



Australian Government



National
Disability
Data
Asset

The National Disability Data Asset Council 2024–2025 Annual Report





Pictured: Professor Paul Harpur OAM speaking at the Community Engagement Workshop in Sydney, July 2024

Contents

Message from the Co-chairs	2
<hr/>	
Introduction	4
Purpose	4
Background	4
The National Disability Data Asset Council	5
2024–25 year at a glance	6
<hr/>	
Advisory Panels	8
Disability-informed Ethical Oversight Panel	8
Disability Indicators Panel	9
Disability Data Development Scoping Panel	9
<hr/>	
Community engagement	11
Community Engagement Workshop	11
New website and logo	12
United Nations Conference of States Parties (COSP) 18 – Official Australian side event	12
<hr/>	
Insights and benefits	14
Disability flags	14
Australian National Data Integration Infrastructure (ANDII)	14
Australia’s Disability Strategy Outcomes Framework reporting	15
Central Analytics	15
Disability project benchmark	15
<hr/>	
Safeguards, access and use	16
Keeping data safe	16
Project requests	17
<hr/>	
Looking ahead	18

***Pictured on cover:** Discussion at the Community Engagement Workshop in Sydney, July 2024. From left to right: Sophie Cusworth, Jeff Smith, Jenny Karavoulous and Paul Harpur*



Pictured above: Co-chairs and attendees at the Council workshop in Sydney, October 2024. From left to right: Luke Mansfield PSM, Jodi Cassar PSM, Kelsie Morley, Rosemary Kayess and Catherine McAlpine

Message from the Co-chairs

We are very pleased to provide the National Disability Data Asset Council's first annual report to Disability Ministers.

The National Disability Data Asset is a key deliverable under [Australia's Disability Strategy 2021–2031](#). It will help us better understand how people with disability experience government policies, services, payments and programs. It will also help understand how this impacts outcomes.

Good progress was made in the 2024-25 financial year on the National Disability Data Asset. This is the first time a linked data project has been inclusively co-governed by the Australian, state and territory governments, together with the disability community.

The National Disability Data Asset Council (Council) was established just prior to the 2024-25 reporting period. It met for the first time in February 2024. In June 2024, Disability Ministers approved the [National Disability Data Asset Charter](#). The Charter lists what the National Disability Data Asset can and cannot be used for.

It also aims to make sure the National Disability Data Asset:

- includes people with disability
- provides benefits to people with disability
- is transparent and accountable
- keeps data safe.

The Council oversees how the Charter is followed. It supports the ethical, inclusive, and safe use of the National Disability Data Asset.

A few highlights of the 2024-25 financial year include:

- the first use of the disability flags for Australia's Disability Strategy Outcomes Framework reporting. The disability flags are community-supported and will help researchers to consistently include people with disability in their work. We will work with disability representatives on new flags for autism, intellectual disability and deafblind disability types next financial year.

- creation of an inclusive research guide for using administrative data. This was written by the Disability-informed Ethical Oversight Panel (Ethical Oversight Panel) to support inclusive, ethical disability research.
- speaking about the National Disability Data Asset at the United Nations (UN) Conference of State Parties (CoSP) in New York, USA. The National Disability Data Asset and the National Disability Research Partnership (NDRP) hosted a panel discussion called Better Disability-Led Data and Research: Empowering Voices, Transforming Policies. It was wonderful to share ideas about disability-led data and research with an international audience.

Further highlights can be found in the '2024-25 Year at a glance' section of this report.

The National Disability Data Asset was the first project to use the Data Availability and Transparency Act 2022 (DAT Act) to share data. Using the DAT Act has been more complex than expected. Authorisation of data linkage and the ability to generate insights have been significantly impacted while legal and other barriers were examined and possible solutions to overcome them were developed. As a result, fewer datasets were linked in 2024-25 than anticipated. Governments are now working together, and with the Council, to settle on an alternative pathway or pathways to deliver disability-informed insights, without relying on the DAT Act. The National Disability Data Asset contributed to a Statutory Review of the DAT Act, and draft findings are available on the [Department of Finance website](#). More information will be available as decisions are taken through the Council communiques.

