



**NSW Council for
Intellectual Disability**



Speak Out Reach Out Committee



**Productivity Commission
Inquiry into Disability
Care and Support**



**Comments on the
Productivity Commission
Draft report**

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Some words in this paper are in purple.

- They are in the Words List.
- It tells you what the purple words mean.
- This is on page 50.

Some words in this paper are in green.

- These are words people with intellectual disability have said.

Some words are in yellow boxes.

- These are very important bits.
For example

We need chances to learn to speak up

Intro letter

27 May 2011



Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2061



Dear Commissioner Scott,

The Speak Out Reach Out Committee (SORO) is happy to be making another **submission** to the **Productivity Commission**.

SORO is part of the New South Wales Council for Intellectual Disability (NSW CID).



Our job is to help NSW CID focus on what is important for people with **intellectual disability** in NSW.



- Thank you for reading our first submission.



- It was great that you came to talk to us about the **inquiry**. We are glad that you made the time to do this.

Now I get it!



- We have talked to lots of people about our lives.
But they have not always listened.
We felt that you really did listen to us.

- We are very pleased that you have put some of the things we said in your report.

- We hope that more **government departments** can work as well with **PWID** as you have.

I want a say
on the NDIA!



- If an **NDIA** gets set up we hope they include PWID too.
Especially when they are making decisions.



We had a good look at the draft report.

- Our submission talks about some of the things we liked in the report.
- We think an **NDIS** could really help us to have a life.

Support for social things

My plan

Support to reach goals

Things we like

- **Support** for social things. We talk about loneliness a lot
- Making plans for your life
- Having support to reach our goals. We thought this was great.

Advocacy

Assessments

Learning to plan

Things we worry about

- How we will get **advocacy** and **self-advocacy** if we need it
- How **assessments** will work
- How we will learn to make plans

SORO hopes that you will think about our ideas.

We hope you will use these to make your next report even better.



We would be happy to meet with you again if you would like to talk to us about our submission.

Kind Regards,

The Speak Out Reach Out Committee

- Roxana Beder
- Michael Bartels
- Pamela Fayers
- Geoff Fayers
- Micheal Herdman
- Fiona McKenzie
- Michael Smith
- Michael Sullivan
- Kim Walker
- Shu Hua Chan

What we liked about the draft report



SORO felt that the **Productivity Commission** really listened to us.

Lots of things that we said in our 1st **submission** were in it.
These are that:



✓ **PWID** should be included in an **NDIS**

NDIS Steps



✓ A new system should be easy to use



✓ It should be very easy to find **information**



✓ The **community** should be more disability friendly

These are all very important
It is great they were included.

We said a lot about support.

We are glad the **PC Report** has said some of these things too.



- ✓ That people would know that they could get support if they needed it



- ✓ People can choose to be in charge of their support



- ✓ People will be able to set **goals** for their lives



- ✓ The support they get will help them to reach these goals



- ✓ The type of support people can get suits their needs



- ✓ Support should come from the community, not just disability services



- ✓ There should be support to help with making decisions and choices



- ✓ Support could be used for social things



- ✓ There should be support at different stages of life



- ✓ We should be able to get support early in life



- ✓ We should get support with small things, to stop big problems later



- ✓ We should get support if there is a **crisis**



- ✓ Adults should get support to live away from their families if they choose to

These ideas are all very important.

- ✓ They could give people lots of **opportunities**
- ✓ PWID will have the chance to set **goals**
- ✓ PWID will be able to have a plan for their lives
- ✓ PWID will have support to reach our goals.



Lots of us have never had these chances before.

There will be a lot to learn.

It is exciting!



We talked a lot about jobs in our submission.

We are glad that the report says that being able to work is important.

We agree with the report that



✓ There should be more help for **PWD** to get and keep jobs



✓ There should be more done to get employers to give PWD a job



We liked that there was an **Easy Read** Report made.

It is really important that we can understand what is happening.

We want to have our say to the **PC** about the **NDIS**.

One of our Members said:



If they get bad advice, they will make a bad decision and we will have to live with it!

The **Easy Read** report

- ✓ helped us to have our say
- ✓ helped us to make choices
- ✓ Emily's story was like real life. This helped us
- ✓ It had steps and actions in it
- ✓ It helped us understand.



