Housing for Disabled People in Aotearoa New Zealand:

A Report – Family / Whānau and Close Supporter Perspectives





Before you start

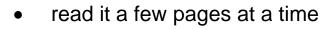




This is a long document.

While it is written in Easy Read it can be hard for some people to read a document this long.

Some things you can do to make it easier are:



 have someone help you to understand it.



What you will find in here

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Housing in New Zealand



Everyone in New Zealand has the right to live somewhere that:

- is safe
- means they can live a good life.



The right to good housing is in lots of human rights agreements that New Zealand is a part of.



These agreements have been with lots of other countries.

Some of the agreements have been around for more than 60 years.



Disability Rights 1 of these agreements is the **United** Nations Convention on the Rights of Persons with Disabilities.

The United Nations Convention on the Rights of Persons with Disabilities says what governments must do to make sure disabled people get the same rights as everybody else.

The United Nations Convention on the Rights of Persons with Disabilities is also called the **UNCRPD**.



New Zealand agreed to the UNCRPD in 2008.





It is important to know if disabled people in New Zealand are getting the rights the UNCRPD say they have.

Checking how well New Zealand is keeping to the law about human rights is called **monitoring**.

About this report



We do not know enough about what it is like for disabled people finding a home that best suits them.



To find out more about this the Donald Beasley Institute did some **research**.



Research is:

- looking to find answers to questions
- trying to find out how to do things better.



With the support of the **Disabled People's Coalition** the Donald Beasley Institute wrote a report called:



My Experiences, My Rights: A Monitoring Report on the Disabled Person's Experience of housing in Aotearoa New Zealand.



You can find this report in Easy Read at:

www.peoplefirst.org.nz



The **Disabled People's Coalition** is also called **the DPO Coalition**.



The DPO Coalition is a group of Disabled People's Organisations. The DPO Coalition is where DPOs can:

- talk to each other
- have a strong voice on issues that affect disabled people.

The DPO Coalition made sure that the research was:

- led by disabled people
- included information about what disabled people:

 \circ think

 \circ experience.



The DPO Coalition chose the Donald Beasley Institute to work on the research.



 Our House

The DPO Coalition wanted this report to:

- show how things are for disabled people
- show that it is very important things change so disabled people get their right to good housing.



The DPO Coalition wants to work with the government to change things.



The research was done with disabled people who could agree to take part.



People who could not agree did not take part.



The people who could not agree were people who could not communicate as they had **multiple and complex disabilities.**

People with **multiple and complex disabilities:**



- often have more than 1 disability
- have disabilities that affect them in lots of different ways
- often need a lot of support.

This report is called:



Housing for Disabled People in Aotearoa New Zealand: A report Family / Whānau and Close Supporter Perspectives



In this document we will call it **the report**.

This document talks about:

- what the report is
- the main things the report found out.

It would be a good idea to read this report alongside the other report that has been written as named on page 8 of this document.



How the research was done



The kind of monitoring we used is called **Disability Rights Promotion** International.

Disability Rights Promotion International is also called **DRPI**.





In New Zealand DRPI is based on:

- Te Tiriti o Waitangi / the Treaty of Waitangi
- the UNCRPD
- the New Zealand Disability Strategy and Action Plan.





done by disabled people.

It was important that the research was

The DPO Coalition chose the Donald

Beasley Institute to work on the

monitoring.



The people who did the interviews are called **monitors**.





For this report we spoke to:

- whānau / family members
- close supporters.



Whānau and close supporters were interviewed as they were:

- close with someone who had complex disabilities
- could communicate with the disabled person.



We did 11 interviews:

- 10 families
- 1 close supporter.











The interviews:

- took 12 weeks to be done
- followed some COVID-19 rules so all the interviews were done over:

 \circ Zoom

- \circ WhatsApp
- $\circ~$ the phone.

Doing the interviews this way meant we could interview more people who lived in different places.





A bad thing about doing the interviews this way meant some people could not speak to us if they did not have:

- internet
- a laptop
- a phone.



The results of the research would have been better if we had talked to more Māori and Pacifika

- family / whānau / aiga members
- close supporters.



We did the interviews to understand what parts of finding accessible housing:

- are working for disabled people
- are not working for disabled people.



We wrote down what the interviewees said.

Report

We used what the interviewees told us to write our report.

