DONALD BEASLEY INSTITUTE

Summary of findings – Monitoring of My Experiences My Rights: Disability Supports and Services

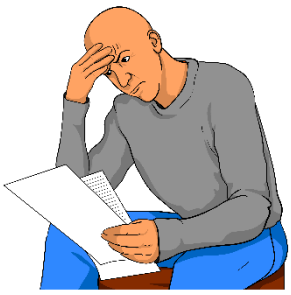
Report 3:

Disability Supports Services

Published: September 2025

Before you start

This is a long document.



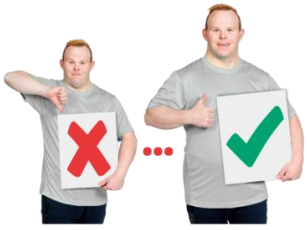
It can be hard for some people to read a document this long.

Some things you can do to make it easier are:

- read it a few pages at a time
- set aside some quiet time to look at it
- have someone read it with you to support you to understand it.

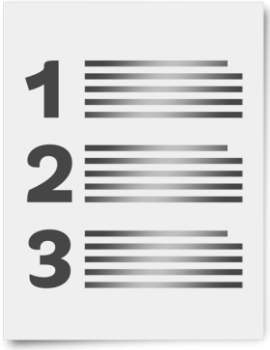
What you will find in here

Page number:



About this Easy Read

This Easy Read is a **summary** of findings from **research** done by the **Donald Beasley Institute**.



A **summary** is:

- shorter than the main document
- tells you the main ideas.

Research is when a lot of information about something is put together to learn about it.

The **Donald Beasley Institute** is a place that researches things to do with disability.

It is based in Dunedin in Aotearoa New Zealand.

In this Easy Read the Donald Beasley Institute will be called the **DBI**.

This is the third report of what the DBI found out from their research.

This report is about what people thought about **disability supports and services**.

Here **disability supports and services** means all the ways the Government supports disabled people like paying for:

- equipment like a wheelchair
- homes for disabled people
- support workers.

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA

The **Ministry of Social Development** is in charge of **Disability Support Services** now.

The **Ministry of Social Development** is the part of the Government in charge of making sure all New Zealanders have enough money to live good lives by:

- paying benefits / money for people who do not have a job
- paying benefits / money so people can pay for things they need like seeing the doctor
- supporting people to find jobs.

The Ministry of Social Development is sometimes called **MSD** for short.

Disability Support Services

Disability Support Services is the part of MSD that pays for supports for disabled people like:

- equipment like:
    - tools that support people to talk to other people
    - a cane for a blind person
- Carer Support so a person who cares for a disabled person can take a break
- Individualised Funding so disabled people can:
    - decide what supports they need
    - pay for their supports.

In this Easy Read Disability Support Services will be called **DSS** for short.

When the research was done **Whaikaha – Ministry of Disabled People** was in charge of Disability Support Services.

Whaikaha – Ministry of Disabled People works to make change for disabled people to make their lives better.

It makes things better for disabled people by working with:

- the Government
- the community
- businesses.

What was the research about?

The **Disabled People's Organisations Coalition** asked the DBI to start doing research in 2021.

The **Disabled People's Organisations Coalition** is a group of people from different disability organisations.

It is also called the **DPO Coalition**.

A **coalition** is a group of organisations that work together.

The DPO Coalition wanted to know how well the Aotearoa New Zealand Government was making the **United Nations Convention on the Rights of Persons with Disabilities** work in this country.

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

It is also called the **UNCRPD**.

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

Rights are things everyone should:

- have
- be able to do.

Rights are things like:

- having a safe place to live
- being able to get married.

The DPO Coalition wanted to know if the rights of disabled people were protected when they tried to get disability supports and services in Aotearoa New Zealand.

Many big changes happened to disability supports and services while DBI was doing the research.

These changes included:

- Whaikaha – Ministry of Disabled People starting in 2022
- changes to DSS in March 2024

- changes to what Whaikaha – Ministry of Disabled People can do in August 2024.

DBI did the research by doing:

- interviews / talking to people
- **focus groups**
- **questionnaires**.