Making an NDIS work for us

There are things that many people will need to make each step of **NDIS** work better

The main things are:



- **Getting info**



- **Support at every step**



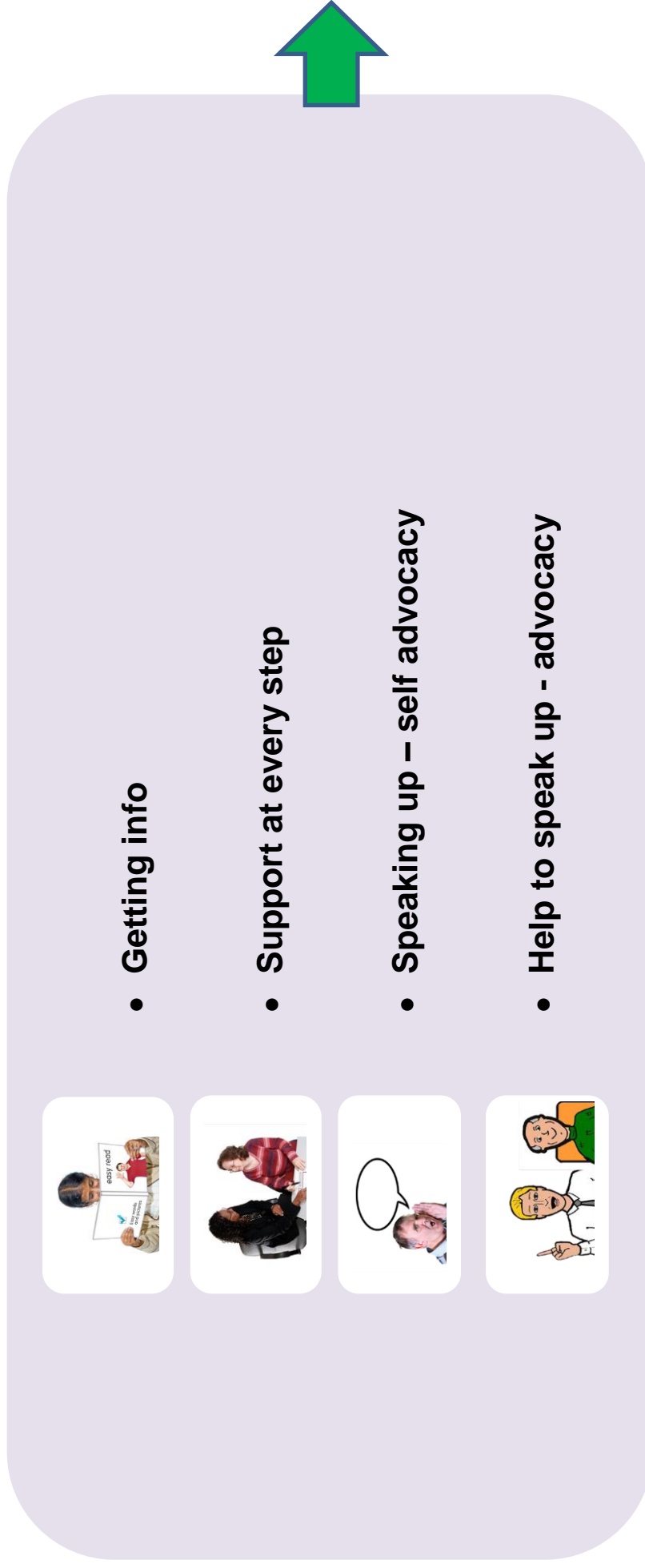
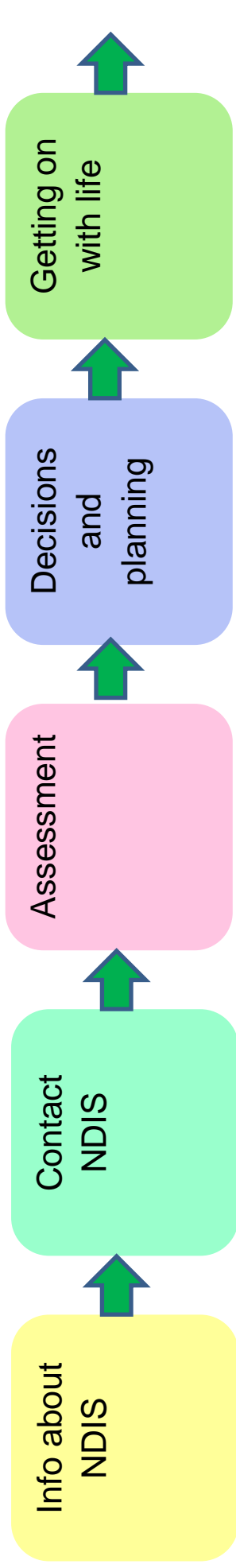
- **Speaking up skills - Self Advocacy**



