

**Submission  
No 120**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** NSW Council for Intellectual Disability Advocacy Group

**Date Received:** 31 July 2018

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NSW Council for Intellectual Disability

Advocacy Group submission to the

**Inquiry on Implementation of the National Disability Insurance  
Scheme and the provision of disability services  
in New South Wales.**

“Too much red tape, too many steps, too many papers, too many workers who don’t know what they are doing. It is a mess!”

## What is in this submission

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Some words in this paper are in “purple”.

These are words people with intellectual disability have said.

## Dear Committee Members

We are the Advocacy Group at Council for Intellectual Disability (CID).

All members of the Advocacy Group have intellectual disability.

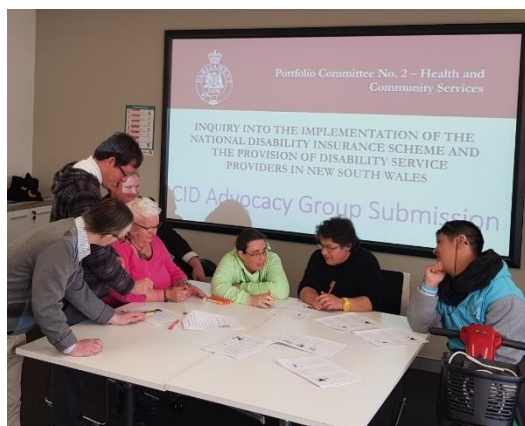
We meet every month to talk about the big issues.

We work to make things better for people with intellectual disability.

We like to run campaigns to change things.

We wrote our submission together.

CID staff helped us to put the words down onto paper.



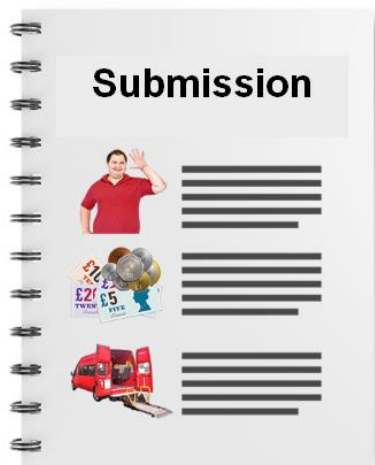
## What our submission is about

It is too hard to look at all the issues and terms of reference.

Terms of reference means the issues the Inquiry wants to hear about.

We will talk about

- Choice and control
- Workforce issues like staff
- State services like housing and TAFE
- And other things we think are important



We have made our submission in Easy Read so lots of people can understand it.

Easy Read uses everyday words with pictures.

Would you like to talk to us about our submission?

We have a lot to say. We would be happy to talk to the Inquiry.

Call us on 02 9211 1611

Or email us [advocacy@nswcid.org.au](mailto:advocacy@nswcid.org.au)

Thank you for reading our submission.

**From CID Advocacy Group members.**

Shannon, Steven, Charlene, Anthony, Tara, Jack,  
Fiona, Quang, Judith, Roxana and Michael.



## Good things about the NDIS



The NDIS is good at responding to some needs.

There is a bit more choice and control.

But some parts of choice and control have got worse.



The NDIS is giving more people a go.

There is funding to help people get out and about and learn new things.

“It helps you to take some risks and give it a go”.



“It helps me to learn how to cook and clean. It is much better to learn from a support worker than your parents”.

We like the NDIS but some parts need to change.

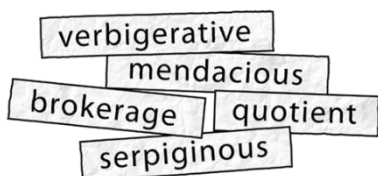
# Things that could be better about the NDIS

## Plans are confusing



We do not understand what is in our plan.

The plan uses big words and is not easy to read.



“They need better information so we can understand. We need our plans in easy read”.



The plans are not always good quality.

“The plans need to be quality and reflect people’s aspirations and passions”.





They do not check with us if they got the plan right.

