



people with  
disabilities  
western  
australia

# Co-design Project Report

## NDIS Transition and Interface issues

Easy Read Report

June 2020



# This report



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This report is from People With disability WA (PWdWA).

PWdWA is an organisation that speaks out for Western Australians with disabilities.

It is written in an easy to read way.

We use pictures to explain some ideas.

We explain words that are written in **bold**.



You can ask for help to read this report. A friend, family member or support person may be able to help you.

Contact PWdWA if you need someone else to help you read the report.



This Easy Read report is a summary of another report.

You can find the other report on the PWdWA website.

# What is the report about?



This report is called **NDIS Transition and Interface Issues**.

The NDIS is the National Disability Insurance Scheme. The NDIS is the organisation that helps Australians with disability who need support services.

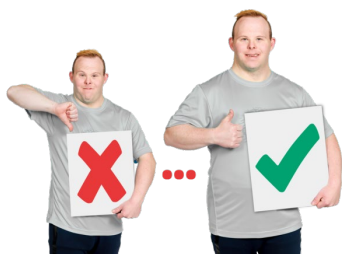
Transition and Interface issues are problems people are having with the NDIS.

This includes problems getting into the NDIS and problems with how it is working.



PWdWA put together a **Co-design Group** of people.

Their job was to look at the problems people are having and come up with ideas for how to make the NDIS work better.



The Co-design Group is made up of people with disabilities, family carers and other people who have useful experience when it comes to the NDIS.



The Co-design Group wrote the main report. It explains the problems and how NDIS should change so it works better.

PWdWA is sending the report to the NDIS and to the WA Government.

# About Co-design



Here is some information about Co-design. This will help you to understand:

- Why it is important
- How it works

Co-design is people working together towards a goal. This could be to design or improve a service or improve the way something works.



The people who work together in co-design have experiences in their lives that help them understand the problems. This helps them to have good ideas to make things better.



PWdWA has written some booklets about how to do co-design called Connect With Me.

You can find these on the PWdWA website:

[https://www.pwdwa.org/our\\_campaigns/connect\\_with\\_me.html](https://www.pwdwa.org/our_campaigns/connect_with_me.html)

# Who took part in this project?



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PWdWA was in charge of the **project** which is this work about the NDIS.

They set up the Co-design Group to help them.

The Co-design Group included:

2 PWdWA staff. They made sure the project met its goals and they supported the Co-design Group to do its work.

There were 8 adults with different kinds of disability and 2 parents of children with disability in the group.

There were also some **external stakeholders** taking part.

These are people from other organisations who had experience that helped the Co-design Group to do its work.

3 external stakeholders came to most of the project meetings.

Some just came to 1 meeting during the project.

The external stakeholders helped the Co-design Group understand more about how the NDIS works.

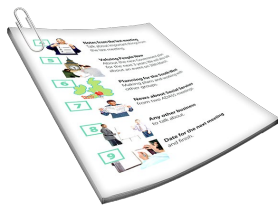


# How the project worked



PWdWA asked people across WA how they were going with the NDIS.

They used different ways to ask people. This included asking questions in an online survey, talking with people in support groups and talking to the project leader about their experience with NDIS.



PWdWA looked at all the feedback about the main problems people were having with the NDIS.

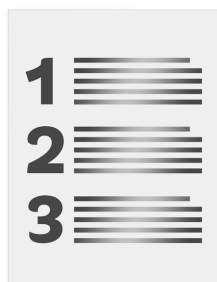


They took the information to the Co-design Group and asked them to think about how the NDIS could fix these problems.



The Co-design Group had meetings for 9 months. They talked about the problems and how to fix them.

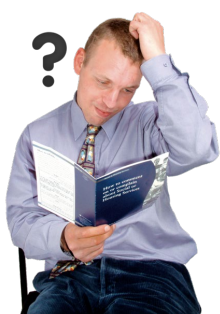
They made a list of the main problem areas and the big things NDIS needs to change.



