



# Our Voice Committee submission to the NDIS Review 2023

## Our Voice Committee members



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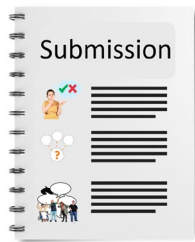
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## About Our Voice



Our Voice is a committee of the Inclusion Australia board.



Our Voice members are people with an intellectual disability.



Each member represents people with an intellectual disability from their state or territory.



Our Voice members connect with people through our state and territory organisations.

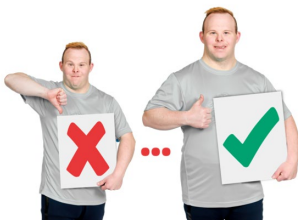
The state and territory members of Inclusion Australia are



- Parent 2 Parent Queensland
- South Australian Council on Intellectual Disability
- NSW Council for Intellectual Disability
- Developmental Disability WA
- Speak Out Association of Tasmania
- Victorian Advocacy League for Individuals with Disability
- Inclusion Australia Northern Territory.



Each year Our Voice chooses to do work on topics that we think are important.



In 2022 and 2023 we have done work on

- The big issues for people with an intellectual disability in the NDIS
- Ideas for changing the NDIS.

## About this submission



This is Our Voice's submission to the NDIS Review in 2023.



Our Voice members spoke to people with an intellectual disability around Australia to make this submission.

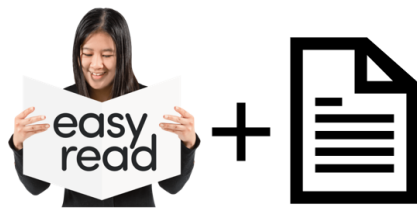


We spoke to

- Self advocacy groups
- Peer support groups
- Friends
- People we work with
- Families and other supporters.



We gave people a choice about what questions they wanted to answer.



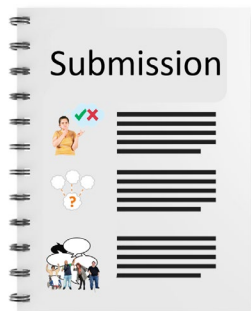
This submission is written in a mix of Easy Read and Plain Language.



When you see this pictures that means it is a personal story.



We have changed people's names to keep their personal stories private.



This submission is a long document and it has some hard words.



It is a good idea to read this submission with support.

## The big issues in the NDIS



These are the big issues for people with an intellectual disability in the NDIS that we heard again and again.

### The NDIS is too hard



We cannot use the NDIS by ourselves.

It is very hard when we do not have family, friends or supporters to help.

The NDIS portal is too hard.

### Planning is too hard



Planning meetings are too hard for us.

Plans are too hard.

We do not get the supports we need because it is too hard.

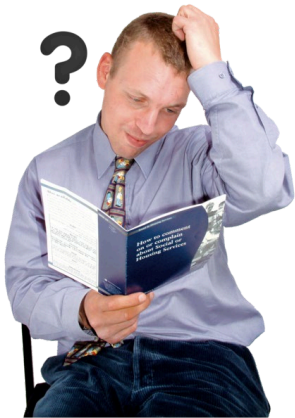
Some people do not go to their own planning meetings.



Susan told us

“I found that my last review it was easier to roll over than to get a new plan as I could not get paperwork on time.

So to make sure I didn't lose funding I had to roll over even though I could use more support.”



### **Information is too hard**

We cannot understand the information the NDIS gives us.

Our supporters cannot understand the information either.

People do not explain the information to us well.



### **Too hard to access the NDIS**

Some people have trouble accessing the NDIS in the first place.





Tilly's story:

The first time Tilly went to get an NDIS plan she was knocked back. Her mum had to advocate very hard to get all this extra information. The NDIS lost the report Tilly's mum organised. It was very frustrating. It was very badly handled.



A parent told us

"My son applied for the NDIS but was rejected because his IQ was 1 point too high."



### **Planners and Local Area Coordinators (LACs)**

Planners and LACs sometimes do not listen to us.

Planners and LACs do not know who we are and what is important to us.

LACs keep changing and we have to tell our story over and over.

It feels like LACs and Planners do not respect us.





Liam's story:

Liam gets frustrated that no one seems to understand what he needs. He wants to have a mentor that he can have greater access to, not just a few hours each day. When Liam is feeling down at night or has a problem, he has no one he can call. Nobody understands that Liam needs something in his plan around this.