We want to thank our fellow Council members for their guidance, support and dedication. It's a pleasure to work with them.

We would also like to thank 3 members who stepped down this year. Thank you, Dr Scott Avery, Dr Phillip Gould, and Marion Hailes-MacDonald PSM, for their important work in establishing inclusive co-governance for the National Disability Data Asset.

In the year ending 30 June 2025 the Council set up 3 time-limited advisory panels to support key areas of our work. More information about the panels is in the [advisory panels section](#) of this report and on the [advisory panel page](#) on our website. Thank you to the Chairs and members of the Disability Indicators Panel, Scoping Panel and Ethical Oversight Panel for their valuable contributions.

We would also like to thank:

- our government partners
- Disability Representative Organisations (DROs)
- everyone involved in building and managing the National Disability Data Asset.

Looking ahead, we are committed to a National Disability Data Asset that supports the needs of the disability community. The Disability Royal Commission called for better, more connected data that gives a full picture of people's lives. The National Disability Data Asset aims to fill some of these gaps and improve our understanding of the lives of people with disability.



(Handwritten signature of Luke Mansfield)

Luke Mansfield PSM
Council Co-Chair



(Handwritten signature of Catherine McAlpine)

Catherine McAlpine
Council Co-Chair

Pictured right: Council member Giancarlo de Vera at the Community Engagement Workshop in Sydney, July 2024



Introduction

Purpose

The National Disability Data Asset Charter and the Council Terms of Reference require that the Council provides an annual report to the Disability Reform Ministerial Council. The report must include information on:

- uses and outcomes of the National Disability Data Asset
- whether the rules and principles in the Charter are being followed
- how data is kept safe, and any data breaches.

Once researchers can access and use the data, the report will also include results of an independent assessment of adherence to the Charter.

Background

The National Disability Data Asset is an exciting national project. Governments across Australia are working with people with disability and the wider disability community on the National Disability Data Asset.

The National Disability Data Asset connects de-identified data from different government departments. De-identified data means the data doesn't include personal information, like names. This data helps us understand what life is like for people with disability.

The National Disability Data Asset will help:

- provide a more complete picture of the programs and services people with disability use
- us understand how we can increase opportunities and improve outcomes for people with disability
- governments improve supports and services for people with disability
- improve how we report on outcomes for people with disability under Australia's Disability Strategy 2021-2031.

At the time of publication, the Department of Health, Disability and Ageing (DHDA) is responsible for the National Disability Data Asset. DHDA works closely with the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) as technical leads, and with state and territory governments as partners.

Prior to the July 2025 machinery of government changes, the Department of Social Services (DSS) led the program.

The National Disability Data Asset was tested in 2020 and 2021 in a Pilot phase. This phase looked at the best ways to share, link, and use data. The lessons learned helped shape the design of the National Disability Data Asset.

More background information is available on the [history and progress](#) page of our website.



The National Disability Data Asset Council

The Council was appointed by Disability Ministers in December 2023. The Council is one way the National Disability Data Asset is inclusively co-governed. Inclusive co-governance means that governments and the wider disability community share responsibility and decision-making for the National Disability Data Asset. The Council has 12 members:

- 3 from the Australian government
- 3 from state and territory governments
- 3 non-government experts in disability and/or data
- 3 disability community members.

The Council reports to the Disability Reform Ministerial Council (DRMC). Its purpose is to make sure the National Disability Data Asset is used appropriately. This means making sure the data is only used for purposes that meet community expectations, as set out in the Charter.

The Charter is a document with rules and principles about how the National Disability Data Asset should be used. Anyone who uses data for a National Disability Data Asset purpose must follow the Charter.

