

**Health Quality &
Safety Commission**
Te Tāhū Hauora



Summary:

A Window on Disability

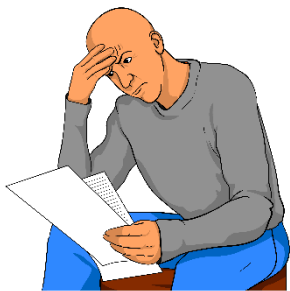


Published: May 2026

Before you start



This is a long document.



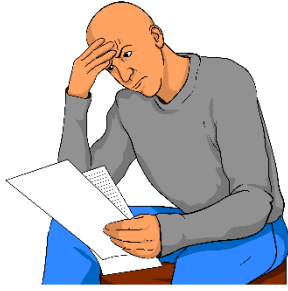
It can be hard for some people to read a document this long.

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.





Some of the information in this document may make people:

- upset
- worried.



This information is not meant to scare anyone.



This information does not mean the things in this document will happen to:

- you
- people you know.





People with learning disability all have different health needs.



If you are worried you can talk to your:

- whānau / family
- friends
- doctor.



What you will find in here

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What this Easy Read is about

Health Quality &
Safety Commission
Te Tāhū Hauora



This Easy Read is from the **Health Quality and Safety Commission Te Tāhū Hauora**.



The **Health Quality and Safety Commission Te Tāhū Hauora** makes sure healthcare in Aotearoa New Zealand:

- works well
- is safe.



In this Easy Read **we / our / us** means the Health Quality and Safety Commission Te Tāhū Hauora.



This Easy Read is about some **research** into healthcare for disabled people we did with the **Donald Beasley Institute**.



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



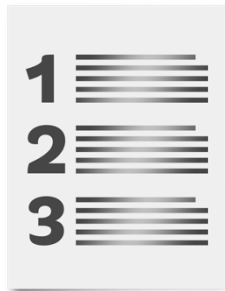
The **Donald Beasley Institute** is a place that researches things to do with disability.



It is based in Dunedin in Aotearoa New Zealand.

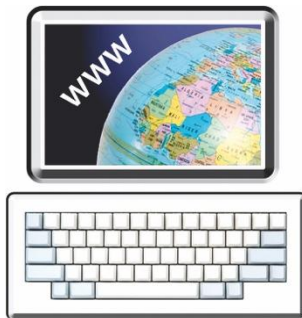


This Easy Read is a **summary** of the full report about our research.



A **summary**:

- is shorter than the full report
- tells you the main ideas.



You can read the full report at:

<https://www.hqsc.govt.nz/a-window-on-disability.html>



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

About the research



Disabled people should have the healthcare they need to:

- be as healthy as possible
- lead an **ordinary life**.

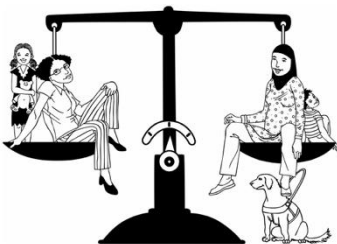


An **ordinary life** means being able to do the same things as other people.



We wanted to find out if the healthcare disabled people get is:

- good enough
- the same as the healthcare non-disabled people get.





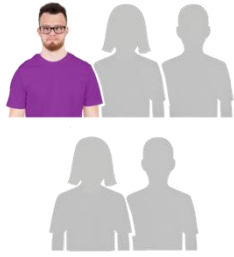
There is not much information about disabled people in Aotearoa New Zealand.



In 2023 the New Zealand **census** found that 5 out of every 1 hundred New Zealanders are disabled.



In Aotearoa New Zealand the **census** is research that finds out a lot of information about people in New Zealand.



The 2023 **Household Disability Survey** found that almost 1 in 5 New Zealanders are disabled.



The **Household Disability Survey** is research that was done to find out:

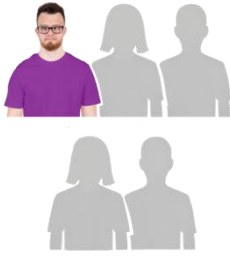
- how many disabled people there are in Aotearoa New Zealand
- what life is like for disabled people in Aotearoa New Zealand.



The Household Disability Survey:

- asked more question about disability than the census
- is more likely to be right about the number of disabled people.