They also made a list of **Recommendations** - actions NDIS should take so it works better for people with disability and service providers.

They put the recommendations in a report to go to the NDIS and to the state government.

# The main problems and what NDIS should do



The Co-design Group saw that people were having all kinds of problems with the NDIS.

One of the main problems was many people not knowing how the NDIS works.

The NDIS is quite new and very complicated.

Sometimes people don't know how to get in to the NDIS.



People sometimes don't know what kinds of support they could ask for.

They often don't know how to find the services they need.

This means that lots of people don't get the supports they need.



The Co-design Group said that it is not fair that it is so hard for people.

The Group said the NDIS needs to understand the main things that are causing problems for people.



The Co-design Group said that the NDIS should listen to people with disabilities.

The Group said that the NDIS should always include co-design with people with disabilities so that things work better.

Here are the main problem areas and how NDIS could make things better.

### **Respect for people's privacy**



It can be hard to give out personal information.



It can make you feel uncomfortable and you might worry about how your information is used.

People have the right to decide what information to give to NDIS.



They have the right to say how their personal information is used.

They should be able to see any information that is about them.

The NDIS needs to understand and respect people's rights to control how their information is used.



The NDIS needs to be open and clear about how it uses personal information.

They need to make sure they never use personal information in a way that is bad for the person.





## Speaking out and making choices

People know best about what they want in their lives and what kind of help they might need.

The NDIS should work in ways that show they respect that people are the experts in their own lives.

Some of the ways they could do this include:

Giving people a copy of their new NDIS plan to look at before saying it is all done and finished.

NDIS helping people to have a plan that they are happy with.

People signing their new NDIS plan to say they are happy with it.

The NDIS respecting and supporting people's rights to **self-advocacy**.

This is people speaking out on what they need instead of other people or the NDIS making decisions for them.





## Empowerment – Knowing your rights so you can be in control

People with disabilities don't always know about their rights.

Because of this, people sometimes don't get what they need and they don't know what to do about it.

The NDIS should be helping people to be in control, not taking away their control.

The NDIS should be explaining to people what their rights are and making sure they can make their own decisions.



This includes things like what is in your NDIS plan and how you will use it.

It also includes your right to choose service providers and get the supports you need.

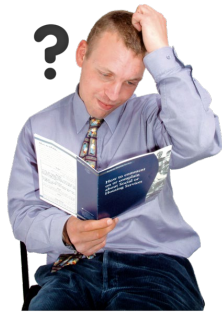


People said the NDIS is not '**user-friendly**' – it can be hard to use.

For example, some people said it is hard to get information from the NDIS.

Sometimes it is hard to contact the NDIS and sometimes it is hard to get the right information.





People said that the language the NDIS uses can be hard to understand.

This includes some of the words they use and not explaining what they mean.

This can be difficult for many people with disabilities and also people who speak other languages.

People find it hard to use the NDIS for other reasons too.

Many people have to get reports from doctors and therapists to show how much help they will need.

This is hard to do and it is unfair for people who can't afford to pay for reports

When the NDIS started, people expected to get better support to live their lives.

But many people have not been getting the supports they need.

The Co-design Group says that the NDIS needs to see that people are the experts about the support they need.

The NDIS needs to respect this instead of making it hard to get what people need.

The Group says that more peer support in the NDIS would help people to learn how to use the NDIS better.



## Being honest, fair and open



People said they often can't get the information they need about how things work in the NDIS.

It can feel like there are secret rules that we don't know.

This can make it hard to get into the NDIS in the first place.

Sometimes people are told they can't get into the NDIS, but they aren't told why. So they don't know how to try again.

This makes it very hard and some people don't try again even if they need lots of support.



People also have problems when they have NDIS plans.

Sometimes they aren't told why they can or can't get something in their plan.

People can be in trouble about how they spend the money in their plan. But they don't know the rules.



