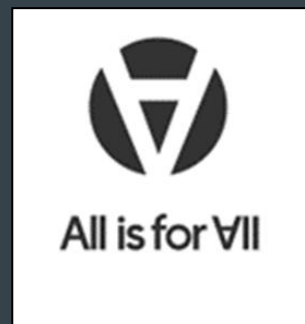




Extra costs and income support experiences for disabled people and people with long-term health conditions

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DISCLAIMER: The views and interpretations in this report are those of the researchers.

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Glossary

Term	Definition
Ableism	A set of beliefs, processes and practices reflecting social structures that value and promote certain characteristics, for example, productivity and competitiveness, over others. Under ableism people with characteristics considered less valuable (i.e. people with impairments, or people who cannot work full time) are subject to barriers and oppressions.
ACC	Accident Compensation Corporation - provides earnings-related compensation and rehabilitation supports and services to eligible injured people.
Blind or low vision	Blindness and low vision refers to reduced vision, vision loss or sight loss.
Communication Disability	Impairment that impacts people's capacity to communicate in traditionally expected manners. People with this experience may be non-speaking, and use communication boards or augmentative and alternative communication (AAC) devices. d/Deaf people are not included in this definition.
d/Deaf or hard of hearing	The 'uppercase D' Deaf is used to describe people who identify as culturally Deaf and are actively engaged with the Deaf community, share a common culture and who usually have a shared sign language. The 'lowercase d' deaf simply refers to the physical condition of having hearing loss. To write d/Deaf is to embrace both communities. Hard-of-hearing is a widely-accepted term to describe mild to moderate hearing loss. Source: AI media
Disablism	Specifically speaks to discrimination against disabled people on the basis of 'disability'.
GP	General Practitioner.
Health condition	In the context of this report, "Health condition" refers to the range of long-term or chronic physical or mental health conditions that participants reported.
Impairment	Refers to the diminishing or loss of a function related to disability. People live with functional impairments (i.e. loss of function of walking).
Income support	Includes first tier payments (e.g. main benefits such as Jobseeker Support and Supported Living Payment), second tier payments (e.g. supplementary payments such as Disability Allowance, Child Disability Allowance and Working for Families tax credits) and third tier hardship assistance (e.g. Temporary Additional Support and one-off hardship payments).
Learning disability	Intellectual disability is a term used when a person has difficulty understanding, concentrating, learning, and remembering new things in their everyday life. The term learning disability is preferred

terminology for this community, and terminology that People First has championed. Source: IHC.

Mental distress	<p>A broad term that encompasses experiences of changes in people's mental health, whether situational, temporary or long term and whether diagnosed or not. People experiencing mental distress might have similar symptoms to a mental illness, but the language they use is up to them. This definition is on the basis of the Mental Health Foundation of New Zealand's webpage.</p> <p>Mental distress, is under the umbrella of disability in the UNCRPD, where it is considered a psychosocial disability.</p>
Mobility	Quality of movement.
MSD	Ministry of Social Development.
Neurodivergence	<p>Neurodiversity is a term used to describe neurological differences in the human brain. This references experiences like being Autistic, ADHD, Dyslexic, or having other variations in neurological experience. The term is rooted in acknowledgement that all neurological diversity is equally valuable. It is not a deficit term. Source: Te Pou</p>
Sensory disability	<p>A term in the United Nations Convention on the Rights of People with Disabilities, referring to the group of disabilities impacting the senses (d/Deaf, blind, and some neurodivergent experiences like being Autistic). We now have terms like Neurodivergent, so this term may be used less.</p>
Social relational model of disability	<p>The social relational model allows for a theoretical and contextualised conceptualisation of disability, which integrates the social oppression of disabled people in the workplace or society with an understanding that some aspects of impairments (such as pain, fatigue) cannot be solved by an accessible environment and this must be understood and embraced.</p>
Support service	<p>A service, funded by the Government or charged at cost that disabled people use or rely on to support their access to and engagement in their home or community.</p>
Total Mobility	<p>A national scheme which supports people who cannot use public transport to travel, all or some of the time. Source: Auckland Transport.</p>
Work and Income	<p>An organisation within the Ministry of Social Development (MSD), that administers income support payments and housing- and employment-related supports. May be referred to as "WINZ" by participants.</p>

Executive summary and examples of people's experiences

Adults and children living in households where someone is disabled and/or has a health condition are more likely to experience financial hardship and other disadvantages. The Ministry of Social Development (MSD) commissioned this research to provide better evidence on income support, additional health- and disability-related costs, and material wellbeing for disabled people and people with long-term health conditions, including both adults and children.

This report presents findings from research into the experiences of 35 people on low- and middle-incomes who are either disabled, have health conditions, or care for a child or adult who is disabled, neurodivergent or has long-term health conditions (such as chronic physical health conditions, mental distress, and learning, physical and sensory impairments). Participants were of New Zealand European and/or other non-Māori, non-Pacific ethnicities, and included migrants. Māori and Pacific people were to be interviewed in other, separate research projects. All participants were adults aged up to 65. They reported a range of situations regarding their household makeup, housing, employment, health, and receipt of income support.

The questions that guided the research cover:

1. Direct costs associated with being disabled and/or having health conditions.
2. Indirect costs and lost opportunities relating to managing health conditions or being disabled.
3. How a household's situation and context are interrelated with their costs.
4. Unmet needs for good and services, and the reasons for these.
5. Compensating for unmet needs.
6. Consequences of costs and unmet needs.
7. Access to appropriate income support.

Interview teams from *All is for All* and *Allen + Clarke* undertook the research. A strength of the team's approach was a combined perspective informed by lived disability experience and social research practices. The research was carried out in person, online or via telephone with accommodations made for participants' availability and accessibility needs. The analysis combines the information collected in different ways to give an overall picture of typical experiences and the range of those experiences. Limitations included the difficulty of recruiting the planned number of non-European participants via the New Zealand Income Support Survey (NZISS). The information gathered means that findings are generally focused on the range and type of costs, rather than the exact financial figures for all costs, given the difficulty people had recalling or estimating exact amounts they spend or would like to spend.

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 highlight several common themes.

Most participants received supplementary income support and just over half received a main benefit

Of the 35 participants, 19 were receiving a main benefit from MSD. Twenty-eight were receiving some form of supplementary income support from MSD (either on top of a main benefit, or on top of their other income if they did not receive a main benefit). Three participants had received income support in the recent past but due to changing circumstances were not currently. The main benefit most commonly received was the Supported Living Payment, and the supplementary income support payment most commonly received was the Disability Allowance.

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

Participants were asked about their costs that related to being disabled or having health conditions. The most common overall group of costs included healthcare, medical treatments, medications and equipment to manage health conditions or impairments. Most participants had extra costs in these areas (that is, costs they had to cover because they were not fully funded). Participants also reported wishing to spend more on such costs but being unable to because of lack of affordability or access. In terms of regular shopping needs, it was common to need to spend more on specialised food, although food expenditure was often inadequate for the household's needs. A number of participants 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 participants 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. People used a combination of funding and their own budget to access home maintenance support services and personal care. Other costs mentioned several times included childcare, education, events, and saving for contingencies.

“Extra” costs can be hard to identify

Participants came to this 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. It was often challenging to define costs that were extra due to the overall rising cost of living from costs that were specific to health and disability. Costs that were sometimes hard to draw out as “extra” due to being disabled or having health conditions included housing, insurance and exercise. An overall theme was that people had worked out their costs based on their means; therefore, 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.

Households make compromises

Participants made budgeting decisions that meant they found ways to afford the basics and meet their household's most acute needs. They employed careful budgeting strategies, compromised with cheaper options, and accepted missing out on some things. Food was often compromised on in terms of quality, variety and amount.

Housing was an example of where participants compromised due to their situations. Those who owned homes often had deferred maintenance and had concerns about rising costs along with impacts of climate change on their housing. One geographic area in the study was noted as both suitable for disabled people and those on low incomes (flat, close to services, with low-cost housing) but also prone to flooding, which led to stress for those living there who felt they had few other options. 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. Those in public housing had mixed experiences. Some found councils and Kāinga Ora to be very responsive landlords, while others did not. Overall they 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.

Needs beyond the basics are harder to access

Most participants spoke with some acceptance of the fact that they could not afford everything they might like to really thrive. Few talked about even considering spending 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). Many participants had heard about alternative medications or therapy options that were touted as more effective but only available to those who could afford to pay privately. Parents had found extracurricular activities that were affordable and accessible, but were aware that their children were not accessing the range of activities that their peers might.

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

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, 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

Some participants were confused about how their income support was assessed and how it had changed over time. There were also concerns about figuring out the threshold at which increasing paid work became less financially viable due to the loss of income support. More commonly, people were 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.

There were also examples in which income support was technically available but had been difficult to access due to other system pressures. For example, while there has been funding available for respite care, some caregivers found that due to lack of service provider capacity, they were rarely able to use it.

Some policy changes that had been recently introduced at the time of the interviews, such as subsidised transport and free prescriptions, made a notable positive difference to participants' ability to access the amount of healthcare they needed. Some participants noted that changes to these settings (which have happened since the time of the interviews) would likely cause a drop in their ability to manage their health.

People's ability to navigate the system and receive their full entitlements is unequal

A major theme, that came through in different ways for participants in different circumstances, 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 individual case workers and sometimes on being in different parts of the country.

Participants were aware of needing to be able to advocate for themselves with case workers. Those who had strong networks among peers with similar conditions or life experiences felt better informed about how to navigate the system, as did those with strong advocacy support from family. Those who already had some form of social capital – speaking English fluently, appearing educated, not presenting with the most complex types of needs – felt more confident that they had been listened to and were getting what they qualified for.

An important indirect cost is the time and effort required to manage life

Many participants found that managing their own and their family members' health or disability needs resulted in opportunity costs. These 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.

People want to work, but appropriate options are limited

Some participants had found a balance with enough paid work that they could manage around their household's other needs. However, others were underemployed due to having to take lower-paid options since they or their family members became disabled or developed health conditions. Participants 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, and flexible enough to accommodate fluctuating energy levels and health needs. 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.

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

Participants had to budget their money and their energy carefully. They strategised about 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 were resigned to missing out on activities that they enjoyed. Making longer-term commitments to spending on things like courses and regular 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 stemming from being disabled or having a health condition flare up, along with logistical challenges like transport.

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

Some participants experienced internalised stigma from having to identify with certain diagnoses in order to access support, or from being identified as a beneficiary due to their current inability to do paid work. Many expressed gratitude for barely getting basics met, acceptance of limited opportunities, and resignation about only having access to less suitable options for work and recreation. On the other hand, those who were more vocal about their dissatisfaction with their situation reported more alienation from, and difficulties interacting with, government-run support systems.

We suggest that the normalisation of the extra burden people in these situations carry, 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. When assumptions like this underpin social structures, people's expectations for what those who are disabled and have health conditions can access will remain low. The imbalance of access towards those who are less severely affected, and who can therefore self-advocate more effectively, will also remain. This research's findings therefore support continued efforts to make income, health and disability support easier to access for all.

Examples of people's experiences

This section presents 10 personas, representing the overall range and most common scenarios that interview participants described. Each persona is a composite profile drawing on multiple participants' stories, using a type of 'vignette' methodology described further in the appendix. The names are not names of anyone involved with this study.

The personas include:

- a description of a made-up person and their situation
- the types of things they experience extra costs for ('extra direct costs')
- what extra things they would like to be able to afford but can't ('unmet extra costs')
- the way that disability and or health conditions have imposed costs on them in indirect ways ('opportunity costs')
- what sort of income support they have typically been receiving
- how they say they are getting by financially.

The persona descriptions also include comments on what would help people in their situation manage better. These comments on what would help relate to:

- support system factors (for example how government service providers offer support)
- environmental and systemic factors (for example accessible workplaces)
- personal or situational factors such as the type of family support they have available, or their feeling about their situation.

Several of these factors interact so cannot be entirely defined as systemic or personal – for example, while many people would be helped by having a coherent plan for managing the next step in their life, this would come from a combination of being provided with timely, useful information and support options, and having the capacity to act on that information and leverage the resources they need to enact the plan.

The personas are:

- Sadie and Maia: A disabled child and her mother adapting and advocating to find what fits
- Liam and his family: Stopping work to manage health needs
- Tyler and his family: A neurodivergent teenager approaching adulthood
- Alex: A young adult adjusting their lifestyle around being disabled
- Laila: Whose circumstances need to align to make paid work possible again

- Ahmed: A migrant whose professional ambitions have been stymied by ill health
- Jay: Long-term experiences of instability
- Shaun: Lives a quiet life
- Pat: Approaching retirement age but needing to slow down sooner due to health
- Stella: Currently not receiving income support.

Sadie and Maia: A disabled child and her mother adapting and advocating to find what fits

Sadie started at primary school a couple of years ago. As a baby, she seemed to develop some skills slower than other babies; her parents were concerned but were unsure she met the 'standard' of diagnosis. She also has some chronic health conditions which she needs support to manage. Health professionals gave the family mixed advice about her health and development, and COVID-19 stopped them from accessing as many Well Child checks as they should have.

Eventually, Sadie's parents paid to have her tested for ADHD and autism and had these diagnoses confirmed. Since receiving these diagnoses, they have been able to access some funded education support. Sadie wants to learn and likes some of the activities at school, but can find the format overwhelming and often needs to be brought back home during the day. She would like to make more friends but often feels uncomfortable at school, and her behaviour when she is uncomfortable makes others less likely to want to play with her.

Sadie's mother, Maia, has been in touch with other parents in similar situations and has heard similar challenges. Maia is considering switching to home-schooling if she cannot see improvements in Sadie's ability to spend full days at school, although she is aware that this option would make finding paid work even more difficult. Her last employer lost patience with her needing to leave to look after Sadie too often.

Maia has reached the point of feeling deeply frustrated with advocating for her family's needs through the health, income support, and education systems. She has met some supportive individuals within these systems but has also experienced being directly dismissed as an "anxious mother" by those who do not believe her assessments of Sadie's conditions. She has frequently felt like she had to fight to get the correct information to the correct places. The more she learns about Sadie's neurodivergence, the more Maia suspects she has something similar. However, getting her own diagnosis would be costly and time intensive, so she is not pursuing this yet.

Extra direct costs:

- private appointments for diagnosis
- traveling to appointments
- Occupational Therapy equipment to help with motor skills
- clothing and foods that suit Sadie's sensory sensitivities.

Unmet costs:

- cannot afford all the learning and behavioural support they would like – some is funded but they are looking into other options that they would need to find private funding for.