### **Bad communication**

The NDIS does not communicate well with us.

People do not know who to talk to about issues or problems with their NDIS plans.



### **Waiting**

We wait too long for decisions to be made about important things in our lives.

We wait too long for plan changes to be approved.



Maria told us

“I had a spot available at a house but the holdback was NDIS and funding.”



### Funding cuts

Many people told us their funding has been cut.



Michael told us

“Half of my funding has been cut. I have less support and no 1:1 now.”



### Costs going up

The cost for supports is going up.

Funding does not last the whole plan.



Anthony told us

“My funding has run out and I am still waiting to get my new plan. I have no support while I wait.”



### **Too many reports**

It is too hard and expensive to get all the reports the NDIS asks for.

Paying for reports takes away the funding that we need for support.



Chloe told us

“I have spent over \$10 000 for this plan review on therapy reports. This money is then not available for therapy sessions.”



A parent told us

“Every 2 years I have to prove my son’s disability again. It can cost up to \$1000 every 2 years.”



### **Problems with providers**

Many people had problems with providers.

These providers do not know how to give us safe and appropriate care.

Some providers take advantage of us and make us do activities they want us to do, not what we want to do.

It is difficult to change providers.



Robert's story:

Robert had a very bad provider when he first applied for NDIS. He didn't get anything he needed in his plan. When Robert changed providers it was much better. But he didn't know which providers are good and which are bad.



### **Not enough transport and travel funding**

People in small towns have to pay a lot of money to travel to other towns for services. Many people need more help to pay for transport.



It can be too expensive to cover a support person's travel costs too. This means we miss out on supports and opportunities.



## Hard to get new equipment

It is hard to get new equipment.

The NDIS asks for more reports which costs more money.

It takes a long time to get approved.

Sometimes they say no and we do not understand why.



Mark told us

“I have had the same recliner chair for years and it is really old and not suitable anymore. NDIS won't approve it to be updated.”



## Supports are not approved

The NDIS says no to important supports that we need.

We do not understand why they say no sometimes.



Meena told us

“I have moved and need more support now, but they won’t let me have more support.”



### **Takes away choice and control**

Because the NDIS is so hard it takes control away from us and gives it Planners or support people.

We do not feel empowered.



Natasha told us

“They say it is about choice and control but I’ve never felt I had a choice.”



## Our ideas



Here are our ideas for how to fix the NDIS issues.



### Easy plans

We need Easy Read plans.

Make Easy Read guides for what people can use their plans for.

Check plans are correct with the right person's name and goals before sending them out.



### Easier information

Give us more information about what we can ask for in our plans.

Make it clear where we can get help.

Make everything in Easy Read.



## Fairer planning

Talk to us about draft plans so we can get it right the first time.

Give us more time and help to plan.

Tells us why you have said yes or no to supports we asked for.



## Respect us

Respect participants.

We are not here to make profits and rip off the system.

Give choice and control back to the participants by making the NDIS easier.



## Support our decisions

Supporting our decisions is 1 way to respect us.



It is good that the NDIS has a supported decision making policy now.

We like that it is in Easy Read.

We want to know how it will work:



- People still need help to learn about supported decision making.
- Is there training we can go to?
- How can we get more self advocacy skills to speak up about decisions?
- Will we get decision making funding in our NDIS plans?
- How do we use this funding?

### Check in with us

LACs and Planners should check in with us.

There should be more follow up to see that our goals and supports are still right.

NDIS should offer workshops to help people get the supports and information that we need.





## How LACs and Planners work

LACs and Planners should

- Listen to what we have to say about our lives and our goals.
- Get more training to understand people with disability better.
- Ask us the right questions so we can tell you what we need.
- Explain funding categories and what different supports can help us with.
- Answer our questions.



## Better support coordination

Support coordinators can help us where planners and LACs cannot.

More funding for support coordinators.

More training for support coordinators.



### **Support us to use the system**

Help us to understand and use the NDIS system.

Especially people who do not have family and friends that can help them.

### **Better communication**

Ask us how we communicate.



Tell us what it all means and help us understand it.

Tell us about what is going on if there is a wait for plan reviews or funding.

Communicate with us more about funding in a way we can understand.

Carla told us



“If NDIS are going to change something, they should tell you how long it’s going to take so that you don’t get stressed that you haven’t heard. Tell me it’s going to be 3 weeks and then stick to that or update me.”



