

Speak Out Association of Tasmania



Speak Out Members' Executive on behalf of Speak Out members



National Disability Advocacy Program
Submission, 21 June 2016

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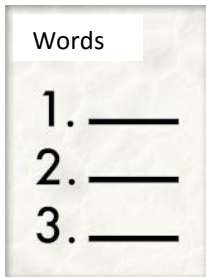
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What is in this Paper



Some words in this paper are in blue.

- These words may be hard words to read
- We explain what the words mean on page 29



Some words are in boxes.

- These are stories or the real words of people with intellectual disability.
- 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



Department of Social Services,
National Disability Advocacy Program
disabilityadvocacy@dss.gov.au



We are happy to make this submission to the Department of Social Services, National Disability Advocacy Program and give consent for it to go on the DSS website, 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. Speak Out also has members who have an **intellectual 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 different types of 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. He is called the Members' President.
- 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



Peter Huett (Members' President) on behalf of members

What we think

Question 1: If you need support to stand up for your rights, what are the most important things for you?

Someone we trust who is on our side.



It is important that we have someone who is on our side.

Someone we trust like an advocate.

Advocates believe what we say and tell us the truth.



Many people said services listen to their complaints but then don't do anything about it.

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.



It's not until an advocate is called that they do something.

Advocates don't give up until they have helped us fix the problem.

Sometimes they can't always fix things.
If they can't fix it, they tell us why.
They get as close as they can to fixing the problem.

Independence is very important.



This means the person is on your side and not on anyone else's side.

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

We think this can be a very big risk.

Services will not do the right thing if they are advocating against themselves.



Leah said:

My service says my key worker is my advocate.

This isn't right.

If she goes with me to work out problems with them (the service), I always come away thinking I'm in the wrong because that's what they do.



Alan said:

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 want our family involved.

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.

Good skills in lots of areas



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

Speak Out members said advocates help with things like Centrelink, Telstra, Housing, Police, Child Protection, going to court, family violence, abuse and discrimination.

We need advocates who know lots of things.

Pete said:

I had a legal problem and I had a lawyer. I had no damn idea what the lawyer was talking about. She confused me.

I got an advocate to help me. She explained what the lawyer was saying in a way that I could understand.



People who are easy to talk to and listen.

Sometimes it takes time to tell your story. We don't want to be rushed.



Many people have trouble communicating. We need advocates who are good at working with people who have all sorts of communication needs.

Easy to find and meet up with

It can be a problem if you do not have transport.

Many people cannot use public transport

It is important that an advocate can come to you or meet somewhere that is okay for you.





Some people don't want other people to know they are meeting an advocate.

Confidentiality is really important.

Helping us learn about our rights



If you do not know your rights you cannot stand up for them.

Speak Out members know that knowing about your rights makes you powerful.



People who do not know about their rights get pushed around by their family, services, workers and even other people in the community.

Standing up for your rights can be scary.



Having self advocacy groups where advocates help us learn about our rights is a really good thing.

Once you know your rights you can start to stand up.



Sometimes it takes time. Sometimes the advocate has to do it for you in the start.



After a while you can do it together. Then once you feel okay you can do it by yourself.

Question 2: What things have stopped you from getting help from an advocate?



Many members have difficulty using the telephone or getting around.

They rely on their service to help them with transport.



They need other people to help them get in touch with an advocate.



This is a big problem when they are told **not** to go to an advocate. This leaves them without help.



Some services do everything for people. They live in their group home and go to their day program.

These services do not let them do things without that service's workers. They tell them they will fix all their problems. They tell them they can not have an

advocate. We think it is unsafe for people to only have one service.

A number of our members who are with these services don't come to our meetings any more.

They say they are not allowed to.

It is hard to stand up against a service who does everything for you.



People who do not know their rights get pushed around.



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.



- Not having someone to help you get in touch with an advocate.
- People telling you **not** to use or go to an advocate. Sometimes service providers put pressure on us.
- People scaring you into not doing it (using an advocate)

- Feeling frightened trying to get things changed or get the help you need.
- Advocates can be too busy. There are not enough of them so they have to work out who needs help first.
- Advocates are out and about so getting in touch with them can be a barrier if I forget what I wanted to say or I can't get near a phone again.
- Waiting lists. It can take a long time sometimes.
- One other advocacy service I used to use have a phone that is hard. You ring and have to press numbers to talk to someone. Or they ask you how to spell your name ... or you need to know your birth date ... if you can't do that you don't get help. I gave up and I know others did too.