Opportunity costs:

- lost income due to Maia being unable to be in paid work
- lost education for the amount of time Sadie has to take off school due to insufficient support.

Income support: Sadie receives the Child Disability Allowance. Maia and her partner receive Jobseeker Support (Work Ready).¹

Financially: They do not have enough money to meet their everyday needs.

What would help:

Flexible employment options: Maia would like to get back to part-time work, but she wants to ensure she does not lose any income support and that she can use her skills in a setting where she is able to finish work from home if she needs to leave during the day.

Alternative education support: Some of the support that Sadie has received has been helpful, but it does not cover all her time at school, and the family observe that most classrooms would benefit from more teacher aide funding. The family would consider moving her to an alternative education system if that will help her manage throughout the day.

A consistent, helpful Work and Income case manager: Maia is exhausted from explaining their situation over and over again to people whose belief in their need for support varies. If she could deal with one person consistently, she would be more confident that their case is being managed well.

Acknowledgement of specific needs: Sadie is very particular about which foods she finds safe and which clothes she finds comfortable. Not having these options available is very upsetting for her and make it harder for her to participate in her everyday activities. She can get her physical health needs met through funded medicines and GP appointments (though there is a long wait for specialist appointments). However, her needs relating to her neurodivergence have to be met through the already-stretched household budget.

¹ This benefit is for people assessed as being available for and seeking full-time employment. As a couple they each receive half the couple rate of Jobseeker Support (Work Ready).

Liam and his family: Stopping work to manage health needs

Liam worked full-time before and immediately after becoming a father. However, in recent years he has been dealing with changes in his own and his school-aged child's health. He also separated from his child's mother and is now the primary caregiver. He had previously experienced mental distress but not taken any time off work for it. More recently he experienced more severe mental distress symptoms and realised he needed to make changes, especially since his child needed more support managing their physical health. He decided to take a break from full-time work to be more available at home and to better manage his and his child's wellbeing.

The reduction in household income has presented some challenges, with all the available budget being used to cover the basics. The family are not able to engage in many extracurricular activities or the occasional lifestyle luxuries that some of their peers can.

Liam feels reasonably confident that the current situation will not be forever. He appreciates having access to income support for now and feels that he can advocate for his needs. Most people he has dealt with regarding income support have been helpful, although he has the impression that this is not always the case for people who have been in the income support system longer than him.

Liam lives with his child in a house that needs some improvements but is adequate. He has found ways to manage with a limited income – it is precariously balanced, but overall, he feels that his family have just enough. He hopes to show his child the benefits of a frugal and non-materialistic lifestyle, with access to the outdoors and a supportive extended family.

Extra direct costs:

- specialised food options because managing his child's health conditions requires a specialised diet
- a savings buffer for likely upcoming housing costs, as these are increasing faster than his income, and a downgrade in housing quality would likely impact his and his child's health
- GP visits to renew medical certificates and prescriptions
- transport to health and education appointments.

Unmet costs:

- would like to be able to spend more on exercise or therapies such as counselling or physiotherapy
- would like more variety of accessible and affordable extracurricular activities for his child.

Opportunity costs:

- lost income as a result of prioritising time out of paid work to manage health conditions.

Income support: Liam receives Sole Parent Support and Child Disability Allowance in respect of his child. Depending on his ability to work, over time he has received some back-to-work grants.

Financially: They have only just enough money to meet their everyday needs.

What would help:

Some flexible paid work: if Liam has some work on top of his income support, he would find life easier to manage. Living on only income support is very tight and requires a much more frugal lifestyle. As the primary caregiver, Liam needs to be available for his child immediately after school and sometimes during the day, so would only look for limited hours.

Extended family support: Liam's child does not tend to socialise at the sort of events their classmates spend money to participate in, so having wider networks of family support would help them to socialise and to have other trusted adults around. It would also help Liam to get a break occasionally.

Funded therapies: Liam could do with some support to manage his own wellbeing. This was easier to access while he was working full-time due to a higher income and funded Employee Assistance Programme services.

Better information about the prognosis of health conditions: although some of the health conditions that Liam and his child are dealing with are likely to be long-term, it helps him to see that the acute difficulties associated with these conditions may resolve in the coming years. If he has good information about what their diagnoses mean, and a solid plan to manage as he and his child get older, he will feel more hopeful.

Tyler and his family: A neurodivergent teenager approaching adulthood

Tyler will be finishing high school soon. He lives with his mother who works 30 hours a week and his older sibling who is studying. His father moved out several years ago, though is still involved in his life. While he has not always had an easy time at school, it did provide some routine in his life. Over the years, he and his parents, teachers and doctors have figured out what types of activities work best for his unique style of learning. As a result, he will be leaving with some academic credits, though not as many as his peers.

Although he is about to become an adult in the eyes of the law – and the health and income support systems – Tyler is not yet ready to take responsibility for all the administrative aspects of adult life. He may always need support from a trusted adult. So, for the foreseeable future, his mother will continue to help him with all applications necessary to obtain income and other support. She has become very well-versed in navigating the system over the years, although she is still sometimes bemused at the level of coordination needed between health, education and income support systems in order to get things signed off. Tyler would like to become more independent. One tension between Tyler's preferred approach and the way his mother has learned to manage is that Tyler is unsure whether he agrees with the various diagnoses he has received related to mental distress and neurodivergence. However, they often need to use these terms if he is to apply for certain types of support.

Extra direct costs:

- clothing and food that suit his sensory sensitivities
- higher rental costs to ensure there is appropriate space for young adults, with burgeoning independence and different needs, to continue living with the family
- fidget toys
- specialised educational programmes
- transport – he has tended to need support if using public transport and is unlikely to learn to drive.

Unmet extra costs:

- Tyler's family would have liked to be able to afford some private tutoring
- Tyler and his (neurotypical) sibling had been unable to continue attending some extracurricular activities they were interested in, like gym classes or Scouts, due to the costs and the logistics of needing extra adult support to enable Tyler's attendance.

Opportunity costs:

- lost income due to limits on the hours Tyler's mother has been able to spend in paid work due to her caring responsibilities.

Income support: Tyler is now getting the Supported Living Payment and Disability Allowance. His mother stopped receiving Child Disability Allowance and stopped receiving child support payments from his father once Tyler qualified for a main benefit in his own right.

Financially: They have only just enough money to meet their everyday needs.

What would help:

Having a plan for accommodation: if they have a plan for their housing setup so Tyler has a space appropriate to his life stage, they would feel more comfortable. Tyler may want to move out at some point, but it seems likely that this option will be further down the track and will take some time to figure out.

Having a plan for the next activities: Tyler is at risk of not having suitable activities to attend once he leaves school. Ideally, the family would establish plans with advice from support workers about options to help Tyler into work experience and further education.

Advice about income support that will not leave the family worse off financially: Tyler is hoping to find some part-time work once he finishes school, and his mother hopes to increase her paid work hours soon, although suitable opportunities have not come up recently. The family need to be sure of exactly how much they can earn and which benefits they can get without further financial penalty. For example, the ending of eligibility for child support was a shock as the family had not been advised this would happen, and led to further tension in the parents' relationship.

Alex: A young adult adjusting their lifestyle around being disabled

Alex is aged in their twenties and has spent a fair bit of their early adulthood adjusting to being a disabled adult. This has been very frustrating at times. Alex still finds that the limits on their energy, and on their ability to afford suitably matched accessible travel, can make full participation in the activities that interest them difficult. Alex has studied at university and done several types of paid and unpaid work; they are still finding the balance of how many activities they can afford to do both financially and in terms of energy costs.

Alex rents in the central city; the accommodation is not the ideal quality they would like, but they had to make compromises to afford to be somewhere accessible. Previously they lived with their parents, which was good for having support, but being further from the city centre presented challenges when they wanted to go places, and they really wanted some independence.

Over the last few years, Alex has found some peer support by identifying more as a disabled person and getting to know fellow disabled young adults. In addition, they have been connecting online with people who have similar conditions and can offer advice about managing both the conditions and the bureaucracy of the organisations that provide support.

Alex is grateful to note that people their age are generally quite accepting of the limits their impairments can cause them and happy to learn what they can do to help make things accessible. However, the financial aspect of their situation provides more social awkwardness. Alex really dislikes the idea of having friends help them out financially, and this feeling limits their approach to socialising at times.

Extra direct costs:

- medical and disability equipment
- specialised computer options to help with learning
- transport
- living in an area with high housing costs to help manage transport costs.

Unmet extra costs:

- cannot afford to make adjustments to living spaces to make them more accessible.

Opportunity costs:

- opportunity cost of limited energy and finances meaning having to select only some activities to participate in
- lost income due to difficulty finding suitable part-time work.

Income support: Alex receives the Supported Living Payment and, in their current living situation, the Accommodation Supplement. Alex has had Temporary Additional Support in the past and is planning to investigate allowances for studying further in future.

Financially: They have not quite enough money to meet their everyday needs.

What would help:

Good access to transport options: Alex would like to use public transport more, but it is not always convenient or accessible. The Total Mobility Card has been very helpful but does not cover longer trips, and Alex has heard that it is administered inconsistently in different regions. Alex finds it stressful to have to budget and plan for taxis while knowing that their health or energy levels might then limit their ability to participate in the planned event.

Ability to work while still receiving income support: Alex has to really calculate the amount they can afford to work – in terms of their energy level and not having their income support cut. They don't quite have enough money now. If they could continue to receive a base-level payment that would cover their costs, they would feel more confident in trying out different amounts of or different types of paid work.

Accessible public spaces: Alex feels nervous in public spaces that are loud, crowded, physically unsafe, or difficult to get around. They want to get out and get involved in events but have to be very careful and research the area first, to ensure they will have an exit strategy.

Laila: Circumstances need to align to make paid work possible again

Laila has previously worked full-time in a sector that she found interesting. A few years back, several circumstances – changes in her family situation, her job and her own health – combined to mean Laila had to take a break from the full-time paid workforce. Although the more acute stresses have now passed, she is still learning how her ability to participate, as a person with health conditions and physical impairments, has changed. So far the opportunities that have come up for paid work have not suited her situation; they have been too physically taxing or not flexible enough with the hours.

Accessible work accommodations and flexible hours are necessary as her energy levels can be inconsistent, she needs to get to health appointments and she experiences discomfort sometimes. In retrospect, Laila realises that when her health conditions and impairments became more apparent, she might have identified sooner as disabled or chronically ill and asked more strongly for accessibility accommodations from her previous employer. These might have even helped her stay in work.

She has been spending most of the energy that would have gone to paid work on managing her health and getting the support she needs. She also needs to be available at times to help her elderly parents. Laila finds that she needs more resources upfront to be prepared to get back into the workforce: for example, access to ways to sharpen her professional skills or renew her professional registration, which has lapsed. Laila is aware of others in similar situations that have started a small business, and she would consider this, but would need upfront resources.

The low income while on income support can become a vicious cycle: Laila has to economise on nutritious food, medication and self-care, which makes it harder to improve her health, which makes it harder to re-enter the workforce and earn enough to afford these things.

Extra direct costs:

- specialised food and supplements
- appointments (some are funded/subsidised, some not)
- medications – she is budgeting to access more effective alternatives to the generic funded option she has been prescribed
- accessible transport.

Unmet extra costs:

- cannot spend as much on specialised food or supplements as she would ideally like to.

Opportunity costs:

- lost income due to time out of paid work
- lost skills and lapsed professional registration due to time out of the paid work.

Income support: Laila receives Jobseeker Support – Health Condition or Disability (HCD). She has only recently become aware, when talking to a health professional, that she might apply for the Disability Allowance to help with specialised foods or supplements. She had not thought of bringing this up with Work and Income before.

Financially: She has not enough money to meet her everyday needs.

What would help:

Accessible work accommodations: Laila now knows more about her health conditions and what she needs. She just needs help to advocate for and explain these to potential employers.

Employers who embrace flexibility: Laila knows some people with her conditions have flexible employers and that this makes the difference to staying in the workforce. She may need help to identify and contact suitable employers in her area of interest.

A boost in resources for healthy living: Laila struggles to afford the products and services that would help her become healthy enough to work more.

A boost to confidence: the last few years have not been easy on Laila, and she needs people around her who can remind her of the value she brings.

Ahmed: A migrant whose professional ambitions have been stymied by ill health

Ahmed has lived in New Zealand with his family for several years. They rent a house and sometimes help, or get help from, extended family members. They find that the cost of living is very high compared with their income.

Ahmed has professional skills but, due to an injury and period of ill health, has been unable to return to his preferred area of work. He is currently getting a combination of income support and casual part-time work with much lower pay than he could achieve in his professional field.

Ahmed has found the health system and income support system, in tandem, confusing to navigate, and is still unsure which benefits he is receiving. He has some concerns about how to stay on top of declaring his variable income, as he is not sure how he would handle finding out he has accidentally over-claimed income support. Getting messages from health providers to other agencies at the right time has been challenging, and he feels fortunate that a friend has been able to explain some aspects of the system to him. He is unsure how other migrant families would manage if they do not have contact with people who understand how medical and income support applications work.

Extra direct costs:

- medication
- GP visits
- physical therapy.

Unmet extra costs:

- would like to spend more on better range of foods and supplements.

Opportunity costs:

- lost income due to time out of paid work and doing work that does not use his professional skills
- time and effort needed for managing bureaucracy including ensuring all documents are up to date
- Ahmed needs to provide support for family with housing, and the increasing costs associated with this mean he spends less on products and activities that might benefit his health.

Income support: has varied – Ahmed received ACC support at the time of his injury, then after a few months was deemed “work ready” and started receiving Jobseeker Support – HCD. He has been unsure of the exact names of the benefits he was eligible for, as he has

experienced some mixed messages from government information, case managers and community contacts.

Financially: He has not enough money to meet his family's everyday needs.

What would help:

Networks: Ahmed would feel better if he had even stronger links to community from his country of origin and local friends. This could help with hearing about job opportunities and with generally being able to manage financially, practically and emotionally. Some migrants in his situation can become very isolated.

Well-explained processes: if Ahmed could get in touch with a MSD case manager who explains things well and ensures he has access to the most relevant information, he would feel much more comfortable interacting with the income support system.

Better information at the point of migration: He now feels that upon arrival, people should be provided with better information to help them become law-literate and understand what the New Zealand government can and cannot do in terms of providing support when financial and health circumstances change.

Jay: Long-term experiences of instability

Jay had a traumatic childhood. She did not receive adequate support throughout her young life and went on to experience periods of homelessness and mental distress.

