

# Speak Out Association of Tasmania



## Speak Out Members



## NDIS Quality and Safeguarding Framework

Submission, 6 May 2015



**Inclusion Australia**  
acting locally - representing nationally - connecting globally  
*National Council on Intellectual Disability*

Endorsed by

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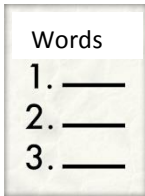
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# What is in this Paper



**Some words in this paper are in blue.**

- These words may be hard words to read
- We have a list of these words on page 29
- This will explain what the words mean



**Some words in this paper are in red.**

- These are the exact words people with intellectual disability have said.

**Some words are in boxes.**

- These are stories.
- We find it an easy way to make our point.
- The stories are real.

**Because it is hard to talk about some things:**

- Sometimes we use our real names
- Sometimes we don't
- We use pictures from PhotoSymbols

# Cover Letter



National Disability Insurance Agency,  
Quality and Safeguarding Consultation Team  
NDISqualitysafeguards@dss.gov.au

We are happy to make this submission to the National Disability Insurance Agency, Quality and Safeguarding Framework Consultation Team and give consent for it to go on the DSS website, [www.engage.dss.gov.au](http://www.engage.dss.gov.au)

We have made our submission “Easy English” so that lots of people can understand it.



## **Who we are:**

We are members of the Speak Out Association of Tasmania.

Speak Out is an advocacy service for people with disability.

We run self advocacy groups that are made up of people who have an intellectual disability.

We talk about things that are important to people with intellectual disability.

Speak Out does individual advocacy, self advocacy, systemic advocacy and family advocacy.

This means sticking up for people as well as teaching people to stand up for their own rights and have a say in their community.

### **What we do:**

- Speak Out Self Advocacy Groups speak out about things that are important to people with intellectual disability (PWID)
- A person with an intellectual disability is on the Board of Management of Speak Out.
- We run monthly self advocacy groups in Burnie, Launceston and Hobart.
- We want to be heard.
- We want to change community attitudes about people with disability.
- We want to show people what PWID can do.



### **Why we wrote this submission:**

- To make sure the voice of PWID is heard.

Thank you for reading our submission.

Regards

Desiree Johnston (Member's President) on behalf of members

Jenny Dixon, Manager



## The main ideas in the framework



We think it is a good idea to have a plan about making sure people are safe when they are in the NDIS.

When we are all in the NDIS we want to get good services.



It is important to us that we are the boss of our own lives.

We should be the ones making the decisions.  
We should be able to choose our services and the way they work with us.

We think the rules should be the same around Australia. If we move we don't want to have to learn new rules again.



It is very important that the government or the NDIA don't try to protect us too much and not let us take risks.

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*"If you don't take risks you don't learn.  
Sometimes you have to get hurt to learn."*

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*"We can't have others take control of our choices otherwise we only learn what they want us to learn."*

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*“Some people are pushy and try and make decisions for you. You should get the chance to try to make decisions, even if you have had trouble before with making decisions about something else.”*

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## Working Together



It is a good idea to work together to manage risk. But there are some things we think the government and the NDIA should know about this.

Not everyone wants their families to be involved in their lives.



Sometimes it is hard for us to say no to our families.

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*"My family treat me like I'm a kid. They tried to tell me where to live. They even tried to tell me not to get married. They are always trying to get me to pay for things. I got an advocate to help me get out of their control. My life is great now."*

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We know it is different for children, but once we are adults we should be in control if possible.

People need to ask us before they involve our families or anyone else.

They shouldn't just assume that we want our families involved.



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*“When I went to do my NDIS plan I didn’t want my mum there. She can be controlling. The NDIA told her about it and said she could come. It wasn’t me. I wasn’t happy that she was there. She had too much to say ..... as usual ...yeah, I’m an adult”.*

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*“I wouldn’t choose family because I have trust issues with them.”*

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Sometimes service providers put pressure on us. It is important to know our rights and have an advocate if we want one.