- **Help to speak up - Advocacy**

**There must be ways to make sure these happen.
It could be part of NDIS.
It could be outside of NDIS.
But there must be plans for them!**

Making NDIS work for us



Getting info



To do any of the steps, you need

- The right info
- In the way you can understand



“Just because it is in Easy Read, doesn’t mean you understand it!”

Many people need **support** to get what it means.

Many people do not have support.



The info must get out to people who

- Live by themselves



- Are homeless



- Are in jail



At every step, **NDIS** people will be talking to **PWID**.

People who give info should

- Be trained in communicating with PWID



- Have enough time to spend with you



- Understand some special issues of PWID



- Know where to find support for you to take the next steps

Even if the info is easy,
working out and doing the next steps can be hard.

Support at every step



To do any of the steps, most people will need support.
Even if they live by themselves.

It will take a long time to learn about

- Changes
- How things work.
- What to do next



**Even if people have self advocacy skills,
it still can be hard to learn a new process.**



It's good to have time to

- Get to know people
- For them to know you





Too many people in the steps is not helpful.



We need a chance to build trust.



Speaking up – self advocacy



To do any of the steps in **NDIS** you need to know

- What you want
- Your **rights**
- How to speak up about it.

People are at different stages of getting these skills.

Many people are still at the start.

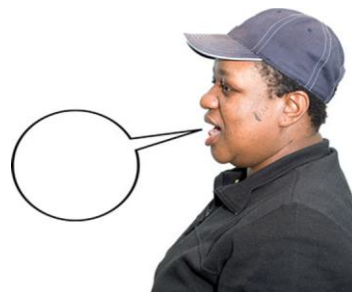
They need extra chances and help to learn.



For example, training.

There must be chances all through your life to get these skills.

NDIS should work out how people can get help for this.



Q How can people learn self advocacy?

A It won't happen by itself.

I know what is best for Anne.



Self Advocacy Sydney says

“For many people with intellectual disability

- Someone else has made decisions for them most of their lives
- They are not given a chance to learn, including learning from their mistakes
- They want to speak for themselves
- And make their own choices about their lives
- Through a **self advocacy group** they can work together to change things”

I won't do that again!



I can tell you!





Self Advocacy Sydney trains people in

- Rights, **responsibilities** and **consequences**
- Disability service **standards**
- Meeting skills – being part of a committee
- Self advocacy
- Relationships
- Money skills
- Getting support to speak up

**Self Advocacy Sydney can't do this for everyone who wants it.
They are not big enough.
They do not get enough money.
There should be ways for more groups like this to start.**

Help to speak up - advocacy



Many people want to speak up for themselves, but they

- Are not listened to
- Are scared
- Get bullied
- Can't speak



People from services or the community might

- Treat them unfairly
- **Discriminate**
- **Neglect** them
- **Abuse** them



**Bad things can happen to people.
Even in a new system like NDIS.
There will always be a need for help to speak up.**



- Some people do not have family or friends to advocate for them.



- Sometimes family are not the best advocates for them.



- A paid advocate is sometimes needed.

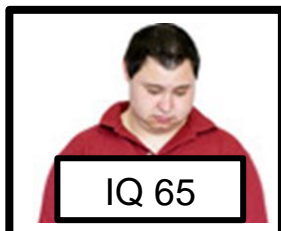


- Many people don't know about **advocacy services**.
Or they can't get an advocate when they need one.

There must always be ways to get an advocate if you need one.

