ALLEN+CLARKE
EVALUATION AND RESEARCH

All is for All

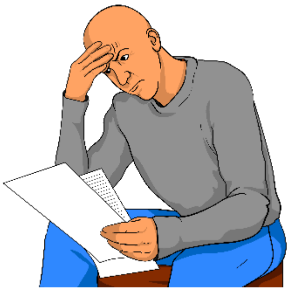
Easy Read

Research – experiences of extra costs and income support

Published: December 2024

Before you start

This is a long document.



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

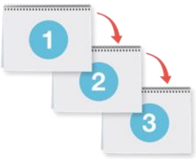
Some things you can do to make it easier are:

- 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:



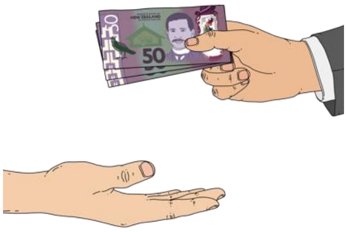
What this document about

The Ministry of Social Development wanted to find out if disabled people / people with a long term health condition are getting:

- the **income support** they need from **Work and Income**

- other things they need for their disability / health condition that are not funded by the Government.

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



Income support is money / payments from **Work and Income**.

These payments are money you use to pay for things you need to live like:

- food
- rent.

Work and Income is a government agency that:

- supports people who are looking for work
- gives money to people to help them pay for the things need.

In 2023 MSD asked 2 organisations to do some research to find out this information.

They were:

- **Allen and Clarke** – an organisation that supports the government to do research

- **All is for All** – an organisation led by disabled people to support all disabled people to be included.

Research is when someone:

- looks at what things have happened

- tries to find ways to do things better.

When you see the words **we** / **us** in this document it means:

- Allen and Clarke

  and

- All is for All.

This document:

- tells you how we did our research

- tells you who we talked to

Extra costs and income support experiences for disabled people and people with long-term health conditions

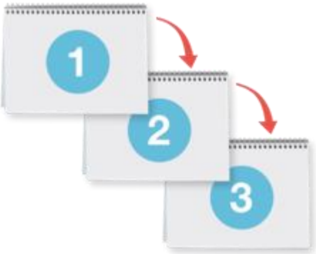
15 August 2024

ALLEN + CLARKE

All is for All

- is a summary of the full report

- tells you about the **key findings** of our research.



Key findings are the main things we found out when we were doing our research.

We did not speak to Māori / Pacific people for this research.

You can read the information about extra costs for Māori / Pacific people at this website:

URL

Extra costs and income support experiences for disabled people and people with long-term health conditions

15 August 2024

ALLEN + CLARKE

All is for ∀ll

You can read the full report about our research at this website:

URL

These websites are not in Easy Read.

How we did our research

To find out if disabled people / people with a health condition are getting the right income support we needed to:

- ask disabled people / people with a health condition to take part in our research

- think of the right questions to ask.

We **interviewed** 35 people who said yes to taking part in our research.

An **interview** is when someone meets with you to ask questions.

The people who took part included:

- disabled people
- people with long term health conditions

- people on **low incomes**
- people on **medium incomes**

- people who cared for a disabled adult / adult with health conditions

- people who cared for a disabled child / children with health conditions
- **migrants** with a disability / health condition.

Low income means people:

- get some money to live on
- do not have enough money to get all the things they need.

Medium income means people:

- get most of the money they need to live on
- cannot get all the things they want to have a good life.

Migrants are people who:

- have come to live in New Zealand
- were not born in New Zealand.

The research asked questions like:

- what kind of life do you have / do you have a good life?

- what **extra costs** do you have because of your disability / health condition?
- what kind of income support do you get?

- what things affect you and the people who live with you in your daily life?

Extra costs will be talked about later in this document.

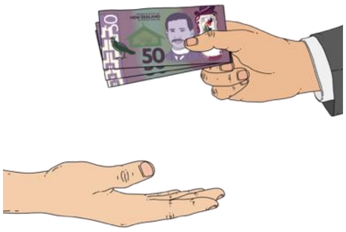
We also wanted to find out what people thought when they were asking for support from the Government.

Did they find it:

- hard
- easy?

This research will help MSD to understand:

- the extra costs disabled people / people with health conditions have

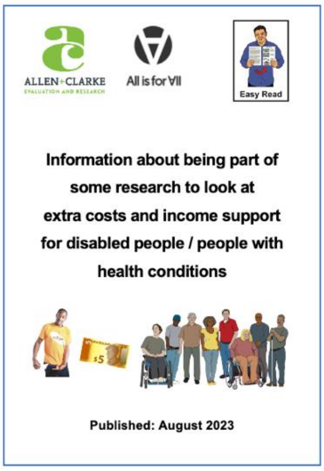


- if disabled people / people with health conditions are getting all the income support they need.