Jay lives in social housing which she accepts is her only option given her history and financial situation. It sometimes has benefits – some neighbours share mutual support. But Jay also has some discomfort around the behaviour of other neighbours, and the inconsistency of how improvements to the units are made. She does not feel control over her housing situation.

Jay tends to self-medicate with various substances. At times maintaining these habits takes precedence over other spending. Although she has some professional skills and qualifications, Jay's work history is patchy due to periods of instability and poor health. She would like to be able to work more and appreciates having had some understanding employers.

Jay has had many interactions with health, housing, justice, income support and other systems over the years. Some of these interactions have been distressing and have made her feel judged for her difficulties and choices. She feels she has often been disrespected, or not been given access to what she needed, or clear information on what support she could get.

Jay has become cynical about the likelihood that any government agency will actually help her become well. She now shies away from asking for more government support due to previous bad experiences. Jay admits that she has lashed out at MSD staff in the past but feels this was in response to poor treatment.

Extra direct costs:

- medications (before prescriptions were free, she was not filling all scripts)
- cannabis, tobacco and alcohol as easily-accessed substances to help manage mental distress symptoms, in the absence of other treatment plans
- health appointments.

Unmet extra costs:

- Jay would like to spend more regularly on better nutritious food or supplements
- she does not see the doctor as often as she should due to cost and feeling judged
- she would particularly like to have access to effective therapy, even if private, but cost is a barrier.

Opportunity costs:

- lost income due to time unable to sustain paid work

- her health situation means she does not travel out of her immediate area to visit people, which she would really like to do occasionally
- cannabis, tobacco and alcohol provide some short-term relief but undermine her health in the longer term.

Income support: Jay receives the Supported Living Payment, and has had some dealings with ACC in the past.

Financially: Jay has not enough income to meet all her needs.

What would help Jay:

Trauma-informed therapy: Jay has had mixed experiences with the health system but knows that access to a trusted therapist could help. Realistically, Jay may be unlikely to stop using substances altogether. She therefore would prefer to talk with someone who can offer non-judgemental advice on how to achieve better wellbeing, and support with harm reduction relating to substance use.

Sense of a secure home: Jay cannot imagine becoming a homeowner but would like to have some choice as to what kind of flat she lives in and to know that her tenure will be secure.

A stable community: Jay's family relationships are complicated. Due to adverse experiences, Jay can find it difficult to trust people. She nonetheless values having a wider supportive community around her and having social and voluntary activities to participate in.

Respect and empathy from Work and Income, housing or ACC case managers: Jay wants to be treated like a person with dignity who can make her own choices. These include things like keeping a pet, choosing which medications or treatments to continue with, and having some say about where she lives and which services she engages with.

Shaun: Lives a quiet life

Shaun has been mostly out of the paid workforce for some time now due to his health condition and being disabled. He feels that it is unlikely he will do more than occasional casual work and voluntary work again. He keeps an eye out for these opportunities.

Shaun has adapted to having a very limited income and is generally satisfied with the workarounds he has developed to get just enough of what he needs. He participates in free and low-cost social activities online and in his community. He gets some support to manage his life at home, although this can be unreliable at times, and his extended family sometimes helps him out with one-off expenses.

Shaun accepts his situation and does not aspire to take on expensive hobbies or activities. He cultivates inner peace and acceptance as a way to manage his mental wellbeing. However, he has found social opportunities have become more limited, especially since the COVID-19 pandemic, as he and many of the people he knows are at more risk of compromised immunity. When Shaun is feeling introverted, this is not a big problem, though sometimes he wishes for a greater variety of contact with others.

Extra costs:

- accessibility aids
- repayment of loans from MSD for glasses/dentistry/hearing and other accessibility aids
- regular GP appointments (travel and appointment costs)
- household support services (some are not funded)
- transport (part-funded via the Total Mobility Card).

Unmet extra costs:

- would like to spend more on healthy fresh food options
- limited ability to promptly replace things like glasses, or get more specialised (and new rather than second-hand) furniture that would help manage discomfort.

Opportunity costs:

- lost income due to time out of paid work
- not going out much due to cost.

Shaun's income support: Shaun receives Supported Living Payment, Disability Allowance and Accommodation Supplement

Financially: He has only just enough income to meet his everyday needs.

What would help Shaun:

Housing security: Shaun's budget only barely covers his housing costs. If any of these costs increase, it is likely to tip him from just managing to not managing. It would be helpful to know that he would have some way of finding a new home, or have the ability to save to afford improvements.

Greater access to community events: while Shaun accepts his life, he did not intend for social opportunities to become as limited as they are. He would not mind getting out to do a few more activities that are cheap and accessible to people who may be lacking social confidence, to keep him active.

Accessible work: Shaun has done paid work in the past, and although he feels it is out of his grasp now due to his health condition and being disabled, he would be open to doing something that interests him part-time. Some accessible options, such as supported employment services, have been closing down in recent years.

Pat: Approaching retirement age but needing to slow down sooner due to health

Pat has worked for much of her adult life. Over the past few years, her health conditions have worsened and led to some physical impairments. This is impacting her mobility and capacity to work. She has recently had to cut down her working hours due to physical discomfort, fatigue, and accessibility issues. She will likely look to retire early or continue with very reduced hours if this is possible.

Pat is proactive about trying to stay independent for as long as possible and carefully structures her days to ensure she can do what she needs to within the limits of her energy. She has made herself reasonably familiar with the health and income support systems.

Usually, Pat lives alone, though she is sometimes joined by her adult son. He has had his own struggles with mental distress including periods out of work, and she worries about him. Pat tries to help her son out with her limited income and notes that he, in turn, helps her with household tasks when he is around. This is particularly important given her decreasing physical strength. Pat still has a mortgage on her home. She is growing concerned that if maintenance costs keep going up while she is less able to work, she might have to sell. She is unsure in the current market about the availability of a smaller, more affordable house to purchase, or a suitable and affordable rental, or retirement home options in her area.

As her opportunities to participate in exercise and other leisure activities decrease (due to both cost and physical discomfort), Pat finds that her social life is also becoming more limited. This, plus the likely end to her working life, makes her feel a bit lonely.

Extra direct costs:

- mobility aids
- health appointments
- household services support (e.g. gardening).

Unmet extra costs:

- gym / pool membership to help her maintain mobility, and transport costs to attend.

Opportunity costs:

- lost income as a result of reduced work hours.

Income support: Pat receives Disability Allowance. In the future she may need to apply for a main benefit until she turns 65 and becomes eligible for New Zealand Superannuation. As she is still working, she is not sure what income support she is eligible for other than the Disability Allowance she is currently receiving. She will consider applying for Jobseeker Support – HCD if she can arrange to reduce her paid work hours further, but is seeking advice on how limited her earnings would have to be in order to qualify.

Financially: She has only just enough income to meet her everyday needs.

What would help:

Accessibility accommodations at work: Pat would ideally like to stay working and needs to know that physically accessible work setups will be available (including work from home some of the time). This includes actually getting into work, as the presence of construction, steps without lifts, and other barriers make accessing the building she works in difficult. There are similar difficulties accessing other buildings in town. Having to consider these barriers makes the planning of her days more tiring.

Access to affordable exercise and rehabilitation facilities: Pat really wants to stay active for her physical health and for her mental and social wellbeing. She finds the costs of parking, classes, and memberships prohibitive.

Opportunities to adjust expectations: Pat is coming to realise that her retirement may happen sooner than planned, and her lifestyle may be more limited than she had hoped. She would be helped by some support and information so she can adjust psychologically to her situation and plan for the types of activities and help that will be available to her.

Stella: Currently not receiving income support

Stella's circumstances have changed recently: more work, new relationship, the resolution of some of her or her family's health conditions. She is very grateful for these changes, and is glad to be able to do more of the type of work she enjoys while living in a happier, healthier situation.

However, money is still tight having been on a low income for a long time. Getting back to a place of stability with enough earnings has taken some time. The financial impacts of her time out of work due to health and disability will linger, and Stella still anticipates that phases of lower earnings and time out of the workforce are likely if her health declines. She dislikes being put into a situation of being financially dependent on her partner, and finds the potential power imbalance very uncomfortable. She also knows that while her current employer is sympathetic to her needs (for example allowing her to take time off for appointments), she has had enough experience in the past to know that not all jobs will be this flexible.

Extra direct costs:

- physical therapies
- health appointments
- mobility and orthopaedic equipment.

Unmet extra costs:

- Stella still finds it difficult to save for emergencies, and for upgrading household contents to make her home more comfortable and accessible
- missing specialist appointments: Stella finds that sometimes physically getting to appointments is difficult in terms of energy and financial costs, therefore there are some therapies that she does not access as frequently as recommended.

Opportunity costs:

- lost income while job-seeking, due to losing income support upon moving in with her partner.

Income support: currently none.

Financially: She has enough income to meet her everyday needs.

What would help:

Easily accessible income support if needed: Stella will feel more secure if she knows what kind of help is there should she need it again, and has a good idea of who she will need to contact and how long it will take to get support. She developed some constructive

relationships with case managers in the past, but always felt that her access to consistent advice and support varied depending on which case managers she talked to.

Not having her income support tied to her relationship status: currently this is a wish only, as the rules state that the partner's income will change an individual's eligibility. Knowing that she would be wholly dependent on her partner should her health prevent her from working again puts pressure on Stella's expectations, both of her relationship and of her workforce participation.

Continued ability to choose work that fits: Stella can stay in work while she has a flexible, supportive employer, or as long as she can design her own work (including via self-employment) to fit around her health and energy needs.

Full report

In-depth study to understand extra costs and income support experiences for disabled people and people with long-term health conditions

1 Introduction

1.1 Context

There are additional costs associated with being disabled and/or having a long-term health condition (hereafter ‘health condition’). Adults and children living in households where someone is disabled and/or has a health condition are more likely to experience financial hardship and other disadvantages. This can be due to the various social, political, legislative, and physical barriers manifested, in part, by the way society interacts with or responds to their disability and/or health condition, and because of the barriers innate to an impairment.² Disabled people and people with health conditions tend to experience poorer life outcomes, but financial hardship need not be an inevitable outcome of disability or a health condition.^{3,4}

The Ministry of Social Development (MSD)’s policy teams requested better evidence on income support, additional health- and disability-related costs, and material wellbeing for disabled people and people with health conditions, including both adults and children. This report presents findings from one study within MSD’s broader programme of research to respond to this request. Findings from the research are intended to inform future policy advice.

This research uses the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) definition of disabled people. Under this definition disabled people are “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This definition is inclusive of people with health conditions.⁵

A team from *Allen + Clarke* and *All is for All* conducted and analysed qualitative interviews with disabled adults, adults with mental distress and/or a health condition, and those who support a child or adult in such a situation. These participants were derived from a defined sample and were all of non-Māori and non-Pacific ethnicities. Two other studies with Māori and Pacific participants are being undertaken as part of the wider project.

The research explored the context of participants’ lives, the extra costs they face, whether they have applied for or received income support, and their experiences applying for payments. The research reported here is qualitative and complements other studies in

² This statement reflects a social relational understanding of disability, which is explained further in the Section 3 Methodology.

³ Welfare Expert Advisory Group (2019). Whakamana Tāngata: Restoring Dignity to Social Security in New Zealand. Retrieved from:

<https://www.weag.govt.nz/assets/documents/WEAG-report/aed960c3ce/WEAG-Report.pdf>

⁴ GUINZ (2023). The impact of disability on young people and their family. Retrieved from:

<https://www.growingup.co.nz/growing-up-report/the-impact-of-disability-on-young-people-and-their-family>

⁵ For MSD’s purposes, long-term refers to those who have a health condition or impairment which is likely to last at least six months.

MSD's work programme addressing quantitative findings around health, disability, and income support.⁶

1.2 Research questions

The overall research questions were developed according to MSD's requirements for insights, and in response to stakeholder feedback on plans for the research. While the questions are listed as separate, the participants provided statements that touched on multiple question areas at once.

1. What are the **direct costs** associated with being disabled and/or having health conditions?

These may include additional out-of-pocket costs required for goods and services such as transport, health services, navigation of disability services, medication, help with daily activities, education, leisure, and health- or disability-specific equipment or assistive devices and their software.

2. Are people able to meet all the costs of the goods and services they require? Or do they have **unmet needs**? And if so, are these unmet needs due to cost and affordability, or due to other barriers?

This recognises that actual spending on goods and services used may not provide a full picture of additional costs because it may be limited by the availability of suitable goods and services and the ability to afford them.

3. How are people **compensating** for unmet needs?

This might include, for example, adapting their social or employment situation, or having other ways of 'getting by' to reduce the impact of unmet needs. It recognises resilience and ways that disabled people and people with health conditions, and their families and whānau, seek to exert agency within the system confines.

4. What are the **indirect costs** and costs of lost opportunities associated with being disabled and/or having health conditions or compensating strategies?

These may include foregone paid work, promotions, training, educational or social opportunities associated with being disabled or having a health condition, or caring for others with a disability or health condition in the household. Some of these indirect costs can be measured by understanding who in the sample has used health- and disability-related subsidies for housing and other needs as use of these subsidies indicates existence of extra indirect costs.

5. How is a person's **situation** and the **context** they and their family live in, inter-related with the costs they face?

⁶ These studies include Wilson and McLeod (forthcoming). Material hardship of children in households with disabled people.

For example, how do costs relate to their health condition and/or impairment and/or that of others in the household, their resources, and their interaction with the environment they live in, including the prices, availability, and accessibility of goods and services?

6. What are the **consequences** of additional costs and any unmet needs?

This may include less money for day-to-day living costs, going without, limited choices, reduced participation and enjoyment, or mental distress.

7. Are disabled people and people with health conditions accessing **income support** payments that help with costs of health conditions and/or disability and, if not, why not?

This question is focussed on income support payments, noting that people could also be entitled to have the cost of equipment or home modifications covered via other government entities and may not be accessing those entitlements.

1.2.1 Areas of enquiry

To address the research questions, the interviews for this study focused on three⁷ main areas of enquiry:

1. Situation

Understanding the context around participants' lives including:

- their characteristics: household type, whether they are a carer, a disabled person, or a person with a health condition and how this affects them
- their housing situation
- their employment situation
- how they access services and activities in their community
- how their impairment or condition, in the context they live in, impacts on their participation in activities, and
- how they manage activities, expectations and financial limitations.

