‘No data about us, without us’

What the community thinks about the National Disability Data Asset

Easy Read report

October 2022

THE UNIVERSITY OF SYDNEY

Sydney Policy Lab

How to use this report

The Sydney Policy Lab is a team of researchers from the University of Sydney.

The Sydney Policy Lab wrote this report for the National Disability Data Asset Team. When you see the word 'we', it means the Sydney Policy Lab.

We wrote this report in an easy to read way.

We use pictures to explain some ideas.

Bold

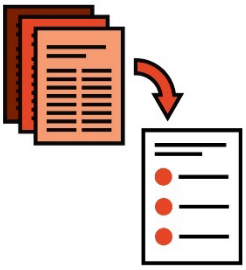
Not bold

We have written some words in **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 48.



This Easy Read report is a summary of another report.

This means it only includes the most important ideas.

You can ask for help to read this report.

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

We recognise First Nations people as the traditional owners of our land – Australia.

They were the first people to live on and use the:

- land

- waters.

What's in this report?

What is the National Disability Data Asset (NDDA)?

The National Disability Data Asset (NDDA) will be a new way to link **data** about people with disability.

When we talk about data, we mean:

- facts

- information

- records.

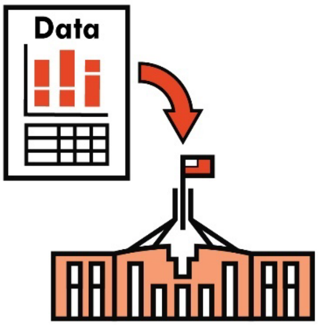
The NDDA will get the data from:

- different parts of the government

- surveys.

The NDDA will also get data from organisations that:

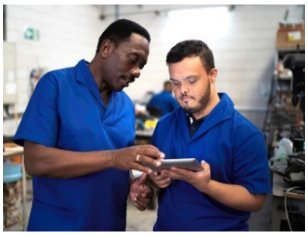
- work with people with disability



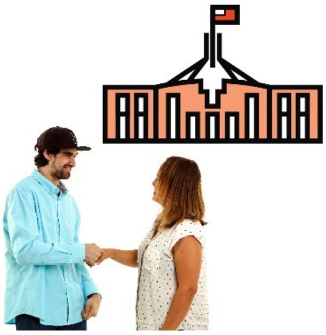
- give data to the government.

The NDDA will include data about people’s lives, such as:

- school and learning



- their work and how they earn money



- what support they get from the government

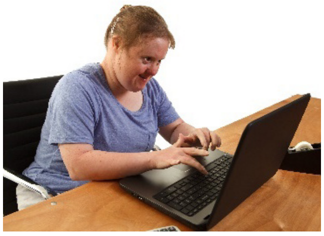
- health care.

The NDDA will help us understand the **outcomes** for people with disability.

Outcomes are the important results we want to get for people with disability.

Why do we need the NDDA?

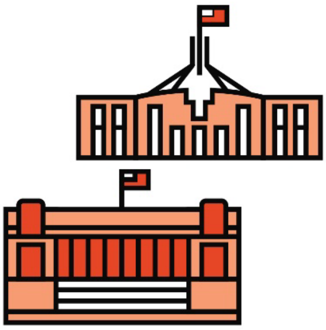
Good data can make it easier for people with disability to:



- find and use services

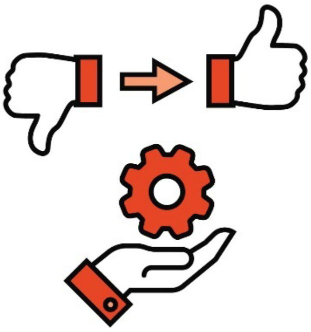
- speak up for what they need.

Good data can also help:



- governments

- **providers** – organisations that deliver a service.



If governments and providers get good data, they can make their services better.

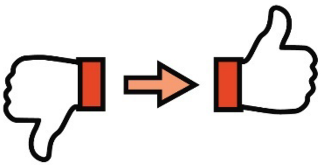
This can help them meet the needs of people with disability.