1 in 5 people means there are more than 8 hundred and 50 thousand disabled New Zealanders.



Most health **data** in Aotearoa New Zealand does not have information about disability.



Here **data** is information that shows what groups of people:

- are doing
- need.

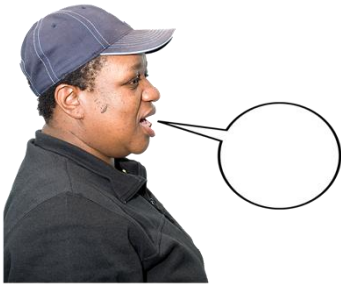


This means there has been very little research about healthcare for disabled people.



The research for this report was:

- led by disabled people
- used a lot of different kinds of data
- asked disabled people about their experiences of healthcare.



This Easy read includes some **quotes** from people we talked to for our research.



A **quote** is an exact copy in writing of what someone has said.



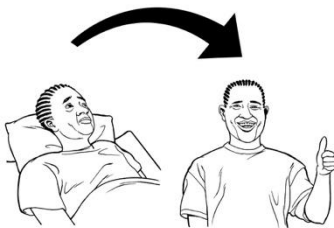
The quotes are in purple boxes like this.

The quotes are **not** in Easy Read.

What we found out



Disabled people are 5 times more likely to die from **treatable conditions** than non-disabled people.



A **treatable condition** is a medical condition that can be:

- made better with treatment

or

- treated so that someone can live with it for a long time.



Māori disabled people are more than 10 times as likely to die from treatable conditions than people who are not:



- Māori
- Pacific
- disabled.



Disabled people are more likely to be **enrolled** in **primary care** than non-disabled people.



Here **enrolled** means you have a healthcare provider who:

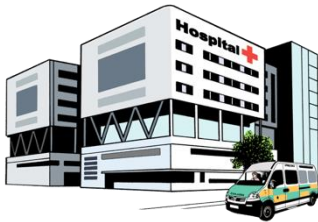
- has your medical information
- you see for most health things.



Primary care means healthcare that is not in a hospital like seeing your usual doctor / GP.



Many disabled people often cannot see a doctor when they need to even when they are enrolled in primary care.



This means that disabled people often go to the hospital emergency department when they are unwell.



Not getting healthcare when they need it means that disabled people are more likely to:

- get more unwell than if they had been treated earlier
- need to go to hospital
- stay in hospital for longer
- have worse:
 - health
 - lives.



It can also mean the government has to spend more money on healthcare.



Getting healthcare is even harder for disabled people who:

- have more than 1 disability
- are Māori
- are Pacific.



One of the people we talked to for our research is Jacinta Tevaga who is:

- disabled
- Samoan
- a disability researcher.





Jacinta Tevaga said:

Disabled people deserve to be listened to. We need staff who are trained in disability awareness.



Accessible communication must be normal, not something we have to beg for.



Accessible communication is communication that works for disabled people like:

- using New Zealand Sign Language
- having written information in Easy Read.





Jacinta Tevaga also said:

The system must understand that disabled people have other health conditions too.



We are whole people, not just our primary disabilities.

Life course stages



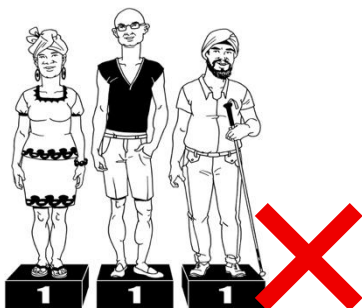
We took a close look at how disabled people experience healthcare at different **life course stages**.



Here **life course stages** means different times in your life.



This supported us to understand why there are such big **inequities** in healthcare.



Inequities are things that are **not**:

- fair
- the same for everyone.

Pregnancy and birth



In Aotearoa New Zealand disabled people are less likely to have a **lead maternity carer** early in their pregnancy.



A **lead maternity carer** is the main healthcare worker when someone is:

- pregnant
- giving birth.

Lead maternity carers are people like:

- midwives
- obstetricians.

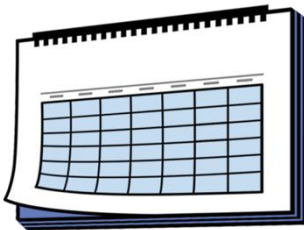




People with more than 1 disability are even less likely to have a lead maternity carer.