DRMC agreed to the Council's Terms of Reference and Charter in June 2024.

In the 2024-2025 financial year, the Council held 6 meetings, and 2 workshops. The workshops focused on community engagement, and our strategic vision. The 'Year at a Glance' section of this report highlights some key decisions and milestones for the Council and the National Disability Data Asset.

In early 2025, the Council developed a Strategic Vision and mission statements for the National Disability Data Asset. These key documents will be published on our website including accessible formats, after consideration by DRMC. The Strategic Vision captures the Council's shared ambition, to build a national asset that:

- empowers people with disability
- supports inclusive policy
- delivers better outcomes through trusted data.

Council members as of 30 June 2025

- Catherine McAlpine, Community co-chair
- Luke Mansfield PSM, Government co-chair
- Associate Professor Sheelagh Daniels-Mayes, community member
- Giancarlo de Vera, community member
- Professor Bruce Bonyhady OAM, expert member
- Rosemary Kayess, Disability Discrimination Commissioner, expert member
- Professor Julian Trollor, expert member
- Gemma Van Halderen PSM, Australian Government member
- Duncan Young, Australian Government Member
- Zoe Dendle, state and territory government member (New South Wales)

- Mark Kingston, state and territory government member (Western Australia)
- Carley Northcott, state and territory government member (Victoria)

Past members

- Dr Scott Avery, former community member
- Dr Phillip Gould, former Australian Government member
- Marion Hailes-MacDonald, former state government member (Western Australia)

More information about the Charter, Council, and panels can be found on the [how we work](#) section of our website.



2024–25 year at a glance



February 2025

- Two Council meetings held

Council agrees to:

- Strategic Vision and mission
- Improvement plan for the Disability flags
- Central analytics forward work plan
- 2025 Community Engagement Plan
- Principles for addition of new data
- the next 2 panels focusing on employment, and children and young people

April 2025

- Implementation report for the 2023 Privacy Impact Assessment published on website

May 2025

- Council meeting held
- Ethical Oversight Panel reviewed the first 2 project applications
- Delivery of 4 datasets to the National Disability Data Asset

Council agrees to:

- Extend the term of current Ethical Oversight Panel members to end 2025

June 2025

- National Disability Data Asset and NDRP present the Australian Government side event at the UN Conference of State Parties in New York.



Pictured left:
Attendees at
the Community
Engagement
Workshop in Sydney,
July 2024. Left to right:
Matt – Luke’s support
person, Luke Nelson,
Dr Scott Avery and
Jeff Smith (back to
camera)

Advisory panels

The Council set up 3 time-limited advisory panels. The work of the panels has helped the Council make key decisions.

The 3 panels were:

1. Disability Indicators Panel
2. Disability Data Development Scoping Panel
3. Disability-informed Ethical Oversight Panel

The Pilot Disability Advisory Council suggested setting up panels. DROs provided advice on the first three panels. This included the characteristics of who should be on the panels and what skills they should have. DROs also helped DSS with the recruitment of panel members.

DSS provided Secretariat support for all panels.

Disability-informed Ethical Oversight Panel

Chair: Dr Lisa Stafford (pictured right)

The Disability-informed Ethical Oversight Panel (Ethical Oversight Panel) first met in September 2024. It has five non-government members with expertise in disability and data, who are connected to the disability community.

The key role of this Panel is to review, from a disability-informed perspective, each research proposal that seeks to access data from the National Disability Data Asset.

The Panel will only recommend projects that are not likely to cause harm to people with disability. In providing its recommendations to researchers, the Panel can help improve the inclusive research skills of researchers.

The Panel will also develop a framework to guide the ongoing, consistent assessment of research projects that seek to use data from the National Disability Data Asset.

The Panel wrote a guide to support researchers to make sure the research they do is ethical, relevant, and inclusive. The guide outlines the 3 main principles for inclusive research:

1. disability-specific considerations
2. trauma-informed research
3. intersectionality.