The NDDA is one way to show everyone if people with disability are getting the services and supports they need.

What is this guide about?

The NDDA team are testing the NDDA to find out what:

- works well

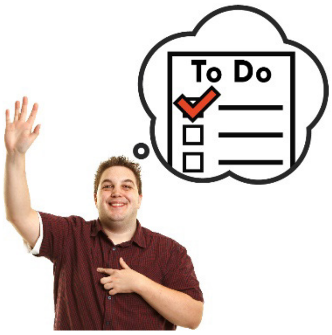


- needs to be better.

A big part of this is making sure the NDDA works well for people with disability.

The NDDA team wanted to make sure people with disability took part in their tests.

They asked us to talk to people with disability to find out:

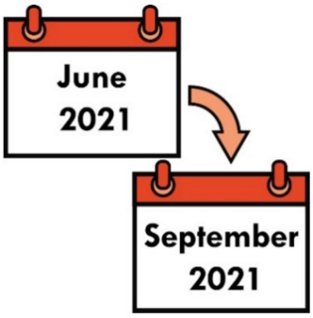


- what they want the NDDA to do

- what they are worried about

- how to fix these problems.

What research did we do?



We did our research between June and September 2021.

40 disability experts told us about their ideas and experiences.

This included people with disability.

They were from different:

- disability organisations

- providers

- **advocacy groups**.

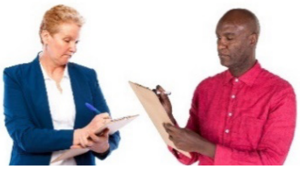
Advocacy groups speak up for people with disability.

They can:

- help you have your say

- give you information and advice.

These people:



- are experts and researchers

- work in disability services

- have **lived experience** of disability.

When you have lived experience of disability, you:

- have a disability

- know what life can be like for people with disability

- can share your story to help others.

How did we do our research?

We wanted to make sure people had time to share all of their ideas.

So we met with each of them up to 3 times.

We spoke to everyone:

- in one-on-one interviews

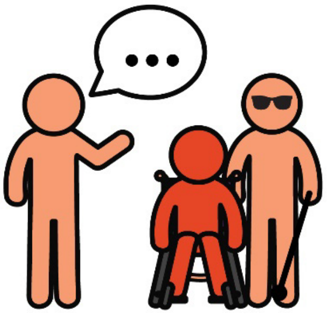
- over a video call.

And we also ran 2 online workshops where people could talk about their ideas in a group.

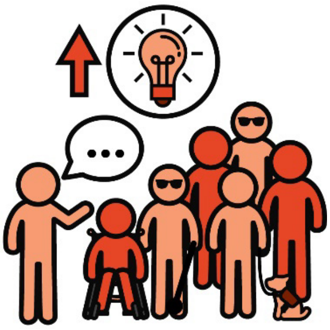
We asked everyone if they wanted someone from the NDDA team to come to their interview.

This meant they could ask questions and get answers straight away.

What affected our research?



We only spoke to a small group of people with disability.



This means we could have learnt more if we talked to more people with disability in Australia.

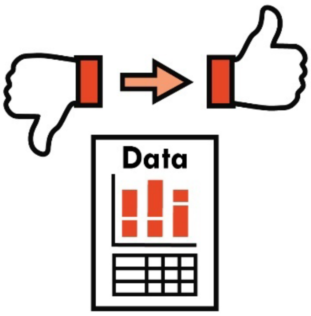
We were doing a small part of the research for the NDDA team.

Other researchers and organisations spoke to other parts of the community.

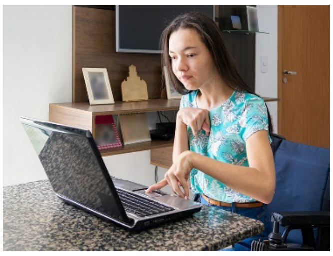
We made sure our research would work well with other research.

What did people tell us?