Shirley lives independently and gets help in her home from a service provider. She has two people help her. The service provider wants to put in a different worker, as one support worker finds it difficult to shower Shirley. That support worker came to Shirley crying saying she didn’t want to lose her shift, she couldn’t afford to lose money because her children would miss out. Shirley is very upset because she thinks it’s her fault.



Services should work with us to make their services better.

We will talk about this later in our paper as well.

But we think that people with disability should be involved in working out what support staff jobs are.



We should be involved in writing [role descriptions](#) for new workers.

## Making sure staff are safe to work with us



We strongly believe that people should have to have a police check to work with us even if they don't work with a service provider.

This should be the law.

We don't know a lot about the Working with Vulnerable People check.

But we think this is probably a good idea.



There should be a [Code of Conduct](#) for all staff who work with us.

This should be clear and easy to understand.

A Code of Conduct for all workers would make it easier for us to know if a worker isn't doing the right thing.

We should know the background of people before they work with us.

Some people go from job to job.

We should be able to talk to their last boss to see if they were a good worker.



Services should have to report bad support workers somehow.

They would have to think about the rights of the support workers though.

But we should know if workers have lots of complaints about them before we use them.



We think support workers could have something like a **'Good Worker's Passport'**.

The Good Worker's Passport could get a stamp in it by their employer if they get a complaint made against them.

It could say what the complaint was about.  
It could also have good things in it like awards or training.  
This could be **voluntary**.



Good support workers wouldn't mind having a passport.  
It wouldn't breach their rights because it is **voluntary**.  
People could choose if they only used people with a Good Worker's Passport.

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*"People should ask me if a staff member is good or not."*

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*"Clients should decide when a staff member is not good".*

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We should always be involved in choosing staff who work with us.

There should always be a person with disability on the **selection panel** when services are employing workers.

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*“Organisations that are accused of abusing people should be investigated. Organisations that allow staff to abuse people shouldn’t be allowed to keep going.”*

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## Making a complaint



Many people had experiences of services listening to their complaints but not doing anything about it.

It's not until an advocate becomes involved that they do something.

Services even lie and say we didn't make a complaint.

There are many times when a service says they have fixed a complaint but it keeps happening again and again.



Kelly is 21 and has an NDIS plan. She thinks the NDIS is good but has problems with service providers over and over again.

Support workers turn up late all the time. They also don't turn up at all sometimes. Kelly has made a complaint to her service provider. They said they had fixed the problem. The next day a support worker didn't turn up at all. Kelly made another complaint. She sacked that worker and got a new one. Two days later the new support worker was an hour late with no phone call to say she may be late.

Kelly changed services. She told the new service it was important to her to have reliable workers. Within three weeks one of Kelly's new workers didn't turn up.

Lindee lives independently but gets ten hours a week support.

Lindee's worker turned up late three times without ringing.

Lindee asked for a change of worker. The first day the new worker was to take her to a specialist doctor's appointment. The worker was an hour late and Lindee missed her appointment.

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*"If people make complaints time and time again and they don't get fixed, there should be somewhere else to go to report them. They (services) should be shut down if they don't fix things."*

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*"It shouldn't be up to us to keep sacking people every day. I just want to get on and live my life."*

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# Quality Services



The kinds of things that would help us decide if services are good quality are:

- Hearing from others – word of mouth
- Visiting them and asking them questions
- Get information from the service
- Looking at their **audit** results
- Knowing if they involve consumers in how the service is run



We think a quality service website is a good idea, but only if it is easy to understand.

It should have a star rating system where each item gets a star rating. They should get rated on things like the number of complaints, consumer involvement and easy to understand information.



There should also be real life reviews from people living with disability.

Many members and clients have been part of the NDAP audit of Speak Out. We think this is a good process.





We get to be interviewed by an independent person.

We can say whatever we want about the quality of Speak Out's service.

Once the results of the **audit** are given, Speak Out show us the report. This report tells us if they are doing a good job and how things can be improved.