⁷ The research was initially planned to cover five areas of enquiry. The fourth and fifth included (4) an expert assessment of whether participants are receiving their full-and correct entitlements for different income support payments and what, if any, payments they appear to be entitled to but are not receiving based on that assessment. A follow up interview would then establish (5) how they understood their assessment went and any changes to their eligibility, whether they plan to apply for payments that they appear to be entitled to but are not receiving based on the assessment, and if not, why not. Ultimately fewer participants than anticipated were interested in proceeding with this assessment. Findings on the outcomes of the few who proceeded, and the reasons others did not, are reported on briefly but not as separate question areas.

2. Additional costs

Understanding the extra costs participants face because of disability and/or health conditions including:

- what direct costs associated with disability and/or health conditions are incurred
- what items people would like to spend on to help with disability and/or health conditions, but cannot due to cost or access
- their experiences with funded and unfunded support
- conceptualising extra costs: what spending adaptations they make, and the dollar versus opportunity costs they face, and
- what they would like to change to make their situation easier to manage.

3. Income support

Understanding participants' experiences accessing income support including:

- what they are receiving
- their experiences with applying for income support
- what they know about their entitlements
- why they might no longer be accessing income support, and
- their interest in a Full and Correct Entitlement (FACE) assessment.

1.3 Expert review

An Expert Reference Group (ERG) was formed to support MSD's programme of research, including this study. This group was established to strengthen the research and minimise the risk that findings could be interpreted without adequate context or in a way that compounds damaging stereotypes. Members of the group provided input at different stages of the research process (including reviewing this report), drawing on their lived-experience and/or policy and research expertise. The ERG has seven representatives from the community and university research groups (including disabled people and people affected by health conditions, and Māori and Pacific representatives), and five representatives from across MSD and from other government agencies (including disabled people and people affected by health conditions, and Māori representatives).

The draft report was reviewed by disability research experts at the Donald Beasley Institute, and their comments are reflected in the final report.

2 Methodology

2.1 Research values and methodological approach bringing in lived experience

This research was designed to centre the voice of participants in a way that acknowledges that often lived experience with disabilities (including health conditions) is a part of people's identity, however, people vary in the extent to which they identify as disabled and may prefer different terminology to describe their lived experience. This research process has been informed by the recognition that disability is a socially constructed concept. Disability is not the inevitable consequence of impairment; it is partly the result of society's interaction with, and response to, impairment.⁸ However, there are limitations innate to a diagnosis (for example, pain) that an accessible society cannot change. These are not personal deficits, but they are realities that require appropriate recognition and support.⁹

Further, this research recognises how diverse systems interlock and reinforce one another. Accordingly, disability or health status, and experience of income support, are not isolated experiences. These experiences work together forming part of the ecosystem disabled people navigate, and are impacted by, in diverse ways.¹⁰

The discussion of findings presented in this report includes references to ableism and disablism. New Zealand is still on its journey to understand ableism. One understanding, backed by scholarship, is that ableism is not just about disability but rather it is an underpinning value structure that places some characteristics above others as more important or valuable, leading to discrimination based on assumptions about people with characteristics that are deemed less valuable. These may include, for example, preference for ability over impairment, or ability to earn money over inability to do so. Ableism normalises the social structure that favours certain groups over others, and in doing so continues to shape social policies and relationships between groups.¹¹

In a society where certain people are enabled, disabled people are consistently systemically disadvantaged. 'Disablism' is also referenced in this report, which relates specifically to experiences of the disability community. Disablism is prejudice that directly targets disabled

⁸ Hosking, D. (2008) Critical Disability Theory. A paper presented at the 4th Biennial Disability Studies Conference, Lancaster University, UK, Sept. 2-4, (2008)
https://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2008/papers/hosking2008.pdf

⁹ Francis, R. (2018). Nothing about us, without us: The pursuit of inclusive and accessible positive peace (Thesis, Doctor of Philosophy). University of Otago. (page 18) Retrieved from
<http://hdl.handle.net/10523/8356>

¹⁰ World Institute on Disability (2022). Moving From Disability Rights to Disability Justice
<https://wid.org/moving-from-disability-rights-to-disability-justice/>

¹¹ Wolbring, G. (2008). The Politics of Ableism. Development 51, 252–258 (2008).
<https://doi.org/10.1057/dev.2008.17>

people, on the basis of their disability, perceiving their impairment as something that is deviant, needs to be fixed or changed.¹²

The researchers understand that different communities may have different understandings of ableism. An analysis of ableism which is not specific to disability, and instead looks at how characteristics are valued or not and responded to, is better aligned with the reality of how disabled people move through the world. We move through the world as disabled, but also as people with a gender identity, ethnic background and country of birth, as renters or homeowners. Each of these characteristics impacts how we are perceived and the access we have.

As qualitative researchers, the research team brings our own positionality to the research. Having the interviews conducted and reported on by members of the disability community meant that researchers could integrate a deeper understanding of dimensions of disability as a natural part of the research and the interview conversations. This enabled the building of trust with research participants, through empathetic and supportive conversations. In addition to having specialist team members from *All is for All* bringing disability perspectives, as disabled people, the *Allen + Clarke* team members responsible for most contact with participants brought additional lived experience. Most contact with migrant participants was carried out by a team member with current experience of the New Zealand health system as a migrant. Most contacts and interviews with parents were conducted by a researcher with current experience of the health and disability system as a parent.

The researchers recognise the will and preference of those we engaged with; for example, we respect people's language preferences about how they described health conditions and disabilities. We aimed in all interactions to recognise identity and diversity, prioritise genuine engagement and ensure participants' comfort, value peoples' knowledge and experience, and ensure voices are heard and people's values are reflected in our analysis and reporting.

¹² Mirfin-Veitch, B., Tikao, K., Asaka, U., Tuisaula, E., Stace, H., Watene, F. R., & Frawley, P. (2022). *Tell Me About You: A life story approach to understanding disabled people's experiences in care (1950-1999)*. Donald Beasley Institute.

2.2 Sample selection and recruitment

The population of interest was disabled adults and adults with health conditions, and people caring for a disabled child or adult or a child or adult with a health condition. Within this population the research focused on New Zealand Europeans and New Zealanders of non-European ethnicities (and excluded Māori and Pacific people).

The majority were recruited by following up with people who had previously participated in the 2022 New Zealand Income Support Survey (NZISS) and agreed to be recontacted about the possibility of answering more questions of interest to MSD. The NZISS was commissioned by MSD and Inland Revenue. It surveyed people aged 18 to 64 on low- and middle-incomes that made them potentially eligible for income support.

In total, 35 individuals participated in this study. Participants were drawn from three main geographical areas: South Auckland, Wellington/Lower Hutt and Dunedin, including rural areas near these cities such as Waitaki north of Dunedin and the areas north and south of Auckland into Waikato.

The sample included people from the following regions:

- Dunedin (12)
- Wellington (11)
- Auckland (6)
- Rural (5)
- Waikato (1).

Out of 17 participants who were migrants or New Zealanders of non-European ethnicities contacted, only eight (all identified as migrants) agreed to and proceeded with an interview. The remaining 27 participants were of New Zealand European ethnicities.

More detail about the sampling and recruitment strategy can be found in Appendix A.

2.3 Interviews

The team developed interview schedules based on the research areas of enquiry. These included a list of structured questions about costs, with optional tables to fill in with dollar costs or comments.

Overall, 16 interviews were conducted in person, 13 via video call (including one participant who related separate experiences and costs for two household members that they supported in different ways) and five by phone. Interviews took place between 7 August and 13 November 2023. All interviews were conducted by a pair of researchers in which one would lead the questioning and one would take notes, interjecting to clarify or follow up on lines of questioning. Interviews took approximately 60 minutes, ranging from 30 to 100 minutes.

The interview and analysis processes are reported in more detail in Appendix A.

2.4 Strengths and limitations

A strength of recruiting participants as a follow-up to the NZISS was that we were able to draw on a panel of people in a range of circumstances who had participated in a nationally representative survey and agreed to be recontacted. This included people who identified as being disabled or having health conditions. It also included people who might not identify as being disabled, but who had received health- and disability-related income support. MSD is interested in the experiences of this second group, who might not have participated in a study had they been approached based on being disabled or having poor health.

The NZISS had several design features that were intended to support participation by a cross-section of people. It:

- had random selection of the areas and households to include
- had up to 10 attempts at contact
- involved face-to-face interviews (or virtual interviews if preferred) with those who met the age and income criteria
- included provision for an interpreter if required
- included provision, where a selected respondent was unable to provide consent themselves, for a welfare guardian, or someone who held enduring power of attorney for the respondent's personal care and welfare, to consent and complete the survey on the respondent's behalf.¹³

However, an acknowledged limitation of using the NZISS is that the limitations in its inclusiveness flow through to this study. The NZISS did not include provision of survey information in alternate formats. This means this research has limited information about those with high and complex needs, and people's experience across the diversity of impairment. The response rate for the NZISS was 50 percent, and 86 percent of respondents agreed to be recontacted. This means participants' agreement to being in the initial survey and to being contacted for further research also introduces some potential for self-selection and non-response bias.

Despite best efforts, and most potential interviewees from the NZISS being selected for contact, it was not possible to engage a large number of migrants or people from non-European (and non-Māori and non-Pacific) ethnic groups. Those who did participate, however, reported a wide range of experiences, which are represented throughout the report.

The limitations with the NZISS sample's representation of different types and levels of impairment were partly addressed by including several participants from a different network of contacts. This was not, however, able to address the low number of non-European participants.

¹³ [https://neac.health.govt.nz/national-ethical-standards/part-two/7-informed-consent#Research with adults who cannot provide](https://neac.health.govt.nz/national-ethical-standards/part-two/7-informed-consent#Research%20with%20adults%20who%20cannot%20provide)

The participants included people in the following situations:

- people who identified as disabled and/or as having health conditions
- people who did not identify as disabled and/or as having health conditions, but who received health- or disability-related income support in the last year
- people who had physical or learning disabilities, health conditions, injuries, mental distress, are neurodivergent, or a combination of these
- people who cared for a child or children who have learning or physical disabilities, or mental distress, are neurodivergent, or a combination of these
- people who provided support for a partner or adult family member who has physical or learning disabilities, health conditions, injuries or mental distress, is neurodivergent, or a combination of these.

But due to the sample, the recruitment strategy and the focus of this study, the findings do not include the perspectives of:

- young carers
- adults with acute learning disabilities, although parents of adults with such conditions who could answer about their family's experiences were included
- people with communication disabilities¹⁴
- people who lived outside of metropolitan areas AND were unable to participate in an interview online or over the phone. As noted, some of the participants were recruited based on having received health- and disability-related income support payments at the time they responded to the NZISS.

One of the research questions was focused on costs. The type of information gathered means that findings are generally focused on the range and type of costs, rather than the exact financial figures for all costs. This was because people had difficult recalling or estimating exact amounts they spend or would like to spend. While some people could give dollar estimates, they commonly noted that it could be difficult to identify the line between costs that were extra due to health and disability and extra because of the cost of living on a limited income. The opportunity costs of spending time managing conditions, and not accessing desired activities due to cost, were harder to quantify but nonetheless a significant part of the findings.

A strength of presenting personas was that it allowed the findings to be made accessible and relatable while protecting participant anonymity. A limitation of this approach is that it relies on researchers' personal judgements, and the content produced may be difficult to assess for reliability. We have made judgements in order to represent the most commonly reported situations, and also the range of situations. Appendix A documents our approach.

¹⁴ Being Deaf is not considered as a communication impairment; it is a culture. Participants were supported with sign language interpreters. In addition, other language interpreters were also made available.

3 Research participants and situation

3.1 Participant characteristics

This section presents an overview of the situational characteristics that participants reported. These include their health conditions and impairments, their household situations, their employment status and the types of income support they received. These findings are listed in the order of how commonly they were mentioned, and may not sum to the entire sample because some people gave multiple responses. More detail about how some of these characteristics and experiences intersected is shown in the personas (see the examples of experiences presented at the end of the executive summary), which describe profiles of the range of participants and their situations.

3.1.1 Ethnicity

As noted in the method section, the sample of 35 participants included 27 people of New Zealand European descent. Some of these participants noted the countries their parents had come from so identified more specifically as, for example, Irish or Dutch New Zealanders, while others had extended family or partners from different countries and ethnic backgrounds. Eight participants were migrants themselves; their ethnicities or nationalities included Indian, Chinese, Thai, Somalian, Nepalese and Lebanese/Arabic.

3.1.2 Perspective

Twenty of the participants were recruited based on living with health conditions or being disabled themselves. This did not preclude them talking about other family or household members who were also disabled or experiencing health conditions. The balance of the sample included:

- thirteen parents with a disabled child or a child with a health condition: three with young adult children, four with one child, six with multiple children/ young adults
- Two partners of disabled people and/or people with health conditions
- One supporter of a disabled adult household member (also responding as a parent).

3.1.3 Health conditions and disabilities

Many participants reported that they, or the people they cared for, had multiple health conditions or impairments. These were, in order of how frequently they were mentioned:

- Chronic health condition/s: 25
- Mental distress: 11
- Neurodivergence: 10
- Physical disability: 7
- Learning disability: 7

- Blind or low vision: 5
- Injury: 4
- d/Deaf or hard of hearing: 2
- Addiction: 2.

Of the 35 participants, 13 identified that they or the person they cared for had one of the groups of conditions or impairments listed above. The rest mentioned a combination of at least two conditions or impairments, including eight participants with at least three.

3.2 Participants' current situation

3.2.1 Income support

There are different types of MSD income support available to people depending on their circumstances. Nineteen people were receiving a main benefit from MSD. Twenty-eight people were receiving some form of supplementary support from MSD (either on top of a main benefit, or on top of their other income if they did not receive a main benefit).

The most commonly noted types of MSD income support received at the time of the interview were the Disability Allowance and the Supported Living Payment. Some participants received more than one type of income support, while a few had received income support in the past but were not currently.

- sixteen received Disability Allowance (a supplementary payment to assist with the cost of disability)
- thirteen received Supported Living Payment (a main benefit from MSD for people who are not able to work because they are permanently and severely restricted in their capacity for work because of a health condition, injury, or disability, or totally blind, or caring for a person who requires full-time care and attention at home)
- seven received Temporary Additional Support (a non-taxable supplementary payment to help people with their regular essential living costs that cannot be met from their income and other resources).
- five received Accommodation Supplement (a non-taxable supplementary payment to assist with accommodation costs)
- four received Jobseeker Support (a main benefit from MSD for people who are looking for work, are in training for work or unable to work due to a health condition, injury or disability)
- three received Child Disability Allowance (a non-taxable supplementary payment available to the principal caregiver of a dependent child who has a serious disability)

- two received Sole Parent Support (a main benefit for sole parents with one or more dependent children).