It explains how to plan, do, and share research using the data. It talks about:

- different ways to think about disability
- understanding trauma
- using co-design during the whole research process.

The guide will be updated over time. The panel has already assessed the first requests to use the data and provided its recommendations.



Disability Indicators Panel

Chair: Peter Tully (pictured right)

The Disability Indicators Panel (Indicators Panel) first met in April 2024. It operated until February 2025. It had 5 members including community members, a disability researcher and a human rights expert.

The Indicators Panel's role was to support the development of the first set of disability flags (previously called disability indicators). It provided advice on how researchers should communicate about the flags. It also provided feedback on the plan for improving the flags.

More information about the disability flags is in the [insights and benefits section](#) of this report, below, and on the [insights page](#) of our website.



Disability Data Development Scoping Panel

Chair: Clare Gibellini (pictured right)

The Disability Data Development Scoping Panel (Scoping Panel) first met in June 2024. It operated until October 2024. It had 10 members: 6 disability representatives and 4 disability researchers. The Panel's role was to report to the Council on priority data and knowledge gaps that future advisory panels could progress.

The Scoping Panel recommended that all future data development panels for the National Disability Data Asset must consider how intersectionality affects people with disability.

The future panels must also consider digital accessibility issues for people with disability.

The Scoping Panel recommended setting up 8 panels in the future to improve data about:

- the impact of intersectionality
- the Deafblind community
- children and young people with disability
- employment and income support
- accessible and affordable housing
- education and disability
- neurodivergent people
- people with intellectual disability

The future panels would advise the Council on:

- how good the data is
- where data is missing
- which datasets could be added to the National Disability Data Asset



The Council agreed to prioritise creation of 2 new advisory panels based on the Scoping Panel's advice. These are:

- Children and young people with disability
- Employment issues for people with disability.

These panels will be set up when there is more data on employment and children available.

The Council also used the Scoping Panel's advice to plan the next set of disability flags. The next set of flags for consultation are on intellectual disability, deafblind and Autism.

A plain language summary of the Scoping Panel's report is available on the website. The summary is also available in Easy Read and Auslan formats.

Additional information about all the panels is available on the [advisory panels](#) page of our website.



Community engagement

The National Disability Data Asset Charter says that people with disability and the wider disability community will help decide:

- how the National Disability Data Asset is used
- what information is collected
- outcomes the National Disability Data Asset should aim for.

In 2024-2025, the disability community was involved in key parts of the project through the Council and advisory panels. The Council made plans based on community feedback to connect with people with disability about:

- what the National Disability Data Asset is
- why it is important.

We also wanted to ask people with disability and the wider disability community what they want to know from the data. We are waiting to do this until there is more data in the National Disability Data Asset. Our plans were also delayed due to the issues we encountered with linking and sharing data, as mentioned in the Co-chairs' message. In 2024-25 we also launched a new website and brand, and took a leading role in the Australian side event at the United Nations Conference of States Parties (COSP).



Pictured above: Attendees at the Community Engagement Workshop in Sydney, July 2024

Community Engagement Workshop

In July 2024, Council members held a workshop in Sydney. They talked about how to better connect with people with disability.

They invited guests who are closely involved with DROs or work in disability research.

The workshop helped shape the Council's engagement plans for 2024 and 2025. The main goal of both plans was to help more people understand the National Disability Data Asset.

The plans focus on reaching:

- people with disability
- the wider disability community
- people involved in disability research.

New website and logo

In December 2024 we launched the updated [National Disability Data Asset website](#). The website is now more accessible and inclusive.

In September 2024, the National Disability Data Asset also got a new logo and branding. The logo has links and circles to represent people, communities, and linking data.

The logo and branding meet WCAG 2.2 standards for readability and colour contrast. They were both developed with input from people with disability and the wider disability community.