The NDIS must think about how advocacy can be there.

Assessments



We know that to get support from NDIS we need to be assessed.
But some of us don't like it!
We think we will get **"put in boxes"**.

This means people might think of us as

- A number
- A label
- A category

People think bad things about you.
You think bad things too.
It can keep you down.



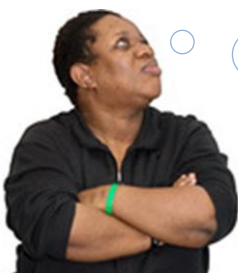
"You take a long, long time to get out of boxes. You want to get to the star shining up above. If people keep putting us in boxes and closing the lid we can't see it and get there"



We looked at assessment questions.
These questions can make people

- Upset
- Angry

Questions can be easily misunderstood.



"It's very personal!"

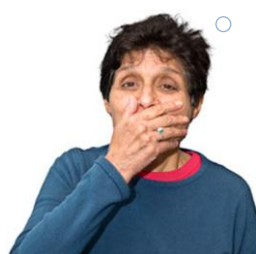
"What are you trying to
get out of me?"



"People might clam up"

"Some people are embarrassed to say
they need help"

"We feel judged"



"In my culture people do
not talk about things that
might upset"

There must be cultural awareness.

There must be interpreters.

And there should be ways to make assessments better.

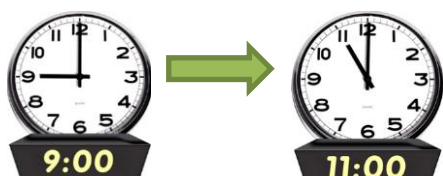


Assessments should be **flexible**.
And meeting 1 time will not be enough.

- There should be different ways to talk about yourself
- It should be in a way that makes sense to you



- Your support needs can show through from your story
- This can help build up a clear picture of who you are.



“You need time and support to think and tell your story”



Assessments are very draining.
They will be hard for people with intellectual disability.
They will be hard for assessors!

Getting it right

It will be hard to get it right for everyone.
There are lots of things to remember in
assessing people:

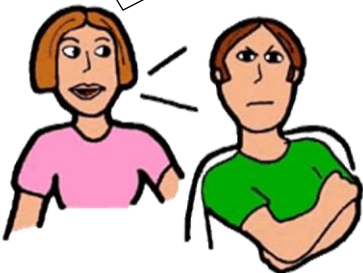


- Has the person had support to get ready for it?



- Does the person have support during it?

Pete could never do that.
He doesn't know. We do.



- Do they have the **right** support ?

“This is what I call ‘ruffling some feathers’. It is really important that people with intellectual disability take the lead in speaking up about their own lives”

I can't think straight
right now.....



- Is the person showing their ability?
They could be
 - scared
 - shy
 - low
 - sick
 - in crisis



A case manager

Some people think a **case manager** should be there from the start.



Private business

- Will our info be private?
- If there are a lot of people in the steps,
how can it stay private?



Making room for change.

We will always have an intellectual disability.
But we **can** learn and grow.

“ As you get older you improve”



Down the track

“People get an idea that because you have intellectual disability you can’t learn and be given responsibilities. You CAN do so much, don’t let anybody say you can’t do it!”



People will change.
What if you can’t get what you need from your package?

The NDIA should make sure assessments

- Don’t keep people down
- Are a good process
- Can be looked at again when you need them to be

Decisions and planning

I know what is best for Anne.



Starting Out

Many people have always had decisions made for them.

They have not

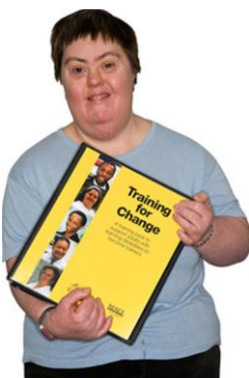
- had a say before about big things
- seen what happens next
- learned from good and bad results

dreaming



Many people will find it hard to dream. They might rely on other people at first.