Planning meetings are hard if you aren't told the rules.





People say nobody at NDIS or LACs tells them what is happening when they are waiting for something to do with their plan.

Some people said they wait for a long time to find out what is happening.

Some people said they have problems when they tell NDIS there is a mistake in their plan.

Or when they need to change something because something in their life has changed

They say the NDIS takes a very long time to do something even when things are urgent for the person.

People said they sometimes have problems with their **Plan Managers**. These are people who help you pay for your support services.

Sometimes Plan Managers say you can't use your NDIS money for something, even if they are not correct. It is not their job to decide.



Many people say they feel the NDIS doesn't work in a fair way.

They feel the NDIS doesn't respect or care about people with disability.

People give lots of information to the NDIS including their personal information and the help they need.

But the NDIS seems to hide important information from them.

They say the NDIS seems to care more about its own rules and saving money than about the support people need.

People say they don't get enough money for the support they need.

This means they can't afford good support and this can mean they are not safe.

People say the NDIS sometimes looks like it cares more about service provider organisations than about people with disability.

The Co-design Group says the NDIS needs to respect people with disability.

They need to get better at:

- Communicating with people
- Sharing important information, and
- Helping people get the support services they need.



## Making sure that people get services that are right for them



People with disability should get services that are right for each person. They need to be safe, fair and done properly.



The NDIS and service providers should work to make sure this happens for everyone.

There are lots of differences between people. This includes the kind of disability and where you live.



It might include how old you are or your language or **culture** – for example if you are Aboriginal or come from another country.



Some people with disability are parents, some people have a family, some don't.



Some people live independently and some may live with someone who supports them



People said the NDIS doesn't seem to understand that people with disability have different kinds of lives.

They said the NDIS doesn't understand what is involved in people's lives when they have a disability.



People with disability who are parents said the NDIS doesn't give them the help they need.

Parents and carers of children with disabilities said the NDIS doesn't help them. They said they used to get more help as carers before the NDIS.



Some older people say it is a problem getting good aged care supports through the NDIS.



People said it sometimes feels like getting what you need in your plan is down to luck.

They say it seems to depend on which LAC or planner you get.



People said it can be hard to get some of the supports they need because the NDIS and other government services don't work well together.

Sometimes they can't find out where to get help. Sometimes the services say to go to the NDIS when this is not right.



This is very stressful, makes people's lives harder and means some people don't get the help they need.





The Co-design Group says the NDIS and service providers need to understand and respect that people are different.

They need to understand people's lives are different and they need different support.



The Group says the NDIS needs to work on making sure LACs and planners have good training.

They need to get better at understanding disability and how it affects each person's life.



This includes where they live, what support is available and the cost of travel.

They need to make sure people are treated fairly and it isn't just good luck to get the support you need.



The NDIS, other government and community services and service providers need to stop arguing about who should provide the service.

They should work together to make sure people get the help they need.

They should make sure people get clear information and support to find and use services.



## **Making sure there are plenty of good services for people to use**

It is important for people to get an NDIS plan that has enough money to buy the services they need.

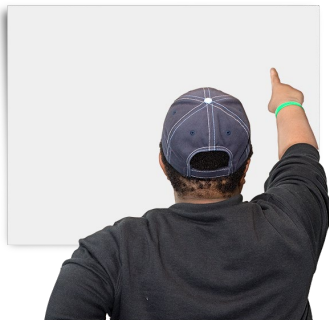
But sometimes it is hard to find the support services.

This can be more of a problem for people who live in the country or a very long way from any towns.



If there are no service providers where you live then you might not be able to get any support.

If there is only one organisation near you then you don't have a choice.



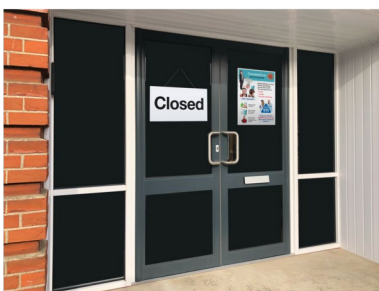
This is a bigger problem if the only service provider is one that acts badly towards people.

