

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

May 2025

This submission is made on behalf of the [Research Alliance for Youth Disability and Mental Health](#) and the [CRE in Achieving Health Equity for All People with Disabilities \(AHEAD\)](#)

Associate Professor Zoe Aitken

Melbourne School of Population and Global Health, The University of Melbourne

E: [REDACTED]

Dr Glenda Bishop

Melbourne School of Population and Global Health, The University of Melbourne

Professor Dennis Petrie

Centre for Health Economics, Monash University

Professor Anne Kavanagh

Melbourne School of Population and Global Health, The University of Melbourne

The *Data Availability and Transparency Act 2022* established the DATA Scheme to address a critical problem: the lack of government-wide linked data needed to deliver more effective and efficient government services, policies and programs. This includes the use of public sector data by accredited users, such as Australian universities, to undertake research to inform government services, policies and programs.

The need for better disability data

From a disability perspective, the need for robust disability data was recognised as a critical problem by the Australian Government [1-3] and a major obstacle to developing effective and cost-effective policies to address the systemic disadvantage faced by people with disability and protect their rights [4-8]. With an estimated \$48.8 billion being spent on the National Disability Insurance Scheme (NDIS) in 2024-25, it is critical to have the evidence needed to ensure that programs like the NDIS are not only sustainable but also have their intended impacts on improving the lives of people with disability [9]. There are policies across all levels of governments that impact on the lives of people with disability and it's important to be able to understand how these different policies interact.

To drive progress towards equity, Australia needs data to understand how people with disability are accessing services and to report on outcomes for people with disability, including monitoring changes over time. This includes people with disability who are NDIS participants as well as people with disability who are ineligible for the NDIS [10]. This requires accurate, consistent data on disability linked to service use and relevant outcomes, such as health, employment, and education. Robust disability data is essential for tracking progress towards the goals of Australia's Disability Strategy 2021-2031 (ADS) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The value of the National Disability Data Asset (NDDA)

The DATA Scheme has enabled the development of the National Disability Data Asset (NDDA), a landmark initiative that brings together whole population linked data from Commonwealth, state and territory sources. This includes data on income support payments and services, NDIS, tax, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, health services, housing, justice and employment.

The NDDA will allow Australia to comprehensively report on the wide range of outcomes identified in the ADS Outcomes Framework. This level of integrated reporting has not previously been possible, with only limited data available for many of the ADS outcomes.

Moreover, the NDDA will position Australia as a global leader in disability data infrastructure and research. The Lancet Commission on Disability and Health launched on 21st May 2025, on which Professor Anne Kavanagh is a Commissioner [11], has expressed strong interest in the NDDA. The Commission seeks to generate the 'best-in-class' evidence to inform actionable policies that improve the lives of people with disability globally. The Commission would like to draw on insights from analyses using the NDDA to understand more about health inequities between disabled and non-disabled people and the drivers of those inequities; test and evaluate policy interventions to improve access to health care and close the outcome gaps for people with disability; and make an economic case for investing in disability inclusion.

The need to extend the DATA Scheme

To fully realise the potential of the NDDA, it is essential that the DAT Act remains in force. While the NDDA officially became available in December 2024, processes for data access are still being established and at this stage no users have yet been granted access to the NDDA for research purposes. Continued operation of the DATA Scheme is necessary to:

- Support ongoing access, development, and refinement of the NDDA
- Enable the NDDA to evolve into a permanent, enduring data asset
- Maximise the long-term return on government investment in the NDDA
- Provide the evidence needed to deliver more effective and efficient services, policies and programs for people with disability
- Cement Australia's leadership in disability data and research globally.

Conclusion

The NDDA represents a transformative opportunity to improve outcomes for people with disability in Australia, improve disability services and supports so that they not only meet the needs of Australians with disability but are also effective and efficient, and contribute to global research leadership. However, despite its significant potential, the NDDA has been plagued by governance challenges that have delayed implementation and limited access. These issues must be addressed to ensure the asset can deliver on its promise.

Given the substantial public investment in the NDDA, taxpayers have a right to know how government funds are being used and what outcomes have been achieved. Transparency, accountability, and effective governance must be at the heart of the NDDA's ongoing development.

Maintaining and extending the DATA Scheme is critical – not only to safeguard this investment and ensure the NDDA becomes an enduring, high-impact asset – but also to uphold public trust in the value and integrity of government-funded data initiatives.

References

1. Productivity Commission, *Disability care and support. Productivity commission inquiry report. No. 54.* 2011: Canberra.
2. Australian Civil Society CRPD Shadow Report Working Group, *Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities* 2019.
3. Davy, L., et al., *Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19].* 2019, Social Policy Research Centre, UNSW Sydney: Sydney.
4. Institute of Medicine (US) Committee on Disability in America, *The future of disability in America*, ed. M. Field and A. Jette. 2007, Washington DC: National Academies Press (US).
5. World Health Organization and United Nations ESCAP, *Training manual on disability statistics.* 2008, United Nations: Bangkok.
6. Ma, B.H., et al., *Exploring the impact of a personalised disability reform on people with disability and their primary carers: Evidence from the Australian national disability insurance scheme.* PLoS One, 2025. **20**(5): p. e0321377.
7. Aitken, Z., et al., *Methodology paper: Identification of people with disability in linked administrative data.* 2022, The University of Melbourne: Melbourne.
8. Aitken, Z., et al., *Methods used to construct disability indicators in linked administrative datasets: a systematic scoping review* Population Health Metrics, 2025.
9. Parliamentary Library, *Budget Paper No. 1, Budget 2024–25.* 2024, Parliament of Australia. p. 211.
10. Bishop, G., et al., *A comparison of the characteristics of people with disability in Australia according to whether they received National Disability Insurance Scheme (NDIS) funding.* 2025, The University of Melbourne: Melbourne.
11. Kuper, H., et al., *Announcing The Lancet Commission on Disability and Health: Creating disability-inclusive health systems that leave no one behind.* The Lancet, 2025.