





AIHW written submission

Joint Standing Committee on the National Disability Insurance Scheme

14 October 2025



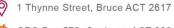














Annual Report No.1 of the 48th Parliament Submission 13

Introduction

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to provide a submission to the above inquiry. This submission highlights AIHW work relevant to the committee's terms of reference.

As Australia's national agency for health and welfare statistics and evidence, AIHW has over 35 years of experience collecting, managing, analysing, and disseminating data to inform policy, service delivery, and research. Our high quality, independent evidence is used to improve policies and services on a range of health and welfare issues and topics, including the experience of people with disability in Australia. In addition to our analysis and reporting function, the AIHW works with others to fill data gaps.

Our key current reporting on disability includes <u>People with disability in Australia</u> and <u>Australia's Disability Strategy Outcomes Framework</u>. These initiatives use a range of data sources, including data from the National Disability Insurance Scheme (NDIS), to present evidence about the experience of people with disability in Australia across life domains such as health, justice and economic outcomes.

However, data gaps remain. We work with partners to fill these gaps through developing the National Disability Data Asset (NDDA), improving reporting, and working to fill specific data gaps such as the use of restrictive practices on people with disability. This builds on earlier collaborative work with the NDIS Quality and Safeguards Commission using linked data to explore mortality outcomes for people with disability.

Our submission provides a brief overview of the AIHW's role in improving evidence for people with disability. We highlight the critical role of data sharing and linkage, collaborative partnerships with the disability and research communities and government agencies, in enabling high-quality, policy-relevant analysis and research. We also emphasise the importance of continually improving data for better evidence, decision making and outcomes for people with disability.

About the AIHW

The AIHW plays a pivotal role in supporting evidence-based decision-making and research by:

- Developing and maintaining national health and welfare data standards, ensuring consistency and comparability across jurisdictions and sectors.
- Collecting and integrating data from federal, state, and territory agencies, enabling comprehensive insights into health, community services, and housing assistance.
- Providing advanced data linkage services, including cross-sectoral and longitudinal data integration, to support complex research questions and policy evaluations.
- Collaborating with universities, research institutes, and government bodies to
 facilitate access to linked data assets through secure and ethical data sharing
 frameworks and share AIHW's analytic, health and welfare systems and subject
 matter expertise.
- Producing high-quality analytical outputs, including reports, dashboards, and datasets, tailored to the needs of policymakers, service providers, and the research community.
- Expanding and enhancing national data holdings, including the development of new data assets to address emerging gaps in health and welfare information.

Annual Report No.1 of the 48th Parliament Submission 13

 Modernising data access and dissemination, offering user-friendly platforms and tools that support diverse audiences – from government agencies to academic researchers and NGOs.

Through its data linkage infrastructure and partnerships, AIHW enables deeper understanding of population health and welfare trends and system performance, supports longitudinal studies, and contributes to national and international research efforts.

AIHW's disability program

The AIHW legislation requires us to report on welfare services, including services for people with disabilities.

Historically, prior to the introduction of the NDIS, the AIHW managed the Commonwealth/State Disability Agreement national minimum data set collection and worked closely under disability minister governance arrangements on a range of projects, such as studies into <u>unmet need for disability services</u>. These activities were conducted using administrative and survey data before the advent of large-scale data linkage that is now possible.

Until recently the AIHW has obtained NDIS data for our work via the NDIS website, through specific ad hoc requests to the National Disability Insurance Agency (NDIA), and through project-by-project data linkage studies.

In October 2023, the NDIA shared detailed NDIS data with the AIHW for use in our own analysis and for use in approved data linkage projects. This data sharing marks a significant milestone, enabling us to build new analytical capabilities and generate insights that were previously out of reach. This data is already proving instrumental in supporting key national initiatives, including:

- Australia's Disability Strategy Outcomes Framework reporting.
- Extensions of the previous <u>NDIS Quality and Safeguards Commission work on</u> mortality and preventative health.
- Cross-agency collaboration on the National Disability Data Asset (NDDA).
- Analysis of younger people in residential aged care who are also NDIS participants (forthcoming).

With access to linked datasets such as the NDIS in our <u>National Health Data Hub</u> (NHDH), AIHW is now in the early stages of conducting new work to analyse health outcomes for people with disability, including mortality, hospital visits and length of stay, and interactions between the NDIS and other systems like health and aged care.

Data sharing and linkage as drivers for improved policy and service delivery

The AIHW has an extensive data linkage program, largely facilitated via the NHDH that includes integrated whole-of-population data from hospitals, Medicare Benefits Scheme, Pharmaceutical Benefits Scheme, immunisation, aged care, deaths and NDIS. We also conduct a large bespoke linkage program through which we support researchers to deliver projects spanning a wide range of health and welfare topics.

We have been the foundational technical partner on the <u>NDDA</u> project since the pilot phase commenced in 2020. Under the leadership of the Department of Health, Disability and Ageing, and working closely with the Australian Bureau of Statistics, states/territories and the disability community, we are pleased to see this data coming together to better understand service use pathways and outcomes for people with disability in Australia. The NHDH is a key enabler for the NDDA.

Annual Report No.1 of the 48th Parliament Submission 13

The NDDA initiative has already enabled us to present new <u>Australia's Disability Strategy Outcomes Framework</u> measures on health service use by people who accessed disability-related government payments and services between 2020–21 to 2021–22 (NDIS participants, people assessed as eligible for or received a Centrelink Disability Support Pension, and people in receipt of disability-related income support such as mobility allowance). We are currently working to expand this analysis to look more generally at health outcomes for people with disability in receipt of disability support.

This NDDA analytics work program is being delivered under the strategic oversight of the NDDA Council and using a disability-inclusive approach.

To date, there has been limited opportunity to examine the impacts of the NDIS on other systems - for example, where NDIS support has decreased the support otherwise provided through housing, healthcare, or justice. While there is clear value in expanding the dataset to include more systems data and more granular information - such as detailed disability classifications or functional needs - the immediate priority is to make insights into systemic impacts accessible by engaging with and analysing the existing data holdings. A persistent and significant challenge remains around the lack of comprehensive and timely integration across data systems.

Collaborative and disability-inclusive approach

The AIHW conducts its disability work program in collaboration with people with disability and researchers with disability expertise. For example, we are represented on the National Disability Research Partnership Board, have our own Disability Data and Reporting Advisory Group with broad representation and have convened a disability-inclusive research team for our NDDA analytical work. We also have established relationships with the disability research community.

Data improvement

The AIHW functions also include a role in working with others to fill data and reporting gaps through the development of data standards, methods and collections. An example is work we are currently doing to provide data-related advice on how to measure a reduction in use of restrictive practices on people with disability participating in the NDIS. The Department of Health, Disability and Ageing is policy lead for this work, which we are also doing in collaboration with the NDIS Quality and Safeguards Commission and a commonwealth/state/territory working group. This work builds on previous AIHW reporting experience in mental health and aged care settings.

The AIHW also contributes expert data advice to the data improvement plans for both the NDDA and Australia's Disability Strategy Outcomes Framework. We work with stakeholders, including government agencies, to raise awareness of key gaps, for example younger onset dementia, and opportunities for filling these gaps through new data collection, data linkage or better use of existing data.