Pictured above: NDDA Logo, updated December 2024

United Nations Conference of States Parties (COSP) 18 – Official Australian side event

We co-hosted a talk with the National Disability Research Partnership (NDRP) at COSP 18. The topic was research and data led by people with disability.

The talk was called *Building Better Disability-Led Data and Research: Empowering Voices, Transforming Policies*.



Photo caption, above: Panellists at the United Nations COSP 18 – Official Australian side event. From left to right: Jutta Treviranus, Clare Gibellini, Robyn Shannon, Mary Sayers, Hope Peisley, Catherine McAlpine, Luke Nelson

The panel members were:

- Robyn Shannon, DHDA (then DSS)
- Hope Peisley, DHDA (then DSS)
- Clare Gibellini, Chair, NDRP Board
- Mary Sayers, CEO, NDRP
- Catherine McAlpine, Community co-chair, National Disability Data Asset and CEO, Inclusion Australia
- Luke Nelson, Inclusion Australia
- Jutta Treviranus, Director and Professor, Inclusive Design Research Centre, OCAD University, Canada

Council co-chair Catherine McAlpine was part of a panel with Mary Sayers and Clare Gibellini from the NDRP. Jutta Treviranus from OCAD University in Canada also spoke. Luke Nelson from Inclusion Australia led the conversation.

The panel discussed:

- building knowledge through research led by people with disability
- using ethical and high-quality data, along with community input
- creating better policies, practices, and systems that include everyone

You can watch the event on the [United Nations website](#).



Pictured below: United Nations COSP 18 panel and attendees



Insights and benefits

The National Disability Data Asset plans to deliver three main benefits to the public. These are:

1. building stronger evidence to help improve laws, policies, and services for people with disability
2. improving data quality and quantity, and access to data about people with disability
3. building better systems for sharing data between governments.

These benefits are being delivered by:

- the development of disability flags
- creating the Australian National Data Integration Infrastructure (ANDII)
- Australia's Disability Strategy Outcomes Framework reporting.

The central analytics work program, and the benchmarking process ([see below](#)) will lead to future benefits and insights.

Disability flags

The National Disability Data Asset includes disability flags. Disability flags are community supported ways of measuring disability. These flags were previously called disability indicators. The Council agreed to the first set of flags in July 2024. People with disability and their representatives, and experts in disability data, designed the flags together. The Council has agreed to an Improvement Plan for the flags. The Improvement Plan aims to expand how people with disability are included and described in the National Disability Data Asset.

The next set of flags that are being worked on are about 3 disability types:

- Autism
- intellectual disability
- deafblind.

Australian National Data Integration Infrastructure (ANDII)

The National Disability Data Asset has tried to make it easier to safely share and link data from different places. This is through:

- data sharing agreements
- common linkage approaches
- the ANDII technology solution.

This has allowed the National Disability Data Asset to link Commonwealth and state datasets for analysis of disability outcomes. More information about the ANDII is in the [security section](#) below.



Pictured above: Attendees at the Community Engagement Workshop in Sydney, July 2024

Australia's Disability Strategy Outcomes Framework reporting

The flags have been used to help report on Australia's Disability Strategy Outcomes Framework (Outcomes Framework). They have been used for three measures:

- [potentially avoidable deaths](#)
- [GP-type emergency presentations](#)
- [involuntary hospital admissions](#).

More than one third of measures in the Outcomes Framework could potentially be improved using the National Disability Data Asset.

Central analytics

The Council agreed to a workplan for the National Disability Data Asset Central Analytics team. This team includes researchers from the ABS and AIHW that are supported by people with disability and experts. The workplan includes:

- reporting for the Outcomes Framework
- improving disability flags
- research on health care, death rates, and hospital stays.

Disability project benchmark

The [Charter](#) states that 1 in 5 projects in every 2-year period will be sponsored by organisation/s that represent people with disability.