Some received financial support from other agencies. Four were receiving ACC payments. Four were receiving “other” types of financial support including child support¹⁵ (2), Best Start¹⁶ (1), and a subsidy from a workplace during a recovery period (1).

Three participants were not receiving income support from MSD or any other payments at the time they were interviewed.

We note that the income support that is provided via MSD to the cohort of people in this research is administered via Work and Income (an organisation within MSD), so Work and Income is referred to when participants are describing their experience with applying for income support.

3.2.2 Employment

Many of the participants had moved in and out of employment or study over time, so the following list is a snapshot of what they reported as their situation at the time of the interview, including their perspective (whether answering about their own health or disability, or as a carer for someone else). The sample included:

- eleven people who were disabled or had health conditions, not working or looking for work
- nine people who were disabled or had health conditions, working part-time
- one person who was disabled and had health conditions, studying and working part-time
- six parents working full-time
- six parents doing full-time parenting/ not working or looking for work
- one supporter of a disabled adult who was not looking for work
- one partner of a person with health conditions, not working or looking for work.

3.2.3 Housing and household

Participants’ housing situations were overall as follows:

Fifteen in private rentals, 12 homeowners, six in public housing, one in a supported living facility, one whose housing situation was unclear.

In more detail, the types of household included:

- six in private rentals, living with their family
- six in private rentals, living alone
- three in private rentals, living with flatmates and others

¹⁵ This is administered by Inland Revenue see <https://www.ird.govt.nz/child-support>

¹⁶ This is a Working For Families tax credit – see <https://www.ird.govt.nz/working-for-families/payment-types>

- ten in their family-owned home, living with family
- two homeowners, living alone
- three in Kāinga Ora¹⁷ rentals, living with their family
- three in public housing (council/Kāinga Ora) rentals, living alone
- one in a supported living facility.

¹⁷ Most commonly referred to by participants as “Housing NZ”.

4 Participation and access

This section addresses how participants managed their participation in society and access to what they needed. Participants described three overall approaches they took relating to their experiences with housing, physical access and transport, support services, activities, and employment. These were:

- *adapting* to their situation
- *accepting* limits on what they could do
- *strategising* to ensure they could optimally balance their needs and what they had access to.

From this point onwards, some representative participant quotes are included. Relevant participant characteristics are noted after each quote.

4.1 Context for experiences with participation and access

For participants in this study, experiences with participation and access were not all due to being disabled or having health conditions. Participants understood there were pressures and lack of capacity in the health, housing, and education systems, and that external events such as climate change-related incidents and COVID-19 could add to pressures and make services harder to access for everyone.

As noted, participants were selected for this study because of being disabled or having health conditions, and having incomes at levels that made them potentially eligible for income support. The challenges noted by participants stemmed as much from limited income as they did from disability or health status. These research findings should be considered holistically as the responses of people who were dealing with limited incomes and system capacity limits, as well as being disabled having health conditions, and other intersecting identities. The impacts of these aspects of participants' circumstances, and the wider issues with system capacity, were not always easy to disentangle. The overall impacts of unmet needs on participation are reported towards the end of the report, following the costs section, because again these unmet needs were caused by a combination of system pressures, individual impairments, and financial insufficiency.

4.2 Housing: compromises and priorities

Participants in all housing situations – public or private rentals, or owner-occupied houses – reported mixed experiences, and a mixture of gratitude, anxieties, and compromises. Most participants pointed to some issues with their living environments, while most also enjoyed some aspects of where they lived.

Housing was an area where participants generally felt limited control, mainly because the cost and available supply meant a low likelihood that they could afford something that met all their needs. In all housing situations, participants accepted some limitations and compromises, but they strategised by deciding what they needed to prioritise.

Some participants experienced anxiety over the impact of climate change in their area of residence; ironically some of the areas that suit disabled people and those on low incomes (on the flat, with cheap housing) are now known to be at risk from climate events such as flooding, and some participants' homes had already been damaged by these events. For those whose disability and housing situation prevented them from undertaking repairs themselves, relying on others' uncertain timeframes added to the stress.

I ask Housing NZ, he take photo but he not do anything. (disabled migrant living in public housing that had been affected by flooding)

In the case of private rentals, the compromise tended to be on renting something lower quality in order to be closer to amenities and activities. This led to people having less ability to modify their environment to be more accessible. For example, some did not want to commit to one-off home modification grants because they did not want to use this allocation if they did not have housing security – an example of support being technically available, but feeling out of reach due to circumstances. Renters had to adapt their own activities to keep themselves safe and comfortable in their surroundings.

[Previous rental] house was falling down, there was black mould - but I couldn't move, because I couldn't risk being in the suburbs because it meant I couldn't go places. People picked me up [to go out] because I was on the [main] road. (disabled young adult, renting with others)

For homeowners, rising costs of insurance and maintenance meant putting off other 'nice to have' expenditure to improve their housing and comfort. Some of these participants lived further out from urban centres, meaning they could afford to own and benefited from more space, but adapted to some compromises around the cost of transport or access.

Only could buy this house because of deferred maintenance on it... it's really cruddy. But we're very fortunate, very grateful. (parent of disabled adolescent)

Those in public housing felt the least control over where they lived, although some found the quality better than in their previous experience in private rentals. Some had very positive experiences with city councils as property managers, while others did not find them responsive or helpful. They compromised on choice in order to access reduced costs and to find any options, given limited supply of other housing in their areas. They had to adapt to close proximity with neighbours they might not have chosen, which could cause increased anxiety. However, some had developed supportive relationships with their neighbours.

I'm grateful to have a roof over my head. The neighbourhood is not ideal, I can hear a lot, they've fixed the windows, but I get second-hand smoke from the neighbours... The neighbour is quite loud and frightening. The day we moved in, a car came screaming past, and someone was yelling at the top of his lungs. I went inside and sat on the floor and shook. (older adult in public housing)

We're in a state house, so we didn't get to choose where we moved to and we didn't get the opportunity to decline this house and wait for another one... It was really slow. It was kind of like we felt like we didn't know what was going on. There wasn't a lot of transparency... [The house is] really good. Actually one of the nicest houses I've lived in... Anything that needs fixed, it gets done ... pretty quickly, which is good. (parent living with children and partner in public housing)

4.3 Employment: flexibility is key

Most participants wanted to work, and most of those who were not employed full-time would like to be able to increase their available hours. However, the effects of both impairments and external circumstances could make it difficult to find suitable employment. Overall, the key for maintaining employment was flexibility – on the part of employers, but also from the participants themselves and from the support systems they had contact with.

I worked 9:00am to 3:00pm... [Child] always needed supervising. One employer I had let me work through lunchtime... And the next one let me take 3 hours' work home. So I've managed to kind of get around it, but it's always a bit fraught... several times over the last five years, something has happened, which meant I've literally had to drop everything and go and see [Child]. I've turned two promotions down. And I probably won't turn the next one down, but I'm still a little bit dubious about it. (parent of disabled adult now in supported living facility)

While parents of disabled children would talk of their gratitude towards employers who allowed them to work flexible hours, they also had to commit to flexibility themselves, including working late at night to complete their tasks around their caregiving responsibilities. Those who had found part-time work that fitted with their family's needs were glad, but often noted it was at a lower hourly rate than what they had previously; their expectations of their earning capacity fluctuated over time, and they had to adapt their lifestyle accordingly. Inflexible aspects of the income support system led to some participants expressing unwillingness to take on work that would ultimately not benefit them financially because it would limit their income support eligibility or reduce their benefit income. Others talked about doing voluntary work, partly for this reason and partly because that was what was available and interesting to them.

Participants had strategised to get access to resources that would make employment accessible for them. In some cases this meant obtaining equipment, advocating for flexible hours or developing their own business that they could run with the hours and personal capacity they had. Overall, many participants saw unmet needs for more accessible workplaces, and for some this was a major reason that they were not in paid employment at the time of the interviews.

Accessibility makes a lot of financial sense - but they don't value it. When (employers) value it they invest in and then reap the rewards. (disabled young adult)

4.4 Amenities and activities: meeting the basics

Most participants had a fair idea of what services and amenities were available in their local environment, although in a number of areas the services were limited in what they could offer and had long waiting lists. They were more likely than not to be quite satisfied with their access to community services. This was not to say that they all had ideal access, but those who had chosen to live further from urban centres accepted the compromise due to the other benefits of rural living, and those who lived more centrally knew where they could go for most of their needs.

An exception to this was some of the migrant participants who reported feeling less informed about services and community amenities in their area. In some cases this was due to language barriers and limited access to mainstream media and information, compounded by being disabled or having health conditions. Some also felt disconnected from local events due to lack of transport options, and being too busy managing their immediate situation to connect much with local communities.

Overall, although most were able to access the basics of what they needed, there were many relatively common activities and amenities that would make a difference to quality of life but were just out of reach, generally due to financial costs and sometimes due to accessibility challenges. These included exercise facilities and social or cultural events.

Participants adapted by identifying the types of activities that were free or low-cost, and flexible or low-impact enough that they could participate. They planned for availability of suitable and affordable transport, which meant committing to fewer trips but prioritising the ones where timing would line up best.

4.4.1 Public and subsidised transport makes a difference

Proximity to, and ability to safely use, public transport made a big difference to access. For some participants who were blind or physically disabled, the safety of the environment was not enough – or not predictable enough – to make all their desired trips realistic. More pedestrian walkways and easier access onto public transport would make a big difference. Several participants did not feel that taking buses would be safe for them, so they had to budget for taxis to get to appointments.

Access to subsidised travel through schemes like the Total Mobility Card made a big difference to participants' likelihood of accessing things that improved their lives, including health appointments that were further away, and social or hobby related activities.

4.5 Support and health services: help with limits

Participants were concerned about the constraints that the health system was clearly facing. In particular, the mental health system seemed rarely available to people who were not already at crisis point. Most participants had engaged with various types of health and disability support services, which varied in how linked up they were and how easy they were to navigate.

4.5.1 Health and diagnosis

Participants had to become subject matter experts on their own or their family member's condition, in order to advocate for getting diagnoses and treatment. The issue of getting an accurate diagnosis could hold up participants' eligibility to access suitable support, and for some the best strategy was to find a way to afford a private assessment. A number of participants only got through the process of diagnosis because they had information and support from a peer who had their own knowledge and could help them find the right questions to ask.

Waiting over two years to see specialist at hospital, still hasn't happened, condition got worse, doctor sent another referral – still waiting on that. I do as much as I can – walking to improve condition. But when you can't see the medical professionals that would guide you better that is pretty frustrating. (adult with health conditions, currently unable to work)

Finding a community of people dealing with similar conditions made a big difference to participants' ability to advocate for what they needed. It was not uncommon for parents (particularly mothers) to be initially dismissed by health professionals or told they were just being anxious, then if they followed up with different appointments and specialists, to eventually land on the diagnosis they suspected. This required a lot of persistence, and often required participants to adopt a strategic approach to engaging with services.

I've had to start writing letters, start being a squeaky wheel... I actually find I don't like doing that, that doesn't sit well with me that I'm pushing myself up over other people. But I have to do it for my son. (parent of disabled adolescent)

4.5.2 Living support services

Participants sometimes got great value from engaging with support workers who could help them with household tasks. However, in several cases, using these services meant the participants themselves had to adapt to the possibility of visit timing being unreliable, limited support worker costs meaning limited time for help, or uncertain shopping timeframes meaning they might run out of groceries. Sometimes other informal support networks including family, friends and housemates were the key to papering over the gaps in this system; sometimes participants just went without certain types of support if it was not available.

I have a support worker who comes once a week, but they can be unreliable, and things like shopping - I could do it, but it would take me a long time to do it. When support workers aren't available, it creates a hassle, especially if I have organised things and have to try and find a solution. (disabled adult living alone)

4.6 Managing financially

Participants talked about their strategies for managing financially. They needed to adapt to their budgets, accept limits, and develop strategies to get most of what they needed. The most common themes are listed below.

4.6.1 Careful budgeting strategies

Participants frequently talked about strategies to make their budgets stretch further, like waiting until items they needed were on special or off-season, buying second hand items and discounted groceries. Some had support with budgeting advice, while others mentioned they wished there was more education about budgeting. Most participants were focused on just getting the basics, meaning that “extra” costs were sometimes hard to pinpoint.

4.6.2 Compromising with cheaper options

Sometimes the cheaper options were the only options that fitted with participants’ budgets. This was acceptable in some cases, for items that people were used to economising on. However, for some items compromising with the cheapest or only affordable version meant not accessing the types of food, accommodation, fitness classes, leisure activities, therapy, and in particular, medical products, that might help them attain better health. It also meant choosing cheaper options for activities like travelling that might be less accessible than the more expensive options, and thus came with costs on people’s energy and resilience.

4.6.3 Missing out

All participants accepted that they were not planning for luxury expenditure or for many wants beyond things they needed. To an extent, they also had to adapt to missing out on things they did need. Food was an area where participants frequently missed out: some limited their meals per day or limited the types of food they included in their diet. Going out was a luxury that many could not afford, or would only plan for if the activities were cheap or free. Families tended to limit extracurricular activities for children unless they were free and easy to get to and from.

4.6.4 Family support

For those who had access to family support, this made the difference in being able to pay for expenses over and above the day to day. Some older participants who lived alone had adult children who could help them from time to time. Some families had a grandparent who could help with one-off appointment or activity costs. In several cases people related situations where they had a large expense come up, and coincidentally had a windfall such as an inheritance or birthday gift, that just covered the cost.

4.6.5 Adapting to available means

Some participants were confident that they had become good at adapting over time, and would be able to continue to do so as costs changed. Those who had houses to maintain, or more household members to cater to, were most concerned about the rising cost of living

and less certain they could adapt; some considered selling their houses although renting did not look much more affordable.

Someone whose health had been changing over the years, along with related decreases in available income, talked about a “gradual lifestyle change” in terms of what they spent money on. Someone else who felt they had “just enough” despite being on a lower income than in the past, clarified:

It's probably the case where we shaped our life more to fit the income rather than the other way around. (parent with health conditions)

Someone who felt they had “not enough” stated:

I don't know anyone that could afford to function off that [income we have left over], but we do because we have to make it work. (Single mother of school aged children, not in paid work)

In other words, what people reported about their spending now was the result of sacrifices and compromises they had already made.

