



Disability data in healthcare: what exists, what is linked, and where the gaps are

Content drawn from Australian Institute of Health and Welfare (AIHW) contributions to the NDRP Evidence to Action event: Let's Talk About Disability Data, 25 May 2026.

Compiled by the National Disability Research Partnership.
For direct enquiries about AIHW data, visit aihw.gov.au

What disability data currently exists in healthcare?

Disability identification

Diagnosis information is available primarily through hospital datasets within the National Health Data Hub (NHDH), including admitted patient and emergency department data.

Proxy identification is also possible using linked datasets such as PBS medication data, though some medications are used for multiple conditions and may not uniquely identify disability.

Health service use and outcomes

Health outcomes and service use can be analysed longitudinally using linked datasets, including:

- Hospital data
- Medicare Benefits Schedule (MBS)
- Pharmaceutical Benefits Scheme (PBS)
- Cancer and mortality datasets

These enable person-centric analysis of care pathways, morbidity and outcomes over time and across health sectors.

Key limitation: reasonable adjustments

There is currently no systematic capture of reasonable adjustments, access needs or disability-specific supports within core health datasets.

Planned improvements

A standardised disability flag is planned for inclusion in the NHDH, subject to the finalisation of governance arrangements. This will significantly improve the ability to consistently identify people with disability across datasets and strengthen population-level analysis.

What linked disability datasets are available and what are their strengths and limitations?

National Disability Insurance Scheme (NDIS)

Strengths:

- Detailed individual-level information on participants, including functional capacity, supports and funding.
- Enables analysis of service use and outcomes when linked to health data.

Limitations:

- Only captures people who apply for and are accepted into the NDIS, limiting population coverage.
- The NDIS commenced in 2017, so longitudinal and outcomes analysis is constrained by the reference period. Prior to the NDIS, disability services were administered by states and territories. That data is not currently included in the NHDH.

Health datasets within the NHDH

Strengths:

- National, longitudinal and person-centred view of health system interactions.
- Enables analysis of health outcomes, service use and care pathways within and across health sectors.

Limitations:

- Disability is not consistently or comprehensively identified.
- Reliance on diagnosis coding or proxies leads to under-identification.
- For information about data in the NHDH, visit [AIHW data and data items](#).

Where are the biggest evidence gaps in disability data?

Population coverage gap

A significant blind spot remains for people with disability who:

- Are not in the NDIS.
- Are not identified through hospital diagnosis coding or other disability indicators captured through administrative data.
- This particularly affects people with mild, episodic or psychosocial disability.

Priority population gaps

- Children and young people.
- People in regional and remote communities.
- People from culturally and linguistically diverse (CALD) backgrounds.
- People with psychosocial disability.

Health system gap

There is currently an absence of data on:

- Reasonable adjustments and accessibility.
- Patient experience and quality of care.
- Barriers to accessing services.

Future improvements

Introduction of the disability flag in the NHDH and inclusion of datasets such as DOMINO will help address some of these gaps, particularly for population identification and cross-sector analysis.

What disability-related data projects are happening in areas such as child protection, health and restrictive practices?

Disability-focused NHDH projects are currently concentrated on NDIS outcomes and health system use, with broader growth expected as disability identification improves and new datasets come online.

There are currently limited or no established linkage projects focused specifically on:

- Disability and child protection systems.
- Disability and restrictive practices at scale.

For more information on AIHW data and current projects, visit [aihw.gov.au](https://www.aihw.gov.au).