People told us they hope the NDDA can make data about people with disability:

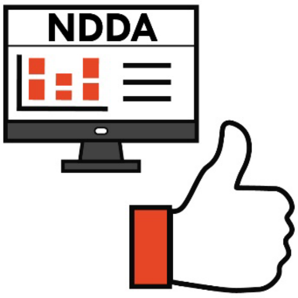


- better



- easier to find and use.

And they hope this data can help make things better for people with disability.



Most people told us that the NDDA is a good idea.

But they wanted to know more about how people will use the data.

And they wanted to know that people with disability will help:

- design the NDDA
- run the NDDA
- make sure the NDDA works well.

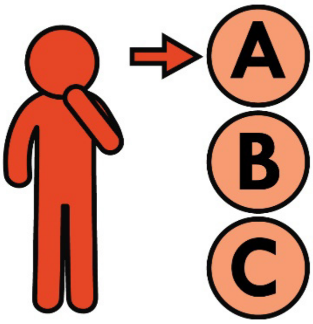
We explain what people told us in more detail on the following pages.

1. Better data for good decision-making

People told us the community needs data that:

- is about all the important areas of a person’s life

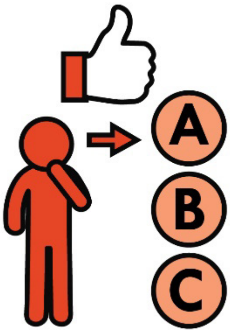
- people know they can trust.



They shared that a lot of people make decisions with data they have now.

This includes decisions about services and supports.

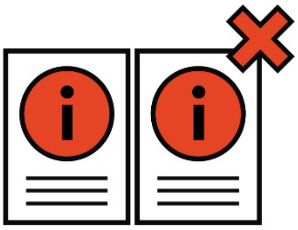
Data is important.



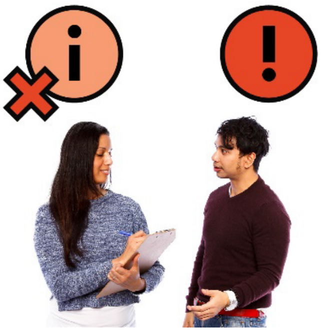
We need good data to make sure people make good decisions.

But people shared that there are some gaps in data about people with disability.

Organisations don't always collect:

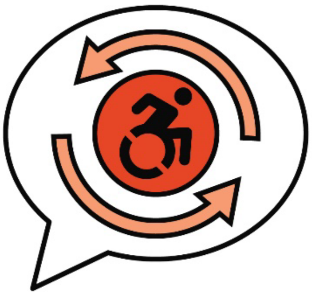


- the same information



- enough information about important parts of a person's life.

People hoped that the NDDA could help fix this problem.



The NDDA could change the way people talk about disability.

And it could change the way people collect data about people with different experiences.

This includes:

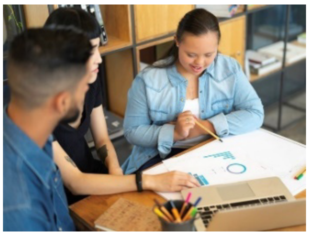
- **culturally and linguistically diverse (CaLD)** people

- First Nations peoples.

CaLD people:

- come from different countries and backgrounds

- speak languages other than English.

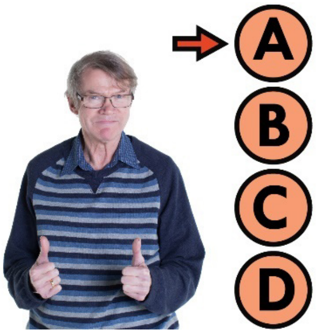


People told us that good data is guided by people who understand the data.

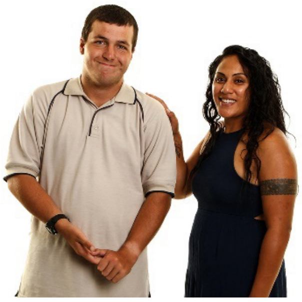
These are people who have experiences with what the data is about.