“We need a draft plan first. Be clear when you can not use the money for your goals”.

“They put the wrong information in your plan”.

We have to ask for a review if they get the plan wrong.



Reviews take a very long time which makes us very scared.

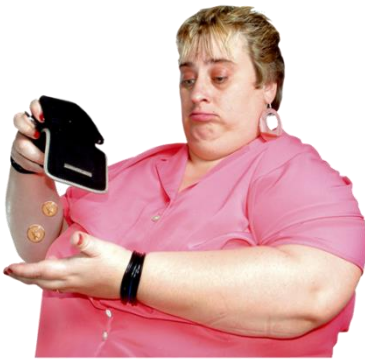
Sometimes we have to wait more than three months.

## Funding is confusing



People do not know how much money is left in their plan.

You can spend up all your funding and not know about it.



Sometimes we can run out of funding.

“Some people are running out of money very quickly. This means the planners don’t understand what to put into our plans”.



Service providers can take funding and not tell you.

“I don’t trust providers. They try to keep things secret like how much funding they take. I don’t know what is going on because the portal is too hard and my plan is too hard to read. Feel I am being cheated”.



The portal is too complex and hard to work out. The portal is on the internet and tells you how much funding you have left.

It is hard to use a computer. The Portal is on MyGov and very hard to use.

“We can’t remember passwords. We don’t want to use a password. They need to make it easy for us to use”.



The NDIS is about choice and control but there are lots of limitations.

“There is not enough flexibility in the funding. You get limitations constantly. Then you can’t even spend the money and have to send it back”.

“I had to send back \$15,000 to the NDIS”.



Many people are scared they will lose funding in their next plan because they did not use it.

We want to use the funding but the NDIA does not make it easy.

## Mental health



We need more funding for psychosocial disability. Sometimes they call this mental health.

“Mental health issues don’t disappear. Some mental health issues are permanent”.

I needed a psychologist and the NDIS funding had run out. I then got a Mental Health Care Plan but now I have to pay money to see her”.

“The NDIS gave me funding to see a psychologist but the funding ran out”.

## Assessments



Getting the NDIS is hard.

“Proving your disability for funding is hard for people. Hard because people have to fork out the money for assessments”.

The NDIS should pay for it not us.



There are too many assessments to get the NDIS. Too much paperwork.

The NDIS told us they would stop assessments over the phone.

But they are still happening.

They ask us very personal questions like if we can have a shower.



We do not like to talk about these things with people we do not know.

“We need people to talk to us face to face. We will understand more that way”.

## NDIS workers need more training



NDIS staff are not always good at their job.

The NDIS do not take time to listen and care.

NDIS Plan Managers are not flexible.

“They are not offering me what I want.  
They are offering me limited options.  
There is less choice and control than  
before with ADHC”.

ADHC is the NSW Department of Ageing,  
Disability and Home Care. It has closed down  
now.



Staff keep changing. No one tells us when  
they change the staff. No one tells us how to  
contact them.

“I had one staff member that I liked and  
then I found out that I have a new plan  
manager. I don’t even have their  
contact details so I can’t call them.”

They need to communicate better with us.

## Information



The NDIS gives us confusing information.

“One time they tell you something is ok,  
the next time they change their mind”.



One time they sent us a two page letter.

It was confusing. We got scared something  
went wrong.



It would be better to put letters in Easy Read.

## Local Area Coordinators



Local Area Coordinators (LACs) can be bad.

A LAC is meant to help you understand the NDIS.

They do not have good training to work with us.

“You might get lucky and get a good LAC, but you might also have bad luck and get a bad one”.

All LACs need to be good.



One of us had a LAC that did not say what was in the plan.

“I didn’t know what was in my plan. They didn’t talk to me. I then got a new LAC and they told me I had \$9000 in my plan I didn’t know about.

I was stuck at home and could have used the funding”.

“The LACs say they will check up on you and they never do”.



