

How do people with disability feel about sharing their data?

What we learnt from our focus groups

Easy Read report

October 2021



Purple Orange



How to use this report



JFA Purple Orange is a team of researchers.

They do research about people with disability for:

- governments
- organisations.



JFA Purple Orange wrote this report for the National Disability Data Asset Team.

When you see the word 'we', it means JFA Purple Orange.



We wrote this report in an easy to read way.

We use pictures to explain some ideas.

Bold

We have written some 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 44.



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.

What's in this report?

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What is the National Disability Data Asset (NDDA)?



The 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.



But when the NDDA shares this data, it won't include people's personal information.



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

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

What is this report about?



We wanted to understand how people with disability feel about sharing their data for the NDDA.



And we wanted to know how they feel about the NDDA Team keeping that data.

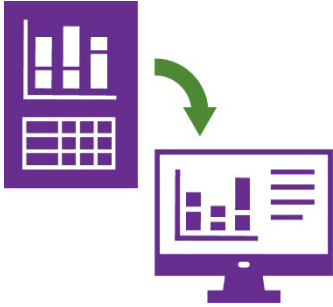


In October 2021, we ran different **focus groups** to work this out.



A focus group is a group of people who meet to talk about their experiences and opinions.

The focus groups helped us work out how people with disability feel about:



- sharing their data for the NDDA



- the NDDA Team keeping that data.

How did we do our research?



To do our research, we wanted to work with:

- people with disability
- their families.

We did this by:



- making our co-design group



- running different focus groups



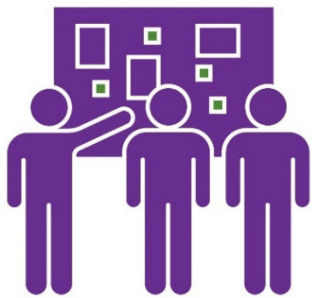
- working out how to connect with people with disability and their families.

We explain each of these on the following pages.

Our co-design group



Co-design is when people work together to plan something new.



When our research project started, we made a co-design group.



The co-design group included people with different disabilities.



At the start of our research project, the co-design group gave us ideas about how to connect with people with disability.



And at the end of our research project, the co-design group had a meeting about:

- what we learned from the research
- how we can write this report.



We used the ideas from their meeting to write this report.

Research participants



A **research participant** is someone who takes part in a research project.

We also call them participants.

36



We had 36 participants in our research.



Most of the participants lived in Adelaide.



And the participants had lots of different disabilities.



We had participants with a **physical disability**.

A physical disability affects how someone moves and uses their body.

We also had participants with a **cognitive disability**.



A cognitive disability affects how someone:

- thinks
- communicates
- understands
- remembers.

And we had participants with an **intellectual disability**.

An intellectual disability affects how someone can:



- learn new things
- solve problems
- communicate
- do things on their own.



We had participants with a disability that affects how they see or hear.



We also had participants with a **brain injury**.

A brain injury can happen when someone:

- has a bad accident
- hurts their head badly
- damages their brain.



We had participants with **autism**.

Autism is a disability that might affect how you:

- think and feel
- communicate
- connect and deal with others.



And we had participants with a **psychosocial disability**.

A psychosocial disability comes from a person's mental health.



10 of these participants were **culturally and linguistically diverse (CaLD)** people.

CaLD people:



- come from different countries or backgrounds



- speak languages other than English.



But we didn't have any Aboriginal or Torres Strait Islander participants.

Our focus groups



We ran 7 focus groups in October 2021.



5 of these focus groups were on a video call.



And 2 of these focus groups were in Adelaide.



The co-design group told us we should run focus groups for different groups of people.



This helps us understand what opinions these groups of people have.



We also had focus groups that everyone could take part in.

This meant lots of people with different experiences.

Doing our research the right way



Before participants took part in a focus group, we asked them to give their **consent**.

When you give your consent, you say it's okay to do something.



And we gave the participants information that:

- was easy to read and understand
- met their needs.

This information was about:



- how we will run the focus groups



- the NDDA.



We recorded the focus groups that were online.

All participants gave their consent for us to record the session.



All the data we collect is saved on a computer.

It is protected by a password.



The data doesn't say who the participants are.



And only we can use the data.

What affected the research?



There were some things that affected our research.



It's important we explain what these things are.



Most participants were from South Australia.

This means we don't know what people with disability in other parts of Australia think about the NDDA.



The people in the CaLD focus group were from the Bhutanese community.

This means we only know what the Bhutanese community thinks about the NDDA.



It's important we connect with more CaLD communities to know what they think about the NDDA.