Les said:

I have been with good services and I've been with bad. The good ones are not scared of advocates. They encourage us to use them.

The bad ones try to stop us from ringing an advocate.

Question 3: What would make it easier for you to get support?



We believe that one very big problem is not enough funding for advocates. They have too much work and not enough time.



Some people are isolated.

Some people can not get out by themselves.

They need someone to help them contact an advocate.

In some places they have a [community visitors scheme](#).

This is where people can just drop in and visit people to see if things are okay.

If things are not ok, they can call the person an advocate.

We think this is a good idea.

- Someone to put you in touch with an advocate if you can't do it yourself
- Information and pamphlets in easy to read
- Internet (information and access to internet) that is easy
- Families need to understand advocacy better
- More government funds for advocacy
- More advocacy staff everywhere
- No hard phone systems
- Not having to tell your story lots of times
- Rules that say services have to help you get an advocate if you want one. Something should happen if they don't.

Question 4: **If you have had good advocacy support what things made it helpful?**

Teamwork and good information



Working as a team with good clear communication is very important.

Good advocacy support happens when things are explained in a way we understand.



When we are given options and told the good and bad things about each option. This helps us make decisions about our own lives. It helps us be more in control.



It is very helpful when we work with an advocate and make a plan together.

Having them follow through on things. Working together so we know who is doing what.



The advocate does things and we also do things if we can.

It is our life and the advocate understands that it is important for us to learn.



It makes us feel powerful when we help to fix our problems.

- Good advice ... from someone you trust
- Being treated with respect
- Having time and not feeling rushed
- Talking about what outcome I want and what to do to get it
- Talking about different options
- Advocates You know them and know where to go. They know where to go and what to do ... they have knowledge ... you feel like a team
- Confidentiality
- Being able to go to the advocate's office makes a difference. Get away from ... (service) people listen in
- Advocate can meet me somewhere if I can't get to the office

- The client handbook is really good ... information in easy English is good.
- Communication and explaining things in easy to understand ways. Advocates make hard things easy to understand and straight to the point.
- Advocate rings me and keeps me in the loop and checks things with me
- Advocates work together, talk and have meetings, so you have more ideas, better advice and get things moving
- Advocates work hard
- Self advocacy groups help a lot. You learn things about rights. You can sound things out and talk them through with an advocate if you are unsure about taking action.
- It is free to see an advocate

A final word about rights



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

Having a say in your life is a right.



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.

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



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.



Standing up and don't let people take advantage of you it takes time.

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.



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.



Our self advocacy groups and the advocates are great, they listen to us and explain lots of things about politics and stuff.

They make sure our voices are heard in the community.

They don't think we're stupid.



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.



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

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.

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

This is how Speak Out did the submission.

Speak Out advocates helped by:



- Explaining what the National Disability Advocacy Program 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 the submission.

We already knew lots about it.

Many people use advocates.

We are members of Speak Out.

We take part in the **audit** of Speak Out.

Step 1
Learning
About it

Speak Out Members Executive met to talk about the paper so our **regional representatives** understood it.



Step 2: Talking about it

Our [regional representatives](#) then went back and talked about it to their own self advocacy groups in each region.

Step 2
Talking
About it

People talked about times when they have used an advocate.



Step 3: Writing about it

An advocate did a draft of this paper from what we said at the meetings.

Step 3
Writing
About

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



Step 4: Checking it

The Members' Executive met to check the draft.

Step 4
Checking
it

They made sure it said the right things.

They also added more ideas.

Advocates fixed the final draft.





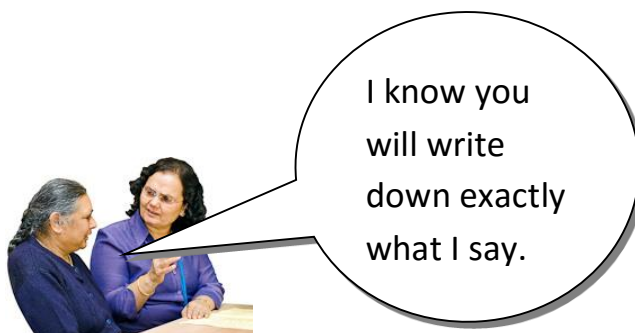
Step 5: Sending it



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 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.

Self advocacy – when people stick up for themselves or have a say about their own lives.

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

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

Submission – a paper that talks about what you think.

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.

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.

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