

Privacy Statement

National Disability Data Asset and Australian National Data Integration Infrastructure

Descriptive Transcript

Purpose

<u>Visual description</u>: On the top right side of the screen, there is a logo with two red, two green and two blue lines connected at a central point. The words 'National Disability Data Asset' are to the right of the logo.

On the left of the screen, text appears against a purple background. The text says 'Purpose'.

An Auslan interpreter dressed in black appears on the screen and starts signing.

The interpreter continues to sign on the centre of the screen and the logo is shown at the top right throughout the entire video.

<u>Audio transcript</u>: This statement gives an overview of how government agencies share information to create the National Disability Data Asset and how the data will be used.

This privacy statement outlines:

- the laws that apply to sharing and use of your data.
- how government agencies ensure your personal information is safely used for the disability data asset.
- how government agencies keep your information secure.
- when government agencies keep and destroy your information.
- information on our privacy practices.

The disability data asset uses de-identified data from different government agencies about people including those who have used government-funded services or participated in selected government surveys.

The disability data asset includes information relating to employment, income, health, education and other support services, among other key markers.

This will help build understanding of the experiences of people in order to better support people with disability, their carers, and the community.

Authorised people from government will access some personal information to combine data. Approved government or university researchers will only access de-identified analytical data.

Data used for analysis has been de-identified using a de-identification policy developed by the Australian Bureau of Statistics.





The Department of Social Services, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare, and states and territories have worked together to create the disability data asset and its underlying infrastructure. The disability community has also been involved in creating the asset and deciding how it can be used.

Key terms in this statement

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'Key terms in this statement'.

The Auslan interpreter re-appears on the screen and restarts signing.

<u>Audio transcript</u>: Accredited means that an Australian, state and territory government agency or Australian university has been approved to collect, use and protect data. This approval has been provided by the Minister responsible for administering the <u>Data</u>

<u>Availability and Transparency Act 2022</u> or the National Data Commissioner. All organisations that use the National Disability Data Asset must be accredited.

Australian National Data Integration Infrastructure (or the underlying infrastructure) is the technical system and governance that supports the disability data asset.

De-identified data is information about people, but the identity of the people is not known, and the risk of re-identification is very low.

Personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable whether the information or opinion is true or not and is recorded in a material form or not. Examples include:

- a person's name, address, date of birth
- government identifiers (such as a Medicare number).

The laws that apply to sharing and use of your data

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'The laws that apply to sharing and use of your data'.

The Auslan interpreter re-appears on the screen and restarts signing.

<u>Audio transcript</u>: A range of government agencies hold your personal information to support their functions and activities, such as employment, health, education and support services.

These government agencies share your personal information for the National Disability Data Asset under the scheme established for the Data Availability and Transparency Act 2022, the DATA Scheme, and other relevant legislation. (Note: Personal information is used for linkage. Data is de-identified before it is included in the National Disability Data Asset).





The DATA Scheme allows data sharing with the right protections and accreditation.

The Data Availability and Transparency Act 2022 works alongside other existing laws and agreements, including state and territory laws and data sharing agreements, to allow data sharing.

A small number of government agencies are approved as Accredited Data Service Providers under the DATA Scheme and can provide data services, such as linking different data together, for the disability data asset and underlying infrastructure.

These government agencies apply protections in line with the <u>Privacy Act 1988</u> (Cth), including the <u>Australian Privacy Principles</u>, and other relevant privacy legislation, when using your personal information for the disability data asset.

If there is a breach of your personal information which is likely to result in serious harm to a person, the Australian Bureau of Statistics or the government agency who provided the data to the Australian Bureau of Statistics must notify affected individuals, the Australian Information Commissioner, the National Data Commissioner and other relevant parties.

If an individual or organisation does not follow the agreed acceptable uses of the disability data asset or underlying infrastructure, they may be subject to sanctions or penalties.

Sanctions may include warnings and removal of access.

Penalties under the Data Availability and Transparency Act 2022 may include a fine of up to \$187,800 or imprisonment for up to 5 years, or both.

How government agencies ensure your personal information is safely used

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'How government agencies ensure your personal information is safely used'.

The Auslan interpreter re-appears on the screen and restarts signing.

<u>Audio transcript</u>: A small number of government agencies that are accredited under the DATA Scheme as Accredited Data Service Providers use your personal information for the purpose of combining data together for the National Disability Data Asset. (Note: Data in the National Disability Data Asset is de-identified).

Many protections work together to keep data safe and secure.

These agencies use the <u>separation principle</u> to protect data in the disability data asset. This means that they keep personal information like names and addresses separate from analytical data, such as employment status.





No one working with the data can see or use both personal and analytical information at the same time. When an Accredited Data Service Provider receives data, they de-identify the data using a de-identification policy developed by the Australian Bureau of Statistics.

