

# Extra Costs and Income Support Experiences for Disabled People and People with Long-term Health Conditions – Summary of key findings

## Background

In 2023, the Ministry of Social Development (MSD) commissioned research from **Allen + Clarke** and **All is for All**.

The aim of the research was to help build better evidence on material hardship among households with disabled people and people with long-term health conditions. MSD defines long-term health conditions as impacting someone for six months or longer.

The team from **Allen + Clarke** and **All is for All**interviewed 35 people on low- and middle-incomes who were either disabled, had health conditions, or cared for a child or adult who was disabled or had long-term health conditions.

The interviews explored the context of peoples’ lives, what extra direct and indirect costs they faced, any unmet needs, whether they had applied for or received income support, and their experiences applying for payments.

The sample of people who could participate in the research was largely pre-determined. It was mostly people who responded to the 2022 New Zealand Income Support Survey of low- and middle-income people aged 18-64. Four interview participants were recruited directly by **All is for All** to ensure inclusion of people with a wide range of impairments.

All the people interviewed were non-Māori and non-Pacific. Some were migrants. Separate studies interviewed Māori and Pacific participants. Most people interviewed received supplementary income support and just over half received a main benefit.

Because the number of people interviewed was small, the findings may not necessarily be generalisable to the wider population of people who are disabled, have health conditions, or care for a child or adult who is disabled or has a long-term health condition. Nevertheless they combine to give a picture of the range of experiences and highlight common themes.

## Key findings

### There are a range of direct costs related to being disabled and having health conditions

Most people interviewed had extra costs related to healthcare, medical treatments, medications and equipment to manage health conditions or impairments in these areas (that is, costs they had to cover because they were not fully funded). They also reported wishing to spend more on such costs but being unable to because of lack of affordability or access.

It was common to need to spend more on specialised food, although within households food was often compromised on in terms of quality, variety and amount. Food expenditure was often inadequate for the household’s needs.

A number of people interviewed also needed specialised clothing and household contents. This was especially mentioned by people who were physically disabled and those who were parents of neurodivergent children.

More than half of the people interviewed had extra costs relating to transport. This was an area that some would also like to spend more on as their access could be limited without subsidised options.

### “Extra” costs can be hard to identify

People came to the research talking about their own “normal”. They did not necessarily know what they would be spending money on if they were not disabled or managing a health condition. While they could frequently identify things they would like to be able to spend more on, it was harder to say how much extra they would ideally spend.

### Important indirect costs are lost employment and the time and effort required to manage life

Many people interviewed found that managing their own and their family members’ health or disability needs resulted in opportunity costs. An opportunity cost is not directly incured, but is the loss of potential or the cost of missing out. These opportunity costs included the inability to commit to full-time work, and missing out on other activities they would like to participate in. Those who needed to be available to monitor health conditions or pick people up unexpectedly, and those who had to constantly adapt food plans and associated budgets, often commented that the major cost was their time and effort, which left less capacity for their other priorities or other things they would like to do, such as participating in social activities.

### People want to work, but appropriate options are limited

1. Some had found a balance with enough paid work that they could manage around their household’s other needs. Others were underemployed. Underemployed means not having enough work or not doing work that makes full use of a person’s skills. People were underemployed due to having to take lower-paid options since they or their family members became disabled or developed health conditions.
2. People in a variety of household situations reported being unable to find work that was worth losing income support for. This was in terms of being well-paid enough, accessible enough not to cause further discomfort or stress, and flexible enough to accommodate fluctuating energy levels and health needs.
3. Parents were particularly impacted by the lack of suitable work that could be done in limited or school hours, since those whose families had more complex care needs found it hard to secure appropriate care from anyone outside the family.

### Households make compromises

1. Some had chosen to live further from city centres to afford housing, which meant accepting they had more transport costs to get to services including those for health and disability support. Many felt a lack of control over where they lived and who they lived alongside. Renters tended to choose proximity to city amenities over housing quality, sometimes to the detriment of their health. The research team heard that homes were sometimes cold, old and in need of infrastructure improvement, and in at least one case had black mould.

### Needs beyond the basics are hard to access

1. Half of the people interviewed said they had “just enough” to get by and most of the remainder said they had “not enough” or “not quite enough”.
2. Most spoke with some acceptance of the fact that they could not afford everything they might like to thrive. Most in the sample had not even considered spending money on things like holidays. They were often just managing their basic costs but were not entirely comfortable or confident they could cover unexpected or optimal expenditure (i.e. buying things or services that might help them achieve better wellbeing).

### Limited income makes it harder to improve health enough to earn more

1. Those who were not in good enough health to return to or take on more paid work often wished they could spend more on nutrition, unsubsidised medical options (medications or interventions that could improve their situation but were full-price), or additional supplements and therapies (both physical and psychological). These could help them be well enough to commit to more work. However, they needed the income boost from working in order to afford these things, because income support did not provide the means.

### The system can reinforce difficulty

1. People were often frustrated by the effort it took to get advice on changes to their entitlements, particularly when these income support assessments related to information that was needed from other systems such as health and education. Diagnosis delays could lead to further delays in accessing support, and it was harder to get a diagnosis promptly through the public system.

### People’s ability to navigate the system and receive their full entitlements is not equal

1. A major theme was the sense that not everyone is treated equally by the income support system. Even those who had good experiences with case managers reported their awareness that others had not. People had the impression that assessments by MSD Work and Income staff were inconsistent, so getting all help available depended on the individual case worker and sometimes where a person lived.
2. Those who spoke English fluently, had educational attainment, stable housing, and did not have the most complex types of needs felt more confident that they had been listened to and were getting what they qualified for. For migrants, barriers to navigate, obtain and sustain support were more pronounced.

### Participation in activities outside the home is limited by both energy and income, and external resource pressures

1. People had to budget their money and their energy carefully. They planned out how they could safely get to places they wanted and needed to be. This included researching the accessibility of spaces and costs of transport. Most had to pick and choose what they were able to afford and commit to, and had accepted that they would miss out on activities that they enjoyed.
2. Making longer-term commitments to spending on things like education courses and attending regular social events was difficult on a limited budget. If the money was committed in advance, people were concerned about the uncertainty of being able to get either themselves or their child there at the allotted time. This was due to difficulties out of their control like having a health condition flare up, along with logistical challenges like unreliable transport.
3. The pressures of managing health on a low income often meant spending a lot of time at home, and a real risk of social isolation. It was notable that the effects of COVID-19 on social life are ongoing for some in the disability community due to activities that have not restarted, support services that have been stretched, and the need to retain caution due to compromised immunity.

### Ableism reduces expectations for what those who are disabled and have health conditions can access

1. Normalisation of the extra burden people carried, in terms of unmet needs and (sometimes hard to specify) costs, relates to ableism. That is, the assumption that people with certain characteristics (including impairments) are less valuable and/or that their needs are lower priority.

## Further reading

To see the full report on ‘Extra costs and income support experiences for disabled people and people with long-term health conditions’, go here:
<https://www.msd.govt.nz/acaa>

**End of information: Extra Costs and Income Support Experiences for Disabled People and People with Long-term Health Conditions – Summary of key findings**

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