This might be charging too much for your support services, or not providing good and safe supports.

Some people said that there is also less choice now even if you live in the city.

Since the NDIS started, some service providers have closed.

Some can't offer the supports people need.





Some service providers don't run groups any more.

But people said they don't have enough NDIS support money to go out, so they don't get to meet people any more.

People said that some service providers want them to sign **Service Agreements** that are not fair.



Service Agreements are when a person and a service provider agree on the service and how it will be provided.

This should be what the person wants. It should be fair to the person and the provider.



But people say some providers are not fair in what they put in the Service Agreements. It can look like they are trying to get too much money from the person.

The Co-design Group says the NDIS and providers need to make sure people have a good choice of services.

People should be able to get all the information they need to make choices.

People should get help with finding services if they need it.

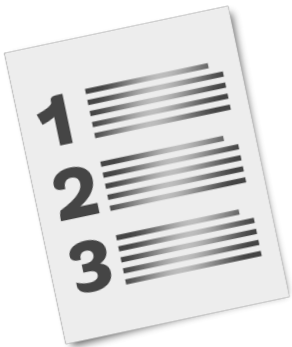


# Recommendations



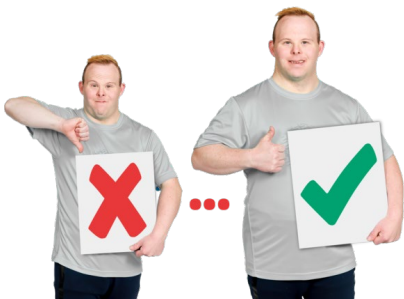
The Co-design Group also came up with some **recommendations**.

These give advice to the NDIS on some actions they should take to work better.



Each recommendation says:

- What the problem is
- How the NDIS should fix the problem and
- How it would help people with disability and service providers.





## Helping people to get into the NDIS

*People shouldn't need to give an address on the form.*



People should be able to give an email address or phone number, or the address of a friend, family or service provider.

This would help people who are homeless or move around a lot to get into the NDIS.



*The NDIS should pay for people to get reports from doctors or therapists to get into the NDIS.*

This would help people who can't afford to pay for reports to show they need support from the NDIS.

These changes would help more people to get into the NDIS and get the support they need.



These changes would mean more people needing service providers.

This would help service providers to provide the kinds of supports people need.

## Making the NDIS user-friendly



*The NDIS should have Peer Support staff to help people with disability:*

- *Get into the NDIS*
- *Learn about how it works*
- *Get a good plan and get the supports they need*



*The NDIS should make sure there is good communication between the person with disability, NDIS and service providers.*



*The NDIS needs to make sure it produces information that everyone can get and understand.*

*This includes information such as **policies and procedures** – rules about the NDIS and how it works.*



*The NDIS needs to make it simple for people to use the money in their plan to get the support they need.*



Everyone should be able to get **Support Coordination** in their first plan. This is help to find the services they need.



The NDIS should help people to become better at **self-advocacy**. This is speaking up for yourself.



The NDIS should help people get ready for their next plan.

This should include telling people:

- What information they will need to have such as reports.
- They should think about whether they need Support Coordination.
- To think if they are happy with how they manage the money in their plan.
- To think about what they want in their next plan.





These changes would help people with disability to:

Understand the NDIS and be able to self-advocate to get the support they need.

Get help from Peer Support staff to help them with their plan and services.

Make it easier to get the right support to live their life and achieve their goals.

Have more choice of services and better services.

Manage the money in their plan themselves with less stress. This gives people more choices.

Feel more confident and supported because they are getting good information when they need it.

These changes would help service providers to:

Support each person with disability better.

Get better information from the NDIS.

Work better and put more money into support services.

Understand what people want and need by listening to self-advocates.





