

National
Disability
Data Asset



National Disability Data Asset

Important ideas and rules we want to follow

An Easy Read summary



How to use this summary



The Australian Government Department of Social Services (DSS) wrote this summary for the National Disability Data Asset team.

When you see the word 'we', it means DSS.



We wrote this summary in an easy to read way.

We use pictures to explain some ideas.

Bold

We wrote some important words in **bold**.

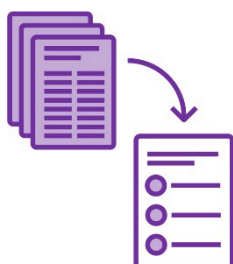
Not bold

This means the letters are thicker and darker.



We explain what these bold words mean.

There is a list of these words on page 21.



This is an Easy Read summary of another document.

This means it only includes the most important ideas.



You can ask for help to read this summary.

A friend, family member or support person may be able to help you.

What's in this summary?

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What is the National Disability Data Asset?



The National Disability Data Asset is a new way to link **data** about people with disability.

In this summary we call it the data asset.



When we talk about data, we mean:

- facts
- information
- records.



The data asset will get data about people with disability from different parts of the government.

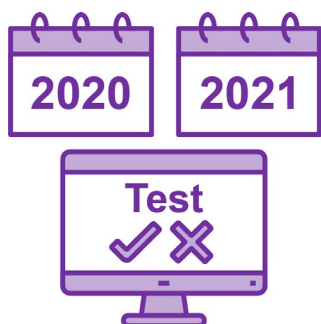


It will help us better understand the experiences of people with disability.



It will also give us more information about programs and services.

What is this summary about?



We spent 2 years testing how the data asset would work.



During this time, a group of people gave us advice about how to make things better.



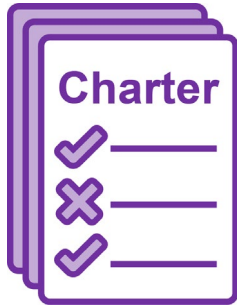
Their advice was about how the data asset should work.



They said we should create a group called the National Disability Data Asset Council.

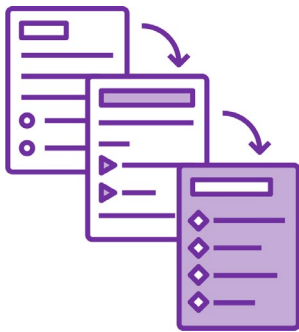
We call them the Council.

They said the Council should make sure people are using the data asset in the right way.



The advice also included rules everyone should follow.

They included these rules in a document we call the **draft** Charter.



A draft is a document that is not finished.

Some things in a draft might change later.

Other people check a draft before they publish it.

The draft Charter is about how the government will work with the disability community to:



- manage the data asset



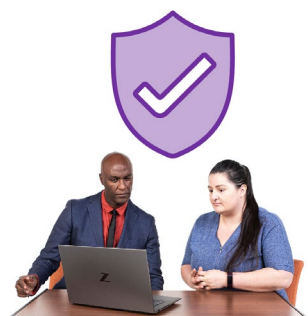
- protect information about people with disability.

How will the draft Charter work?



The draft Charter includes rules about what people can use the data asset for.

And what they can't use it for.



These rules will protect:

- who can find and use the data
- how they can use the data.

We explain what the rules are on page 16.



The draft Charter also includes 8 **principles**.

Principles are important ideas we always want to think about.



The principles explain how to manage the data asset.

What principles are in the draft Charter?

1



1. It's important to:

- include people with disability
- support people with disability to be part of decisions that affect them.



The disability community should help to decide how people use the data asset.



When people do research, they should include:

- people with disability
- their families and carers.



2. It's important to:

- share what people find
- let everyone see how things work.



People should share information they find with the community.



And the information should be **accessible**.

When information is accessible, it is easy to:

- find and use
- understand.



3. It's important to be responsible for how people use the data asset.



This includes having ways to check that everyone only uses the data asset for the right reasons.

This includes:



- researchers



- governments.