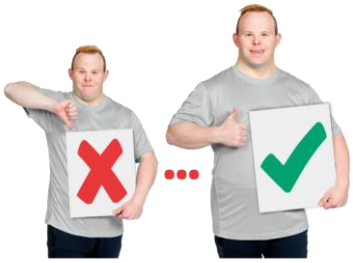
A **focus group** is a group of people who come together to talk about a thing they have in common.

A **questionnaire** is when people write down their answers to questions.

This report talks about:

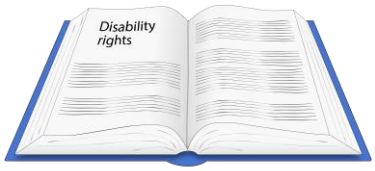
- what disabled people think about disability supports and services
- what using disability supports and services is like for disabled people.

It talks about what disabled people think about the changes to disability supports and services.



It says what disabled people think needs to happen to:

- make disability supports and services better



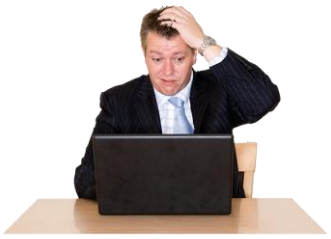
- protect the rights of disabled people.

In this Easy Read the people who took part in the research are called **participants**.

What the research found out

Information about disability supports and services

Participants said they need good information so they know what disability supports and services they can get.



It is hard to find information about disability supports and services.

Many participants said information was **inaccessible**.

Here **inaccessible** means hard to understand.

Information was inaccessible when it was not in alternative formats like:

- **plain language**
- New Zealand Sign Language.

Plain language means writing that people can easily understand.

Funding

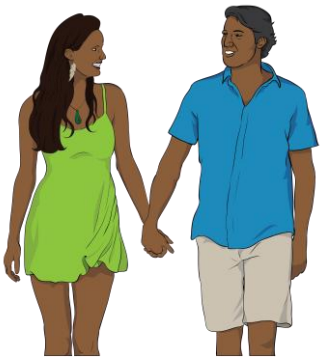
Here **funding** means:

- money that pays for disability supports and services
- benefits like money the Government pays you when you do not have a job.

Some participants could not get funding.

Some of the reasons why people could not get funding were:

- the Government did not think their disability was a disability
- they were in a **relationship**
- they had **natural supports**
- they were older than 65
- they got their disability **diagnosis** overseas.

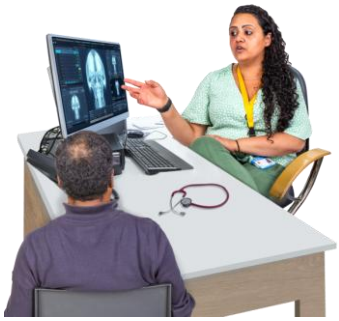


Being in a **relationship** means you have someone you love like a:

- partner
- boyfriend / girlfriend
- husband / wife.

Having **natural supports** means you have people in your life who support you without being paid.

Having a parent who goes to the doctor with you to support you is an example of a natural support.



A **diagnosis** is when you find out you have a disability.

A diagnosis is usually done by a healthcare professional like a:

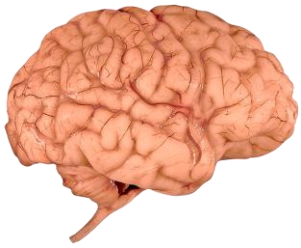
- doctor
- psychologist.

A **needs assessment** is the main way to get funding.

A **needs assessment** is when someone talks to you to find out:

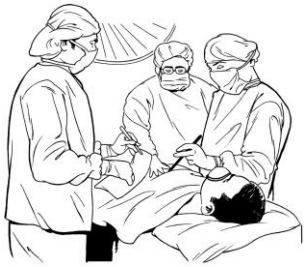
- what support you need
- if you can get funding
- how much funding you can get.

Participants said that needs assessments were based on the **medical model of disability**.



The **medical model of disability** says that disability:

- is a problem with the:
  - body of a person
  - mind of a person
- needs to be fixed.



Participants often had to wait a long time to get a needs assessment.