At 30 June 2025, the ABS has received 7 project requests for the National Disability Data Asset. More information is in the Project requests section of this report. Reports will be provided to the Council on approved projects so they can monitor how many projects are led by people with disability or their organisations.

Safeguards, access and use

Safeguarding data and protecting privacy is a priority for the National Disability Data Asset. A range of safeguards are in place to ensure the National Disability Data Asset is used to help improve outcomes for people with disability.

Keeping data safe

Privacy

In 2023, privacy experts looked at how the National Disability Data Asset and ANDII protects people's privacy. This is called a Privacy Impact Assessment (PIA).

On 24 April 2025, the [PIA Implementation report](#) was published on the website. The report explains how the 6 privacy recommendations from the 2023 PIA were addressed.

The Council also agreed on a set of principles to help decide which datasets should be included in the National Disability Data Asset. [The principles](#) were published on the website in mid-2025.

Before adding new data to the National Disability Data Asset, the ABS checks for privacy impacts. In 2024, the ABS reviewed the re-use of ABS Person Level Integrated Data Asset (PLIDA) data in the National Disability Data Asset. This included re-use of data from the ABS Survey of Disability, Ageing and Carers (SDAC).

The re-use of PLIDA data for the National Disability Data Asset was also included in the update of the 2025 PLIDA Privacy Impact Assessment. A summary of the update is on the Privacy Impact Assessment register on the ABS website.

Security

The ANDII technology solution is used to bring data together and store it safely. It also helps make sure information that could identify people is not included in the National Disability Data Asset.

The ANDII technology solution follows rules from:

- the Protective Security Policy Framework
- the Information Security Manual

An independent professional from the Infosec Registered Assessors Program (IRAP) checked the ANDII technology solution and our security practices

IRAP is a detailed security assessment. The IRAP assessment looked at the processes we use, how suitable they are and how well they work. The IRAP assessment also looked at how well we follow the Information Security Manual. The results help us keep the National Disability Data Asset very secure.

In 2024-25, there were no data breaches, and no data compromised. The ABS is always working to maintain and improve data security in the system.

More information on privacy and security can be found on the on the [keeping data safe](#) page of our website.



Project requests

Researchers could apply for access from 19 December 2024.

In 2024-25, researchers made 7 project requests:

- 5 from Australian universities
- 2 from the Australian Government.

Researchers worked to add details to their requests for review and approval.

There were no project requests from organisations that represent people with disability. There were no approved or refused project requests at the end of the 2024-25 financial year. Information about approved projects will be available on the website.

Pictured below: Council members at the Council Workshop in Sydney, October 2024.
From left to right: Gemma Van Halderen PSM, Professor Julian Trollor and Kayla Jordan (proxy for Duncan Young)



Looking ahead

Governments are working hard to address issues around sharing data for linkage and making data available to researchers. The Council will support all efforts to deliver meaningful insights for the disability community. The Council and Ethical Oversight Panel aim to reduce the potential for harm to people with disability that can be caused through research and analysis.

In the coming year the Council will oversee:

- improvement of the disability flags, including engagement with DROs
- publication of the Strategic vision and mission, once endorsed by Disability Ministers
- publication of the guide produced by the Ethical Oversight Panel: Towards more inclusive research: a guide to inclusive disability research using administrative data (the guide)
- work with governments and academia to promote the principles in the inclusive research guide
- an independent audit of program adherence to the Charter
- working with the disability community to progress the disability benchmark in the Charter
- development of a Disability-informed Ethical Oversight Framework for assessing applications to use data for a National Disability Data Asset purpose.



Pictured above: Attendees at the Council Workshop in Sydney, October 2024. From left to right: Rosemary Kayess, Catherine McAlpine, Luke Mansfield PSM, Jodi Cassar PSM, Giancarlo de Vera, Clare Gibellini, Professor Bruce Bonyhady OAM, Peter Tully, Frances Foster-Thorpe, Kayla Jordan and Professor Julian Trollor