We believe all services should get **evaluated** by someone independent.

Anyone should be able to see the results of the audit. This will help people choose a good service.



The audit should cover things like:

- Consumer rights
- Consumers being part of how the service is run
- Complaints
- Independent interviews with consumers and their families
- Consumers being part of worker training and selection

It should be made law that serious complaints have to be reported.

This will help us choose a quality service.



Someone should be in charge of looking at these complaints like a **Commissioner**.

They should have the power to stop these services or people from working with people with disability.

## Knowing your rights and learning is powerful



We know that knowing about your rights makes you more powerful.

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*“We can’t let others take control of our choices otherwise we only learn what they want us to learn.”*

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*“When we make complaints but things keep happening over and over these complaints should get looked at by someone else, someone higher like a Commissioner.”*

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*“One of the things that I think keeps me safe is having my advocate. They (services) seem to sit up and listen then.”*

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Many of our members link their independence to learning about their rights through Speak Out.

Many people became members because they were in an awful situation, things like abuse and being isolated.

After they got the help of an advocate, they then became members and learnt self advocacy skills through Speak Out and other members.



We get peer support through our self advocacy groups. This is very important to us.



People who don't know about their rights get pushed around by family, service providers, workers and other people in the community.

If you know about your rights you might not have the confidence to stand up for yourself to start with.

But because you know what is happening is not right, you can ask someone like an advocate to help you.

If people don't understand that some things are not ok, this is a big risk.



This is why teaching us about our rights is so important.

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*“Standing up and don’t let people take advantage of you ..... it takes time.”*

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*“You know getting taught about my rights is the best powerful thing I’ve done. Getting taught by an advocate who knows about rights is the best. They give you confidence, it makes you feel good, like I can do anything in the world. They’re always on your side .... always.”*

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We know that being involved with Speak Out has helped us to become strong self advocates.

It has given us a chance to do many things like:

- Speaking in front of others.
- Learning self advocacy skills to speak up for ourselves and others through the Road to Success Self Advocacy Training.



- Going to conferences and learning new things and meeting new people.



- Linking us with the community, not just in the disability area.



- Sharing with our peers through our self advocacy groups and at Speak Out conference.

- Talking to the media about what people with disability want.

- Having a say in things like this submission and also local government community plans.



- Talking to Members of Parliament and Ministers about what is important to people with intellectual disability.

- Taking part in community events like Human Rights Week, International Women's Day, International Day for People with Disability, and National Youth Week.

It is important to get information from people you trust.

Those that you don't trust or you don't know really well can rip you off or not be honest with you.



We find it best to learn about things in small groups with people we know, like our self advocacy groups.

We can talk about things, exchange ideas and share experiences.



At Speak Out when you become a member you have **voting** rights.

We vote to elect our **regional representatives** and our Members' President.

This is how we learn about **voting**.

Many people now vote for real even though their parents don't think they should.

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*"Our self advocacy groups and the advocates are great, they listen to us and explain lots of things about politics and stuff, and they make sure our voices are heard in the community. They don't think we're stupid."*

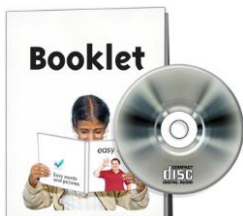
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We should have training in the NDIS.

It should be broken up into small bits. For example planning, transport, employing workers.

People can come and learn about the bits that they are interested in.



All the information about the NDIS needs to be put into ways that we can understand.

Not everyone has a computer or can read.



We like things like the Decisions, Decisions DVD that Speak Out made – <https://youtu.be/WmWO3E1kJT4>

It helps us to learn things like, what is a decision.  
There should be more like this about the NDIS.

It is a problem when people run things about the NDIS and they don't know how to communicate with people with intellectual disability.

Some of our members went to the public meetings about the Quality and Safeguarding Framework.



They didn't understand it because it wasn't explained properly.

This happens all the time.

We need to learn from people who understand and have experience with intellectual disability.