Finding and using the data

People told us the community must be able to find and use the data so they can:



- have more choice and control



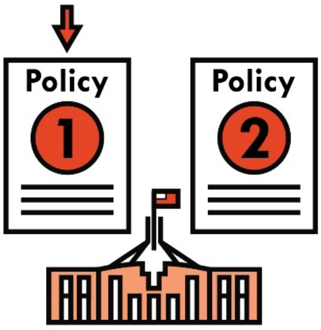
- speak up for what people with disability need.

They told us data should be online.

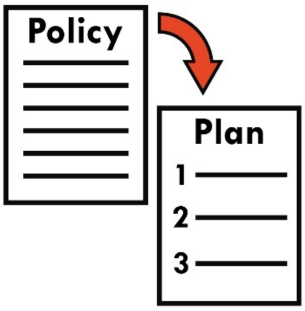
And the online data should:

- be easy for everyone to find and use
- share information in different ways.

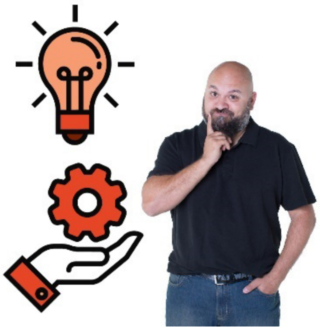
People said advocacy groups could use the NDDA to support their work.



They also said the government can use the data to make decisions about **policies**.



A policy is a plan for how we should do things.



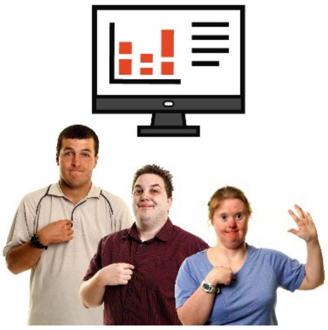
Some people said providers could use the data to come up with new ways to support people with disability.

For example, new ideas and services.

But people also told us it's very important to protect people with disability and the data about them.

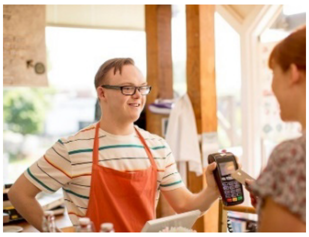
They want people with disability to be part of deciding who can use the NDDA.

What data should the NDDA collect?



People told us that the data should focus on all types of experiences that people with disability have.

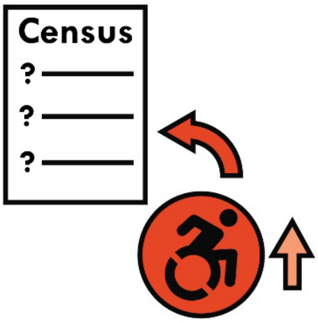
This can include:



- their strengths

- how they take part in the community

- what services they can get.



For example, people shared that the Australian Government didn't have enough questions about disability in the **Census**.

So they didn't collect enough of the right information in the Census.

The Census is a big survey that collects information about everyone across Australia.

2. What people worried about

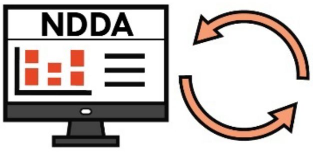
People shared that their experiences with the National Disability Insurance Scheme (NDIS) meant they didn't trust governments as much.

And they worried about how people would use the data.

They worried that governments could use the NDDA to help themselves and not help people with disability at the same time.

For example, the government could collect the data but not share it in a way that's easy to find and use.

Some people said they wanted more information before they could be sure the NDDA would work well.



People were also worried about how the NDDA would change over time.

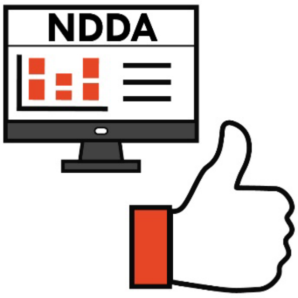
They wanted to make sure the NDDA works well for people with disability in the future.

People told us that the best way to stop these things is to make sure people with disability help:

- decide what data to collect

- collect and understand data

- run the NDDA

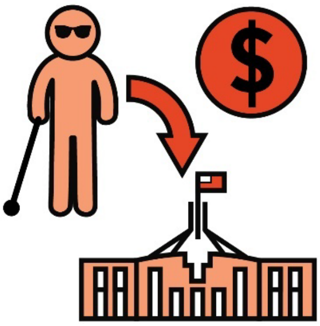


- make sure the NDDA works well.