Participants said there was not enough funding.

There not being enough funding meant participants:

- did not get enough support
- got no support.

Participants thought that not spending much money on disabled people shows the Government does not care about disabled people.

How a person became disabled changes how much funding they can get.

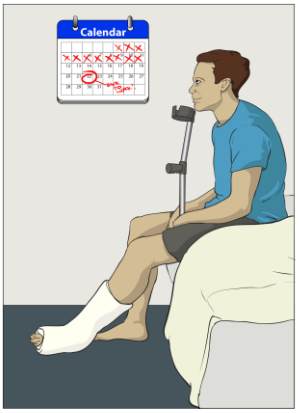
DSS funds disability supports and services for people who:

- were born disabled
- have a **genetic condition**
- have a disability caused by a health condition.

A **genetic condition** means a health condition that gets passed down from parents to their children.

The **Accident Compensation Corporation** funds disability supports and services for people whose disability was caused by an:

- accident
- injury.



The **Accident Compensation Corporation** pays for support for all New Zealanders who:

- have an accident
- get hurt.

It is called **ACC** for short.

We already know that DSS and ACC give disabled people different:

- amounts of funding
- types of support
- ways of using the support.

People have been saying this is a bad thing for a long time.

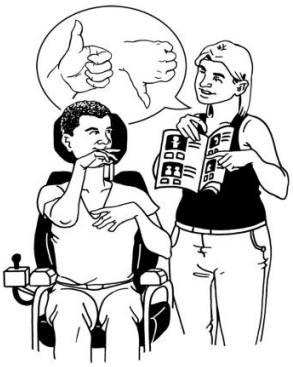
Choice and control

Participants said having **choice and control** was important for:

- them
- their whānau / families.

Here **choice and control** means disabled people get to have a say about:

- what supports they get
- how their supports work.



Having choice and control means people:

- feel sure they can get the right disability supports and services
- can get disability supports and services in a way that works for them.

Participants said they need to be good at speaking up for themselves to have choice and control.

Sometimes participants did not have real choice and control over:

- their funding
- when they got support
- who their support workers were.

Many participants in **residential care** did not have choice and control.

Residential care is when you live in a home for disabled people.

Some of the reasons why participants in residential care did not have choice and control were:

- there were not enough staff
- the staff did not know how to support people
- people were not supported to do things that were important to them like cooking their own food
- people did not feel like they were:
    - free
    - **respected**.

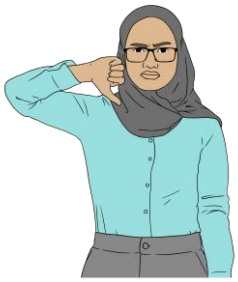
Here feeling **respected** means other people:

- take care of your:
    - feelings
    - rights
- treat you like you are important.

Not having choice and control in residential care also made some participants feel:

- uncomfortable
- **frustrated**.

Feeling **frustrated** means feeling really annoyed about something you cannot change.



Whānau / families of people in residential care also thought there was not enough choice and control.

They said:

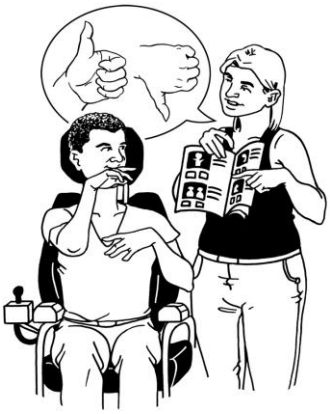
- they were worried that their whānau / family member was not being cared for properly

- staff did not support people to do things:
    - for themselves
    - with other people

- staff did not have enough training
- they did not trust residential care.

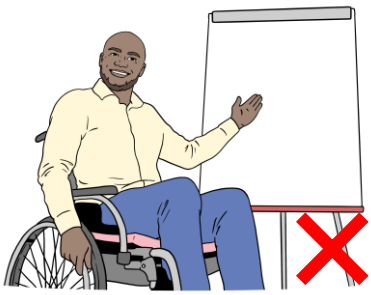
Disability support workforce

The **disability support workforce** means all the people who have jobs supporting disabled people.