Disabled people are more likely to have **pre-term births** than non-disabled people.



Pre-term birth is when a baby is born too early.



Disabled people are also more likely to say they did not have a good experience during:

- pregnancy
- birth.



We talked to Tamara Grant who is a disabled mother.



Tamara Grant said:

We deserve a health system that sees us, listens to us and believes we know our own bodies.

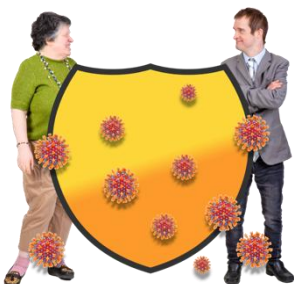
Children and youth



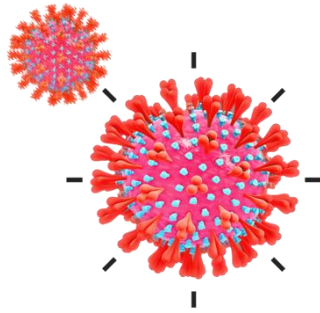
The health system seems to work well for disabled children.



Disabled children were about as likely to get **vaccines** as non-disabled children before **COVID-19**.

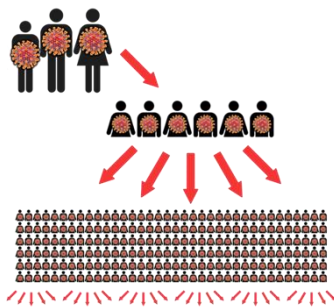


A **vaccine** is a medicine that can stop you getting very sick from a disease.



COVID-19 is a virus that can make people very unwell.

The COVID-19 **pandemic** started in 2020.



A **pandemic** is when a lot of people become unwell with the same disease at the same time.



We think that COVID-19 changed things so that disabled children are less likely to get vaccines now.



We do not have enough information to say this for sure.



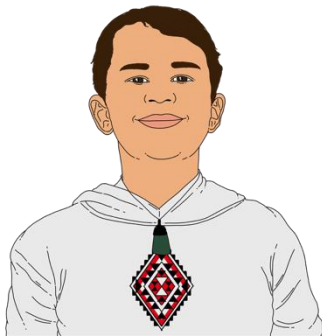
Disabled children often have problems with their teeth.



These problems often last for their whole lives.



Disabled children are more likely to have such bad problems with their teeth they need to be treated in hospital.

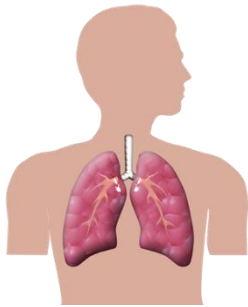


Disabled children are even more likely to need to have their teeth treated in hospital if they are:

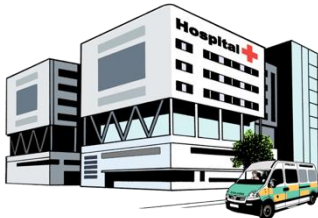
- Māori
- Pacific.



Disabled children are less likely to get the right treatment for **asthma** than non-disabled children.



Asthma is a condition that can make it hard to breathe.



Disabled children are more likely to need to go to hospital because of asthma than non-disabled children.



Disabled children are more likely to experience **avoidable hospitalisation** for a lot of reasons like:

- tooth problems
- gastroenteritis / stomach bugs
- constipation / not being able to poo.





Avoidable hospitalisation means someone has to be in hospital when getting treatment earlier would have stopped them getting so sick.



Disabled children often do not have all their needs met for:

- primary care
- medication
- **assistive equipment.**



Assistive equipment means things that make life easier for disabled people like:

- wheelchairs
- hearing aids.





There can also be problems when disabled young people start using adult healthcare services.



It can be hard to have to leave healthcare providers who:

- know you well
- you trust.



Some adult healthcare providers do not know a lot about disabled young people.



We talked to Kimberly Graham and her son Finlay Butcher.

Kimberley Graham and Finlay Butcher said:

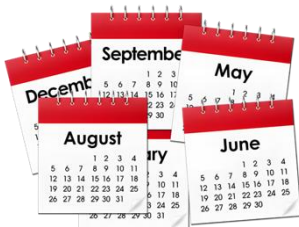
Instead of the steady, familiar support we used to have from long-term **paediatric specialists**, every service now seems to require constant and **persistent advocacy**.