We didn't have many participants with:



- psychosocial disability



- autism.



And we didn't have anyone in the focus groups tell us they were Aboriginal or Torres Strait Islander.



It's important we try to connect with these groups to find out what they think.

What did we learn from our research?



Participants were happy with how the NDDA keeps their data safe and private.



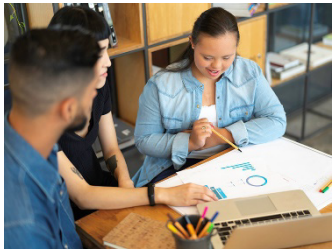
But they worried about how safe their data would be after it is shared with other organisations.



Participants want more choice and control about when they want their data shared.



They also shared that the data being collected should be true and good quality.



And they told us people with disability should be involved in all parts of the NDDA.



There were 8 important ideas that came up in our research.

We explain these ideas in more detail on the following pages.

1. What participants think about privacy

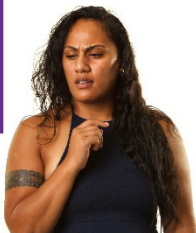


We asked participants to share what they thought about the **privacy** of the data.

Privacy means keeping your information safe and private.



Participants thought that their data was always going to be collected at some stage in their life.



But they worried about their data being used in the wrong way.



They explained there should be more rules about who can use the data.



This includes keeping a record of:

- who used the data
- why they used it.



Participants told us they worry about certain organisations using their data, like other **providers**.

A provider supports other people by delivering a service.

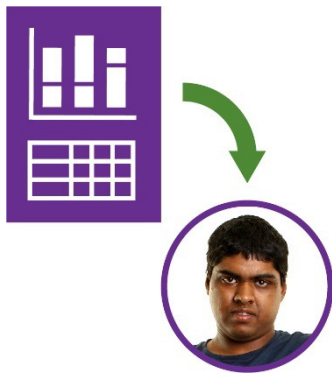


One participant explained they worry about sharing data about their child.

Another participant who works with providers said they worry about providers:



- not using data the right way



- knowing who the person was because of their data.



They worried that providers might know who to go to so they can get more work.

Participants also worried that:



- governments might use their data in the wrong way



- people don't understand what data is collected about them.



Participants also told us they worry about their privacy when they share information over the phone.

2. What data should be used for



We asked participants to share what they think people should use their data for.



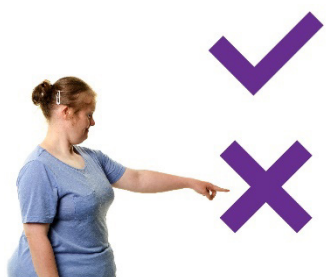
Participants told us their data should help the disability community.

And people with disability should be involved if this happens.



Participants explained that data can make it easier to plan supports.

For example, you might only need to share your information one time.



But participants wanted choice and control about sharing their own data.



Participants told us sharing their data can help them get supports they need.



Participants explained that researchers also use data to make disability services better.

They also shared that data can help work out:



- if programs are working well



- what services need more **funding**.

Funding is money from the government.



Participants also shared that people need to collect stories from people with disability to support the data.

What data shouldn't be used for



We also asked participants to share what they think their data shouldn't be used for.



Participants don't want their data to be used against them.

For example, using their data to make people with disability look bad.



And they said the NDDA must manage their data carefully.



Participants explained that providers shouldn't use data to choose one type of service they think will help all people with disability.

They want providers to think about what each person needs.



Participants also said people with disability should be part of making decisions about collecting and using data.



And some participants explained that data shouldn't be used to take advantage of people with disability.



One participant explained that data must be used well to make sure people don't use it to say bad things about people with disability.



Another participant said they worry about people collecting and sharing information that wasn't helpful.

3. Using data



Participants told us that they worry about how data is collected now.



They also said that more work needs to be done before the NDDA can be helpful.



Participants explained that data collected by providers doesn't show what they are doing.

And they told us the way governments collect data now doesn't help them:



- collect good data to use



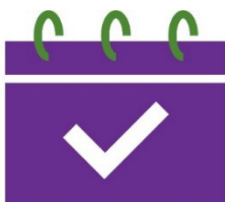
- understand what life is like for people with disability.



Participants said that the data governments collect and use doesn't focus on people's lives.



And CaLD participants told us it can be hard to share the right information if you don't speak English well.



Lots of participants talked about keeping data up-to-date and true.

4. How the NDDA will affect the disability community



We asked participants how they think the NDDA will affect the disability community.

Most participants thought the NDDA will help the disability community.

