built up and the promises that were made and the fight that's gone on to maintain its integrity of a co-governance structure. (#2)

The Pilot DAC offered benefits over an ad hoc group given the level of **expertise and knowledge it accumulated** about disability and data. The NDDA Council has the **potential to provide advice on other disability data related issues** beyond the NDDA if the need arose (#1, correspondence).

There was also evidence that the **co-governance approach was being translated to other policy contexts**, particularly where a social licence to work with the community was required (#1). However, what is required to make this approach successful may come down to those driving the process; as one person said 'the force of nature, the whirlwind' (#2).

Another learning expressed by different participants was **the need to use different activities on the participation spectrum as needed**.

> The biggest thing is when you, you know, you're always talking about Co design for example, and not everything's Co designed and not everything has to be Co designed like some things are, some things are genuine Co design and other things are really just deep consultations. … let's call it what it is. … it's not exactly co-governance, it's toward co-governance and it's getting better. Are we going to get there? I'm not sure, but I'd like at this point to stay optimistic.(#4)

There was also evidence that government staff had also benefited from having more access to community members which has increased their knowledge of disability and improved the way they communicated technical work. This was taken to other areas of their work:

It really does sharpen your language and thinking … it helps for technical people. It helps you to get out of your [language] and try to speak in English. (#12)

5.4 Summary of practice: Identifying outcomes achieved by the Pilot DAC

Objective	Consideration	NDDA Case study
Outcomes from collaboration activities	What organisational outputs has the group achieved? (e.g. plans, theories of change/action)	Recommended governance arrangement for the enduring NDDA (structure, terms of reference, charter) and other mechanisms to safeguard disability data.
	What outcomes has the group delivered that are *additional* to what would have otherwise been achieved?	Created a social licence for the NDDA to operate – this would not have been achieved without a co-governance mechanism and leadership by and engagement with people with disability.
Outcomes from process of collaboration	How have power imbalances been resolved?	Decision-making ultimately rests with government. The new governance mechanism reduces the distance between community representatives and the Ministerial Council.
	Have new relationships formed, have existing relationships become stronger?	Relationships within the disability community are well established. New relationships with government are continually forming as government staff change.
	Has trust increased?	Mechanisms have been established to hold government to account.
	Is there a willingness to continue or apply the lessons learned here elsewhere?	Co-governance will continue in a stronger form for the life of the asset. Decision-makers will be closer to government; however, there will be less representation by community organisations due to representation by different governments in a co-governance forum instead of all non-government members of an advisory group.

6. OTHER CONSIDERATIONS

In addition to the four-step process and related activities identified in the evidence review, two other considerations emerged from this case study. They relate to transparency and training.

6.1   Cultural considerations

The Pilot DAC did not specifically address cultural considerations. The DAC included First Nations' researchers and advocates. The format of co-governance drew on learnings from Closing the Gap.

6.2   Data

The work and priorities of the Pilot DAC were largely informed by earlier public consultations (during the preliminary work) and by the group itself. The priorities for the test cases were also informed by the broader consultations around Australia's Disability Strategy.

6.3   Transparency

Participants in both consultations and the Pilot DAC raised the need for greater transparency in the process and also about the information generated through the use of the asset (SPL report); 'to me, that lack of transparency raises some questions' (#13). Having greater transparency about the development and use of the asset would help resolve some of the mistrust and potentially reduce the stigma around disability (SPL report).

> 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 'redlines' that they identify. (SPL report)

In relation to suggestions for an ethical safeguard mechanism, the SPL report summarised:

> This committee could oversee all aspects of the Asset – how it is controlled and governed including [NDDA] Council appointments, the data it holds and how that data is used – to increase trust and transparency and acknowledge the existing governance capabilities within the disability community. (SPL report)

Being transparent was recognised as 'not the same as being understood. This risks, techniques and language swirling around data innovation are new, complex, and seldom intuitive, particularly for non-specialists' (document review). Therefore, while there was a need for transparency in decision-making, it was recognised that transparency was not just about decisions made but why they were made – 'its more than a communication strategy' (#9).