Participants said they are worried about not having support due to:

- **agencies** not giving them the right support
- support workers not having enough training
- there not being enough support workers.

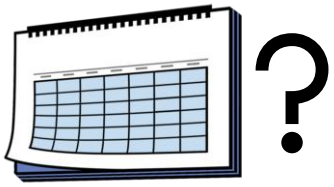


Here **agencies** are organisations that:

- employ support workers
- connect disabled people with support workers.

It is not safe when disabled people cannot get the care they need when they need it.

People stop working in the disability support workforce all the time.

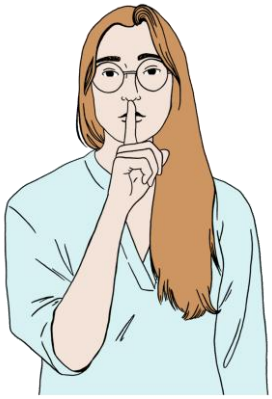


Participants said people stop working in the disability support workforce because they are:

- not sure how long they will have a job for

- not paid enough
- treated badly by agencies.

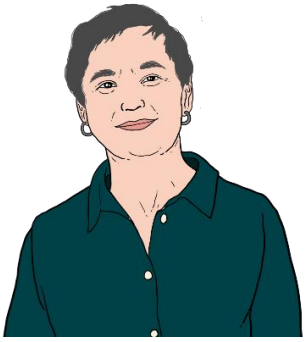
Participants were also worried that their information was not kept private.



Keeping information **private** means that agencies / support workers only share information about disabled people with people who need to know the information.

Participants said information is shared when it should not be shared with:

- other people who work in the disability support workforce
- people who do not work in the disability support workforce.



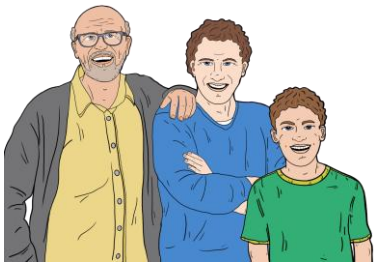
Intersectionality

Intersectionality is a way of thinking about how different things about a person change how they experience the world.

For example if you are a disabled woman things might be different for you than they are for:

- a woman who is not disabled
- a disabled person who is not a woman.

Some participants said they had trouble with disability supports and services due to their:



- **culture**
- **gender**
- age.

Culture is a way of:

- thinking that a group shares
- doing things as a group.

Some examples of different cultures in Aotearoa New Zealand are:

- Māori culture
- Pacific culture
- Deaf culture.

Gender is if you are:

- a boy / man
- a girl / woman
- another gender like nonbinary.

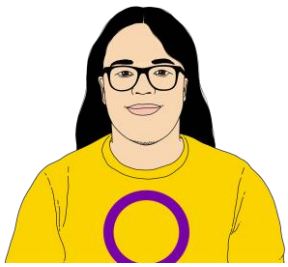
Some participants said disability supports and services did not support them in a way that worked in their culture.

Some participants said disability supports and services believed things about their culture that were wrong.

This made it harder for these participants to get support.

LGBTQIA+ participants said they had trouble getting healthcare due to health professionals not understanding:

- disability
- intersectionality.



LGBTQIA+ stands for people who are:

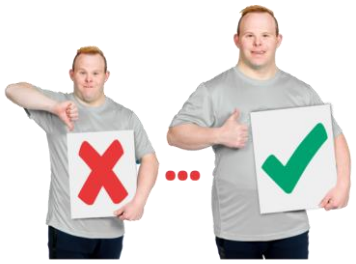
- lesbian
- gay
- bisexual
- transgender
- queer
- intersex
- asexual
- + is for other people who fit in similar groups.

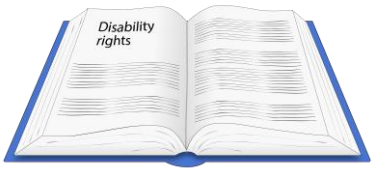
Some participants said they got the wrong support like when young people were put in residential care with older people.

Participants got different amounts of support depending on how old they were like:

- young people who became too old to access services for children
- people over 65.

