



The National Disability Data Asset Draft Charter

The Australian, state and territory governments are working together to create the National Disability Data Asset. The disability data asset will bring together de-identified information from different government agencies about people with disability.

This will help us to better understand the experiences of people with disability. The disability data asset will give people with disability better information. It will also help governments to make decisions about their programs and services to better support people with disability, their carers and families.

The disability data asset went through 2 years of development and testing called the Pilot. A disability advisory council guided the Pilot. They also created a **draft** of the Charter. The Charter will make sure the disability community knows how their data is being used and are comfortable with how it is being used.



What will the Charter do?

The Charter includes principles and rules for the disability data asset. There are 8 principles. The principles explain how we will manage the data asset. The rules list what the data asset can be used for and what it can't. These will protect the information and how the information is used. We discussed the principles and rules with people with disability during the Pilot.

We will finalise the Charter after consulting with representatives from the disability community. We will then give it to disability ministers for approval. All researchers, including government researchers, will need to follow the principles and rules in the Charter. The National Disability Data Asset Council and disability ministers must agree to any changes to the Charter. These changes will then need to be tested and agreed with the disability community before governments agree.

The principles recommended in the draft Charter

1. Including and empowering people with disability

The disability community will help decide how the disability data asset can be used. Research projects should include people with disability, their carers and family members.

2. Transparency

Information about the disability data asset should be shared and accessible. This includes sharing research findings and sharing any decisions that we make about how the data can be used.

3. Accountability

There will be processes in place to check that data can only be used for approved reasons. There will be independent checks to make sure researchers are following the principles in the Charter.

4. Privacy and security of data

We will keep all information safe and will maintain people's privacy. The disability data asset will meet all privacy and legal requirements. We will de-identify all the data in the disability data asset. This means no one will be able to find out who people are or contact them.

5. Conditions of access

Data will be protected under the *Privacy Act 1988* and *Data Availability and Transparency Act 2022*. If someone doesn't meet legal requirements under either of these acts, they will face penalties. We will only give people access to data under strict conditions. If they don't meet these conditions, we will take away their access.

6. Public sharing of findings

All research projects that use the disability data asset must make some of their findings available to the public.

7. Creating lasting benefits for all people with disability

The disability data asset will be fair and focus on improving outcomes for all people with disability. It will also focus on improving outcomes for groups of people with disability with different needs.

The asset will create more evidence for decisions to support people with disability.

8. Access, testing findings and data improvement

We will give secure access to researchers as quickly as possible for approved research projects. Data will be made available to test research and government findings. Governments will work together to improve data quality and share information about how they have learned from the disability data asset.





What the asset can't be used for

The **draft** Charter recommends that the disability data asset **is not** used to:



identify people



make a decision about an individual's access to government funding



do anything that goes against human rights laws



do anything that goes against privacy laws



support automatic decision-making tools – this is when a computerised process helps or replaces a human decision-maker



decide how much funding the Australian, state and territory governments will share with one another.

The rules

What the asset can be used for

The **draft** Charter recommends that the disability data asset **is** used to:

- improve understanding of the experiences of people with disability, their carers and families
- improve government policy
- help make decisions about disability services
- carry out research in an ethical way
- evaluate programs that support people with disability
- improve outcomes for people with disability
- understand Australia's progress to meet international disability standards
- support people with disability to understand the benefits of different services
- help people with disability when they deal with governments and providers
- support people with disability being included by sharing information about their experiences and outcomes.



You can find more information about the National Disability Data Asset at <https://ndda.gov.au> or by emailing NDDA@dss.gov.au.