What the research found out



This part of the document is about the things we found out in the research.







The things we found out in the research have been put into 5 sections:

- 1. Choice and control
- 2. Access
- 3. Physical and psychosocial wellbeing
- 4. Relationships
- 5. Advocacy and awareness.

1. Choice and Control



It is important for disabled people to:

- be able to make their own choices
- have control over their lives.

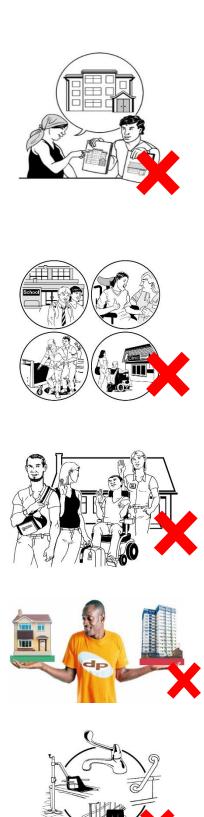


These ideas were an important part of the things most interviewees said about the lives of the disabled person they supported.

Interviewees felt they had to **compromise** a lot.

When you **compromise** it means you get some of the things you want but have to decide not to get other things.





In the interviews people said they did not have much:

- choice when trying to get the housing they needed for the disabled person they supported
- choice or control over who came into their homes to provide support as there are not a lot of support services to choose from
- access to respite care as there are not many respite care providers
- choice in renting accessible housing
- choice in changing their house to be more accessible as they did not get enough money to help them.

Another big thing most families told us in their interviews was how they felt about **residential services.**

Residential services are places where people can be taken care of if they:

- have long term health conditions like dementia
- are elderly
- are disabled.

Lots of people live together in residential facilities.

Interviewees felt that residential services do not have what they need to support their disabled family members.











This meant families had to take care of their disabled family member for their life.





The families who have disabled family members living in residential services felt like they had to choose between the health and wellbeing of:

- their disabled family member
- the rest of the family.



Families also felt like they had to compromise the happiness of their disabled family member.





The things the interviewees said about their lives showed how hard it is for:

- disabled people to get the housing they needed
- families with disabled members to have a good life together.

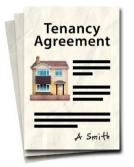


It is hard for families as they did not have much choice about:

- where they lived
- who comes to support them
- how they lived.



2. Access







Access means things like:

- getting somewhere to live
- making changes to a home that meet the needs of the people who live there
- information
- ways of making sure people get their rights.



UNCRPD says that disabled people have a right to access good housing







The interviewees said they have problems accessing good housing when:

- owning a house
- building a house
- renting
- getting Kāinga Ora housing.

Kāinga Ora is the new name for Housing New Zealand.











People who own their homes

Interviewees said that most houses that are already built do not meet accessibility standards.

Accessibility standards tell you how a house can be built so that disabled people can get in and use the house easily.

They also said that the size of a house can be a problem with:

- disabled people moving around the house
- amount of equipment used by disabled family members
- the size of the equipment used by disabled family members.



Building a house

Building a house can be a way of making sure the house is accessible for everyone who lives in it.





If your home is **accessible** it means you can do the things you need to do in it safely.

For example if you use a wheelchair your home might be made more **accessible** with a ramp to the door.





Some problems with building are:

- it costs too much money
- building and designers do not:
 - understand how to make houses accessible
 - support making houses accessible.





Renting

Money is a big reason people cannot live in accessible housing.

Taking care of 1 or more disabled family member costs a lot of money.



A lot of family members do not work as they support their disabled family members.



This means the only money the family gets is from government funding,



Interviewees said they do not get enough funding from the government to make sure they are living in accessible housing

Some interviewees talked about the big differences between funding from:



• the Ministry of Health.



People who get funding from ACC get a lot more funding.

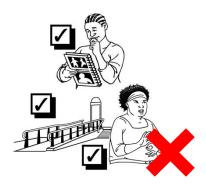
This means that:



- disabled people are not treated equally
- some disabled people have more access to the housing they need than other disabled people.



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Kāinga Ora is the new name for

Accessing Kāinga Ora Housing

Housing New Zealand.

The UNCRPD said that disabled people must be able to get into public housing.

An interviewee told us they have been waiting for more than 2 years to move into an accessible Kāinga Ora house.