Recommendations





Participants had **recommendations** about what the Government can do to make disability supports and services in Aotearoa New Zealand:

- better
- be based on **Te Tiriti o Waitangi / The Treaty of Waitangi**
- protect the rights of disabled people.

Recommendations are ideas about how to make something work better.

Te Tiriti o Waitangi / The Treaty of Waitangi is an important agreement between:

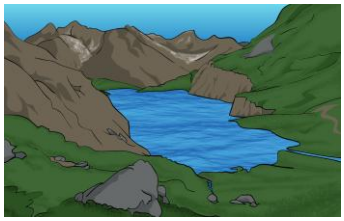
- Māori

and

- the Crown which means the New Zealand Government.

The purpose of Te Tiriti is to:

- protect Māori:
    - rights
    - **taonga**
- keep **peace and order**
- set up government.



Taonga means treasures like:

- land / rivers
- te reo Māori / Māori language
- objects like pounamu / greenstone
- traditional food growing places
- spiritual ideas
- ways of life.

Peace and order means having rules / laws everyone follows.

Recommendation 1

Disabled people and their whānau / families should lead DSS.

This means disabled people and their whānau / families should decide things like:

- how needs assessments happen
- what funding people get
- how to support disabled people.

Disabled people should also train disability support workers.

Recommendation 2

People should be able to get information about DSS:

- early
- easily.

Information about DSS should be in:

- plain language
- alternative formats like:
    - New Zealand Sign Language
    - Easy Read.

Recommendation 3

Healthcare professionals need to:

- know what disability supports and services disabled people can get
- support disabled people to get disability supports and services.

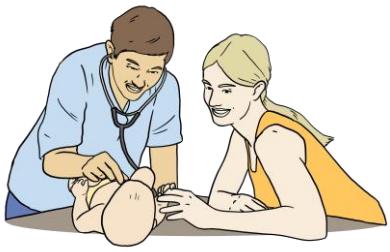
Recommendation 4

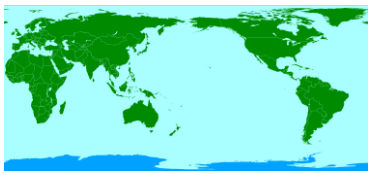
Getting disability supports and services should be based on need.

Getting disability supports and services should **not** be based on what caused someone to become disabled.

People should be able to get DSS if they:

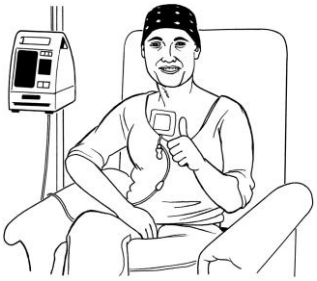
- have:
  - a **psychosocial disability**
  - **chronic health conditions**
  - **fetal alcohol spectrum disorder**





- were diagnosed overseas
- are over 65.

A **psychosocial disability** is when someone is disabled due to having a hard time with their mental health.



Chronic health conditions are health conditions that last a long time like:

- diabetes
- cancer
- fibromyalgia.

Fetal alcohol spectrum disorder is a disability a person might have if their parent drank **alcohol** when they were pregnant.

Alcohol means drinks like:

- wine
- beer
- spirits.

Recommendation 5

People should be able to get needs assessments quickly.

Needs assessments should be based on:

- what strengths the person has
- human rights.

Needs assessments should use **flexible eligibility criteria**.

Eligibility criteria means the rules DSS uses to decide:

- who can get funding
- what they can spend their funding on.

Flexible eligibility criteria means people can use their funding in a way that works for them.

Recommendation 6

The Government should put enough money into DSS so disabled people can:

- be part of their **communities**
- live good lives.

Communities are groups of people who have something the same about them like:

- living in the same place
- being LGBTQIA+
- belonging to the same culture.

People who get DSS funding should get the same amount of money as people who get ACC funding.

Recommendation 7

DSS should understand how:

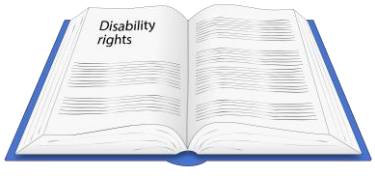
- being disabled affects the health of a person
- being healthy can change how disability affects a person.