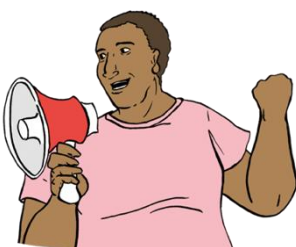
Paediatric specialists are healthcare workers who know a lot about giving healthcare to children.



Here **persistent** means to keep trying to do something a lot of times.



Advocacy means speaking up for someone.



Adults



1 of the biggest **barriers** to healthcare for disabled adults is having to wait a long time.



Barriers are things that make it harder for people to do things.



Disabled adults have more problems with **mental health** like:

- anxiety / feeling very worried a lot of the time
- depression / feeling very unhappy a lot of the time.



Mental health is about how you think / feel in your mind.



Disabled adults use more:

- mental health services
- **addiction** services.



Addiction means not being able to stop yourself using things like:

- drugs
- alcohol.



There are not enough mental health services for disabled adults.



We talked to Abel who is he tāngata turi / a Deaf Māori man.

Abel said:

It shouldn't be this hard to be seen, heard and supported in our own health system.



Disabled people are more likely to have to wait longer than 4 months to get treatment after a treatment plan has been made.



Disabled people are more likely to have problems getting better after an operation than non-disabled people.

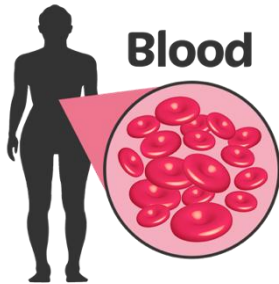


There are more problems getting better after an operation for people who:

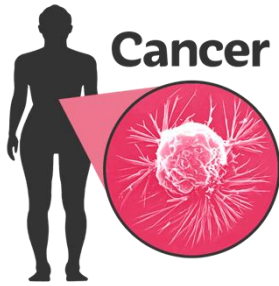
- have more than 1 disability
- are Māori
- are Pacific.



Disabled adults are more likely to have **diabetes** than non-disabled adults.



Diabetes is when someone has too much sugar in their blood.



Disabled adults are also more likely to get many kinds of **cancer** than non-disabled adults.



Cancer is a disease that can make people very sick.



There is not enough primary health care that works for disabled adults.



A lot of disabled adults who are less than 64 years old live in aged care homes.



Aged care homes are not set up to meet the needs of younger adults.



We spoke to Waata Houia who is a Māori man with learning disability.



Waata Houia said:

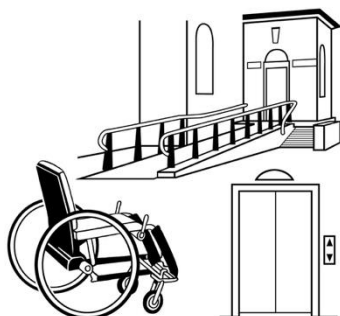
We're the same as everyone else, but we've got a learning disability.



We know what we can do, we know what we want to talk about, and we know what they need to learn so they can be **accessible** to us as who we are.



We won't be changing! Treat us as equal.



Accessible means everyone can do the things they need / want to do.

Older Adults



Disabled people are living longer than they did in the past because of better:

- medicine
- supports
- services.



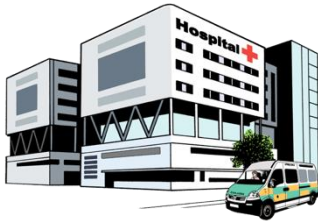
A lot of people also become disabled as they get older.



People who have become disabled when they are older often have different needs from people who have been disabled for a long time.



There is not a lot of information about the differences between these 2 groups of people.



Older people with more than 1 disability are more likely to:

- go to a hospital emergency department
- need to stay in hospital.



Older people with more than 1 disability often stay in hospital longer than other older people.



Disabled people who live in aged care homes are less likely to say they get good care than other people who live in aged care homes.

Recommendations



Our research shows that there is not enough data about disabled people in Aotearoa New Zealand.

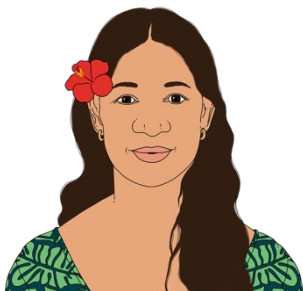


The data we do have shows that disabled people often:

- have worse health than non-disabled people
- are less safe than non-disabled people.