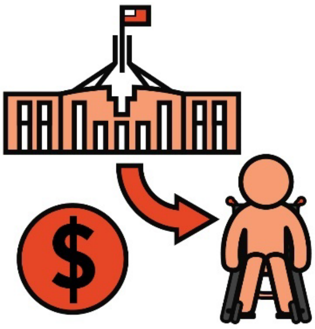
Ways people shouldn't use the NDDA

People also shared 3 things people must not use the NDDA for.

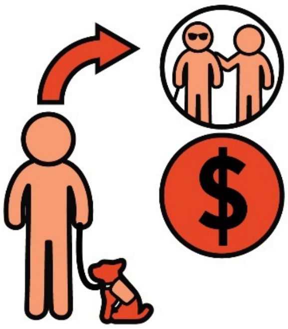
The NDDA shouldn't be used for anything to do with how much money people with disability:



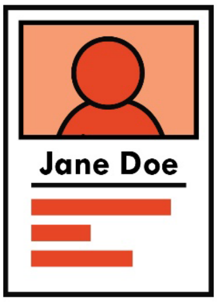
- must pay to the government, like taxes



- get from the government, like funding.



They also said the NDDA shouldn't be used to take money or support away from people with disability.



The NDDA shouldn’t be used to make **personas** that governments can use to guess how much support a person needs.

When someone collects data about a group of people, they can use the data to make an example of a person from that group.

But the person isn’t real.

We call this example a persona.

Companies shouldn’t use the NDDA to sell things to people.

For example, banks.

But some people shared that this would be okay sometimes.

For example, a provider using this information to make their services better.

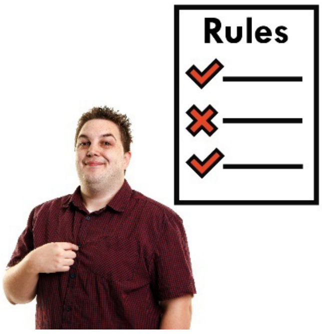
3. Including and working with people with disability

People shared that it's important to make sure:

- the NDDA works well

- people with disability are involved.

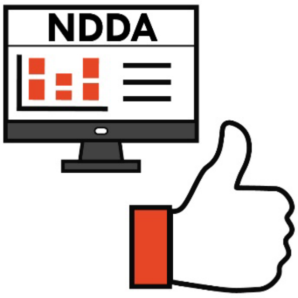
They said it's about working with people with disability, not working for them.



And they said people are experts in their own lives, so they should be the ones who make the rules.

Governments can fix most of the problems people worry about by working with people with disability to:

- run the NDDA



- make sure the NDDA works well.

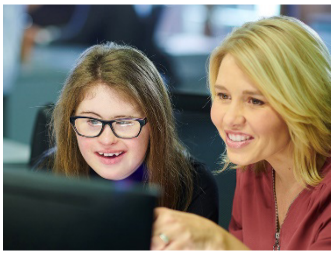
People told us it’s important to work with people with disability for the whole project, not just at the start.

They told us it’s important to work with people with disability who:

- are experts at their jobs, for example in data
- have lived experience of disability.

And it's important to work with people:

- who have different disabilities
- from different backgrounds
- with different experiences.



They shared that people with disability should run the NDDA.

This means hiring people with disability to work:

- on the NDDA
- with the community.

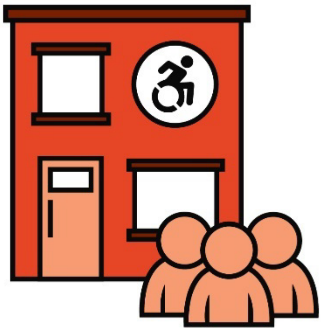
They also shared that people with disability should be part of checking that:

- the NDDA works well
- people with disability and their data are safe.

And they told us that other people in the community must also work with them on this.

