

February 2024

---

# National Disability Data Asset

---

## Our position

We support the development of a National Disability Data Set. We believe the development of any data linkages project must be done in a way that centres people with an intellectual disability and protects their privacy.

An inclusive, effective, and safe mechanism for collecting data is essential to centring the experiences of Australians with an intellectual disability in data collection and to strengthen our evidence base. This will help improve the quality of the research, policies, and laws that impact people with an intellectual disability and their family members, and ensure they are grounded in lived experience.

Inclusion Australia is committed to working collaboratively with government to ensure that data that is collected about people with disability is done in partnership with the disability community.

## What is the NDDA?

The National Disability Data Asset (NDDA) has been developed to bring together de-identified data from Australian, state and territory government agencies to provide linked information about the needs and outcomes of people with disability. The aim of the NDDA is to create information to help improve programs and services for people with a disability.

In 2020-2021, the NDDA implemented a pilot to test how people with disability, the disability sector and governments could use linked data to gather better information about how programs and services are working for people with disability. A National Disability Data Asset Disability Advisory Council was set up to guide the pilot. The Council included people from the disability sector, including representation from Inclusion Australia.



The Council made recommendations regarding the future development of the NDDA, including the role of people with disability, safeguards and ethical oversight, quality improvement, and how information about the test cases should be shared.<sup>1</sup>

At the December 2022 Disability Reform Ministers Meeting, it was agreed to continue to work together to progress the NDDA.<sup>2</sup> As of March 2023, the NDDA is establishing a governing Council to oversee the development of the NDDA, running a privacy impact assessment, providing data on the National Disability Strategy, and working with the disability community on key design elements.<sup>3</sup>

## Why is data important?

When used effectively, data can provide governments with important insights about people with disability, families, and their communities. Data can aid in decision-making, policy development and lead to better outcomes and services for people with disability and their families. Access to accurate data and statistics about people with disability will support government to develop better policies, programs and to monitor outcomes under the National Disability Strategy.

In Australia there is a lack of accurate data to understand the experiences of many people with disability, including people with an intellectual disability. In 2020, Inclusion Australia commissioned work to collate recent data on people with an intellectual disability living in Australia with a focus on prevalence, demographics, government support, restricted decision-making, schooling, employment, living situations, and access to technology. This report highlighted the difficulties in accessing reliable and comparable information about people with an intellectual disability in Australia. It demonstrated the need to improve the collection and analysis of disability data within Australia.

However, data access and sharing also comes with risks to individuals and organisations. These include the risks of confidentiality and privacy breaches, misuse of data for purposes of monitoring or enforcement (e.g., Robo-debt), or the misinterpretation of data which may lead to poor policy and service development for people with disability. The disability community is particularly sensitive to these concerns due to their reliance on government services and programs, and the history of stigma and discrimination experienced by people with a disability.

Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outlines the responsibilities of State parties to collect appropriate information and data to enable them to develop and implement policies and programs that give effect to the Convention. It also notes that this must be done with consideration to appropriate safeguards and ethical principles.

## How do we know it's important?

An inclusive, effective, and safe mechanism for collecting data is essential to enhance our understandings of the experiences of Australians with an intellectual disability. Those enhancements strengthen our evidence base.

A stronger evidence base—one that is grounded in the lived experience and expertise of people with an intellectual disability—improves the quality of the research, policies, and laws that impact people with an intellectual disability and their family members.

Better quality research, policies and laws lead to improvements in the services that people with an intellectual disability use and rely on.

All this points to a more inclusive society: one in which the lives, experiences, and expertise of people with an intellectual disability are genuinely valued and accurately reflected in our policies and laws.

## What needs to happen

Inclusion Australia has identified a set of key principles that must be adhered to in the collection, analysis, and distribution of linked data about people with disability.

### **People with disability must be at the centre of the data work**

People with disability must be involved in the governance, collection and interpretation of data that is collected about them. Participation is a principle of the human rights-based approach to data and an obligation under Article 4 of the UNCRPD.<sup>4</sup> People with disability must be involved at all stages of data-collection processes, from strategic planning, identifying data needs and testing data-collection methodologies to collecting, storing, disseminating, and interpreting data. People with disability also have a right to know how data collected about them will be used and should have an opportunity to provide input regarding the priorities for future projects.

### **People with disability are the experts**

People with disability are experts on the barriers they face and the service systems that they utilise. Data produced by organisations of persons with disability and their networks, can contribute substantively to data-collection effort, and make it reflective of their experiences. Disability organisations can also utilise their own experience and data collection over the years to assist in the interpretation of outcomes through data linkage projects.

