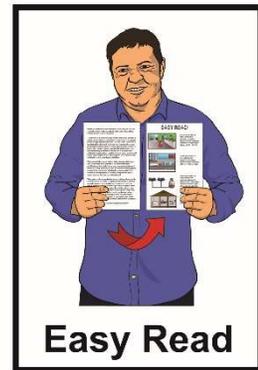




**DONALD BEASLEY**  
INSTITUTE



# My Experience

# My Rights



**A report about Health and Wellbeing  
for disabled people in Aotearoa New Zealand**

**Published: March 2022**

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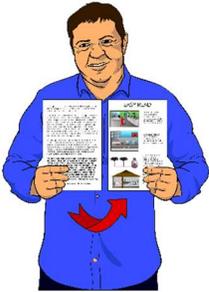


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## Before you start



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:



- read it a few pages at a time
- have someone help you to understand it.

# About this report



This report is by the Donald Beasley Institute.



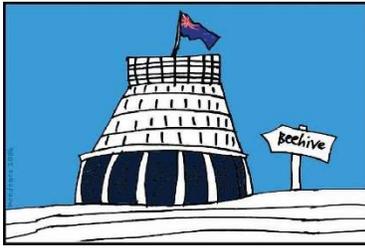
The Donald Beasley Institute is an organisation in Ōtepoti / Dunedin that does **research** about things to do with disability.



**Research** is when we find out about things.



In this Easy Read document we sometimes use **DBI** as a short way of saying Donald Beasley Institute.



In 2008 the New Zealand Government said that they agree with the **United Nations Convention on the Rights of Persons with Disabilities**.

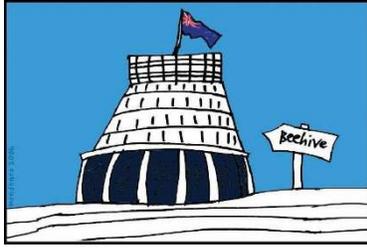


The **United Nations Convention on the Rights of Persons with Disabilities** is a law lots of countries have agreed to.

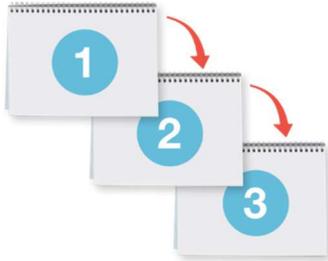


The United Nations Convention on the Rights of Persons with Disabilities is also called the **UNCRPD**.

It says what governments must do to make sure disabled people get the same rights as everybody else.



The UNCRPD says the government has to **progressively realise** the rights of disabled people.



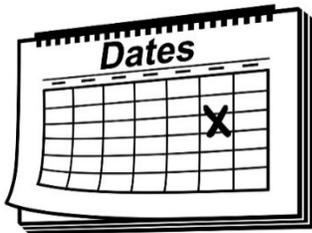
**Progressively realise** means to do something bit by bit.



The UNCRPD does not say the government has to make everything happen at once.



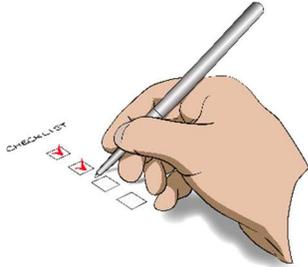
The UNCRPD does say:



- the government needs to be working on things now
- some things need to happen fast.



The UNCRPD says that disabled people have to be part of checking how the government is doing.



This is called **monitoring**.



The **DPO Coalition** has chosen the Donald Beasley Institute to do a lot of the monitoring.



**DPO** is short for Disabled People's Organisations.



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 DPOs that belong to the DPO Coalition are:

- Balance Aotearoa
- Blind Citizens of New Zealand Incorporated
- Deaf Aotearoa
- Disabled Persons Assembly New Zealand Incorporated
- Kāpō Māori Aotearoa New Zealand Incorporated
- Muscular Dystrophy Association of New Zealand Incorporated
- People First New Zealand / Ngā Tāngata Tuatahi.





1 part of the monitoring is a project which is called:

## **My Experiences My Rights**

As part of the project DBI looked at:



- what experiences disabled people had of health and wellbeing in Aotearoa New Zealand



- if the health and disability system is good enough for disabled people.



To find this out DBI talked to:

- disabled people over the age of 18
- family members / whānau / close supporters of people with multiple and complex disabilities.



We call the people we talked to **interviewees**.



The interviewees included people with different kinds of disability.

# What the DBI found out



Article 25 of the UNCRPD is about health.



An **article** is a part of the UNCRPD.

Article 25 has 6 articles in it.



