National Disability Research Partnership

National Disability Data Asset (NDDA): responses to questions from the Let's Talk About Disability Data event

Response from the NDDA program team, provided to the National Disability Research Partnership following the Evidence to Action event, 25 May 2026.

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1. **What is the NDDA in 2026? What does it currently do, what has changed, and how should the disability community understand its role?**

   The intent of the NDDA program is to build an enduring, stand-alone data asset that links Commonwealth and state and territory administrative datasets to provide a more holistic picture of the experiences of people with disability. The asset would be co-governed with people with disability, and have disability-informed ethical oversight of research, to reduce the potential risk of harm to people with disability. The plan was for the NDDA to be enabled by the new Data Availability and Transparency Act 2022 (DAT Act).

   The program has had several successes:

   - Establishment of inclusive co-governance, including the NDDA Charter (endorsed by disability ministers in June 2024), the NDDA Council (which includes Commonwealth and state and territory representatives, as well as non-government data experts and disability community representatives), and the Disability-informed Ethical Oversight Panel, which provides advice on NDDA project proposals and includes five non-government members with expertise in disability, data, and strong connections to the disability community.
   - Some datasets were linked.
   - Disability flags were built (a way to capture people with disabilities in the data).
   - Reporting against outcomes under Australia's Disability Strategy Outcomes Framework was improved.
   - New ICT infrastructure was created: the Australian National Data Integration Infrastructure (ANDII).

   However, the NDDA program has also experienced challenges, including using the DAT Act. A statutory review subsequently found the DAT Act unfit for purpose. It became clear in 2025 that disability research insights could not be delivered using the DAT Act.

   For now, the program is using an alternative, interim delivery model. The model relies on existing data assets, PLIDA and NHDH, and supporting legislation for those assets, to provide faster access to data for disability research. The aim is to facilitate the earlier dissemination of insights from disability research.

2. **What does the NDDA program currently do?**

- The NDDA Council continues to meet quarterly and advises the government and disability ministers in accordance with its obligations under the NDDA Charter.
- The NDDA program is continuing work on the disability flags and data improvement, that is, negotiating to add more datasets to PLIDA and NHDH.
- The NDDA program also provides disability-informed ethical oversight of research projects. In practical terms, this involves disability research teams answering a few additional questions in their applications to NHDH or PLIDA, and having their applications considered by the Disability-informed Ethical Oversight Panel. The Panel offers advice on improving disability-informed ethical considerations in projects and recommends whether projects should proceed. Ultimately, final project approval decisions rest with data custodians.

A project will be considered an NDDA project if it meets one or more of the following criteria:

- The project title, objective or scope explicitly mentions a focus on disability.
- The research questions explicitly focus on understanding, improving, or evaluating outcomes for people with disabilities.
- The data access request includes NDDA disability flags or National Disability Insurance Scheme (NDIS) participant data to explicitly design a research cohort of people with disability.

3. **How should the disability community understand the role of the NDDA program?**

- The program's work is technical and difficult, and progress is slower than anyone would like or anticipate.
- The co-governance model established by the NDDA program is unique, and looked to as an example by governments across the world.
- The NDDA program is working to:
- Give people with disability a say in how their data is used (through inclusive co-governance).
- Reduce potential harm to people with disability through disability-informed ethical oversight of research projects.
- Increase inclusion of people with disability in research.
- Improve how people with disability are captured and described in data, including limitations of the data.
- Improve data quality in Australia in the longer term.

4. **Who can access NDDA datasets and how are they used?**
Can state and territory governments, researchers or others access the data?

The NDDA is being supported through existing assets:

- Person Level Integrated Data Asset (PLIDA)
- National Health Data Hub (NHDH).

Access to these assets for eligible projects will be made through the Australian Bureau of Statistics (ABS) and Australian Institute of Health and Wellbeing (AIHW).

ABS provides access to integrated data, including datasets related to people with a disability, via the ABS DataLab. Access to the ABS DataLab is supported for:

- Government employees (federal, state and local)
- Individuals or entities sponsored by government (including contractors)
- Academics (including international)
- Researchers from public policy research institutes (including international)

For more information, see: DataLab User Guide | Australian Bureau of Statistics
AIHW provides access to integrated data, including datasets on people with a disability, via the National Health Data Hub (NHDH). Access is supported for:

- Universities and research institutes
- Government agencies (Commonwealth and states/territories)
- Clinical quality registries and research networks
- NGOs and non-profit research organisations
- Private sector analytics/consultancies (generally on behalf of clients listed in the above categories)

For more information see: About - Australian Institute of Health and Welfare

5. **What are the biggest evidence gaps the NDDA could help fill in the future?**

Current disability data is fragmented, with no consistent way to identify people with disability across health, disability and social datasets. As a result, large parts of the population are either partially captured (e.g. through NDIS participation, hospital diagnoses or income support) or not identified at all. This limits the ability to undertake robust population-level analysis, compare outcomes across groups, or understand inequities, particularly for groups such as children, people with psychosocial disability, and those in regional or culturally diverse communities.
The NDDA has significant potential to address several longstanding evidence gaps in disability data.

While the NDDA's disability flags are still evolving, they represent an important step forward in using administrative data to identify and analyse the disability population. Continued refinement over time will improve their robustness and expand their analytical value.

A key contribution of the NDDA is its ability to complement and enhance survey and Census self-reported data. By providing more regular, administrative data-based insights, the NDDA can help fill gaps and support more timely analysis.

The NDDA also creates new opportunities for deeper disaggregation of the disability population, including by employment sector, finer geographic levels, and priority groups such as First Nations peoples and culturally and linguistically diverse (CALD) communities. This enhances the ability to understand population diversity and supports more targeted policy and service responses.

In addition, the NDDA enables stronger analysis of intersectionality, allowing for a more comprehensive understanding of how disability interacts with other characteristics and life circumstances.

The NDDA also offers opportunities for analysis that reflects the full experiences of people with disability across multiple life domains, rather than focusing on isolated service systems. It can support a more complete understanding of how individuals interact with, and transition between, different systems and support, such as health, education, employment and social services, over time. This will generate stronger evidence to inform more coordinated, person-centred policy and service design.

6. **How are people recruited or involved in NDDA governance or advisory processes?**

The NDDA is inclusively co-governed through:

- The NDDA Council
- The Charter, which outlines acceptable and unacceptable uses of the de-identified data
- Advisory panels that support the Council.
    - The only panel active in 2026 is the Disability-informed Ethical Oversight Panel.

The NDDA Council consists of representatives from the Australian Government, state and territory governments, the disability community, and disability data experts. NDDA Council members are formally appointed by the Australian Government Disability Minister, in consultation with the Disability Reform Ministerial Council (DRMC). The recruitment process for the NDDA Council depends on the type of member. For the most recent recruitment of disability community members, an expression of interest was shared with Disability Representative Organisations (DROs), the National Disability Research Partnership (NDRP), Council members, and other stakeholders. An Evaluation Group, consisting of Australian, state and territory government representatives and a disability community member, assessed candidates and provided recommendations to the Australian Government Disability Minister and DRMC.

Members of the Ethical Oversight Panel were recruited through a public expression-of-interest process. This process was led in collaboration with Disability Advocacy Network Australia (DANA) and promoted widely through DROs. Applications were jointly assessed by the department and DANA against criteria developed in consultation with DROs. The NDDA Council then reviewed the shortlisted candidates and recommended appointments to the department.

For more information on the NDDA Council, please visit the Council page of the NDDA website, and for the Ethical Oversight Panel, the advisory panels page.