They shared that the NDDA could:



- use data to make services for people with disability better



- collect data about different communities



- share data to help the community understand disability.

5. Being worried about the NDDA



Participants shared what parts of the NDDA they worry about.



One participant explained that they worry about how safe the data would be.



Some participants talked about how some sets of data don't have all the information they need.



Participants also worry about data being used without other information to support it.



Another participant said they worry about how the government will use their data.



Some participants talked about how things need to be explained in a clear way.

This can help people feel safe when the NDDA is being made.



Participants also said it's important to have information that's easy to understand.



And they told us the NDDA should be checked from time to time to see if it:

- works well
- needs to change.

6. Using the NDDA data



We asked participants about who they think should be able to use the NDDA data.



Lots of participants told us people with disability should have control over who can use the data about them.



And participants said they were comfortable with their data being shared.

But only if this data doesn't say who they are.

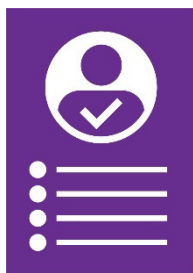


Participants explained that the community should be able to use the data.

And it should be easy for them to use.



One participant told us it's important to explain who can use the data.



And participants shared a list of people who they think should use the data.

This list included different groups of people,
such as:



- people with disability



- government departments



- disability organisations



- service providers.

7. Managing the NDDA



We asked participants:

- who should use the NDDA
- why those people should use the NDDA.



Participants told us that people with disability must be part of big decisions about the NDDA.



And participants shared ideas on how people with disability can be more involved with the NDDA.



For example, having a group of people with disability meet to talk about:

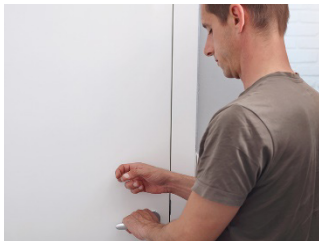
- who can use the NDDA data
- how they can use the NDDA data.

8. What different focus groups had to say

Focus groups with people with intellectual disability



Participants with intellectual disability told us the word 'privacy' was hard to understand.



They thought it meant physical privacy, like knocking on a door before going into someone's room.



Participants with intellectual disability also explained the word 'data' was hard to understand.

They thought data was just a number.



But they liked it when we used the word 'information' instead of 'data'.



Participants with intellectual disability said data about them isn't enough to help other people understand them.



Governments need to work with people with intellectual disability to help them know how their data is being used.

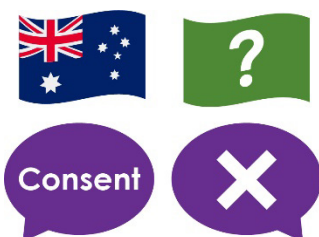
Focus groups with CaLD people



CaLD participants said they trusted government to use their data in the right way.



They also told us that speaking English as a second language stopped them finding and using information.



One CaLD participant explained that there are words that other languages don't have, like 'privacy' and 'consent'.

Word list

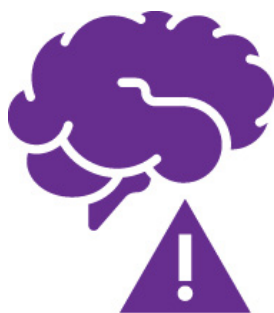
This list explains what the **bold** words in this summary mean.



Autism

Autism is a disability that might affect how you:

- think and feel
- communicate
- connect and deal with others.



Brain injury

A brain injury can happen when someone:

- has a bad accident
- hurts their head badly
- damages their brain.



Co-design

Co-design is when people work together to plan something new.



Cognitive disability

A cognitive disability affects how someone:

- thinks
- communicates
- understands
- remembers.



Consent

When you give your consent, you say it's okay to do something.

Culturally and linguistically diverse (CaLD)

CaLD people:



- come from different countries or backgrounds



- speak languages other than English.



Data

When we talk about data, we mean:

- facts
- information
- records.



Focus groups

A focus group is a group of people who meet to talk about their experiences and opinions.



Funding

Funding is money from the government.

Intellectual disability

An intellectual disability affects how someone can:



- learn new things
- solve problems
- communicate
- do things on their own.



Outcomes

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



Physical disability

A physical disability affects how someone moves and uses their body.



Privacy

Privacy means keeping your information safe and private.



Providers

A provider supports other people by delivering a service.



Psychosocial disability

A psychosocial disability comes from a person's mental health.



Research participant

A research participant is someone who takes part in a research project.

We also call them participants.

Contact the NDDA



You can visit the NDDA website.

www.ndda.gov.au



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

NDDA@dss.gov.au



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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