The Kāinga Ora house they have been waiting in is not fully accessible.







Access to the community

The UNCRPD says that disabled people have the right to be part in their community.

Most interviewees said they little choice about which community they lived.

This is because they often had to take the accessible housing that was offered to them even if it was in a community they did not know well.

3. Physical and psychosocial wellbeing



Physical wellbeing means how healthy your body is.

Psychosocial welling is how healthy your social life and mental health are.

Interviewees said they were very:



- tired
- anxious

lonely



 worried with the long term wellbeing of the disabled person they were caring for.







They said they felt this way from:

- not being able to get good support
- feeling like they were the only ones who could care for their disabled family members.

They also said that taking care of a family member with complex disability sometimes meant they got hurt.





The interviewees also said that the brothers and sisters of children with complex disabilities are sometimes the only support.

All the interviewees said that having accessible housing would help them a lot.

4. Relationships



Many interviewees said that having good housing was connected to the relationship between:



- the disabled family member
- the family
- support workers
- services providers.







Interviewees said it was hard for the family members to trust the support workers as:

- they changed a lot
- they had to train every new support worker
- did not get any money to train the support worker.



Interviewees also said that life was easier when there was a good relationship between:





- support workers
- family members
- disabled people.

5. Support and Awareness



As of the research we also wanted to find out how much interviewees knew about their **rights**.







Rights are things that you should get to live a good life.

For example everyone has a right to things like:

- housing
- being kept safe
- having enough food to eat.

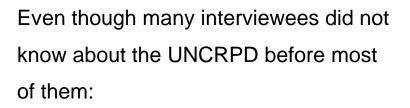


The interviewees were asked if they had heard of the UNCRPD.

About half of the interviewees:

- had not heard of the UNCRPD
- did not think people with multiple and complex disabilities had the same rights as disabled people.





 understood what rights disabled people should have



 said the government is not doing enough to make sure disabled people have the housing disabled people need.



Interviewees also said disabled people felt they had to thankful for whatever housing they got.







Interviewees said they try to support:

- other families who have family members with multiple and complex disabilities
- their community to help them understand:
 - what it is like to support disabled people
 - how to make the community more accessible.

They do this by sharing:



- information
- advice
- support.

What should happen next?



Interviewees said that family / whānau and close supporters of people with complex and multiple disabilities are some of the best people to:



- speak up for the disabled community
- help make sure New Zealand is giving disabled people the rights UNCRPD says they have.

Interviewees told us:



- about ways of making it easier to meet the rights of disabled people
- examples of how they are speaking up for disabled people rights.







- Aotearoa New Zealand should follow kaupapa Māori way of making sure disabled people get good housing
- make family / whānau members and supporters accessible housing designers



- make more accessible rental houses
- make it easier for people to want to make accessible rental houses

Interviewees also said:





- talk to family / whānau and close supporters about:
 - how much money they need for accessible housing
 - $\circ\;$ what the money will be used for
 - \circ when they need money.



 understand that disability needs change so sometimes people need more:

 \circ money



- o support
- there needs to be more respite services.





1	
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3	





Interviewees also said:

- to make sure families / whānau and support workers can easily access information so that they know:
 - \circ what rights disabled people have
 - o why they have those rights
- put disabled people and their family / whānau on the top of the list for accessible state housing
- give more money to:
 - parents caring for disabled children
 - $\circ~$ single parents.





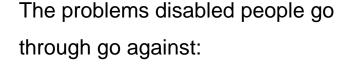




This report shows:

- how getting accessible housing is a problem for a lot of disabled people
- how disabled people do not get their human rights
- a lot needs to be done to make things better.





- Te Tiriti o Waitangi
- the rights in the UNCRPD
- the New Zealand Disability Strategy.







A big reason housing issues are worse for people with multiple and complex disabilities is communication.

It is harder for people with complex and multiple disabilities to tell people:

- what they want
- what they need.



A lot of interviewees were very tired because they have to support a disabled family member as well as fight for their rights.



There are a lot of ways disabled people can be an important part of making things better for disabled people in Aotearoa New Zealand.





Donald Beasley Institute. (2020). Housing for Disabled People in Aotearoa New Zealand: A Report - Family/Whānau and Close Supporter Perspectives. [Easy Read Monitoring Report]. New Zealand Disabled People's Organisation Coalition.



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