## **Stop funding cuts**

Stop cutting our funding.

Stop taking away our funding if we could not use it all in that year's plan. We need it.

There are lots of reasons why we didn't use the funding.

For example long waiting lists or not enough good providers.

Without funding our independence is taken away.



## **Treat us as individuals**

Get to know us.

People with intellectual disability are not all the same.



## Shorter wait times

Fix wait times for

- Plans
- Home and living decisions
- Reviews
- Change of circumstances
- Equipment
- Assistive Technology



## Fund 1:1 supports

We need enough funding for 1:1 supports, not just group supports.

Group supports take away our choice and control.



## More screening for workers

Make sure workers have the right training to support us properly.



## Better support for people in rural areas

People need transport funding to access the services that they need.



Funding should be worked out based on your location and how many services are available in the local area.

There needs to be more providers in rural areas.



## Fund the supports we value

Fund the supports that we value in our lives.

For example being part of mainstream community activities like a local sports club.

This is what helps us with our goals.



## Fund support when we travel

Fund support workers to help us with travel if it fits with our goals.





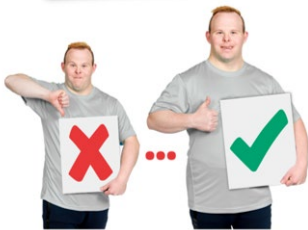
### Cheaper therapy

Stop providers from making therapy more expensive so our funding can last the whole plan.



### Reports

Fund reports and assessments so we can afford them.



Stop asking us for so many reports.

Intellectual disability does not go away.



### Easier access

You can make it easier for us to access the NDIS by not asking us to give so much proof of our disability.

Talk to other government systems who already have proof of our disability, like Centrelink.



### **Make the system fair**

Some people get lots of funding and other people don't get enough.

The NDIS needs to be fair for everyone.



### **More support for participants turning 18**

Help us to understand the big changes coming up when we turn 18.

Give more support and easy information to young people who are turning 18 soon.

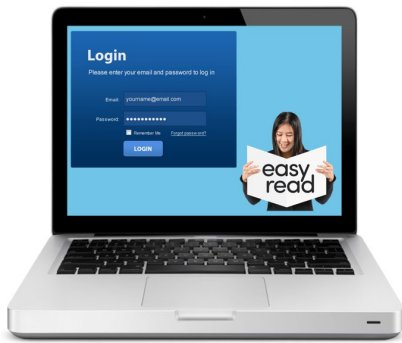
Help us transition to an adult NDIS plan.



### **More help finding and keeping a job**

NDIS should fund more supports for finding a keeping a job.

Especially mainstream jobs.



## Make it easier to self manage

Make the portal easier and give us more tips about how to use it.

Give us more Easy Read information about self management so we can have choice and control.

## What families told us



Some family members told us what it is like to support a loved one on the NDIS.

This is what they said:

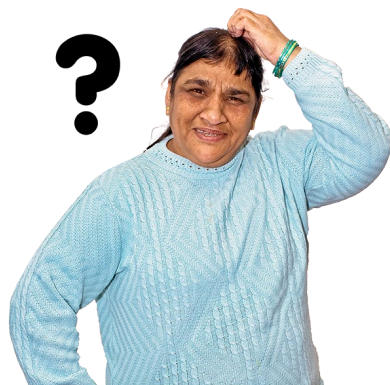


“The NDIS has the power to break families - it causes increased stress and anxiety and it can leave families feeling isolated and vulnerable. We are so busy supporting our child/person that requires care, that we don’t have the opportunity to live our lives.”



“It can be SCARY.”

“It is such a difficult system to understand that it causes anxiety.”



“Some families don’t use the funding to the best capacity as they don’t understand how to use it.”

“It is very difficult for families to understand the system and people with intellectual disability have limited to no hope of understanding it.”



“Some people get ok plans one year and then terrible plans the next year with no reason for the reduction. The funding seems to keep getting reduced yet the complexities of the disability and the needs for the participants increase.”



“Power is taken away from the individual and handed to the supports or families which reduces the participant’s independence. Families feel as though they have to oversee the whole process because it is so difficult to understand.”



“As a family member we are sick of fighting the system, people who don’t understand and don’t have any knowledge of the complexities of disability. The older we get as family members the more afraid we are of leaving our kids to try to fight this system on their own.”