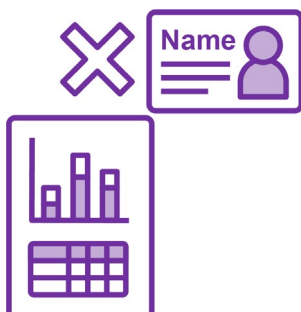
And there should be people who don't work for the data asset who check that people follow these principles.



4. It's important to keep data private and safe.



This includes following all the laws about keeping information safe and private.



We will take people's information out of the data, like their name.



This means no one will know who the data is about.



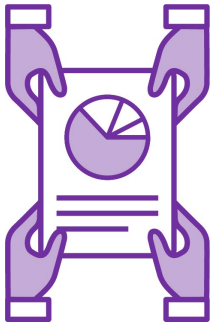
5. It's important to control who can use the data asset.



This will make sure people only use the data for the right reasons.



And if they don't, then we can stop them from using the data asset.



6. It's important to share what the research finds.



All research projects that use the data asset must share key parts of what they find with the community.



7. It's important to make a difference for all people with disability.



The data asset will be fair.



And it will focus on making **outcomes** better for all people with disability.

Outcomes are important results we want for people with disability.



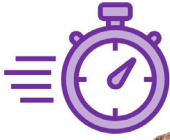
The data asset will also focus on outcomes for certain groups of people with disability.



And it will create more **evidence** for decisions to support people with disability.

Evidence is proof that something is true.

8. It's important to make sure:



- people can find and use the data quickly



- people can use the data to test what they find



- the data is good quality.



We will make sure people can find and use the data quickly once they are allowed to.



Governments will work together to:

- make sure the data is good quality
- share how they learn from the data asset.

What rules are in the draft Charter?

What can people use the data asset for?



People should use the data to understand the experiences of:

- people with disability
- their families and carers.

They should use it to help make:



- government plans and projects better



- decisions about disability services.



They should use the data to do their research in an **ethical** way.

When you are ethical, you think about how research affects people.

People should only use the data to:



- check how well programs support people with disability



- improve outcomes for people with disability.



They should use the data to check how well Australia is meeting international rules about **human rights**.



Human rights are rules about how everyone can expect people to treat them.



They should use the data to help people with disability understand how different services can help them.



And to support people with disability when they deal with:

- governments
- organisations that deliver services.



People should also use the data to support people with disability to take part in research.



They can do this by sharing information about their:

- experiences



- outcomes.

What can't people use the data asset for?



No one will be able to use the data to work out who people are.



People won't be able to use the data to do anything against the law.

This includes laws about:

- privacy
- human rights.



They won't be able to use the data to make decisions about a person's government **funding**.

Funding is money to pay for supports and services.

For example, NDIS funding.



People won't be able to use the data to support computers to make decisions about funding instead of people.



They also won't be able to use it to decide how much funding governments share with each other.

What happens next?



We will work with people from the disability community to make sure the draft Charter will work well.



Then we will give the draft Charter to the disability **ministers** to agree to.



A minister leads an area of government.



If we need to change the Charter, we need to test it with the disability community.



Then the Council and disability ministers need to agree to what we change.

Word list

This list explains what the **bold** words in this document mean.



Accessible

When information is accessible, it is easy to:

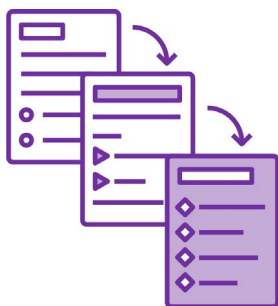
- find and use
- understand.



Data

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- records.



Draft

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Ethical

When you are ethical, you think about how research affects people.



Evidence

Evidence is proof something is true.



Funding

Funding is money to pay for supports and services.



Human rights

Human rights are rules about how everyone can expect people to treat them.





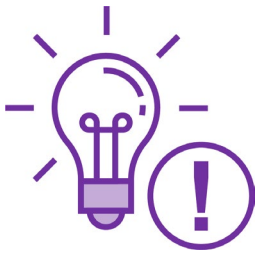
Minister

A minister leads an area of government.



Outcomes

Outcomes are important results we want for people with disability.



Principles

Principles are important ideas we always want to think about.

Contact us



If you want to find out more about the National Disability Data Asset, you can contact us.



You can visit our website.

www.ndda.gov.au



You can send us an email.

NDDA@dss.gov.au



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