Different **agencies** should work together to make sure disabled people get good care.

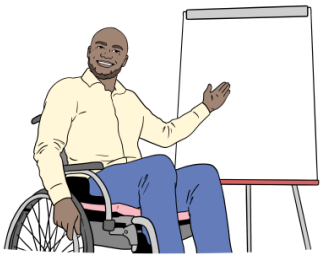
Here **agencies** means:

- parts of the healthcare system like:
  - hospitals
  - GPs
- parts of the Government like:
  - DSS
  - Whaikaha – Ministry of Disabled People
- disability supports and services.

Recommendation 8



Everyone who is part of DSS should get training about disability rights.



This training should be run by disabled people.

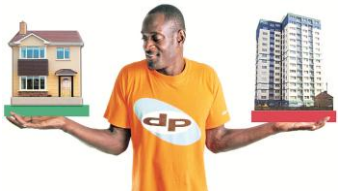
The people who should get this training are:

- people who work in the Government
- people who run disability supports and services
- connectors who support people to get the disability supports and services they need
- assessors who decide what DSS funding a person can get
- support workers.

Recommendation 9

Disabled people should have more choice and control over the disability supports and services they get.

This includes disabled people who live in:



- residential care
- other places.

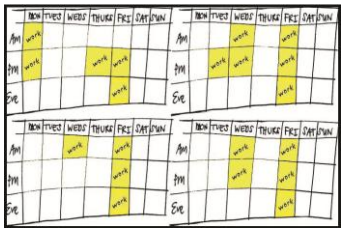
Supported decision-making should be used so disabled people can decide:

- what organisation they want to get support from
- who they want their support workers to be

- how they want to be supported
- how to use their funding.

Supported decision-making is when disabled people make choices about their own lives with support from people they choose.

Recommendation 10



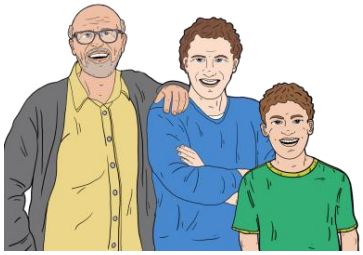
Support workers should:

- have enough hours of work each week so they can afford to live
- be paid well
- get good training
- know what they need to do to:
    - get paid more
    - move into other jobs in the disability support workforce.

Recommendation 11

People should get disability supports and services that:

- are flexible
- work for them based on their:
    - culture
    - gender
    - age.

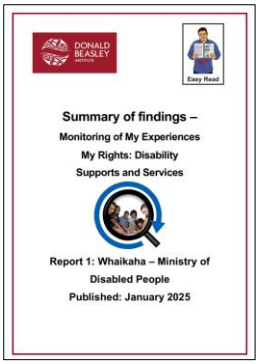


More information

You can read the full report on the DBI **website** at:

https://tinyurl.com/yn5sjpdk

The full report is **not** in Easy Read.



You can read Part 1 of the report in Easy Read at:

https://tinyurl.com/2z6er67s

You can read Part 2 of the report in Easy Read at:

https://tinyurl.com/2zb7v3xr

For more information about what DBI does you can go to the DBI **website** at:

www.donaldbeasley.org.nz

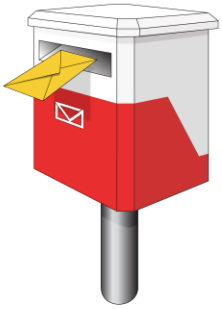
You can contact DBI by **phone** on:

0800 878 839

It does not cost money to phone this number.

You can **email** DBI at:

admin@donaldbeasley.org.nz



You can **post** a letter to DBI at:

Donald Beasley Institute

Suite 4

Level 2

248 Cumberland St

Dunedin 9016

New Zealand

This information has been written by the Donald Beasley Institute.

It has been translated into Easy Read by the Make it Easy Kia Māmā Mai service of People First New Zealand Ngā Tāngata Tuatahi.

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