This includes families and carers.

It also includes people who work for:



- disability organisations

- advocacy groups

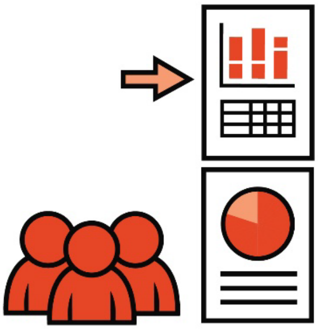
- providers.

Protecting people with disability and the NDDA

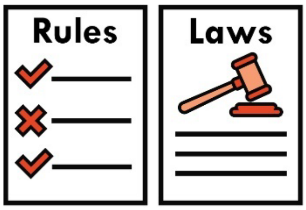
People shared that there should be a group of people who make sure:

- other people use the data well

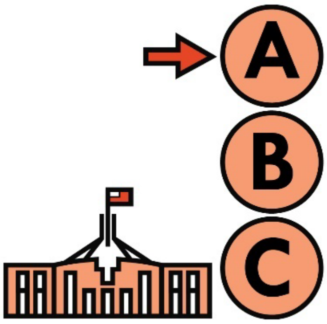
- people with disability are safe when people use their data.



This group would also decide what types of data the NDDA collects.



People told us there also need to be laws and rules to make sure everyone does the right thing.



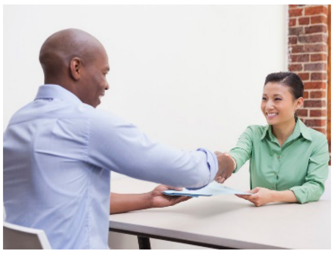
And governments need to share information with the community about:

- how they make decisions
- what decisions they make.

But people also worried if there are too many rules, it can be hard to find and use NDDA data.

How can governments include people with disability?

People shared that governments can include people with disability by:



- hiring them

- sharing data about people with disability.

They told us that governments need to keep working with the community.

And they need to work with them in different ways for different people.

Governments can:

- make sure people have time to share their ideas

- connect in different ways, for example on social media

- work with people who don't use technology that much.

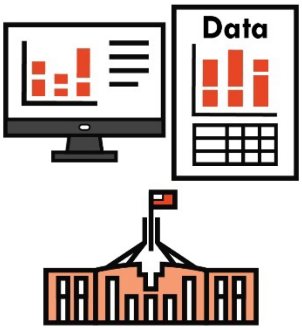
People shared that governments must support people with disability to help run the NDDA.

For example, sharing information that is easy to understand.

They also told us that people with disability must be able to find and use all parts of the NDDA.

This includes how:

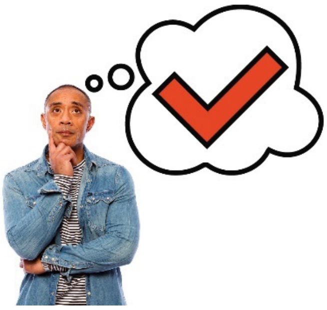
- people can use the data



- the government shares the data.

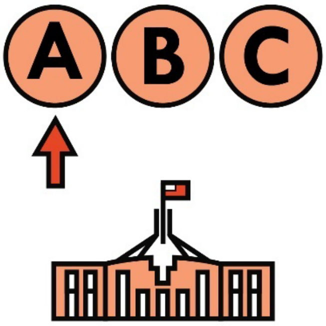
People shared that they would be able to trust governments more if they do all these things.

What we learnt from our research



We learnt a lot from people's ideas and experiences.

Data can really affect what:



- decisions governments make

- services they provide to the community.

And the way people collect and use data can affect the lives of people with disability.

When we started our research, we wanted to know if the NDDA can make the lives of people with disability better.

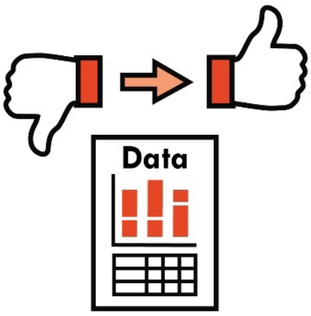
And from what we learnt, it can.