In this part of the document we will talk about:

- what each of those articles are about
- what interviewees told us about how well the New Zealand Government is doing to **progressively realise** the things in that article.



## Article 25.a



**Article 25.a** is about providing healthcare for disabled people.



Article 25.a says that the New Zealand Government must provide healthcare for disabled people that is as good as what it provides for everyone else.



Article 25.a also says the New Zealand Government must provide all the same kinds of healthcare to disabled people as it does to everyone else including:

- **sexual and reproductive health services**
- **population based public health programmes.**





**Sexual and reproductive health is health to do with:**

- sex including illnesses people can get from having sex
- getting pregnant
- giving people ways to not get pregnant if they do not want children.

**Unite  
against  
COVID-19**

**Population based public health programmes** are big programmes to do with the health of everyone in the country like the response to the COVID-19 pandemic.



Interviewees talked about lots of things to do with Article 25.a.



Many interviewees said that money was a big problem.

Some of the ways in which money was a problem were:



- there not being enough money for services
- services costing disabled people too much
- money not being used in a fair way like more money for ACC than for other health services.



Interviewees also said that it was hard for disabled people to get good **sexual and reproductive health** services.

Unite  
against  
COVID-19

People also talked about population based public health programmes like the response to the COVID-19 pandemic.



These programmes sometimes did not give enough attention to what disabled people needed.



Interviewees had problems with access to healthcare.

Some of the kinds of access people had problems with were:



- physical access like:
  - not being able to get into a building
  - not having things like beds or scanners that disabled people can use



- mental access like feeling too stressed from bad experiences to get medical care



- communication access like not having a New Zealand Sign Language interpreter



- sensory access like hospitals being too loud for people.



Many interviewees did not think **formal complaints procedures** worked well.



**Formal complaints procedures** are ways of:

- saying a healthcare provider did something wrong
- asking for things to be changed.

## Article 25.b



**Article 25.b** of the UNCRPD says that the New Zealand Government must provide the health services disabled people need because of their disabilities.



These include services:

- to find out they are disabled early
- to stop them becoming more disabled.



Interviewees said there were lots of problems getting the services they needed because of their disability.

These problems included:



- not having enough choice about their treatment
- services not working together well
- services not understanding how their different disabilities fit together
- getting a diagnosis which means finding out what medical condition they have
- having to wait a long time for medical services.





Interviewees also talked about the problems with disability support services like:



- having to rely on family for support
- not enough money for the kinds of support people needed
- not enough services including for people who had:



- more than 1 disability
- a disability that does not get enough attention like **Fetal Alcohol Spectrum Disorder**.



**Fetal Alcohol Spectrum Disorder** is also called FASD.

FASD is a condition that some people get because their parent drank alcohol when they were pregnant with them.

FASD can affect the:

- brain
- body.

## Article 25.c



**Article 25.c** says that the New Zealand Government must make sure there are health services as close as possible to the communities people live in.



This includes in **rural areas**.

**Rural areas** are places away from large towns.



Interviewees said that health services were very different in different places around New Zealand.

It was harder to get the right healthcare in some places than in others.



People living in rural areas had a lot of **barriers** to getting the right healthcare.

**Barriers** are things that make it hard for disabled people to live their lives.



Some people had to travel a long way to get the healthcare they needed.

## Article 25.d



**Article 25.d** says that health professionals must provide disabled people with as good care as non-disabled people.



This care has to be by **informed consent**.

**Informed consent** means you:

- choose what healthcare you have
- can choose not to have healthcare
- have the information you need to make a good decision.





To make this happen the New Zealand Government needs to make sure health services workers have the right training in disability rights.



Interviewees said the way that people working in health services thought of disabled people was often a problem.

For example some people working in health services:



- thought being disabled was always bad



- did not take disabled people seriously
- did not look into medical issues enough to find out what was going on.



Interviewees felt these people working in health services did not get enough training on things to do with disability.

Attitudes were worse for patients who belonged to other groups of people that society makes things harder for like:



- **whānau hauā / whaikaha Māori**
- **disabled trans people.**



**Whānau hauā / whaikaha Māori** are words for Māori disabled people.



**Trans people** are people who were thought to be a different gender when they were born.

For example a baby people thought was a boy might grow up to be a woman.

Trans people often change things to better fit their gender like:

- their body
- their name
- the clothes they wear
- how people talk about them.



Some interviewees also said things were not set up right for informed consent.

There was often no information in a way that worked for disabled people.

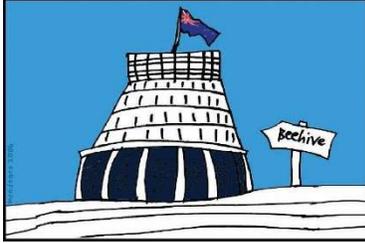


The UNCRPD also says the government has to make sure people know about the UNCRPD.