## Making the NDIS clearer

Recommendations:

*The NDIS should tell people how long it will take them to do things or sort out problems.*

This will help people with disability feel more confident that things will be done. It also means that they know when to get in touch if they don't hear anything.



*The NDIS needs to explain clearly why not, when it tells people:*

- *They can't get into the NDIS*
- *They can't get some kinds of supports*
- *They can't use NDIS money in some ways*



This will help people to understand how the NDIS works.

It will also help them get the information they need to try again.





*The NDIS needs to be open and clear about any feedback they get and what they did because of the feedback.*

People with disability will feel more comfortable about giving feedback if they feel it was worth it.



They will see the NDIS as better and more reliable.

*The NDIS should write a policy about privacy, confidentiality and Freedom of Information that:*

- *Says it will only use people's information to help people get the support they need*
- *Respects the rights of people with disability*
- *People can easily get, read and understand.*



These changes will help people with disability feel more in control of their information.

They will be less worried about how the NDIS uses their information.

It will be easier to get **Freedom of Information** from the NDIS. This is when you ask for copies of any information about you.





Service providers will be better at respecting people's rights to control their own information.

They will only keep information they need to provide a service to the person.



They will make sure people's information is only used in the right ways.

Service providers will learn what information is needed and what is not, and more providers will learn to do the right thing.



Service providers would have their own policies that have the same kinds of rules as the NDIS policy.



## **Making sure NDIS staff know how to make good, fair decisions**

Recommendations:

*NDIS should employ people with the right knowledge and experience.*

*This includes people with disability, or other lived experience such as a parent.*

*Or people with qualifications and experience working in disability.*

*The NDIS should make sure its staff get good training to help them make good and fair decisions.*

*The NDIS should work to make sure its staff and plan managers follow the rules, work in the right ways and make fair and good decisions.*

*NDIS should make sure everyone in the disability sector and other services can have training and information so they know how the NDIS works.*





These changes would help people with disability by:

Making sure they get the same, correct information from everyone.

People will be less confused and will see the NDIS as more reliable.



*People should be able to keep the same LAC or planner for future plans as much as possible unless they choose not to.*

People with disability won't have to keep telling their story to new staff.



People will feel more supported if they know the staff.

*NDIS should employ Peer Support workers to help people with disability getting into the NDIS and with their NDIS plans and services.*



People say that peer support helps them to be more hopeful and confident in using services and speaking up if things aren't right.



Service providers will be better and more confident in giving information to people with disabilities.



Service providers will be able to provide better support when people have good and fair NDIS plans.



Plan Managers will provide better services when they have a better understanding of NDIS rules.

This will help people with disabilities and other service providers.



## **NDIS, government and services working better together**

Recommendations:



*NDIS needs to work more and better with government and community services, private organisations and with families.*



*NDIS needs to work with state government departments to work out who should provide different services to people with disability.*

*They need to work together and write out the rules clearly so that everyone understands.*



*NDIS should provide training and information to people with disabilities and carers.*

*This will help them know where to get the supports they need from different departments and how they work.*



*This includes departments and services like housing, health, transport, education, mental health and aged care.*





These changes would help people with disability by:

Helping people to feel more secure, and that they can get all the help they need in the different parts of their life.



Helping people get the support they need as an individual person, instead of different departments that are not able to give what they need.



People and their families and carers would know about the different kinds of help they could get from government, so they can find and choose what they need.



Service providers would understand and be able to work better with other providers and government department. Everyone would be better off because of this.



# Conclusion



To end this report, the Co-design Group says it hopes the NDIS will make these changes so that it works better for people with disability and service providers.

The Group also believes that the NDIS should use co-design as part of how it works. This would:

Respect people with disabilities as the experts in their own lives.

Actively involve people with disabilities in decision-making.

Make sure the NDIS and disability organisations keep improving. This will help people with disabilities to get the best from their NDIS supports.