Services need to get lots of input from people with intellectual disability.

They need to ask us how we want to be supported and how their services should be run.

This needs to happen regularly.

## Restrictive Practices



We understand that sometimes, some people with disability need help to be in control of their behaviour.

Sometimes workers and families use [restrictive practices](#).

Restrictive practices should only be done when there is nothing else that can be done.

When everything else has been tried services should have to get permission before they can use a [restrictive practice](#).

In Tasmania there is a [Senior Practitioner](#).

Services have to ask the [Senior Practitioner](#) before they use a [restrictive practice](#).

But this does not always happen.

Our members have many examples of [restrictive practices](#) that have been put in place by services.

No one has been asked if it is ok to do this.

We don't think this is ok.





We strongly believe there should be a law that says Services and support people have to:

- Try everything else first
- Get permission from the [Senior Practitioner](#) or someone else high up like a Disability Commissioner before they use [restrictive practices](#)
- Have a plan of when the [restrictive practice](#) must stop
- Have to report to the Disability Commissioner or [Senior Practitioner](#) regularly
- Have training about [restrictive practices](#)

We think lots of services and support people don't know what restrictive practices are.

Some services say the things they do are consequences but are really restrictive practices.

Cathy lives in a group home with three other ladies. She likes to have lots of hot drinks. The staff said Cathy was drinking too much hot chocolate and coffee so they locked the pantry. They said it was 'the consequences' for Cathy drinking too many hot drinks. No one in the house could access any food because the pantry was locked. This is not a consequence. The consequence would be that there was no more hot chocolate or coffee. This is actually a restrictive practice.



Some other examples that people talked about are:

- Staff putting the door handles on upside down so people couldn't freely move from room to room
- Turning the water off so someone couldn't come home from work and have a bath every day
- Giving medication to make people feel drowsy so they don't yell
- Tying a housemate to the toilet because staff were too busy to stay with them while they used the toilet

## Independent Advocacy



We know that independent advocacy keeps us safe.

Having an advocate that you can call if you are treated badly or if services don't listen is a powerful thing.

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*"I've been with good services and I've been with bad. The good ones aren't scared of advocates, they encourage us to use them. The bad services try to stop you from ringing an advocate."*

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We say independent advocacy because some services say they can be your advocate.

We think this can be a very big risk.

Services won't do the right thing if they are advocating against themselves.

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*"My service says my key worker is my advocate. This isn't right. If she goes with me to work out a problem with them (my service), I always come away thinking I'm in the wrong because that's what they do."*

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Independent advocacy helps us make decisions.

They help us work out what our options are, what choices we have and what are the good and bad things about each choice.

Then we can make a decision that is best for us.



Independent advocacy is important in helping us and our families to make a complaint if we need to.

They are good at working with us and our families if we want our family involved.

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*“My mum said she was at our wits end before she got ..... (advocate) to help. No one was listening to us. She helped us to make a complaint then they sat up and listened.”*

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Independent advocacy is important not just around disability service providers and the NDIS but in general.



Advocates help with things like Centrelink, Telstra, Housing, Police, and Child Protection, going to court, family and abuse.

People with intellectual disability should be and are out and about in their communities.

The NDIS is supposed to make this happen more.



## How we did the submission



**Step 1  
Learning  
About it**



**Step 2  
Talking  
About it**



**Step 3  
Writing  
About it**



**Step 4  
Checking  
it**



**Step 5  
Sending  
it**

## Why we use Easy English:



Speak Out thinks this is really important.

Information must be easy to understand so we can take part fully.

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*"I don't always know what the words say,  
so I like the pictures to help explain it."*

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The Quality and Safeguarding paper is very big and covers lots.

This is how Speak Out did the submission.

**DANA** met with advocates from Speak Out, Advocacy Tasmania and ACD (Tas) to talk about the Quality and Safeguarding framework.

