

Submission to the Statutory Review of the Data Availability and Transparency Act 2022

May 2025

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Executive summary

The timing, broad scope and independence of this Statutory Review of the Data Availability and Transparency (DAT) Act 2022 is very necessary, because it is not working as intended.

Reform is not only necessary, it is urgent. Governments are investing tens of millions of dollars in the development of the National Disability Data Asset (NDDA) – the only linked data project utilising the DAT Act – with insufficient progress, when the NDDA will be showcased at the United Nations later this year.

This submission provides key background information, details the current challenges and recommends that the DAT Act should be changed so the NDDA and other potential linked data assets seeking to improve outcomes for vulnerable citizens built on the ANDII platform can achieve their objectives.

Changes to the DAT Act should be informed by lessons from data linkage and sharing through the governance and operations of the Australian Bureau of Statistics and the Australian Institute of Health and Welfare and their Acts.

Specifically:

- The DAT Act should not be allowed to sunset
- Changes to the DAT Act should be brought forward to improve the establishment of the NDDA as quickly as possible, and
- Section 143 of the DAT Act should be amended to provide for a further review in 3-5 years to ensure the ongoing refinement and optimal performance of the DAT Act.

Melbourne Disability Institute

The Melbourne Disability Institute (MDI) is an interdisciplinary research Institute at the University of Melbourne. Our Vision is “to transform the well-being, health, social and economic outcomes for people with disability”.

As part of our Mission “we bring people with disability, families, government and non-government organisations together with researchers to co-produce research that has real-world impact on policy and practice and helps to build a more inclusive and equitable society”.

Access to linked data is critical to our Vision and Mission. More broadly, access to linked data is essential for improving government policies in complex areas and

research. As a result, the DAT Act is a critical piece of government legislation which must operate effectively and efficiently.

National Disability Data Asset (NDDA)

Early advocacy

In 2018, MDI organised and hosted an initiative called Democratising Disability Data, which brought people with disability, disability representative organisations, governments service providers and researchers together to advocate for better data access.

This initiative played a crucial role in the development of the NDDA, because it:

- anchored the vision for the Asset on impact to benefit people with disability and their families
- recognised that personal data belongs to citizens, and
- began to build a consensus in the disability community that data should be shared provided it was done safely using the ‘5 safes’ (safe people, safe projects, safe settings, safe data and safe outputs).

NDDA Pilot Phase

When the NDDA Pilot was established both the Director and the then Academic Director of MDI became members of the Advisory Council, which then guided the development of the NDDA.

During the pilot phase there was significant engagement with stakeholders who said that to improve outcomes through data-informed decisions, better data is needed by Australian governments, by people with disability and their families and carers, by those who provide services, and by researchers.

- Governments need higher quality data to guide their policies, to evaluate short-term impact and measure longer-term outcomes, and to help them shift resources in response to changing circumstances.
- Individuals and those who provide services need better data to navigate services and make decisions on care, education, careers, and where to live or invest to increase security and opportunity. People with disability want richer data to inform the understanding the broader community has of their experiences and outcomes.
- Researchers need more timely and rigorous data to support service innovation to meet new or unmet needs, to build an evidence base about what is working

and for whom, and to contribute to a richer understanding of disability over time.¹

All three of these objectives are essential when linking and sharing data.

In December 2021, reflecting the feedback from stakeholders, the NDDA Pilot Phase Advisory Council set out a clear vision for the NDDA: To build trust and develop policy and research insights which would benefit people with disability and their families.

To realise this vision, seven key building blocks were recommended. The first three were national data building blocks and the other four building blocks applied to specific population group/policy asset, notably the NDDA:

1. National data linkage and integration infrastructure via a platform that connects the existing network of linkage infrastructure in jurisdictions to create enduring keys, and streamlined and reusable data curation processes, surpassing project-by-project approaches to data linkage.

2. National data system governance to institutionalise collaboration between jurisdictions by establishing a National Data Integration and Infrastructure Board, enabling joint governance of co-funded national data infrastructure that unlocks what is technically possible and supports trust between jurisdictions for data linkage on an unprecedented scale.

3. Streamlined data sharing agreements for multiple uses via an agreement between Australian governments that will provide a template for the creation of enduring assets of this kind. This kind of agreement will ensure data is not locked into a single department or environment and create safe parameters for streamlined access within existing legislation and authorisation pathways.

4. Co-governance of use of data by governments and the relevant community to build and maintain trust – in the NDDA case people with lived experience of disability.

5. Data development and a knowledge sharing platform to maximise value of data linkage. In a data context, this primarily focusses on improvement of data quality practices, as well as sharing knowledge of how to use the data effectively across government siloes, and with community organisations and researchers, and filling priority data gaps that would enrich insights.

6. Centrally coordinated analysis delivered through a centrally coordinated but distributed team, drawn from across Australia for their expertise relevant to the

¹ Blueprint for enduring human services data linkage, governance, insights production and sharing
Adapted to achieving outcomes for people with disability December 2021

given policy context. In the NDDA context, analytics directed by Disability Reform Ministers is proposed to also be centrally funded.

7. Insights sharing for specific decision makers & communities via a portfolio of mechanisms (including dashboards, summaries, aggregated data tables) will deliver actionable insights in useful formats to governments, communities, and researchers.²

The second and third national building blocks are particularly relevant context to the review of the DAT Act, because these building blocks rely on the DAT Act for their practical implementation.

In addition to national governance, the NDDA Pilot Phase recommended a “hub and spoke” model where jurisdictions could nominate analytics and linkage units to work with the ABS and AIHW in a national network. The hub and spoke model was designed to allow individual jurisdictions to progress work on their own disability-related priorities, while using consistently curated and therefore comparable data. Encouraging other data custodians to offer, for example, safe storage with enhanced analytical capability was also envisaged as being central to the vision for the NDDA.