> I think some of the issues in the with people with disability are absolutely reasonable concerns to have. But I don't think there's enough counter and positive and messaging about how the asset actually will support progress. You know Australia, is, I think we're good at criticizing, we're good at finding the flaws in things, the holes, we're not very good at saying good job and this is fantastic and promoting things. (#13)

Transparency improved over time for the Pilot DAC with communiques being published on the NDDA website providing summaries of meetings. The learnings from Pilot DAC also appeared to be addressed by the NDDA Council established for the enduring asset.

6.4   Training

Engagement in co-design required 'genuinely transformative capability development' for those 'involved in the design, delivery, governance and administration of the NDDA' (document review). To date, other than the

secretariat working with individual NDDA Council members to provide information, this capability mapping and capability development was missing (#13, #14).

6.5 Summary of practice: Other considerations

Objective	Consideration	NDDA Case study
Respond to cultural needs	What are the cultural needs? Have stakeholders been identified? Are cultural protocols and different relationships understood? Is the community engaged and being heard? Are community groups (both services and advocates) engaged and heard?	The cultural needs and considerations for the NDDA were not specifically identified. The Pilot DAC included a member from FPDN. All members of the Pilot DAC appeared to be able to contribute and were valued. Reports on engagement suggest cultural needs in relation to First Nations were not identified or addressed in broader engagement processes beyond engagement with FPDN. It is unclear whether they were met within the functioning of the Pilot DAC.
Data informs actions	How does data inform need? How does data inform priorities? How does data inform whether outcomes are achieved? How does data identify the health and functioning of the group?	Broader consultations informed the need for the NDDA and the priorities of the NDDA.
The work of the group is transparent	How is the work of the group made public?	The Pilot DAC released communiques of meetings. Additional engagements were commissioned with community members to promote the NDDA and understand concerns.
The group has capability to participate in decision making	Have capabilities been mapped? Have capabilities been developed?	Capabilities were not mapped. Capabilities were not specifically developed. Some support was provided by the secretariat to provide information and support to individual members as needed.

7. CONCLUSION

This case study provides insights into the development of a recommended co-governance arrangement for the enduring asset by the NDDA Pilot Disability Advisory Council (Pilot DAC). The need for co-governance of the enduring asset came from one of the members of the Pilot DAC and was recognised and driven by some of the public servants involved. This case study captures the very detailed process of establishing a co-governance arrangement which in itself displayed many similarities (and therefore learnings) related to co-governance.

The process of developing the design for the recommended co-governance arrangement commenced in early 2021 and finished at the end of 2021, with recommendations to the Ministerial Council. The Pilot DAC met 12 times, with greater frequency when required. The group was supported by other engagements with the community delivered by other parties (SPL, JFA Purple Orange).

The learnings from developing recommendations for the co-governance arrangement spilled over into other activities within departments and organisations, and helped shape the future co-governance arrangement for the enduring asset.

Like the Waterloo case study, while the Pilot DAC was a distinct collaborative group, it also accompanied by a variety of other activities on the participation spectrum. That is, the resulting **co-governance does not appear to operate in isolation on the participation spectrum** – and the spectrum should also include co-implementation.

The findings of this case study will be combined with two other case studies to inform future practice.

APPENDIX A SUMMARY OF ENGAGEMENT AND DESIGN

Timeline and steps of engaging the group in the case study

A member of the original Pilot DAC secretariat approached members for permission to compile a case study of co-governance based on the Pilot DAC's work. As with other case studies:

- The aim was to minimise burden and maximise use of existing information

- The research team drew heavily on document review

- Interviews were conducted with key stakeholders involved in the Pilot DAC, including secretariat, and other attendees

- The draft findings were shared with participants for feedback to ensure data was accurately represented.

Discussion guide

About your organisation and you

- What is your organisation?

- What was your relationship to the Pilot DAC? (organisation and you)

- What was your role in the Pilot DAC? (you)

About your understanding of co-governance

- What does co-governance mean to you/your organisation?

- What did co-governance mean to you in terms of the Pilot DAC?

- What did you hope to get out of the Pilot DAC? (you/your organisation)

How was co-governance was established and organised for the Pilot DAC?