5 Additional costs – met and unmet

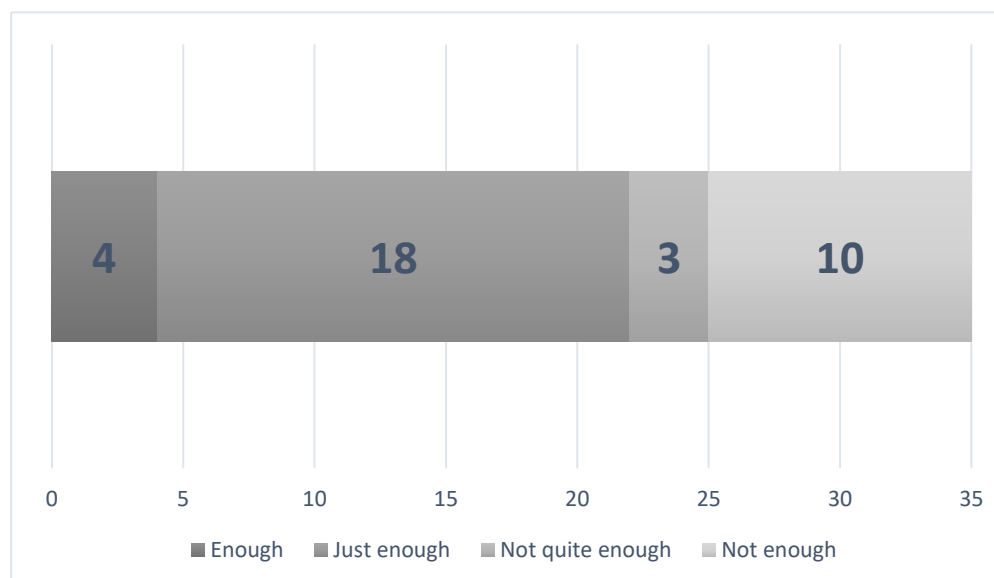
Participants were asked for an overall idea of how well they were getting by financially, and whether their income was enough to meet their needs. They were then asked about a series of areas where there might be extra costs due to health or disability, and whether they either spent extra on these things or had unmet needs in these areas (that is, they would ideally spend more if they could afford to). Where possible, participants gave dollar estimates for how much more they spent or would like to spend if they could afford it, and over what timeframe (that is, whether the costs were weekly, monthly or more occasional).

This section presents participants' comments about how they managed and conceptualised “extra” costs relating to health and disability, and more generally, how they were managing on their current budget. It then covers specific cost areas that participants discussed spending and wishing to spend on. Appendix D provides further detail, including the range of cost estimates if these were given.

5.1 Getting by financially

Figure 1 shows the number of people who said that overall they had “enough”, “just enough”, “not quite enough”, or “not enough” to meet their everyday needs.

Figure 1. Whether participants have enough income to meet their everyday needs



The 18 participants who said they had “just enough” were in varied living situations with regard to housing type, family and employment. Those who added comments indicated that this was a rather bare-bones understanding of “just enough”; that they would be comfortable if they had a bit more because just one increase in costs, or unplanned for payment, could transition them into not having sufficient funds.

Several said they could easily spend more on groceries, that a little bit of extra income would make a big difference. Some mentioned they were able to meet their immediate expenses but not medium-term needs such as home repairs or saving for contingencies. Several also

had a sense that they were only just stable unless things changed – such as settling into a new house, changing job, losing access to child support or certain benefits.

We have just, barely enough - emptying the account every week and living paycheck to paycheck. (disabled young adult living with family)

I have enough to survive. I don't have enough to thrive. (disabled young adult renting with flatmates)

Overall, it could be interpreted that a number of those who said “just enough” had “not quite enough”. They were just managing their basic costs but were not entirely comfortable or confident they could cover unexpected or optimal expenditure (that is, buying things they needed to achieve wellbeing).

5.2 Conceptualising extra costs

A number of people brought up the difficulty of separating costs that were extra due to the overall cost of living and their life situation, from costs that were specific to health and disability. This section includes the overall themes about how people thought of extra costs.

5.2.1 Difficulty of knowing what is “extra”

Many participants, and particularly the parents, talked about adjusting their budget to account for changing needs over time, and being unsure how many of the new costs they experienced were different due to health or disability, or similar to what other families would need to spend anyway. Those who spent more on specialty food items spent less on other types of food, but they might have needed to do this as their child’s dietary needs changed over time even if there was no underlying health consideration.

But that's what you do for your kids, wouldn't you? It's hard to say [whether we spend more due to child's disability]. I was like, “this is just having kids”. (parent with a disabled child and a non-disabled child)

Another participant pointed out that because they were always adapting their budget, but many of their costs were everyday items that anyone would need, it was hard to put exact figures on how much “extra” financial assistance they needed due to the family’s health and disabilities:

‘Unexpected’ costs are always expected – we are used to pivoting. No exact figures, but extras always come up. (parent of disabled adolescents)

Overall, at the time of the interviews, participants had already made significant compromises and adjustments and built these into their spending, so it could be hard to conceptualise what aspects of their spending were “extra” purely due to health or disability needs.

5.2.2 Time and effort as a cost

Many participants found that managing their own and their family members' health resulted in opportunity costs – that is, 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.

5.2.3 Summary on identifying extra costs

The difficulty that some participants had when asked to identify extra costs should not be considered evidence of the absence of extra costs. Rather it illustrates how embedded these are. This meant adaptation was the expected practice, and most participants spoke with some acceptance of the fact that they could not afford everything they might like to in order to really thrive, so focused on their specific priorities and basic needs.

5.3 Extra costs by type

This section covers participants' extra costs due to health conditions and/or disability. Areas for expenditure are presented in order of most to least reported, and the discussion covers what people spent and what they talked about wishing they could afford to spend. Overall, the comments were qualitative rather than quantitative, however when participants gave dollar estimates, these are listed in more detail in Appendix D. Figure 2 shows the most commonly mentioned areas of extra costs, and Table 1 shows the types of expenditure.

Figure 2. Type of extra costs due to health and disability, by number of mentions

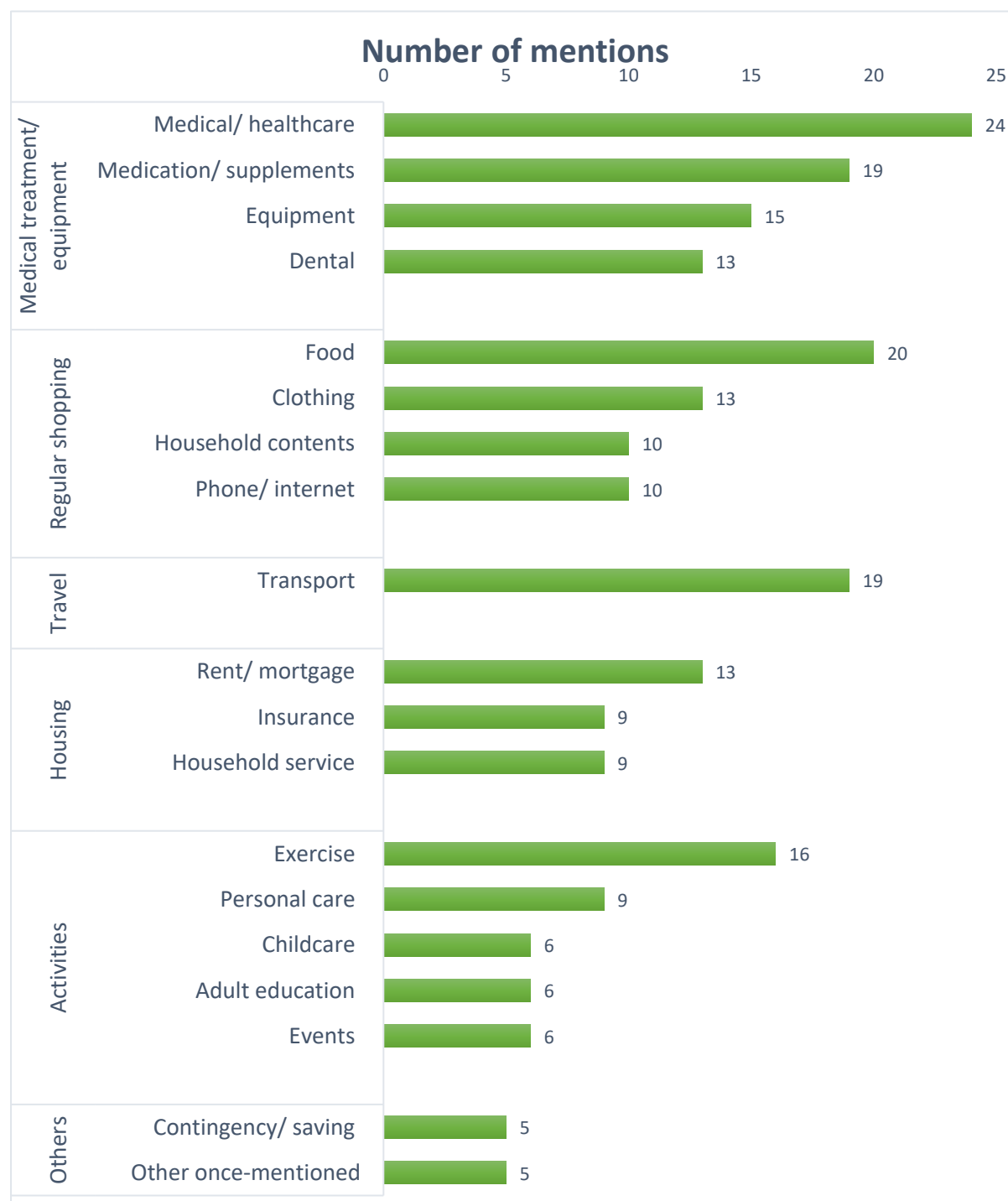


Table 1. examples of costs in each area of expenditure

Area of expenditure	Kinds of costs in this category	Number mentioned
Medical/healthcare	Additional medical or healthcare costs that are not covered for example GP visit costs, specialist costs.	24
Food	Special food required, or additional food requirements to manage and maintain health or meet needs of family. For example, gluten free or low sugar food, specific brands to meet neurodivergent needs.	20
Transport	Extra costs related to mobility and transport such as wheelchair vans, travel to and from appointments or other private transport costs.	19
Medication/supplements	Cost of supplements or medications not covered by government funding.	19
Exercise	Personal trainers, exercise classes, equipment – which help manage health and disability needs.	16
Equipment	Canes, white noise machines, motorised scooters, Bluetooth headsets that works with hearing aids, kitchen appliances and other equipment which may not be covered by other funding.	15
Clothing	Seamless, tagless, sensory friendly or adaptive clothing; clothing with higher regular replacement costs due to wear and tear.	13
Rent/mortgage	Less choice about where to live associated with health conditions or being disabled so extra costs related to rent, or mortgage payment because of those constraints.	13
Dental	Costs of going to dentist.	13
Phone/internet	Additional phone/internet data costs to accommodate needs and because people spend more time at home.	10
Household contents	Specialised furniture, bedding, other devices not covered in other categories.	10
Household services	Cleaner, gardener, support with household maintenance.	9

5.3.1 Medical care, equipment and treatment costs

This section covers the most commonly noted extra cost, “medical/ healthcare”, and the related costs of medications/supplements and medical or disability aid equipment. It also covers dental care, which was sometimes mentioned as a healthcare cost.

Unsurprisingly, given the topic of this research, most participants had some extra costs covering appointments and items to help with their health or disability. Some of these costs were funded or part-funded by the government and, in a few cases, by participants’ employers. The extra costs are what participants said they had to pay themselves. Twelve of the participants who reported these extra costs were receiving the Disability Allowance, which should help to cover them up to a cap.

5.3.1.1 Medical costs covered or required by participants

The most commonly noted costs, mentioned by 11 participants, were regular medical appointments such as GP visits to monitor conditions and get repeat prescriptions every few months or as needed.

Six participants mentioned costs for specific types of therapies. These varied in their frequency and the extent to which they were subsidised by government agencies or employers.

Several participants mentioned that their frequency of attending appointments was less than optimal due to the financial and energy costs of going. This was especially true for appointments requiring significant travel to out-of-town specialists, which two participants noted costs for.

Other costs included one-off private appointments for diagnosis, which often required family support in order to afford the fee.

5.3.1.2 Unmet needs for medical costs

There were a number of therapies and specialist appointments that participants were aware might help them, but that were not accessible due to their situation and income. Five participants mentioned mental wellbeing support, five mentioned mental, physical, and movement therapies, and two mentioned eye or vision specialists. Participants noted that some things were subsidised but not enough to make them accessible, and some things they had been told about could only be accessed privately.

5.3.1.3 Medication and equipment costs

Participants talked about the types of health and disability medications and aids that they used. These were things they either paid for themselves and/or were funded by government or other organisations, or things they were aware of but could not currently afford. Funded medication was mentioned by 14 participants, and unfunded medications by six, including three whose needs were not fully met. Participants were often aware of different vitamins and supplements that might help with their health, and while several (three) had been taking such products, more (six) intended or wished to be able to take them. Several participants’

family members had diabetes equipment, the price of which varied, and the ideal options were not funded to an extent that made them affordable.

A policy change (now reversed) to remove prescription fees had been recently introduced at the time of the interviews and was frequently brought up. It had made a positive difference to participants feeling confident that they could access all their recommended prescriptions. Despite this, participants still often had to pay the GP in order to get access to these prescriptions, and in some cases the options that were fully funded were not the optimal medications for their condition. Some participants worked with their GP to access the least costly medication, although this did represent a compromise:

My GP picks subsidised meds to help keep costs down. (adult with health conditions)

We would prefer Ritalin, but it's not government funded the same way the Concerta is. So at the moment, it sounds terrible, but it's what's not going to cost us anything, you know? (parent of neurodivergent child)

5.3.1.4 Accessibility equipment

Fifteen participants made specific mention of types of accessibility equipment they paid for or had subsidised or funded. There was some inconsistency in reports about how equipment such as canes was funded; some people with low vision had canes provided but others reported having to fund replacements themselves. Some participants had sourced equipment themselves while others had it fully or partially funded.

5.3.1.5 Cost for dental care

Fourteen participants mentioned costs for dental care. Cost was a barrier that prevented some from getting care as regularly as they would like. This was an area where people found ways to economise, including travelling far from their home suburb to find a cheaper clinic, going to dental schools for cheaper treatment, and saving up. Some had received government funding for dental emergencies or had borrowed money from Work and Income.

It was unclear how much of the dental costs noted were directly related to participants' impairments and health conditions as separate from the usual or expected maintenance needs.