Some of the people we asked did not know about the UNCRPD.



Many of these people were Deaf.



This means the government needs to do more to tell people about the UNCRPD in ways that work for different communities like the Deaf community.



Interviewees felt they had to use **self advocacy** to get the care they needed.

**Self advocacy** is when you speak up for yourself.



Having to self advocate made people tired.

Some interviewees felt they had not been treated well because of their disability.

## Article 25.e



**Article 25.e** of the UNCRPD says the New Zealand Government has to stop **discrimination** against disabled people when they get **insurance**.

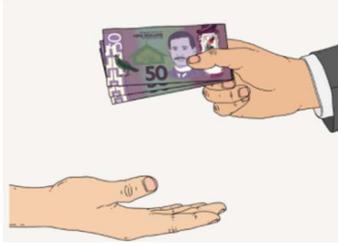


**Discrimination** is when you are treated unfairly because of something like being:

- disabled
- Māori
- a woman.



**Insurance** is when you pay money so things will be paid for if you need them.



We looked at 2 kinds of insurance:

- **private insurance**
- Accident Compensation Corporation / ACC.



**Private insurance** can pay for people to get:

- kinds of healthcare that are not paid for by the government
- healthcare faster than if they used the healthcare paid for by the government
- money to support their family if they:
  - die
  - have a condition that means they are going to die.





Most interviewees did not have private insurance.

This was often because:

- they could not get private insurance because of their health conditions
- private insurance charged them a lot more money because of their health conditions.



Te Kaporeihana Āwhina Hunga Whara

ACC is run by the government.



It covers people whose disability is caused by accidents.



ACC does not cover people:

- whose disability is caused by illness
- who were born with disabilities.



Interviewees who got ACC talked about problems like ACC:

- expecting them to be able to do the same things as before
- trying to give them as little support as possible.

## Article 25.f



**Article 25.f** of the UNCRPD says that the New Zealand Government must make sure that disabled people are not stopped from having some things they need to live because of their disability.

The things they must not be stopped from having because of their disability are:



- healthcare
- health services
- food
- fluids like water.



None of the interviewees said they were stopped from having food or water because of their disability.



Interviewees did talk about not getting the healthcare they needed because they were disabled.



This included not having healthcare because of:

- the bad ideas some doctors had about disabled people
- the ways COVID-19 made it harder to get health services
- there not being good enough healthcare for people in prison.



## What the DBI thinks about the things we found out



In this research DBI found a big range of different things that make it hard for disabled people to have as good health as they can.



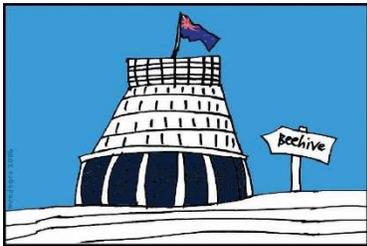
1 thing that came up in a lot of interviews was the way the health system is.

This causes a lot of problems with **wellbeing** for disabled people.

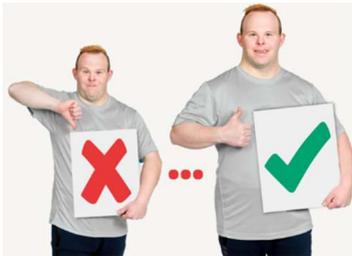


**Wellbeing** is to do with:

- feeling well
- not being too stressed.



In April 2021 the government said there would be a new health and disability system.



This system can sort some of the problems we found out about in this research.



There are also things that do not seem to be part of these changes like:



- which medicines the government pays part of the cost of

- disabled people in prisons



- complaints procedures that are hard for disabled people to use.

A lot of people in the health system do not understand disability in a way that is based on the rights disabled people have.



There has also been research done for the Waitangi Tribunal that looks at what it is like for tāngata whaikaha / whānau hauā.



**Unite  
against  
COVID-19**

The research found that tāngata whaikaha / whānau hauā have lots of barriers in the health and disability system.

DBI research found that population-based health programmes like the work to stop COVID-19 often do not meet the needs of tāngata whaikaha / whānau hauā.



The health and disability system must work in a way that is a good fit with Māori ways of thinking about disability.



Many interviewees found that they got better healthcare if they knew how the health system worked.



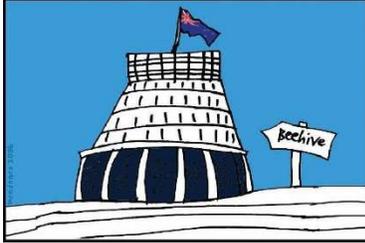
It is important to support disabled people to know how the system works.