## **Data Integrity is essential**

For data to be useful it needs to be accurate and complete. As part of ensuring the accuracy of linked data, there is a need for agreement on definitions of key variables (including intellectual disability) to inform consistent data collection at Commonwealth and state and territory levels to enable comparison and accurate reporting. Across Australia, numerous definitions of intellectual disability have been used for data collection and research,<sup>5</sup> including those based on clinical diagnosis (of intellectual disability or IQ, support needs, and functioning). Without consistency of definition, linked data will be flawed and difficult to interpret.

## **Limitations of data must be acknowledged**

Data which is utilised to inform government policies must be accurate data and limitations of existing methods of collecting data must be considered regarding interpretation of that data. Part of the work of the NDDA should be to identify current limitations in government-held data and identify priorities for additional data that needs to be collected based on existing gaps.

For example, in the NDDA test case on education to employment in South Australia, the data identified only 1704 students with autism in South Australia (making up less than 1% of the population). This finding is not consistent with data from the NDIA on the number of young people in South Australia with a diagnosis of autism. This issue with the data was not identified or discussed as one of the limitations of the data and therefore was not appropriately considered in any interpretation of data.

## **Disaggregated data by disability type (e.g., intellectual disability) and intersectionality must be made available whenever possible**

People with disability, including people with an intellectual disability, are diverse in terms of needs, experiences, and outcomes. Grouping all people with disability together in statistical analysis provides a very simplistic and inaccurate outcome that is open to misinterpretation.<sup>6</sup>

For example, there is evidence that the stigma and discrimination experienced by people with an intellectual disability is of a different magnitude than that experienced by people with physical or sensory disabilities.<sup>7</sup> Therefore, data that tries to look at attitudes about disability without looking at different disability types is problematic. Similarly, employment outcomes vary significantly across different disability groups, and aggregating this information will lead to distorted interpretations.

Analysis must be done in such a way that disaggregates the data to be able to look at specific cohorts (e.g., intellectual disability/autism) where possible, and recognises that the diversity of experiences of people with disability.

### **Appropriate ethical oversight must be in place.**

Data linkage must not be utilised for surveillance, compliance purposes or enforcement (for purposes of government payments or access to programs). This standard must be set out clearly as part of the Governance of any data linkage or collection program.

Ethical oversight of any program of data must consider not just the ethical standards of data collection, but also of how the data will be utilised and interpreted. This independent ethical oversight mechanism must include a majority of people with disability. This was a key recommendation of the Disability Advisory Council in the development of the Data Asset.

### **Data must be available to the public and accessible to people with disability**

Government agencies should enable as much public access to data as possible as standard practice, while protecting the privacy and confidentiality of individuals and organisations. Summary data should be easy to access and available in accessible formats, including Easy Read. The NDDA should provide an accessible format for stakeholders including Disability Representative Organisations to request data to inform policy and advocacy work.

## Reference list

---

<sup>1</sup> National Disability Data Asset. 2022. Message from the Council. Retrieved from:

<https://ndda.dss.gov.au/message-from-the-council-november/>

<sup>2</sup> Department of Social Services. 2022. Communique 13 December 2022. Retrieved from:

<https://www.dss.gov.au/disability-and-carers-programs-services-government-international-disability-reform-ministers-meetings/communique-13-december-2022>

<sup>3</sup> National Disability Data Asset. 2023. Message from the Team. Retrieved from:

<https://www.ndda.gov.au/message-from-the-team-2/>

<sup>4</sup> United Nations Department of Economic and Social Affairs. Convention on the Rights of Persons with Disabilities—Article 4. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html#:~:text=States%20Parties%20undertake%20to%20ensure,on%20the%20basis%20of%20disability.>

<sup>5</sup> Inclusion Australia. 2020. Gathering the Evidence: Data on people with intellectual disability in Australia: A report for Inclusion Australia. Retrieved from: [https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions\\_2020\\_10\\_Submission-to-the-DRC-on-Data-on-Intellectual-Disability.pdf](https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions_2020_10_Submission-to-the-DRC-on-Data-on-Intellectual-Disability.pdf)

<sup>6</sup> Bigby, C. 2020. Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together, *Journal of Intellectual & Developmental Disability*.

<sup>7</sup> Centre of Research Excellence in Disability and Health. 2018. Attitudes matter: findings from a national survey of community attitudes towards people with disability in Australia. Retrieved from:

<https://credh.org.au/projects/community-attitudes/community-attitudes-towards-people-with-disability/>