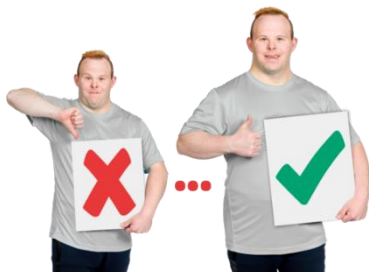


It should not be that leading a good life depends on a good NDIA worker or LAC.

You need to make sure that LAC and NDIA workers have good training.

All of the workers like LACs and planners need good training from the start.

Let us train them. We can tell them how to do a good job.



They can improve with better training.

## NDIS transport



“Transport is our ticket to the community. We want to be out in the community but many people can’t”.

There is very little transport funding in the NDIS.

“I need more funding so that I can do my shopping. I need to take a taxi to go shopping and this uses up all my transport funding in one trip.”

The NDIA told us that Transport Allowance would be on-going but now it has changed.

“I was told that you need to get a letter from your doctor every year to say you need Transport Allowance.

Why do we need to get a new letter every year and prove ourselves”?

The NDIS money does not pay for Community Transport.



The NDIS is asking our family to take us places now. This means they need to stay at home more.

## Impact on state services



The NDIS does not work well with state services like.

- Housing
- Education
- Health

## Housing



The NDIS does not help us with housing.

We want the same things as everyone else like to live independently.

We need more public housing.

Housing and living independently is hard.



“Need to start planning for when my parents die and I need to live independently. How can the NDIS help with that? Who helps with that if there is no housing to move into”?

The NSW Government needs to do more and build more housing for people with disability.

## TAFE and education



My plan can not be used to achieve all of my goals like education.

TAFE is not inclusive yet and do not give us enough support.

The NDIS says they will not fund support at TAFE.

TAFE is not giving us enough support.

More people with disability want to go to TAFE now to learn skills but they can't.

The NSW Government needs to think about putting in more support for us at TAFE.

## Health



Going to hospital is very scary. People with intellectual disability need the right support.

But the NDIS says they will not fund support workers at hospital.

They say it is the job of the NSW Government to make hospitals inclusive.

This means things can go very wrong.

Nurses and doctors do not know how to work with us.

They need more training.

The NSW government needs to put more money and time into making hospitals inclusive.

## Advocacy funding



The NDIA said they will not fund disability advocacy.

Advocacy helps us to speak up about the big issues. Advocates also help us when things go wrong.

The NSW Government tried to silence us. They wanted to shut down CID and other disability advocacy services.

We had to run a campaign to stop this from happening. We won the campaign but the Premier said she would only fund advocacy for 2 years.

Without advocacy we will be silenced.

We need advocacy when things go wrong with state services like housing or health.



“We need disability advocacy to make sure people with disability in NSW have a voice, someone to turn to when things go wrong”.

## Recommendations



Recommendations are ways you can fix things.

You should remember our recommendations when making up your mind about how you will fix the NDIS in NSW.

1. Put plans into easy read so we can understand what is in our plans.
2. Make sure you check in with us before you give us a plan. We do not want to ask for a review and wait a long time.
3. Stop providers from taking our funding without telling us.
4. Make sure LACs tell us what is in our plans and support us better.
5. Make the NDIS portal easy for us to use.
6. Take the portal away from MyGov.
7. Make sure NDIA planners give consistent information.
8. Give us more flexibility to use the funding.



9. Make the NDIA pay for assessments, not us. Many people will miss out if they have to pay.
10. Less red tape, less paperwork. Make it simple.
11. Stop telephone assessments. They are silly questions and are not appropriate.
12. Make sure all NDIA staff and LACs get good training to work with us. Let us train them.
13. Stop the NDIA from sending out confusing information.
14. Make the NDIA put everything in easy read.
16. Make the rules for NDIS transport better and easier.
17. The NDIS does not help us with housing. The NSW Government needs to build more public housing for us.
18. The NSW Government needs to make sure TAFE gives us more support.
19. The NSW Government should fund disability advocacy into the future.