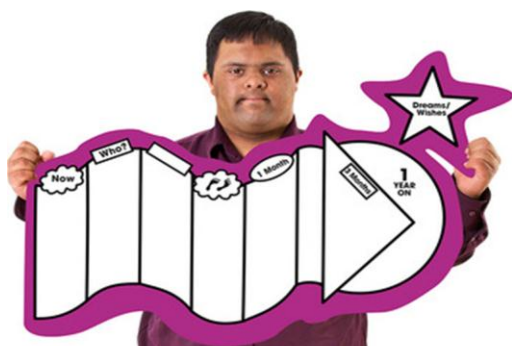
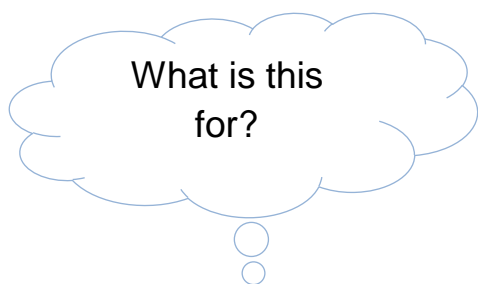
“Little by little they could get their confidence up.”



People will learn by doing. But they also need training to build the skills.

NDIS should make sure PWID have extra chances to

- **Learn about decisions and planning**
- **Take as much control as they can**



Thinking ahead

We thought about what it would be like to plan ahead:

"It can take a long time to get used to things, especially when there are new things to work out."

"It is very complex stuff"



"It can be hard to predict what you need"

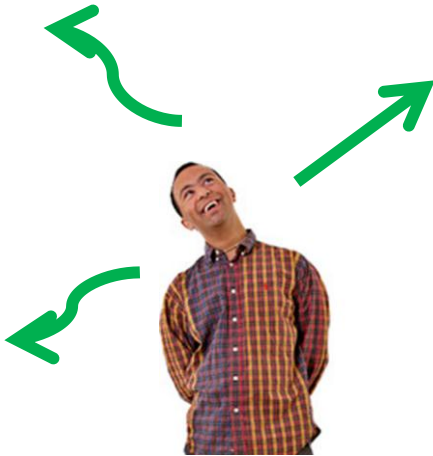
This means It's hard to see what might happen in the future



"You might not know what you need to be asking for"



At first taking charge might be scary.



Building on skills

Over time your abilities can grow

“When you are a teenager, you are not mature.
You don’t have life experience.
You don’t know what you want.
You might stay on 1 track or need to change tracks”



Learning by doing

PWID want a chance to try.

“We want help –but we want to trial how to use the money-but we want to *learn* how to do that”



Training

Getting training is 1 important way to build skills.

“I am not capable yet, but they can teach me”

“You have to learn to crawl before you can walk”

My mistake!
Let's fix it.



Trial and error

"Trial and error is good. It's hard, but you've got to try it"

"Power and choice is responsibility, which I like"

"Learning to problem solve"



Have faith in us

"You know you are trusted when you are given your own keys"

My day

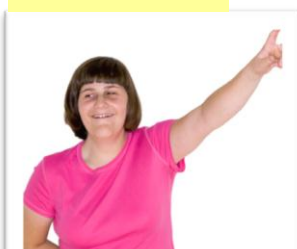


Changes and life-stages

"There should be ways to teach people planning from a young age"

Also

My year



"Some people will be learning to make decisions later in life"

"Attitudes to planning changes through your life"

What support is good for decisions and planning?

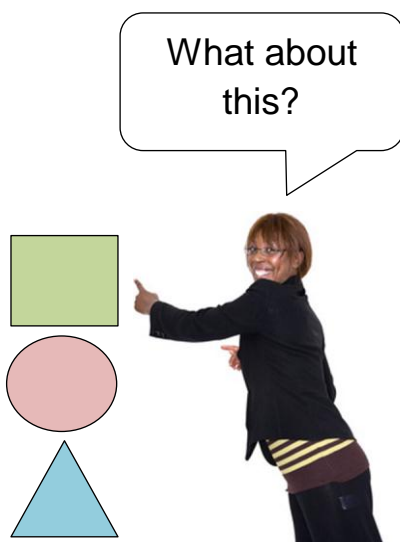


A person who

- Has time to get to know you



- You feel good with
- Is good at talking and listening



- Gives good **guidance** but is not in charge
- Believes PWID can do things.