It is also important that the system:

- treats all people well
- is fair for everyone
- is easy to use.

# Recommendations



**Recommendations** are things that the government should do.



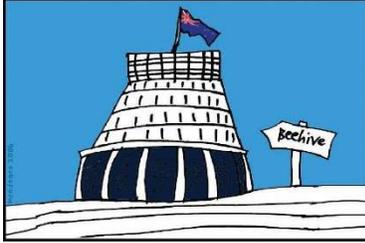
Disabled people are the best people to give recommendations on how the government should work to do the things in Article 25 of the UNCRPD.



These are some recommendations that:

- lots of interviewees told us should happen
- we worked out from the things the interviewees were telling us.





The interviewees recommend the government set up a Ministry focused on:

- disability
- disabled people.



This will mean disability is not treated as the same thing as health.



Te Kaporeihana Āwhina Hunga Whara

There should be an end to the system where:

- some people get support from ACC
- other people get support from the Ministry of Health.



Instead there should be 1 system that is fair to everyone.



The interviewees also recommend the government:

- put tāngata whaikaha / whānau hauā first in all parts of healthcare
- make sure new laws are a good fit with the UNCRPD
- make regular healthcare including **dental care** for disabled people not cost any money



**Dental care** is healthcare for your teeth.



- make there be more money to pay for carers / support people who have done lots of training.

The interviewees also recommend the government:



- have more Deaf and disabled people as healthcare workers like:
  - doctors
  - nurses
  - physiotherapists
- make sure people know more about:
  - disability rights
  - the UNCRPD
- support disabled people to know more about how the health and disability system works.



The interviewees also recommend the government:



- make training about disability rights for:
  - health professionals
  - people who are studying to be doctors



- make sure there is enough health and disability support in rural areas
- agree to make it so people anywhere in New Zealand can get **Enabling Good Lives** very soon.



**Enabling Good Lives** gives people more choice about disability support.



The interviewees also recommend the government stop surgery on **intersex people** unless there is a medical reason.



**Intersex people** are people whose bodies are not like what people usually think of as:

- female bodies
- male bodies.



Often intersex people are given surgery on their bodies when they are small children.



This surgery is to make their bodies look more like the bodies of people who are not intersex.

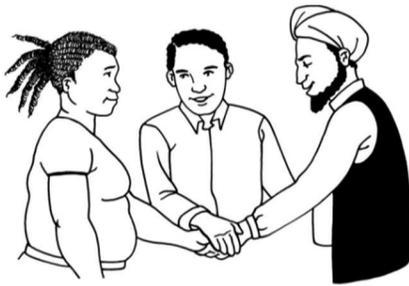


Lots of intersex people say the surgery is bad because:

- these people are too young to choose if they want the surgery or not



- there is nothing wrong with intersex bodies.



The interviewees also recommend the government:

- make different parts of the health and disability system work together better

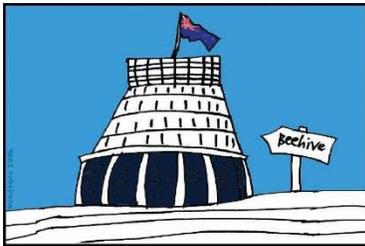


- understand FASD is a disability
- make sure people with FASD have things they need like services.



The DBI recommends that when the government makes future decisions about health and disability it thinks about:

- disability rights
- the UNCRPD.



The government should agree to improving the things we have found out about in this research.



The government should also keep checking how well they are doing things.

# Final thoughts from the DBI



Interviewees shared important information in this research about lots of things to do with healthcare.



There are 4 main areas where change is needed:



- upholding **Te Tiriti o Waitangi** for tāngata whaikaha / whānau hauā



- sorting out unfair ways of deciding where money goes



- making it so disabled people can understand health better

- making it easier to complain.



**Te Tiriti o Waitangi / Treaty of Waitangi** is an important agreement between Māori and the British Crown.



Things have got better for the rights of disabled people in Aotearoa New Zealand.



There is still a long way to go.

It has taken more than 13 years to begin to sort out some of these problems.



This monitoring research shows the way forward to a future where all disabled people get the rights in the UNCRPD.



That way forward must be led by:

- disabled people
- whānau / family.

# Where to find more information



If you want to find out more information you can **phone** DBI on:

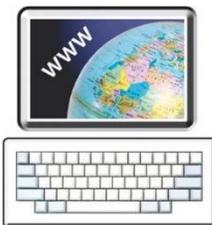


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You can **email** us on

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You can also look at our **website**:

**[www.donaldbeasley.org.nz/](http://www.donaldbeasley.org.nz/)**



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