This research will also help MSD to understand:

- how they can make things better for disabled people / people with health conditions.

You can find out how we asked people to take part in our research in this Easy Read document:



ALLEN+CLARKE

All is for VII

Easy Read

Information about being part of some research to look at extra costs and income support for disabled people / people with health conditions

Published: August 2023

Information about being part of some research to look at extra costs and income support for disabled people / people with health conditions

URL

Key findings

Key finding 1

People have a lot of direct costs because of their disability / health condition.

Here **direct costs** means things you have to have buy because of your disability/ health condition.

Disabled people / people with a health condition have to pay for extra things like:

- health care
- medical treatments.

Disabled people / people with a health condition also have to pay for extra things like:

- medications
- special clothes

- equipment to support them
- transport.

Our research group told us they did not always have enough money to buy:

- good quality food

- enough food
- the special food they needed to support their disability / health condition.

More than half of the people in our research group had to pay extra money for transport because of their disability / health condition.

Some of these people did not have extra money to pay for this.

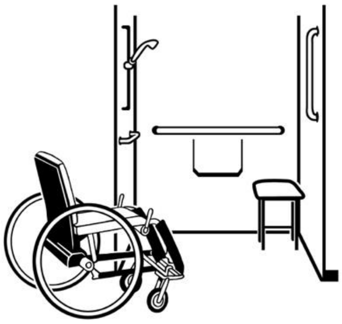
This meant they could not:

- do the things they wanted to do
- do the things they needed to do
- get to places they needed to get to.

Key finding 2

It is hard to work out what the extra costs are for disabled people / people with a health condition.

We wanted to find out about the extra costs disabled people / people with health conditions had because of their disability / health condition.



We found that each person spent their money on different things like:

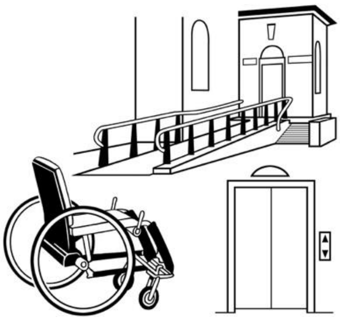
- things they needed for their disability / health care condition

- getting to places they needed to go to because of their disability / health condition.

It was hard for people to know what the extra costs were because they:

- would buy the things they needed to including things for their disability / health condition

- did not know how much it would cost to live without a disablility / health condition.



We found out that everyone has different:

- needs

- costs.

Key finding 3

There are a lot of **indirect costs** because of a disability / health condition.

Here **indirect costs** means people were not able to work to their full **potential**.

This means people were not able to work in the best job for them because:

- of their disability / health condition

- they were looking after somebody with a disability / health condition.

Here **indirect costs** also means people were not able to work in the best job for them because:

- of the time / effort it takes to look after a disability / health condition.

Here **potential** means that a person:

- has the skills to do something like a job to earn money

  and

- is not able to do it because the job does not fit in with their disability / health condition

  and

- earns less money than they could earn.

People in our research group told us dealing with a disability / health condition meant there were **opportunity costs**.

An **opportunity cost** is not something you pay for.

It is something you miss out on doing because you have to deal with a disability / health condition.

For example you may not be able to work because you are:

- managing your disability / health condition

- you are caring for somebody with a disability / health condition.

For example you also may not be able to work because:

- your job does not have work hours that work for you and your family.

People caring for somebody with a disability / health condition told us they had to be ready for when they are needed.

This often meant they could not do social things they wanted to do like:

- spending time with friends and family

- belonging to a sports club.

Key finding 4

People:

- want to work

  but

- do not have many choices.

Disabled people / people with a health condition told us that they wanted to work.

Some people in our research group told us that they had enough work / money to live their lives.

Other people said they did not:

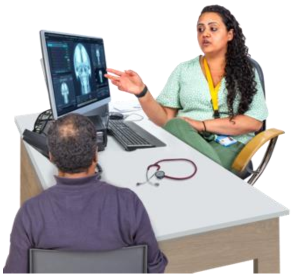
- have enough paid work

- use the skills they have in the job they are doing.

Our research group told us they needed the right job so that they could:

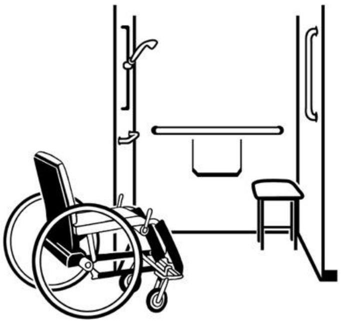
- manage their disability / health condition
- put the person they are caring for first

- fit in with school hours
- manage their stress



- go to appointments because of their disability / health condition.