Some people like the idea of a coach.
A person who

- Works beside you
- Is positive
- Knows how to set goals and get to them



Worries about legal supports

Some people are worried.
Someone has a legal right to make decisions for them.
This could include NDIS money.

?

?



Who decides

- What you can do yourself?
- When you need help?
- What you can't do?
- Who can take charge for you?
- What they can take charge of?



My plan

Example:

Tim lived with his dad.

Tim had a job and friends.

He looked after his money with a bit of help.

He made his own decisions about things like

- Going out
- Buying clothes.



Dad moved to a nursing home.

Tim went to live with his brother Dave.

Dave took charge of all Tim's money.

He decided when and where Tim went.

Tim didn't even get enough food.



Dave told Tim to sign some legal papers.

- How will the NDIS know when someone takes over when they shouldn't?
- What will the NDIS do to protect the rights of PWID?

Making the community more disability friendly

We think this is important.
We want to be included.
Just like everyone else.

Community



The report says that

- 1 job of the **NDIS** would be to make the community more disability friendly

We think **PWID**

- Should take part in campaigns or projects to do this
- Are the best people to show others what PWID can do.



Person centred planning



We show people by example what we can do.



For example:

- As **ambassadors** in the Don't Dis my Ability campaign.



- As guest speakers in **community education**.

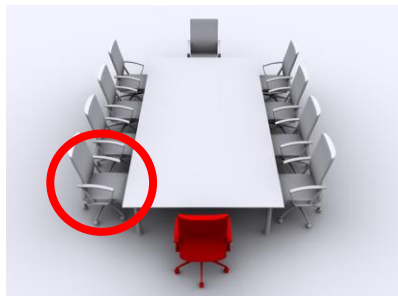


- Sharing our stories with others

We like to be involved from the start with projects and campaigns.

It means that the right message gets out.

Who will part of the NDIA?



We think at least 1 **PWID** should be on the **Governance Committee** or **Board** of the **NDIA**.

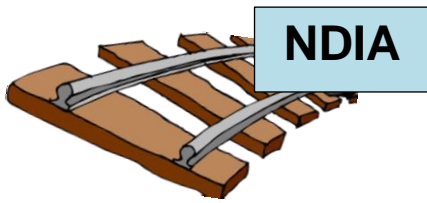


They would be involved in decision making. Not just an **advisory group**. They should be a representative of **PWID**. They might be from a **peak body** or an **advocacy group**.

They would help make sure the NDIA and the NDIS



- Know about **intellectual disability**
- Know how to **communicate** with PWID
- Know how to work alongside PWID
- makes good choices about how things work.



They would help keep the NDIA on track!



They might need some **support** to do this.

For example

Most of the Board Members of **NSW CID** have an **intellectual disability**.



NSW CID has a **Participation** worker.
This person helps PWID to take part.

They do things like



- Make Easy Read Minutes



- Help PWID prepare for meetings.



The Board also works as a team to make sure the voices of **PWID** are heard.

NSW CID would be happy to give the NDIA more info about this.

Questions for the Commissioner



We talked about lots of things after we looked at the **draft report**.

We could not say all of them in our **submission**.

This was for 2 reasons



1. Because there was not enough time.



2. We did not know enough about the topic.

We still thought that they were important.
We still wanted the **PC** to know about them.



Ageing

- What happens after you turn 65?
- Aged care is different to disability care. We are not sure aged care will meet our needs.



Health

- PWID do not always have great health.
- How will the **NDIS** work with the health care system?



Mental Health

- Things can be really tough if you have **ID** and a **mental health problem**.
- The health care system and the disability services don't deal with this well.
- It can be hard to get help.
- Will the NDIS make this easier?

How we put this together



Lots of people have asked how we do our work.

We hope that by sharing this other PWID will learn to speak up too.

These are the steps we took to write this **submission**.



Step 1 - Learning about it

- Staff helped us look at the key points from the Standard **Report**. We read the Easy report too
- Checking to see if it said things we said in our 1st Report
- Asking questions
- Working out how much time we had to do it

Step 2

•Group Work

Step 2 – Group Work

- We worked as a big group to share our ideas
- We did lots of **brain- storming**
- We shared stories. This really helps us to make sense of things
- We used pictures too
- We talked about what we would like to focus on
- We also worked in small groups to talk about things we were interested in
- We met a few times. This meant we had time to think about things
- We asked lots of questions
- Some people who could not take part in the groups shared their ideas.