- How did the Pilot DAC come about? (if you were involved)

- How did you get involved? (your organisation, you)

- How was co-governance organised?
    - Leadership
    - Formal arrangements/agreements (one or more?), resourcing
    - Processes
    - Tracking progress
    - Informal arrangements
- What worked well? What could have been improved?

How did the Pilot DAC operate in terms of:

- Strategic planning

- Operational activities

- What worked well? What could have been improved?

What are the outcomes from the Pilot DAC?

- In terms of the co-governance process

    o Were your expectations of co-governance met?

    o Did co-governance had a positive or negative impact on your or your organisations involvement? (has it encouraged you to be a part of the group or discouraged you from being involved)

    o Do you think co-governance has any impact on relationships and trust?

- What outcomes were achieved?

- What were the outcomes for the community (if different from above)

- What worked well? What could have been improved?

Learnings for this group and others

- Any final thoughts about

    o How the approach could be improved?

    o What would you keep, what would you get rid of?

- If you could do things differently, what would you do?

- Have you seen good examples of co-governance elsewhere?

APPENDIX B DATA SOURCES

Data sources are denoted in the report in parentheses and italics.

Public documents

Short form	Full title
NDDA Charter	The NDDA Charter See https://www.ndda.gov.au/about/the-national-disability-data-asset-charter/ for accessible versions
NDDA Council	About the NDDA Council See https://www.ndda.gov.au/about/the-national-disability-data-asset-council/about-the-council/ for accessible versions
NDDA Privacy Policy	Privacy for the NDDA See https://www.ndda.gov.au/privacy-policy/ for accessible versions
NDDA Pilot findings	Preliminary summary of analytical findings: Emerging lessons from NDDA pilot See https://www.ndda.gov.au/about/public-phase/ for accessible versions
NDDA Test cases	The interim learnings from test case analyses See https://www.ndda.gov.au/about/public-phase/
JFA Purple Orange report	NDDA Focus Group Report, JFA Purple Orange 2021. See https://www.ndda.gov.au/about/public-phase/ for accessible versions
SPL report	No Data About Us Without Us: Community responses to the idea of a National Disability Data Asset, Sydney Policy Lab 2022 See https://www.ndda.gov.au/about/public-phase/ for accessible versions
NDDA Pilot DAC Nov2021	Message from the Council [Pilot DAC] November (published 3 December 2021) See https://www.ndda.gov.au/message-from-the-council-november/
NDDA Pilot DAC Feb2021	Message from the Council [Pilot DAC] February (published 3 February 2021) See https://ndda.gov.au/message-from-the-council-3-february/
NDDA Pilot DAC Oct2020	Message from the Council [Pilot DAC] October (published 27 October 2020) See https://www.ndda.gov.au/message-from-the-council-october/
NDDA Pilot DAC Sept2020	Message from the Council [Pilot DAC] October (published 27 October 2020) See https://www.ndda.gov.au/message-from-the-council-september/
NDDA Pilot DAC Aug2020	Message from the Council [Pilot DAC] August (published 6 August 2020) See https://www.ndda.gov.au/message-from-the-council-august/
NDDA Pilot DAC July2020	Message from the Council [Pilot DAC] July (published 17 July 2020) See https://www.ndda.gov.au/message-from-the-council-july/

Internal documents

Short form	Full title
Document review	Several internal documents were also reviewed for this study.

Interviews

Short form	Stakeholder group#	Number of participants
Participant 1	Government (n=2)	2
Participant 2	Government	1
Participant 3	Academic	1
Participant 4	Disability DPO/DRO	1
Participant 5	Government (n=2)	2
Participant 6	Disability DPO/DRO	1
Participant 7	Academic	1
Participant 8 - declined	Disability DPO/DRO	0
Participant 9	Disability DPO/DRO	1
Participant 10	Government	1
Participant 11	Government	1
Participant 12	Government (n=2)	2
Participant 13	Academic	1
Participant 14	Academic	2
Participant 15	Academic	1
Total	Government (9) Academics (6) Disability DPO/DRO (3)	18

Key stakeholder group recorded. We have not recorded the number of people with disability included in this study as this personal information was not sought.