To be able to do these things people needed an **accessible** job.



Accessible means that it is easy for everyone to:

- do the things they need to:
  - at home
  - in their community

- get the information they need in a way they can understand

- get around their community easily
- get to the places they need to .

Some of the people in our research group told us:

- they could find a job they wanted / needed

  but

- this could mean they will no longer get the income support from Work and Income.

Parents looking after children with very high care needs found it hard to get good:

- care for their children
- support from outside the family.

Key finding 5

Households had to make **compromises**.

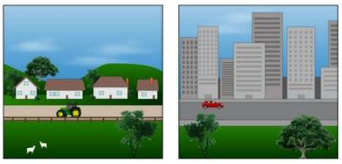
Here making a **compromise** is when you want to do one thing but you make a choice to do something different.

Disabled people / people with a health condition had to make compromises to save money.

This could mean making a compromise on where they should live.

This might mean living further away from the city because buying a house costs less money.

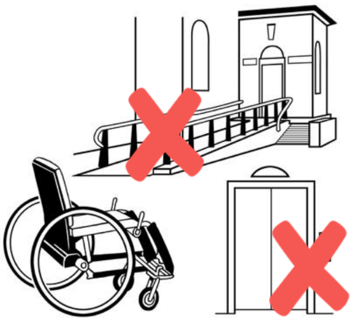
Living further away from the city means it:



- takes longer to get to places
- costs more for petrol
- costs more for public transport like buses.

People who rented houses told us they rented houses close to the city centre to be closer to the places they needed to go.

Our research group told us the houses they could afford to rent were:



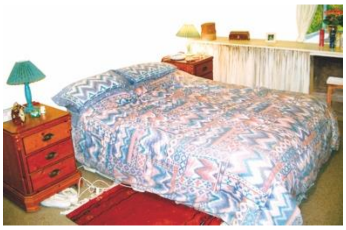
- not good quality
- cold
- bad for their health
- not accessible.

They also told us they did not feel like they had a choice of:

- where they lived
- who they lived next to.

Key finding 6

People found it hard to pay for more than their **basic needs**.



Basic needs are the things you need to live like:

- food
- water
- clothing
- somewhere to live.

Half of the people in our research group told us they had just enough money to pay for their basic needs.

Other people in our research group told us they:

- did not have enough money
- did not have quite enough money.

Most of the people said they did not have enough money to **thrive**.

Here **thrive** means to have money to:

- do all the things you want to do
- do all the things you need to do
- have all the things you want to have a good life.

Most of the research group told us they did not have enough money to:

- buy the things they needed to thrive
- have a break like having a holiday.

The people in our research group also worried that they did not have the money to pay for:

- things they had not planned for like extra healthcare
- services that might support them to have a better life.

Key finding 7

People need to be able to earn more money to improve their health.

Earning more money means people with a disability / health condition can buy the extra things they need to support their health.

Our research group told us they were not able to:

- work because of their disability / health condition

- take on more paid work because of their disability / health condition.

Disabled people / people with a health condition needed to earn more money to improve their health.

Our research group told us they did not have enough money to spend money on things like:

- good food to support their disability health condition

- other healthcare choices that were not funded by the Government

- a **therapy** to support their disability / health condition.

A **therapy** is something that supports you to manage your disability / health condition.

It can be something like talking to someone like a doctor about your disability / health condition.

Getting these things could help them:

- to manage their disability /health condition better

  and

- support them to work more.

Income support was not enough money for disabled people / people with a health condition to thrive.

Key finding 8

Government systems can make things harder for people to get the support they need.

Disabled people / people with a health condition told us it was very hard to get information about what money they are **entitled** to.

Here **entitled** means getting the money from the Government to support someone with a disability / health condition.

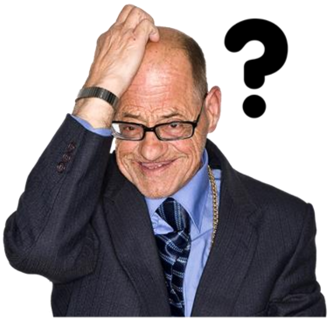
It was harder for people when they were working with more than one government **system**.

Systems are the things the Government has in place to do different jobs.

Systems include things like the:

- health system which is run by the Ministry of Health
- education system which is run by the Ministry of Education.

Sometimes it takes a long time for somebody to find out what their disability / health condition is.