Enduring NDDA

Following the report from the Advisory Council during the pilot phase of the NDDA, governments embraced its recommendations. Key actions included:

- The Commonwealth Government committing \$80 million to establish the NDDA and for the Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare (AIHW) to build the Australian National Data Integration Infrastructure (ANDII), which is the underlying infrastructure for the NDDA. Very importantly, ANDII is secure and scalable. In time it will be able to be leveraged to deepen our understanding of other priority policy issues such as homelessness, children in child protection and victims of domestic violence.
- The Commonwealth Parliament passed the DAT Act in 2022 and all governments agreed that they would rely on this legislation when establishing the enduring NDDA. As noted in the Issues Paper there have been just eight data sharing agreements under the DAT Scheme since the DAT Act commenced and all of these are related to the delivery of the NDDA. This means that the NDDA provides the only test case in relation to the effectiveness and appropriateness of the DAT Act.
- Governments agreed to the co-governance arrangements. When the NDDA was established in December 2023, I was appointed as a member of its inaugural Council and so this submission is informed by my insights as a Council Member.

² *ibid*

At the Melbourne Disability Institute, I also work closely with quantitative researchers who are attempting to gain access to use the NDDA, as part of their research.

Over the past one and a half years, while the ANDII platform has been built and appears to be working well, progress towards the vision that the NDDA should be an agile platform for policy analysis and research has been disturbingly slow. This would appear to be due to restrictions in the operability of the DAT Act. Specifically:

- At this stage, there has only been an initial release of the NDDA, in December 2024, many months behind schedule and with only 18 datasets included. Since then, an additional four datasets have progressed to the point that they can be added to the asset, as it is taking 4-5 months per dataset to get all the legal approvals, despite enormous goodwill and effort from data custodians. There is therefore no prospect of 200 datasets being available at the end of 2025, as set out in the timetable for development of the full NDDA. Getting data into the NDDA in a timely and cost-efficient way is therefore proving to be a major stumbling block.
- Second, while there is great interest in accessing the NDDA from researchers, not one data access request has been approved. It is possible that this is due to the fact that the DAT Act has been written to provide for access to identifiable data and so may not be fit for purpose when governing access to de-identified data.
- Third, the DAT Act authorises institutions, not individuals to access the data. Whether this is practical is untested.
- Fourth, a key part of the vision for the NDDA is the ability to create State versions of the national data asset to facilitate policy development at the State level. There have not been any attempts to create State versions of the NDDA and so it is unclear whether this is feasible under the DAT Act.

At the same time as the NDDA has been established, there have been significant improvements to other linked datasets, such as the ABS's Person Level Integrator Data Asset (PLIDA). The data in PLIDA is collected and stored under the Census and Statistics Act. PLIDA originally only included Commonwealth data, but it now includes State data and so it is able to link data across jurisdictions. There are also plans to add significantly more State datasets to PLIDA. PLIDA is also widely accessed by researchers and there is an active research community. PLIDA is also in the process of being shifted across to the ANDII platform to scale access, so it can be used by many more researchers at the same time.

Because PLIDA is collected and managed under the Census and Statistics Act, it is governed by the Commonwealth Government and so does not provide national governance as set out in Building Block 2 for the NDDA. However, given the impressive

growth in PLIDA, significant growth plans and its wide use in the research community, it is recommended that the Strategic Review consider what can be learnt from its governance, structure and operations.

It is also recommended that lessons from the governance, structure and operations of the Australian Institute of Health and Welfare (AIHW) and the AIHW Act should inform the Strategic Review.

Therefore, while lessons need to be learnt to address the current teething problems with the NDDA and DAT Act, without the national governance structures built into the NDDA and the DAT Act it is very possible that State and Territory governments would have not agreed to contribute their data to the NDDA. The DAT Act has therefore been a catalyst for change and improved information flows between public sector bodies and accredited entities.

Further, without the DAT Act, the NDDA, in which governments are investing tens of millions of dollars, would be stranded without a legislative basis. This would be a huge setback at a time when linked disability data is poised to provide critical policy and research insights during a period of rapid disability reforms.

However, from the experiences with the NDDA, it is clear that the realisation of effective timely and safe data linkage through the DAT Act has not been achieved so far. The DAT Act needs to be revised significantly and as soon as possible. Ideally this should occur before 2027.

It is also notable from the University of Melbourne Submission to this Strategic Review, to which I have contributed with colleagues, that there are other aspects of the DAT Act which need to be improved. (See the University of Melbourne submission.)

It is therefore recommended that:

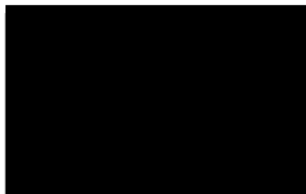
- The DAT Act should not be allowed to sunset
- Changes to the DAT Act should be brought forward to improve the establishment of the NDDA as quickly as possible, and
- Section 143 of the DAT Act should be amended to provide for a further review in 3-5 years to ensure the ongoing refinement and optimal performance of the DAT Act.

In summary:

- Changes to the DAT Act are urgently needed so the NDDA can deliver its potential benefits to people with disability and their families. This is especially the case given that the future benefits of the NDDA are being showcased at the United Nations later this year and so a lack of timely and effective action could be internationally embarrassing. A complete, effective and efficient NDDA is also

urgently need to provide evidence to support rapid and very substantial disability reforms following the NDIS Review and Disability Royal Commission.

- Changes to the DAT Act are also needed to generate its full benefits to the Australian community and place Australia at the cutting edge of evidence-based policy and reform and support research, as set out in the University of Melbourne Submission.



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