

# Submission to the draft Guidelines on Deinstitutionalization, including in emergencies from People First New Zealand

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# About the organization

People First New Zealand Nga Tangata Tuatahi is a Disabled Persons Organization and a national self-advocacy organization run by and for people with learning disability.

People First NZ uses the term “learning disability” rather than “intellectual disability” as members think it is more respectful.

People First NZ was set up in New Zealand in the 1980’s and has been an independent Incorporated Society for over 18 years. There are 40 local groups around New Zealand where members meet monthly to learn about their rights and how to speak up for them.

To be a member of People First NZ you must be a person with a learning disability, over 18 years of age.

People First NZ members speak up on issues that are important to them such as:

* having the same rights as all other New Zealanders
* being a member of the community
* being a citizen of New Zealand.

People First NZ works in a human rights framework and works to implement the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to make sure people with learning disabilities have a good life. People First NZ is also a member of the Disabled Persons Organizations Coalition who work to implement the rights in the UNCRPD.

People First NZ runs a translation service called Make It Easy, which translates information into Easy Read – everyday words and pictures. Easy Read is a format that is more accessible for people with a learning disability, low-literacy, or English as a second language.

People First NZ also provides information and advice about rights and supports for people with learning disability. We run courses for people with learning disability and deliver educational presentations to the wider community.

# Why we want to make this submission

People First NZ believes it is particularly important to speak up on issues for disabled people and in particular the rights of people with a learning disability.

Deinstitutionalization is a big issue for people with learning disability in New Zealand and around the world and a lot of work still needs to happen in this area.

# How we did this submission

People First NZ hosted a virtual consultation meeting with 9 People First members. All members have a learning (intellectual) disability and range in age are from their 20s to 60s. Some had experience of living in a large institution or a group home (small institution).

People First used the Easy Read guidelines for the consultation. These were shared on screen and the facilitators went through them page by page and ask members what they thought. We have written this submission using direct quotes from members and used the quotes to make key points the members want to see the guidelines cover.

# What we think

Overall, we are very pleased to see the draft Guidelines on Deinstitutionalization.

People First members looked at the Easy Read version of the guidelines and were asked the following questions:

Do you agree with the points of guidelines?

* If you don’t agree with some, what else is missing?
* Or do you have anything to add?

# Contents- Introduction

Members agreed with all the points.

# Contents- Institutions

Members agreed with a list of description about Institutions generally.

Comments are:

# Page 6, paragraph 3

“I had got electric shocks in the past, being kept on my own for a period time, didn’t allow to the community.”

“The Institutions is form of the prison, the fridge is locked, the pantry is locked, the staff locked the food and had the key.” “The staff decided the food what you ate, no choices, if you didn’t like, you missed out, didn’t get feed.”

“Being sent to isolation and kept away from everyone.”

The key points from the comments are:

* Make sure that bad treatment will not happen in the future, such as the use of drugs to sedate people, electric shocks and being isolated from others.
* Make sure people have choices and can choose their own food and eat when they want to unless there is a medical reason to have food controlled.

# Contents- the Guidelines

Members agreed with all the points**.** Comments are:

# Page 7, paragraph 1

“It is true, the big one has been closed but people have been put into the small institution-group homes.”

“Support services still have their institutionalised thinking and mindset.”

“Some support funding is flexible and support in communities, but it is still limited.”

“Some of the disabled young people have to be put into the Rest Home or Dementia Care Home.”

The key points from the comments are:

* + Institutions are not only the buildings, but also the mindset of people - institutions and institutionalised thinking needs to end.
  + Support staff need training in human rights and how to support people choosing how they want to live.
  + Group homes are small institutions.
  + There needs to be different living options available for all disabled people.

# Page 9, paragraph 1&2

“Increase income benefit payment, making money available, when the people move out institutions, so they can / are able to support themselves.”

“Training the people and get them ready to have life skills to live in the communities.”

“People have to learn to live all over again.”

The key points from the comments are:

* Make sure disabled people won’t be forced into poverty when they moved out of institutions because of lack of the life skills and financial support.
* Make sure disabled people have enough money to live.
* Make sure everyone has a support plan and receive training.

# Contents- Following the Guidelines

Members agreed with all the points**.** Comments are:

# Page 10, paragraph 1&2

“Government needs to follow the guidelines no matter who is in power.”

“Making the support system easier to follow and all government agencies work together.”

“Start early for family support.”

“Safeguarding, a safe community to live for all.”

“Right resource and right training for workforce/support workers/service providers.”

The key points from the comments are:

* The guidelines should be used by all governments and deinstitutionalisation plans should not stop if the government of the country changes
* Governments have a responsibility to support the disability workforce for with the right resources and the right training.
* Make any new system easy to access and understand.
* Support families from early on with the right information and resources.

# Page 11, paragraph 4&5

“Social housing is not in a safe area, an affordable housing for disabled people should be in a convenient area, it means the housing is easy to access to transport, health care and education, shopping centre, etc.”

“My support service doesn’t care my needs but money, they try to keep me in the service only for the money, also the service makes changes all the time what they like without telling people, they are very much institutionalised thinking.”

The key points from the comments are:

Governments must provide support for housing for disabled people when they moved out the institutions. This will assist people to live the life they want in the community.

# Page 12, paragraph 4

“We need more support decision making. We want people who know us well to support decision making. In terms of decision making, we need accessible and inclusive information, e.g.Easy Read.”

“Stop putting people in a small group home- small institutions.”

The key points from the comments are:

* Inclusive and accessible information needs to be provided for all disabled people. For people with a learning

(intellectual) disability, this is Easy Read information and videos explaining things. Accessible information assists with understanding and decision making.

# Page 15, paragraph 2&3

“Moving people out of the institutions, a plan must be made to follow, and research to be done to show how people live in the communities.”

“Lots of the family/parents have no way to turn to for their very high needs young/adult. Children to be care for, in terms of stopping go back to institutions, government needs put more money into support the family/parents.”

“Stop telling family and disabled people this is you only option, instead of providing choices.”

“Closing down the institutions, must involve disabled people and their families, working together. Sometimes the family will decide is not the person wants, and not align with Human Rights.”

The key points from the comments are:

* Disabled people and families must get involved in the process of moving out the institutions.
* Share research that shows how disabled people live in the community.

# Unfair treatment of certain groups

Members agreed with all the points

# Women and girls with disabilities

Members agreed with all the points

# Children with disabilities

Members agreed with all the points

# Final comments on the draft guidelines

Comments are:

“Hope the change will happen around the world soon.”

“It was good, I used to be in a big institution, but I didn’t realize the small group homes is a form of small institution, I hope we are in a real community.”

“Amazing to attend the meeting and have my say, can’t wait to read the document.”

“The guidelines will help the disabled people & family around the world.”

Thank you for the opportunity to submit to the draft guidelines. For anything further please refer to the contact:

# People First New Zealand Nga Tangata Tuatahi

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