The data shows this is even worse for:



- Māori
- Pacific people.



We have some **recommendations** for how to make healthcare better for disabled people.



A **recommendation** is something we think would be good to do.

1. We need to know more



It is important that data about disability is part of health data.



The work to get better data about disability should be led by:

- disabled people
- tāngata whaikaha / Māori disabled people
- whānau / families of disabled people.





A good first step would be to make a rule that organisations must ask about disability when they ask people for health data.



2. We need to train healthcare workers

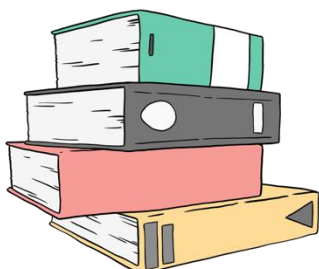
All healthcare workers should get training about disability.



Information about disability should be part of all stages of training healthcare workers.



We need to write a **curriculum** for teaching healthcare workers about disability.



A **curriculum** says the things that should be taught in a course of study.



Everyone who trains healthcare workers should have to use the disability curriculum.



A good first step would be to start a **working group** of:

- disabled people
- tāngata whaikaha / Māori disabled people
- people who know a lot about healthcare for disabled people
- people who decide how healthcare workers are trained.





A **working group** is a group of people who:

- know a lot about something
- work together to get something done.



The working group should have the power to say what healthcare workers must learn about disability.

3. We should employ the right people



Employ means to give someone a job.



All healthcare services can give better care by having disabled people working for them.



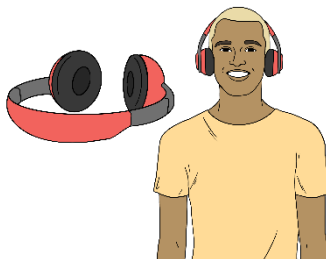
Disabled people are best at understanding what it is like to be disabled.



Healthcare services should do everything they can to:

- find disabled people to work in healthcare
- keep disabled healthcare workers in their jobs
- train disabled healthcare workers so they can move ahead in their jobs
- make **reasonable accommodations** for disabled healthcare workers.





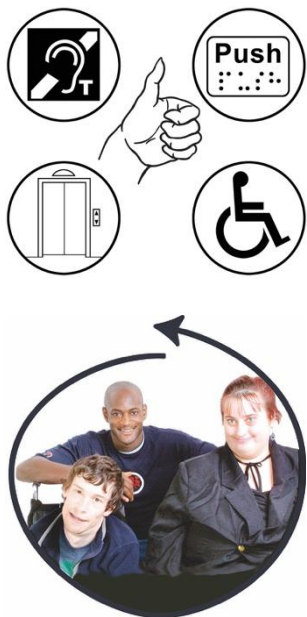
A **reasonable accommodation** is making changes to something so disabled people can do things like:

- work
- get information
- use services.

Reasonable accommodations might include:

- having a different kind of chair at work
- being allowed to wear headphones to block out noise.

A good first step would be to look at how services choose which healthcare workers to employ.



We need to make sure the way services choose healthcare workers is:

- accessible
- **inclusive.**



Inclusive means that:

- everyone can take part
- no one is left out.



We need to think about how healthcare services:

- advertise jobs
- interview people for jobs
- support healthcare workers to do well in their jobs.





4. We need to involve

We need to make sure disabled people can be part of choices about their healthcare using:

- **self determination**
- **supported decision making.**



Self determination means disabled people have control over their own lives.



Supported decision making is when someone has support to:

- understand their choices
- make the decision that is right for them.





We need to make sure disabled people have what they need to make decisions about their healthcare like:

- information they can understand
- support with communication
- enough time.



A good first step would be to work with disabled people to:

- design ways of doing supported decision making that can be used all over Aotearoa New Zealand
- train healthcare workers to use supported decision making.





We need to make sure healthcare is done in a way that supports the rights of:

- disabled people
- tāngata whaikaha / Māori disabled people.



Rights are things everyone should:

- have
- be able to do.



Rights are things like:

- getting the healthcare you need
- making your own choices about healthcare.



This information has been written by Health Quality and Safety Commission Te Tāhū Hauora.



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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