Step 3

•Putting it together

Step 3 – Putting it all together

- We went over all our ideas
- We talked about what was the most important
- We decided to focus on a few things
- We then asked staff to put our ideas onto paper

Step 4

•Checking It

Step 4 – Checking It

- We checked that it meant what we said
- We changed some bits
- We asked Self Advocacy Sydney to look at the bits about advocacy
- Making sure the pictures were right

Step 5

•Sending It

Step 5 – Sending it

- Printing it
- Sending it
- Putting it on the internet.

What happened after our 1st submission?

This is really
important work.

Well done on
speaking out for
PWID

This report is excellent.

It is so good you made it
easy to read

Congratulations SORO!

This is fantastic work.

PWID that read our report said:



- They thought some of the stories were like their lives
- The issues we talked about were very important to them too
- That it can be hard to speak up about things



BIG Voices about BIG Change:

Getting heard about the BIG Issues

We talked about our report at the VALID Having a Say Conference.

There were over 1000 people with disability at the conference.

We did a talk called “Big Voices about Big Changes – Getting heard about the Big Issues”.

PWID who came along said:

- they found **life transitions** hard too
- they did not have **advocates**
- other people made decisions for them

CDS

**Centre for
Disability
Studies**

We talked about our report at the University of Sydney.






This was for the Centre for Disability Studies. They were running a course on **inclusive research**.







Some things we said were:






- **“It is good to have the chance to speak up”**
- **“If we didn’t do this how could we get the word out to the government?”**
- **“This stuff takes time”**
- **“It has helped people out of their shyness”.**



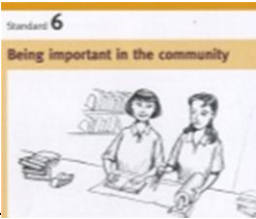










Word list








Word	What it means	Picture
Ability	What you can do.	
Abuse	Is when someone treats you badly. It could be things like <ul style="list-style-type: none"> hurting you with words hurting your body scaring you to control you 	
Advisory group	A group of people who are asked to give their ideas on a topic.	
Advocacy	Someone finds out what you want and speaks up for you. An advocate works with you to help you sort out your problem. That person will speak for you and help you to speak for yourself. They will help you to get over the barriers.	
Advocacy services	Are places that have paid advocates. They are places people can go to when they need help to stand up for their rights.	

Assessment	A way of working out what people can do, what they want to do and what support they might need to do it.	
Board	<p>This is a group of people who are in charge of an organisation or company.</p> <p>They make decisions about how the organisation does its work.</p> <p>Members of some boards are paid, others are not.</p>	
Brainstorming	<p>A group of people say their ideas about a topic or problem.</p> <p>They try to come up with things together.</p>	
Choice	<p>Being able to pick things.</p> <p>Having different things to pick from.</p>	
Committee	A group of people who are chosen to work together and help a larger group of people.	
Community	<p>A group of people you belong with.</p> <p>We talk about living in the community.</p> <p>This means alongside people without intellectual disability too.</p>	







Communication	How we share info, ideas and feelings with each other.	
Conference	A group of people with a shared interest get together. They share new ideas and look for ways to make them happen.	
Confidence	Knowing you have the skills to do something. Feeling good about what you are doing.	
Consequences	What happens after you make a choice and take action on it. For example, Tom spent his money on a new DVD. He didn't have any money left for lunch. He was hungry all day. He couldn't think straight.	
Crisis	When you <ul style="list-style-type: none"> • have a bad accident or get very sick. • When you have no money for things like food, bills or a place to live • When you lose your supports. <p>Something must be done fast to help you get out of trouble.</p>	