But only if people with disability have a big part in it that keeps going.

How to make sure the NDDA will work well

The NDDA must include people with disability in all parts of:

- running it



- making data better

- explaining the data

- checking to make sure it works well.

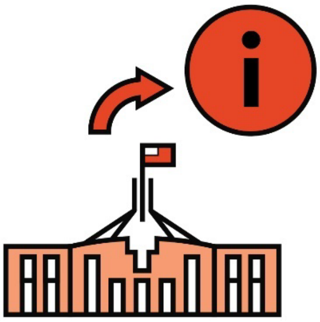
The NDDA must collect good data.

And it must fill any gaps in the data.

The NDDA must be online.

It must also be easy for everyone to find and use.

And governments must build trust with the community by:



- sharing information about what they do

- working with the community

- being leaders in including people with disability.

How research should work in the future

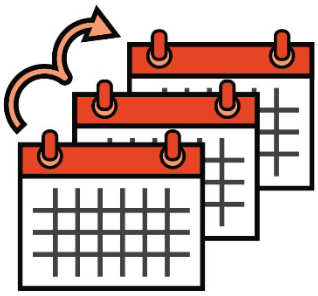
People who do research should understand that people with disability:

- have many strengths

- are the experts in their own lives

- should be supported to work towards their goals.

Research shouldn't just be for people with disability, it should work with people with disability.



It can take governments longer to make decisions when they work with the community and researchers.

But governments and researchers need to make sure they make time to work with people with disability.

Word list

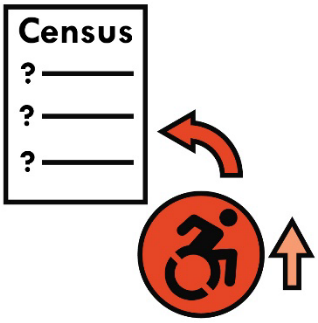
This list explains what the **bold** words in this summary mean.

Advocacy groups

Advocacy groups speak up for people with disability.

They can:

- help you have your say
- give you information and advice.



Census

The Census is a big survey that collects information about everyone across Australia.

Culturally and linguistically diverse (CaLD)

CaLD people:

- come from different countries and backgrounds
- speak languages other than English.

Data

When we talk about data, we mean:

- facts
- information
- records.

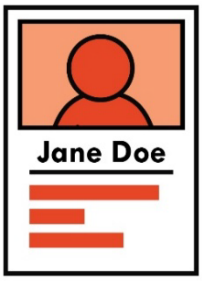
Lived experience

When you have lived experience of disability, you:

- have a disability
- know what life can be like for people with disability
- can share your story to help others.

Outcomes

Outcomes are the important results we want to get for people with disability.

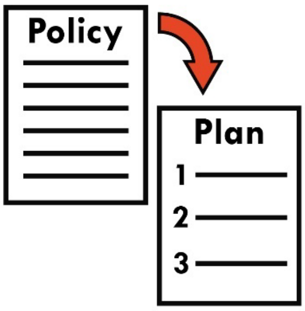


Persona

When someone collects data about a group of people, they can use the data to make an example of a person from that group.

But the person isn't real.

We call this example a persona.



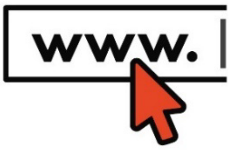
Policy

A policy is a plan for how we should do things.

Provider

Providers are organisations that deliver a service.

Contact the NDDA



You can visit the NDDA website.

www.ndda.gov.au

THE UNIVERSITY OF
SYDNEY
Sydney Policy
Lab

You can email the Sydney Policy Lab for more information about this report.

policy.lab@sydney.edu.au

You can also email the Department of Social Services (DSS) for more information.

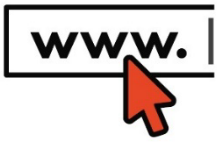
NDDA@dss.gov.au

National
Relay
Service

If you have trouble hearing or speaking, you can contact the National Relay Service.

You can call them.

133 677



You can also visit their website.

www.relayservice.gov.au

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