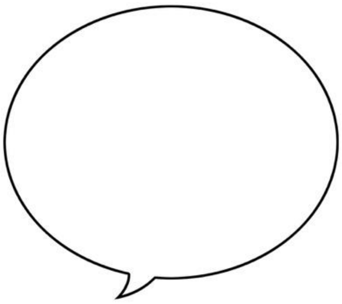


This makes it hard to get the support they need to deal with their disability / health condition.

Our research group told us

- that some MSD staff make it hard to get the support they were entitled to

- that some MSD staff make it easy to get the support they were entitled to



- people who spoke good English were treated better than those who did not

- people who had a good education were treated better than others

- people with very high needs did not always get the support they needed.

Key finding 9

It hard for disabled people / people with a health condition to take part in activities outside of their home.

People in our research group told us they had to carefully plan:

- where they needed to be

- what they needed to do
- what they wanted to do

- how much money they needed to be able to do something

- if the thing they wanted to do was accessible.

They had to think very carefully about what they did with their:

- money

- **energy**.

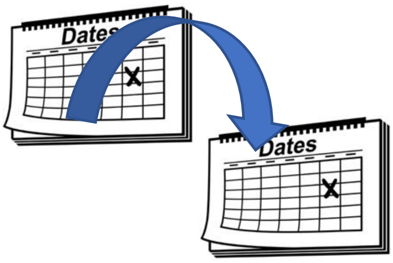
Here **energy** means how you feel when you need to be able to do something.

This can be how your:

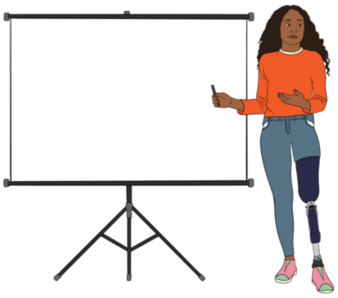
- body feels if you want to go for a walk

- mind feels if you want to go out with friends.

  For example if you are feeling sad you might not want to go out.



People in our research group found it hard to make plans to do something later on.



This could be things like:

- taking an education course like finding out more information about their disability / health condition

- going to a regular social event.

Our research group told us it was hard because they:

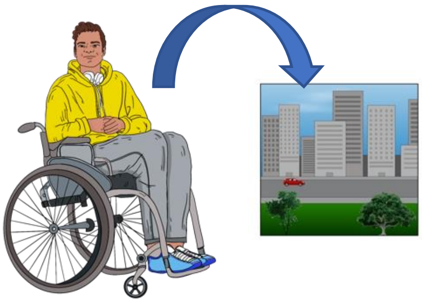
- were worried they would not be able to get there at the right time
- would not have the money to be able to take part.

Our research group also told us it was hard because they:

- did not know if their health would be okay on the planned date.

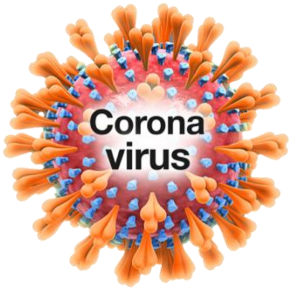
- were worried transport like buses / trains would not be working on the day they had planned to go.

Their disability / health condition made it hard to:



- go out
- see other people.

They also told us they spent a lot of time at home because they did not have enough money to go out.



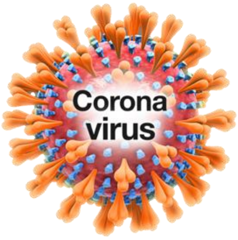
Disabled people / people with a health condition told us that some things had not changed much since the COVID-19 pandemic had started.

Our research group told us:

- some things that people used to do before COVID-19 had not started again

- support service providers were very busy making it hard to get the right support

- people still had to be careful because they could catch things like:
    - the flu
    - COVID-19.



Key finding 10

Ableism makes life hard for disabled people / people with a health condition.

Ableism is when:

- somebody thinks that a disabled person is not worth as much as a non-disabled person
- a disabled person is treated badly because of their disability
- some non-disabled people think disabled people can do less things.

Our research found that ableism can mean some non-disabled people think:

- supporting disabled people is a waste of money

- disabled people are not worth as much as non-disabled people.

Contact information

You can contact Allen and Clarke by:

- **calling**:

  04 890 7300

- **emailing**:

  office@allenandclarke.co.nz

- visiting the website:

  www.allenandclarke.co.nz

This information has been written by Allen and Clarke and All is for All.

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

The ideas in this document are not the ideas of People First New Zealand Ngā Tāngata Tuatahi.

Make it Easy uses images from:

- Changepeople.org
- Photosymbols.com
- SGC Image Works
- Huriana Kopeke-Te Aho
- T. Wood.