5.3.2 Costs of shopping for regular needs

This section covers participants' reporting of their extra costs relating to food, clothing, household contents and bills. As noted, it could be difficult to separate out how much of these costs in particular were "extra" due to health and disability needs.

5.3.2.1 Food

After medical costs, food was the area that the most participants (20) reported extra expenditure on (for specialty items to meet health and neurodivergence needs) or unmet needs. It was also an area frequently cut back on in order to meet other costs. Many participants noted that if they had access to any extra weekly income it could easily be spent on groceries to more adequately meet their household's needs. Overall, 14 participants reported unmet needs for food shopping, with many commenting on the overall increasing costs. People wished to have more fresh produce and meat, and better varieties of food to meet all household preferences and needs.

5.3.2.2 Clothing

Clothing was another high-cost area experienced by participants, mentioned in detail by eight participants. Families with children who have particular sensitivities due to neurodivergence often needed to purchase specialised clothing to accommodate these needs, leading to increased expenses. Some health conditions caused people to experience sensitivities to certain fabrics and clothing shapes. Additionally, frequent washing and subsequent wear and tear of clothing necessitated regular replacements.

5.3.2.3 Household contents

Household contents was another area where participants faced substantial expenses. Three participants mentioned specific contents. These costs included repayments to Work and Income for whiteware, resulting in possible financial strain. Five participants expressed desire to be able to afford items that enhanced their overall wellbeing, such as exercise equipment or aids that assist with day-to-day activities, such as kitchen tools tailored for people with low vision.

5.3.2.4 Bills: phone, internet, energy

Six participants mentioned extra spending on phone and internet, three spent more than they might otherwise on power, and five mentioned they would prefer to be able to spend more on household bills. For some participants, the internet served as a primary means of socialising and staying connected, particularly important when spending extended periods at home. Consequently, some opted for internet plans that cater to their connectivity needs, even if these are more expensive. Conversely, some households had internet primarily for their children's use and would prefer more cost-effective options if available.

5.3.3 Costs of transport

Extra transport costs were mentioned by 20 participants, while another 14 had unmet needs or felt they could spend more. Transport was a big issue for those who lived far from city centres and need to get to appointments, school etc. Some accepted this and worked around it, others found it severely constrained their lives. Support worker funding could also be eaten up by transport costs, which left less time for the actual support activities.

A number of participants had the Total Mobility Card and found it very useful. However the card features a subsidy cap. It does not cover the entire cost of longer trips, so people who

lived further out still had to plan for a considerable outlay of their own money if they were to commit to a trip.

5.3.4 Costs of housing

5.3.4.1 Rent/ mortgage

Spending more on rent or mortgage was mentioned by 13 participants. In this context, they were aware that costs were rising for everyone, so it was difficult to assign these costs as impacts of their health conditions or disabilities specifically. However, some did say they had less choice about where to live associated with health conditions or being disabled, and had extra costs related to rent, or mortgage payment because of those constraints. Some participants were concerned about deferred maintenance on their home. Of those who wanted to spend differently on housing, seven participants talked about being aware of better options for their situation (that were more accessible or better for maintaining health) that they could not quite afford.

5.3.4.2 Insurance

Insurance was a cost many would like to spend on (medical, rental, and contents). Nine participants said they spent extra on insurance now. Some had to cancel existing coverage due to being unable to afford the rising costs. One family took out health insurance specifically because they expected that one of their children would need an unpredictable number of extra, unfunded appointments.

5.3.4.3 Maintenance and household services

Cleaning services and maintenance on household items were mentioned by nine participants, several of whom were not finding their needs fully met.

Lawn and garden maintenance was the most frequently mentioned household service, paid for by three participants who could not carry out the tasks themselves due to health conditions.

5.3.5 Costs of activities

5.3.5.1 Exercise

Five participants were currently spending extra on exercise activities. More participants (14) spoke about activities that they would like to afford but currently could not. Currently they were participating in activities that are low impact or low key, such as walking, or free activities they could access through a school. Activities that participants said they would like to be able to experience were yoga, specifically for those with low vision, gym to help with arthritis, swimming and aqua aerobics. Barriers were cost, as well as paid support staff to assist with access.

5.3.5.2 Personal care

Some were able to access funded home care for mobility as well as shopping, and also access mobility training through Blind Low Vision NZ. Overall, seven participants reported spending or receiving funding for personal care items and activities. Four participants stated that they would like to be able to access things such as haircuts, but cost, as well as anxiety, were barriers to access.

5.3.5.3 Adult education

Eight participants wanted to be able to spend on adult education. Little information about the specific costs was provided. Preferred spending encompassed things such as professional registration lapsing and needing to be re-addressed, access to university to take up a diploma or moving from free online education to paid courses. One participant mentioned vocational training through ACC. They had attempted to access this but had yet to hear back. Another participant utilised free English for Speakers of Other Languages classes.

5.3.5.4 Childcare

Expenses in this area included afterschool care and occasional activities for children. Three participants were currently spending extra on childcare or education activities, while four participants would like to. Some expected the cost in this area to rise as children started school. Some participants expressed additional concerns about the care of their children, which had the potential to impact costs when looking at who and where was more suitable.

5.3.5.5 Events and holidays

Not many spoke about events in interviews, with some noting that they had few expectations of being able to afford things like concerts. Some participants said they would like to participate or go out more to events as these are places in which they could socialise. Three participants spent money on specific events while five participants said they would like to attend more.

Some participants talked explicitly about not expecting to be able to afford trips, so they did not consider them. Five participants said they would like to have the option to spend more and go on holiday. Three participants talked about how they afforded occasional trips; this was usually with help from extended family.

5.3.6 Contingencies and “other” costs

Three participants were currently trying to save for extra projected expenses and four wished they could.

6 Income support

This section covers participants' experiences with income support, their understanding of their eligibility and their interest in getting further assessment of their entitlements.

6.1 Understanding of eligibility

6.1.1 Overall understanding

More often than not, participants were able to name the benefits they were receiving and to discuss the different types of income support they had received or applied for in the past. Some participants' reports of which benefits they received may have been inaccurate. There was some uncertainty about the name of the income support payments they were currently receiving. This was particularly among migrants and among those who had been on different benefits over a long period of time and had either circumstances change or the names of benefits change.

6.1.2 Challenges with understanding what to apply for

6.1.2.1 Perceived loopholes and inconsistencies

A number of participants found that there were gaps in the system, or complexities in dealing with multiple agencies, that made their eligibility harder to establish and understand. This was often to do with the timing of changes in circumstances related to changes in eligibility for different types of income support. For example, a seasonal worker was injured while on a break from their job, which made it harder to apply for support. They had the impression that had it happened during a period of employment, the process for engaging with ACC along with MSD might have been more straightforward.

Some, reaching pension age, were concerned that their income might go down because Disability Allowance might not be renewed once they received New Zealand Superannuation, although their health and disability costs did not reduce and their living costs continued to increase. We note that Disability Allowance can be received alongside New Zealand Superannuation.

Some single mothers found that once they established their teenager's eligibility for income support as an adult based on their disability, they stopped receiving child support from their former partner, although their caring responsibilities and expenses had not changed. This meant losing child support up to three years earlier than they would have otherwise. Other mothers found that they became eligible to receive the child support being paid once they were able to get back to work. However, in the past when they were more impacted by health conditions and caring responsibilities, they did not receive the child support being paid, due to receiving income support themselves. This policy was changed in 2023 so that sole mothers receiving income support can now receive child support.

6.1.2.2 Challenges with getting the information to get the right support

Some participants needed to first pay to see a doctor or specialist, which they could not afford, in order to get the right diagnosis to apply for certain allowances. This meant they put off applying. There was also a high time cost. Several others had got as far as getting forms from doctors but at the time of interview were just finding the time to get an appointment and an application submitted.

6.1.3 Some benefit rules have unintended consequences

6.1.3.1 Fears of losing income support reduce participation in paid work

Several participants described their fear of losing benefits and being worse off if they got more paid work; there were a number of calculations they had to make to decide whether it would be financially viable to work more hours, as some of the extra hours' pay would immediately be absorbed by loss of income support. These calculations could limit the type of work they could look to find.

6.1.3.2 Income support that is hard to use

Some participants were aware of funding that was technically available, but was difficult to use in reality. For example, a parent noted their awareness of a grant for dental work. However, because their adolescent was so resistant to this type of treatment, they would need to be fully sedated before any procedure could take place, and this would eat up a large amount of the funding before any actual work. Others were aware of respite care funding, however found that there were not enough service providers available to enable them to use it much. As mentioned earlier, some one-off housing modification grants seemed to be less worth applying for when people did not own their home or feel that they had secure long-term tenure.

6.1.4 Perceptions of beneficiaries

Some participants discussed feedback they had heard about people who took advantage of the benefit system. They pre-emptively or defensively acknowledged they understood this might happen, before talking about how they wished they would be treated with less suspicion by case workers when they applied for genuine needs. Some participants described an awareness that others had great needs. They felt reluctant to take up benefits when there were those who need them more, even if they were struggling too.

I'm grateful to be in such a country where I can do that for this season. And hopefully it is again only going to be a season. Hopefully, once (child) is a little bit older and we've got everything sorted out, then I can just get back into some more sufficient work situation. So you know, I'm not looking for anything else. I feel a little bit guilty in a way. (single parent of a child with health conditions)

Some participants talked about losing self-determination and independence when entering relationships, because this resulted in loss of their income support.

I lost my mana, I lost my ability to be a contributing member of my relationship and also to society. It binds you to poverty, and it causes so much stress and pressure on your relationship and your self-worth. My costs didn't go away, but he's had to take them on and...What if I were in an abusive relationship, how would I get myself out? (disabled person not currently receiving income support)

6.1.5 Awareness of home modification support

Participants had not accessed house modification grants (for which the income and asset test is administered by Work and Income) although some were aware that they existed. On discussion, several said they would consider applying for one. A major limiting factor was living in private rentals with uncertain tenure, as participants understood these grants were one-off.

6.2 Experiences with the income support system

6.2.1 Sense of unequal treatment

Participants reported a wide range of experiences, positive and negative, when interacting with people responsible for their income support. Some participants reported having helpful case managers.

A major theme, that came through in different ways for participants in different circumstances, was the sense that they felt not everyone is treated equally by the income support system. Even those who had good experiences reported that others do not; one participant described talking with their helpful case worker while they could hear someone next to them having a much worse experience:

The caseworker I got was amazing. And I know that that was just luck of the draw. 'Cause I could hear people at the desk next to me going "please. I qualify for this. Why won't you give it to me?" And the person just going "cause? I don't feel like it". And it shouldn't be like that. (disabled young adult with health conditions)

Relatedly, people had the impression that assessments could be inconsistent between case workers, so getting all help available depended on individual case workers. Those who had helpful case workers were highly grateful to them, sometimes mentioning them by name or describing their appreciation years after the fact. Those who did not were very unhappy with their interactions.

The woman I dealt with for quite some years... Had been in the system a long time and she knew that the funding had changed and the day services had closed and that if I didn't have enough extra money to pay (support service) to take (child) in the afternoons, and I was gonna lose my job... she just said "nobody has thought

about where these people are gonna go during the day. It's terrible", she said. "I understand where you're at. I can get this process for you". And she did. But if I had been somebody else, she might not have done that. I don't know. (parent of disabled adult)

[Named Work and Income case worker] is who helped me. Once I got her working with me, she makes sure I get the right support. (migrant with health conditions)

Some participants had been told by case workers that their case would have been assessed differently in another part of the country where they had previously lived or had directly experienced differences in available support in different places. Participants valued having access to an individual case worker who could follow through, take time to assess all eligibility, and did not need to be re-told the relevant information every time. However, they had the impression this was not consistently available in different parts of the country, because practices varied between offices.

You can't have your own caseworker as a disabled person anymore. Yeah, it's a real big deal. So you just have to see whoever is available. The problem with that is that I now have to explain – so me talking about my challenges and health, and trying to justify myself ... it's traumatic. They have to go back through it again. (disabled person not currently receiving income support)

The most difficult experiences involved feeling judged or misunderstood, and denied access to the right information or to the full range of income support that they might qualify for. One person described calling for emergency income support during a traumatic situation, and the case worker berating them for asking for help, using very insulting language to tell them that they did not deserve it. Others described repeated upsetting interactions.

I hate going and asking for help, they make me feel like shit...I've had experiences where they keep wanting me to prove how my injury affects me, they treat me horribly and like I'm faking it. (person unable to work due to health)

6.2.2 The energy costs of managing applications through income support and health systems

Managing applications required participants to become experts in the different support systems and how they interact. MSD is not the only source of income support, as a number of other agencies may be involved as part of the overall support system that people experience. In some cases interactions with different agencies like ACC and MSD may be conflated in participants' recollections.

While this section detailed participants' perceptions of why they had certain experiences in the income support system, some of these relate to past experiences. There is some wider contextual information that indicates processes may become more

straightforward; this includes changes to how primary healthcare workers and community workers can access information about relevant income supports.¹⁸

Participants who had positive experiences tended to mention their own relative privilege (in terms of education level, demographics, knowledge of the system and ability to advocate for themselves), when discussing what they knew about applying for income support.

I'm decently good at self advocating. I'm pretty clear when talking on the phone, I try to do it when I don't have [health condition flare-up] that day. (young adult with health conditions)

This participant was one of several who noted that in order to be good at self-advocating, they had to strategise: to pick a time when they were feeling as resilient as possible. Some others noted that if they ever called while already feeling upset or unwell, help might be less forthcoming and the interaction would go downhill.

Many disabled people and people with health conditions had adapted to become experts in the system to get what they need. This was often through community connections and relationships where information is shared and support given. Participants were aware of needing to be able to advocate for themselves with case workers. Those who had strong networks among peers with similar conditions or life experiences felt better informed about how to manage their way through the system, so felt more confident that they were getting what they qualified for.

Participants described a high burden to prove their disability and level of capacity for work. Receipt of income support was linked to regular reviews and sometimes depended on being able to visit medical professionals in the right timeframe. Those who had, or cared for someone with, long term conditions expressed frustration around the need to continually prove their disability or health condition and limited capacity for work – especially when it was lifelong or long term, with a low likelihood of changing. Meanwhile those dealing with newer diagnoses did not always have access to the right information from other health professionals, in order to “prove” what their condition was and therefore how long it would affect their capacity for work and how long they would require support for.

Something has to give. It's obvious that his arm is in pain – ACC can't just look at the rulebook and say “no here's \$200 good luck”. They're pushing people away now which is really upsetting. (spouse of migrant with injury)

Application processes could be exhausting and disempowering. Getting information through took a lot of time and energy.