A range of techniques are used including removing identifiers (such as name, address, and date of birth) from the rest of your personal information.

Once the data is de-identified, your identity is no longer known and the other data is no longer considered personal information.

Before data in the disability data asset can be used, the research project needs approval by an authorised Australian Bureau of Statistics officer.

This officer will make sure the data is only used in line with the <u>National Disability Data Asset</u> <u>Charter</u>, data provider agreements and other project requirements (including ethical oversight).

The National Disability Data Asset Charter defines the principles and 'acceptable uses' of the disability data asset.

The Charter lists things the data cannot be used for or 'unacceptable uses'. For example, the disability data asset cannot be used for law enforcement purposes.

The <u>National Disability Data Asset Council</u>, which includes members from the disability community, will make sure the disability data asset is only used for the things that governments and the disability community have agreed to and in line with the Charter.

After a project has been approved, access will be provided to the minimum data that researchers need to achieve their project's goals.

Access is provided in line with the Australian Government Data Sharing Principles and guidance from the National Data Commissioner. The Australian Bureau of Statistics only allows approved researchers to access the disability data asset.

Researchers must belong to an Australian, state and territory government agency or Australian university, and be accredited under the DATA Scheme. Other organisations, such as foreign organisations, cannot be accredited.

An approved researcher can request that the results of their analysis are made available outside of the underlying infrastructure.

The Australian Bureau of Statistics and Australian Institute of Health and Welfare check all outputs for risk of re-identification prior to release from the underlying infrastructure.





Only aggregate, de-identified data that can't identify people will be approved as vetted outputs that can leave the secure environment.

Other measures to ensure information is used safely include:

- training of all people involved with the data around their responsibilities to keep data safe
- monitoring and auditing of activities involving use of the data.

How government agencies keep your information secure

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'How government agencies keep your information'.

The Auslan interpreter re-appears on the screen and restarts signing.

<u>Audio transcript</u>: The Australian Bureau of Statistics securely stores information for the National Disability Data Asset in the underlying infrastructure.

The Australian Bureau of Statistics developed this secure computer system to comply with the Protective Security Policy Framework and the Information Security Manual.

An <u>Infosec Registered Assessors Program (IRAP)</u> professional reviewed the system to ensure it is secure. An IRAP is an Australian Signals Directorate initiative to provide an independent assessment of the implementation, appropriateness and effectiveness of a system's security controls.

An accredited government agency could store information in approved computer systems when working on a project. Those systems must be approved by the Australian Bureau of Statistics and Australian Institute of Health and Welfare as safe to link or analyse the data.

Detailed data (including personal information and de-identified analytical data) must be stored, provided and used only within Australia.

When government agencies keep and destroy your information

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'When government agencies keep and destroy your information'.

The Auslan interpreter re-appears on the screen and restarts signing.

<u>Audio transcript</u>: In line with the Australian Privacy Principles and data sharing agreements, government agencies will destroy or delete your personal information when it is no longer required.

This aims to protect personal information by ensuring data is only retained while there is a need to do so.





Information in the National Disability Data Asset will be retained as long there is a legislative requirement, consistent with data sharing agreements.

Where the personal information is also a Commonwealth record, government agencies will follow the data retention requirements in the *Archives Act 1983*.

Information on our privacy practices

<u>Visual description</u>: On the left of the screen, text appears against a purple background. The text says 'Information on our privacy practices'.

The Auslan interpreter re-appears on the screen and restarts signing.

Audio transcript:

Accessing, changing or removing your information

The National Disability Data Asset uses information from multiple Australian, state and territory government agencies.

You will not be able to access, change or remove information about yourself from the disability data asset.

The Australian Bureau of Statistics and Australian Institute of Health and Welfare cannot remove information in the disability data asset because the data is de-identified and your identity is no longer known.

Making a privacy complaint

To make a complaint about how data is used in the disability data asset, you can contact the Australian Bureau of Statistics Privacy Officer by emailing privacy@abs.gov.au.

You can send complaints by mail to:

Privacy Officer
Privacy Section
Australian Bureau of Statistics
Locked Bag 10
Belconnen ACT 2617

If you are not happy with how the Privacy Officer handles your complaint, you can refer your complaint to the Office of the Australian Information Commissioner.





Accessible versions of the privacy statement

This privacy statement is available in Easy Read and as an Auslan video on the disability data asset website <u>Privacy for the National Disability Data Asset</u>.

If you would like this information in another format, such as braille or hard copy, please contact ndda@abs.gov.au.

Learn more

You can find more information about the disability data asset at www.ndda.gov.au.

You can also email questions about the privacy of the disability data asset to ndda@abs.gov.au.