Speak Out advocates helped by:



- Explaining what the Quality and Safeguarding paper is about
- Asking us if we wanted to take part
- Using easy words
- Helping us to talk about it
- Getting us to think about what we think is important



### **Step 1: Learning about it**

Speak Out advocates talked to us about making sure the NDIS is safe for people with intellectual disability.

We talked about staff and services. We talked about making sure the NDIS is good quality.

#### **Step 1 Learning About it**

Some of our members attended [public consultations](#).

[Speak Out Members Executive](#) met to talk about the paper so our [regional representatives](#) understood it.



## Step 2 Talking About it

### Step 2: Talking about it

Our **regional representatives** then went back and talked about it to their own groups in each region.

We also talked about it in smaller groups in each region of Tasmania.

Some people talked about times when they didn't feel safe in their services.



## Step 3 Writing About

### Step 3: Writing about it

The advocates did a draft of this paper from what we said at the meetings.

The Members' President checked to see if it was ok and easy to read.



## Step 4 Checking it

### Step 4: Checking it

The Members' Executive met to check the draft.

They made sure it said the right things.

They also added more ideas

Advocates fixed the final draft.







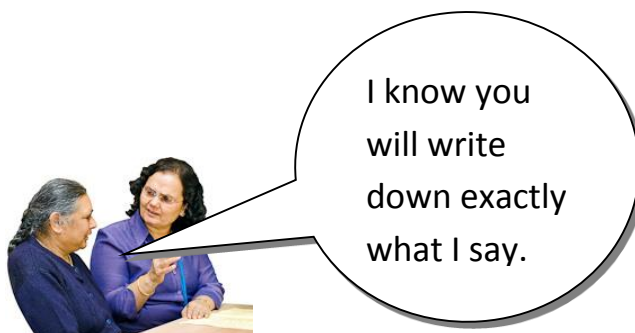
## Step 5: Sending it



It takes a lot of time to learn and understand some things.

Speak Out members said it is important to have people you trust to help with making [submissions](#).

When there are important things that people with intellectual disability should have a say about, we want to make sure the government and the NDIA know that they have to give us time to do these steps.



## List of hard to read words

**People with intellectual disability** – when some people are born they have an intellectual disability, they may need extra help with things like reading, working things out or learning new things.

**Board of Management** – a group of people who help to run Speak Out.

**Attitude** – what people think and how they act.

**Community** – your area where people live, work, shop.

**PWID** – a short way to write people with intellectual disability

**Submission** – a paper that talks about what you think.

**Role description** – written information about the job and what the person has to do. The hours they work, how much pay they get and who is their boss is in the role description.

**Code of Conduct** – written rules about how people will behave. If someone signs the Code of Conduct they agree to follow the rules.

**Voluntary** – people choose to do something because they think it is a good idea. The law is not making them do it.

**Selection panel** – a small group of people who work together to choose the best person for a job. They look at applications, work out who to interview,

develop good interview questions and interview people. The group decides the best person for the job.

**Audit** – when specially trained people visit a service to inspect information and check how things are going. After the audit there is a report that says what is going well and what needs to improve.

**Evaluated** – getting information and opinions to work out if something is good quality or not. Telling services what they do well and where they need to improve.

**Commissioner** – an official person in charge who has authority and power. They can investigate things and say what has to happen.

**Voting** – when we choose one thing or one person over another. We do it in a way that can be counted and checked.

**Regional Representatives** – Members of Speak Out from around Tasmania who are elected to speak for other members in their region.

**Restrictive practices** – ways that people use to try and control how people with disability behave. Restrictive practices limit rights or freedom of movement.

**Senior Practitioner** – a person who gives advice about the ways to work with people. Their job is to make sure that services know how to help people well.

**Public consultations** – meetings where people in the community are asked questions and have a say about things that affect them.

**Speak Out Members' Executive** – Regional Representatives and the Members' President who meet each month to help run Speak Out.

**DANA** – a short way of writing Disability Advocacy Network of Australia. DANA helps advocacy organisations in their work of advocating for and with people with disabilities. They know a lot about advocacy and human rights.