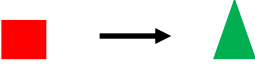
Cultural Awareness	<ul style="list-style-type: none"> • Knowing what is important to people from lots of cultures in Australia • Knowing that some things are the same as your culture, and some things are different. • Respecting this when working together 	
Decision Making	<p>This is making choices about things. It is about picking what you want to do. It may be about:</p> <ul style="list-style-type: none"> • something small, like what to eat. • Something big, like where to live 	
Disability Services Standards	<p>These are the rules that services that support people with disability must follow. They are meant to make sure that the services do a good job.</p>	
Discriminate	<p>This is treating someone differently because of something about them.</p>	
Draft Report	<ul style="list-style-type: none"> • You write about what you find out. It is not finished. • You ask people to read it and make comments. • You make changes to it. This might happen more than 1 time. • Then you write a final report. 	
Easy Read	<p>This is making info easier to understand. Using pictures and easy words. There are many people who need Easy Read info</p>	

FaHCSIA	<p>This stands for Family Housing Community Services and Indigenous Affairs.</p> <p>This is an Australian Government Department who plans community supports.</p>	 <p>Australian Government Department of Families, Housing, Community Services and Indigenous Affairs</p>
Flexibility	<p>This means that things can change if they need too.</p>	
Goals	<p>Things people want to do. It is something to work towards. Examples are get a job, go on a holiday or learn to drive.</p>	
Government Departments	<p>Government runs your state or country. It is split into smaller parts or departments For example FaHCSIA .</p>	
Guidance	<p>Support and good ideas from someone you trust. You still get to make your own choice.</p>	
ID	<p>Intellectual disability.</p>	
Inclusive research	<p>Making sure PWID have chances to be researchers. They can look into things that are important to them. They can write reports about it. They can work as a team with researchers without ID.</p>	

Independent	This is being able to look after yourself or do things for yourself.	
Individual Funding	Money just for you, for your support needs.	
Individual Planning	Talking and thinking about the things you want to do in your life. Planning can be about help you may get from disability services. It can be help from your friends, family or other supports like an advocate.	
Information	Facts about something.	
Inquiry	Is a committee of people that looks into something and writes a report.	
Insurance	A way of planning and budgeting to make sure there is enough money for now and the future.	
Interpreters	A person who tells you information in your language.	

Learning	This is working out how to do something and then being able to do it again.	
NDIA	National Disability Insurance Agency. This agency would be set up to be in charge of the NDIS.	
NDIS	National Disability Insurance Scheme. A way of budgeting and planning for disability support for all of Australia.	
Neglect	Not giving proper care and help to someone who depends on you. That person's health and happiness will go downhill.	
Opportunities	Having chances to do things. Having choices to do things.	
Planning	Working out what you want to do and the steps you need to take to do it.	
Productivity Commission PC	Part of the Government. It's job is to find out the best ways to make systems work.	

PWID	<ul style="list-style-type: none"> • Person with intellectual disability • People with intellectual disability 	
PWD	People with disability	
Report	<p>A paper telling others what</p> <ul style="list-style-type: none"> • has happened • you have found out • you think should happen next 	
Responsibility	Something you are in charge of.	
Rights	<p>Everyone has rights.</p> <p>They are about the things everyone should be free to do.</p> <p>These are in laws.</p> <p>An example is the right to vote.</p>	
Self Advocacy	<ul style="list-style-type: none"> • Learning your rights • Speaking up for yourself. <p>There are some groups that help you to learn how to 'speak up'.</p>	

Social	<ul style="list-style-type: none"> • Having friends • being together with people • talking on the phone or internet • going out. 	
Submission	When people or groups put together their views and give them to the government. It is a way for the government to hear lots of different voices.	
Support	People or places that you can go to and get help to do the things you want. These people or places are called supports.	
System	This is an organised way of working.	
Systemic Advocacy	Speaking up about big issues that affect a lot of people. Trying to improve the lives of many people.	
Training	A way to learn something new.	
Transitions	Moving from one thing to another. Example: School to work, or changing houses.	

Where do our pictures come from?

We have used pictures we have bought and free pictures too.



- Photosymbols



- Symbols for Life



- Valuing People (Inspired Services)



- Free Clip Art like Clips Ahoy



New South Wales Council for Intellectual Disability



Address: Level 1/418 A Elizabeth St
Surry Hills NSW 2010



Phone: (02) 9211 1611



Email: info@nswcid.org.au



Web: www.nswcid.org.au