People First New Zealand Inc. – Ngā Tāngata Tuatahi

‘LET’S TALK’
SELF ADVOCACY FORUM
Kia Ora from New Zealand!

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People First New Zealand is a self advocacy organisation run by and for people with learning disability.

It is the only disabled persons organisation (DPO) for learning disability in New Zealand.

There are 32 local groups and over 600 members.
In November 2012 People First held a forum at the ASID conference in Wellington, New Zealand.

- It was a self advocacy forum for people with learning disability.
- Over 50 people took part.
In the groups we talked about 6 topics that People First members think are all part of having a GOOD LIFE.

They are also rights in the UN Convention.
The topics were:

- Friends and relationships
- Making my own decisions
- Real work, real pay
- Being in the community
- My money
- Having the right support
In 2014 the New Zealand ASID conference is going to be called ‘Let’s talk some more’.

The conference will be based on the same six topics as the People First self advocacy forum.

We think this is a great response to what people with learning disability had to say!
Here is some of the things that were said about ‘Friends and relationships’: 
- It is important to have friends – to talk to and do things together.

- It's good to have friends who are both disabled and non-disabled.

- Self advocacy groups like People First are a good way to meet friends.
Some people take advantage of us and abuse us or want to take our money.

Sometimes its hard to trust people and let them into my life.

Some people pretend to be a friend.
- It is hard to keep friendships if you don’t have a lot of money - doing things with friends can cost money, even having a coffee.

- Family relationships are really important.

- Not everyone has family.
I want a relationship when I am ready.

We should be able to get married or live together if we want to – it is our right.

It is hard when relationships break up.
Here are some challenges for you about the topic ‘Friends and relationships’:
- Give the right support to make friends and keep friends and relationships going.

- Support us to learn skills so we are not taken advantage of.

- Some people in supported living end up being lonely. Make sure this doesn’t happen.
Here are some of the things that were said about ‘Making my own decisions’:
We want to make decisions in all parts of our lives.

I wanted to buy a café. I had $500. I told Mum and Dad. They said I didn’t have enough money to buy a café so I didn’t. I trusted them so I talked about it with them.
Before I went flatting I was living at home. I said to Mum and Dad I want to be more independent. Now I have my own TV, couch and computer – I made my choices and Mum and Dad listened.

We can talk about big decisions with people we trust.
- We can learn from our mistakes.

- It is our right to choose where we live and who we live with - this is in the UN Convention.

- We need easy read information to be able to make our own choices.
Here are some challenges for you about the topic ‘Making my own decisions’: 
- Don’t make decisions for us.

- Listen to us and support our decisions.

- We want support and knowledge and to learn from our own mistakes.

- Guide us, not control us.
- Support us to make our own wills and have them in easy read.

- Make sure people with learning disability who are prisoners can come out and have a second chance.

- The UN Convention says that we have the right to choose – get to know the UN Convention and use it in your work.
Here are some of the things that were said about ‘Real Work, Real Pay’: 
- Give us a chance to work.

- Sometime I get paid in petrol vouchers - I don’t have a car.

- I was discriminated against in my job. I left it, it made me unhappy.
- It's hard to find a job, I think it's who you know.

- I would like to go off the benefit.

- I have been doing my job for 8 years and I would like to do this full time.
I do voluntary work, like this job I have been doing for 22 years, selling my art, it would be nice if it was paid.

Many of us cannot read and write.

I need to know about my rights at work.
Here are some challenges for you about the topic ‘Real Work, Real Pay’:
- Help people to sell their art.

- More training to read and write.

- Include us in staff training.
- Use the People First easy read employment agreement.

- There should be no minimum wage exemption, people should all be paid the minimum wage.
We need support to understand how paid work and the benefit work together, or don’t.

All of you work for organisations like support services, universities, government departments and hospitals. You must have jobs we can do. Think about giving us jobs.
Here are some of the things that were said about ‘Being in the community’: 
- It is about being free and independent.
- Having volunteer work.
- Being involved in community groups.
- Going to mainstream schools and further education.
- Lots of paper work to fill out if we want to go out and do something. We are treated like a risk.

- We need more money than just the benefit to be in the community - the cost of living keeps going up but our money does not.

- Some people can be horrible and call us bad names. This makes me depressed.
Here are some challenges for you about the topic ‘Being in the community’:
- Have all signs around the cities and towns in easy read.

- The whole community needs more disability awareness.

- Support us to learn to use computers and the internet.
People who drive buses, taxis and work on trains need more training so that they know how to give us a good service and talk to us, not our support people.

Empower us to access the community independently.
Help us be able to go to further education. This is a great thing to do. We can learn skills for work and make friends there.

Stop treating us like a risk.

If people have a medical condition don’t let that stop them from living in their own flat - get a medic alert button.
Here are some of the things that were said about ‘My Money’: 
- I need support to do my banking.

- I want my own bank statements - some staff members throw them in the rubbish.

- I want to choose what I spend my money on.
Before I had a job I couldn’t go out as I had to spend all my money on bills.

Banks and their services are hard to understand.
Here are some challenges for you about the topic ‘My Money’:
Money is hard to understand. I need support to budget my money so I have enough money for my bills and can save for special things.

Trust us with our own money.

Have an easy read course on how to do internet banking.
- Help us tell banks to make clear information about their options and fees.

- Banks should have easy read statements.

- Have all EFTPOS and ATMS the same.
Here are some of the things that were said about ‘Having the right support’:
- Don’t talk down to us.
- Let me live with people my own age and choose my own food and bedtime.
- Staff should ring if they are not coming.
- Too many staff changes.
Here are some challenges for you about the topic ‘Having the right support’:
- Let us do as much as possible for ourselves.
- Teach us, don’t take over.
- Staff stay in background.
- Respect us and treat us with dignity.
Let us choose our own staff.

We have the right to choose where we live and who we live with - make sure this happens.

No more large group homes - no more than 3 people in a house.
- Respect our values and our culture.

- Staff and services should be trained in emergency preparedness. After the Christchurch earthquake some disabled people were left in their beds for 7 days.
Staff should maintain professional relationships and not treat us like their children.

Protect us from staff who bully and abuse people or steal their property – these people need to lose their job, not be able to work at other services and be reported to the Police.
Here are some overall challenges:

- If you think you have a bright idea for research or a service, check it out with People First NZ or a self advocacy group in your country before you start.

- We can tell you if it is any good or not.
Make sure people with high support needs are thought of in everything you do – if we get it right for them, we get it right for everyone.
Respectful language:

- When you talk about us, think out the words you are using. We are not children, we are not burdens, we are people just like you.

- If you use good words, then others will too.
People First NZ members prefer the term **learning disability** rather than intellectual disability as we feel it is more respectful and it’s much easier to say.

We would like you to help us change the language and use this term too.
Thank you to ASID for asking People First NZ to host the ‘Let’s Talk Forum’ in 2012 and for letting us share our findings with you today.
And finally, please remember the People First saying:

NOTHING ABOUT US, WITHOUT US.