¹⁸ An information sharing platform using Health Pathways is nearly complete and will link the information GPs see about patients with other relevant support service information, including links to income support via MSD. <https://healthpathwaysglobal.org/>

I had a go at trying to follow through online, it said you don't qualify... sometimes the callback will work sometimes it won't. Sometimes you have to stay on hold the whole time. Notes may or may not be kept by whoever you call... it is hard for people who are busy, have jobs, to get hold of them if you have to use either phone or in person. (working parent of disabled adolescent)

I tried getting Temporary Additional Support, but because I had other income I was only eligible for \$13 a week. It wasn't worth it given the admin involved and having to give them my bank statements. Hours and hours and hours on the phone, like on hold to WINZ and things like that. And many times they'd just be like "we're too busy, call back later". So it just, yeah, it was quite a frustrating process. (working parent of child with health conditions and learning support needs)

6.3 FACE assessment

At the end of the interviews, all participants were asked whether they would like to proceed with a further Full and Correct Entitlement ('FACE') Assessment, to be carried out by a case manager from Work and Income. The majority declined. Several others took some time to think about it and to consult with external advocates, before deciding they would not proceed at that time but might consider such an assessment later.

Those who gave reasons for declining most commonly said they did not feel it would be relevant because they believed they were getting what they were entitled to. Some were nervous about potentially finding out they could lose entitlements, and some had had enough negative experiences in the past that they were not interested in engaging with a further advisor associated with Work and Income.

Of the five participants who did decide to proceed:

- one received a food grant
- one could not be contacted directly, but was sent Disability Allowance forms to fill out
- one got their family member's application for a new form of income support finalised, although this had already been in process
- one had no change to income support but some change in job seeking strategy
- one had no changes.

One participant who had already had the FACE assessment done prior to their interview said they learned more than what their case worker had told them, which was useful for future reference, though their income support did not change at the time.

Although all Work and Income site contacts were sent a standardised note explaining both the research and the requirement for participants to be booked in for the FACE assessment, there appeared some lack of clarity in how this request was processed in different offices. Sometimes these assessments were assumed to have already been done as standard procedure for all clients.

In other areas, while participants were called for the assessment, it was carried out as more of a standard check in about where they were at with their job seeking and support needs. It

was not the type of line-by-line assessment of all possible support options that some participants had expected. A participant gave the following feedback, which is linked to the widespread impressions about unequal treatment depending on existing system knowledge:

Thought I'd go through list of everything and see what I might be eligible for... I can navigate these things, and I trust (case manager) - but it worried me the direction it took. The question was "what do I need" rather than "here are the things we can offer". For a lot of other people, if you ask them what they need, nobody knows. And other people are unable or unwilling to initiate a request for something. (parent with health conditions and working part time)

7 Impacts and areas for improvement

7.1 Impacts on participation

This section covers the main themes about the impact of participants' situations on their ability to participate in society.

7.1.1 Delays due to diagnosis

As discussed, participants sometimes found that several different appointments and pieces of information had to align in order to get them the diagnostic information they needed to access income support. This process took significant energy to navigate, and it also meant delays in participants' ability to fully participate in their desired activities, from education to work and social events.

7.1.2 Difficulty planning/ committing to activities

While participants often wished to commit to regular activities like classes, clubs and work hours, it could be difficult to commit time and money to these activities with the knowledge that they might not always be able to attend, particularly for people with whose capacity varied due to fluctuating levels of impairment or discomfort. Across the sample, reasons for absence of commitment to regular activity included uncertainty around health and energy, uncertainty whether a child would be willing to or capable of participating on the day, affordability and logistics, and relying on inconsistent support services.

Everything I do is modified around capacity. It changes so I miss out on a lot of appointments, I cancel on a lot of things – postpone, lost opportunities. (disabled adult with health conditions)

Can't put her into the class because they're not sure how they deal with a child with special needs. How can you teach someone that refuses to listen?... You can't plan for anything ... you can't plan for school holiday activities because she could wake up in the morning and just be like, "I'm not doing it. I'm not going. You can't make me." So then you know, everybody misses out. (parent of disabled and non-disabled children)

7.1.3 Social isolation

Related to the difficulty in committing to plans, socialising could become difficult. The fatigue from managing health and disabilities, plus the pressures of having a low income and needing to know exactly how much they could afford to spend on any social event, often led to spending a lot of time at home. When participants or their dependents had more pressures on their health, spending money and energy, they were unable to see people as often, and maintaining relationships despite the internalised feeling of "flaking" could be challenging. Some people had challenges with communication due to their impairment or health condition and with getting others to understand the limits on their ability to participate.

Older people tend to be less sympathetic or believing [about limits due to health]. People who have had health conditions themselves get it. They don't need to know exactly what you've got going on. That you have something going on is enough for them to understand. (younger adult with health conditions, living alone)

Socialising is hard when you have a learning disability because of people's attitudes. I can connect with some disabled people because they understand, but it's hard when you don't have the connection, because they don't understand. More needs to be done to educate non-disabled people about how to communicate with people who have learning disabilities. (disabled adult, living alone)

Low incomes could make it less likely that people would go out to have new experiences. They might only be able to afford one outing over a long period of time. This meant it could feel risky to do something new or challenging, with the possibility of spending all their disposable income but then finding they were not able to participate as much as they would have liked. Some in-person social activities had also ceased and not restarted due to the COVID-19 pandemic. While the height of the pandemic is now considered 'over', the disability community remains impacted, and this impacts participation.

I don't go out as much and affects me mentally, I'm not a recluse but I don't do well in social environments like I used to, and I can't work like I used to which is frustrating ... I'm really into music but that's something I can do from home, although having the money to go out and attend a concert would be a cool thing. (adult with health conditions)

He goes to local cossy club. Indoor bowls, a few drinks and a van will bring him home. Getting out in community and social interaction is so important. I don't think [support agency] realise how important this is from a mental health perspective. (supporter of disabled adult)

7.1.4 Loss of independence due to lack of accessibility

Some participants struggled, psychologically, with being in a situation contrary to their sense of self. This could occur, for example, when having to use equipment that they would associate with much older people, or having to ask for assistance for something they believed they should be capable of. This is exemplary of internalised disablism and stigma. Having to factor in other people's ability to help with participation and access to places meant, again, committing to fewer activities.

In terms of navigating, the easiest thing is to be with someone. I'm pathologically independent...It would be nice to go out and not have to worry about how much you're spending. I could ask people for rides, but it makes me feel like a burden. (disabled young adult, renting with flatmates)

Structural barriers included physical infrastructure that made it difficult to get around. Some participants described having to research the places they were going to in order to decide on

the strategies they would need to use to get around construction activity, across roads without pedestrian crossings, or up stairs without lifts.

The construction all over the town, makes it so hard to get around... you just have to work round it. Up and down stairs – I can't, if no lift it's a waste of time [going to the appointment]...if I want to go somewhere I don't know and it's second floor, I research or call to find out. (older adult with health conditions, working part-time)

Families took on a lot of stress when there were limited opportunities for others to help with their health and disability needs. This again led to less opportunity for carers to do things they would like for themselves, and for the family members to develop more independence from each other. As noted, there were some cases people were aware there was funding for respite care, but had still been unable to access it due to the lack of service provider staff actually available to provide the care.

It's just something that always is on the back of his mind and is on the back of my mind and something that we're always working to everyday... There aren't too many minutes go by that I'm not thinking about something to do with managing his circumstances. (single parent of child with health conditions)

7.2 Participants' wishes for change

Participants discussed the context of their lives, their costs, and their overall experiences with income support relating to being disabled or having health conditions. They made some final suggestions for what they felt would make their lives easier to manage.

7.2.1 Access to earlier intervention

Many participants wished for a health system that was easier to access and understand. Frequently, they knew of things that might help them stay well but were aware they would be unable to qualify for these things until they were suffering more – they saw the system focused on being the 'ambulance at the bottom of the cliff', rather than the 'fence at the top'. This analogy came up several times, with participants wishing they could access the services that would act as the fence keeping them well, "getting out before we get near the edge". Mental healthcare provision was especially noted as a 'bottom of the cliff' situation.

7.2.2 Access to specific products and services

Participants needed a range of equipment and medical products to manage their health. Some of this was funded and some was not. Specific medicines, that may not currently be government-funded, were very much coveted by those who had heard how much it might improve their quality of life. Other participants brought up the confusing disconnect between the funding that support agencies received and what was passed on to the end user, i.e., disabled people with need of the services.

7.2.3 Impact of health and income support policy change

Participants pointed out that policy changes could make a big impact on their lives. The (now reversed) change to having prescriptions fully subsidised, which had recently come into force at the time of the interviews, came up multiple times. It made a difference to some participants' likelihood of maintaining the full medication regime that their health professionals recommended. Better access to subsidised transport for health appointments and activities would also make a notable difference for some.

Even relatively small increases to income support payments or inflation adjustment could go a long way. As living costs were an issue for everyone, participants would like to see increasing benefits to align with the real cost of living. The Winter Energy Payment was noted as a policy that made a difference to wellbeing.

7.2.4 Service improvements

Many participants wished they could be sure they would have positive interactions with support services, particularly Work and Income. Several participants wished for Work and Income staff to receive more training in dealing with people with complex needs.

A "person-centred approach" was alluded to: the idea that income support services should function to take into account the whole picture of people's lives and needs, and that people who required support would be treated with more respect. "One size fits all" support provision did not fit all, particularly where there were highly specific individual needs and a strict cut-off for the support available.

Participants wanted to see more joined-up agencies that were easier to navigate. They also wanted better communication to people with complex needs and who were unfamiliar with the range of systems and the way they interacted. Several participants recommended having better access to a guide, navigator or advocate who understood disabilities and understood the interactions between Work and Income and different support systems or agencies including health, education, housing and ACC.

8 Discussion and implications

This research explored the experiences of 35 low- and middle-income people with costs related to being disabled or having a health condition, getting by financially, and obtaining and sustaining income support.

8.1 Discussion overview

Much of what we found in this research lines up with other research and with the perspective of disability advocates. For example, the difficulty obtaining a diagnosis and accessing supports, the stigma of receiving support, the concern related to losing supports, and the need for self-advocacy are well trodden grounds.^{19,20}

Many disabled people who read this report will not be surprised by its contents. In many ways, the struggles articulated repeat the concerns of generations of disabled people. For example, as far back as 1979 there have been calls for increased emergency and transitional housing for disabled people. Academics identified a lack “of foresight historically in considering this group which they felt had led to the subsequent need for so many houses to be adapted in order to be suitable.”²¹ In 2023, the New Zealand Productivity Commission noted that “people experiencing disadvantage and those trying to support them are constrained by powerful system barriers. Barriers include siloed and fragmented government agencies and short-termism.”²² The insights in this report, designed for an audience of decision-makers and policy-thinkers, echo concerns expressed in earlier work. They show that disabled people and those with health conditions know the issues they face.

This report was not able to provide a high level of quantitative analysis, because participants struggled to precisely identify costs. However, other complementary quantitative work is occurring within MSD. The implication of not being able to precisely label the “extra” cost is that it is an implicit norm of life as a disabled person or person with a health condition. The norm is that people adapt, strategise, and accept going without. Accordingly, in many ways, the absence of specificity around defining “extra” costs speaks to the lived experience of this cohort and how the “extra” weight they carry, or cost they pay, is normalised.

This normalisation occurs in part because ableism has created a value structure, where people with certain characteristics, including accessibility or health needs, are faced with more barriers as a regular feature of daily life – making it harder to reach opportunity, exercise power and earn income. Therefore, realising a system where earning power,

¹⁹ King PT. (2019). Māori with lived experience of disability: Part I, Wai 2575, #B22. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575%2C%20B022.pdf from pg 200.

²⁰ Mills, A., Thom, K., Maynard, A., Meehan, C., Kidd, J., Newcombe, D., & Widdowson, D. (2015). Meeting the housing needs of vulnerable populations in New Zealand. Auckland: Transforming Cities, University of Auckland. <https://cdn.auckland.ac.nz/assets/auckland/creative/our-research/doc/urban-research-network/housing-vulnerable-groups.pdf> pg 13

²¹ *ibid*

²² New Zealand Productivity Commission (2023). A fair chance for all: Breaking the cycle of persistent disadvantage. Available at www.productivity.govt.nz

income and opportunity are equal, and “extra” costs are readily identifiable, is arguably tied to weeding out the influence of ableism.²³

8.2 Positioning recap

To discuss the implications of this report’s findings, we recap the positioning of this report. Disabled people, and people with health conditions, should not be treated as passive beneficiaries of the systems they interact with and that impact them. Their experiences are a taonga that they have shared, and their insights have been sought to drive change.

This report positions ableism in line with longstanding literature. Ableism, as the active valuing of one characteristic, or outcome, over another, speaks to the value systems that underpin society²⁴. These value systems produce ‘isms’ impacting and stigmatising specific communities; for example, classism impacts the ‘poor’; sexism impacts women, and disablism impacts disabled people.²⁵ Each of these specific oppressions stem from norms in society and these norms, including preferences for people to have non-disabled bodies and minds and higher capacity to earn money, are informed and shaped by ableism.²⁶

Due to ableism’s role as an umbrella “ism”, we can consider the role that gender, race, class and other characterises play in shaping the experience of the cohort we spoke to. For many participants in this study, disability or health status was only one dimension of their lives and they identified with disability to varying degrees. Accordingly, it is appropriate to assess their experiences as a whole, looking at how disability and health status sit alongside or inform many other variables like gender, ethnicity, housing security or economic status.^{27,28}

For example, we noted an attitudinal difference between the male carers and female carers we interviewed. The male carers often had greater trust in the system, confidence in their ability to be understood, and believed things would “work out”, whereas the female carers of disabled children expressed greater exasperation, concern and anxiety accessing support and being understood. Some female carers who were employed full-time were an exception, and seemed more content in the way they were treated compared with those who were not currently in a position to maintain paid work. This points to how people with lower support needs, who start from a position of more power, find the system easier to handle. Ultimately, people’s experiences and perceptions, both of their disability or health condition, and of income support, are informed by the other characteristics they have and must navigate.

²³ Wolbring, G. (2008). “The Politics of Ableism”, *Development*, 51(2): 252–258. doi:10.1057/dev.2008.17

²⁴ Mirfin-Veitch, B., Tikao, K., Asaka, U., Tuisaula, E., Stace, H., Watene, F. R., & Frawley, P. (2022). *Tell Me About You: A life story approach to understanding disabled people’s experiences in care (1950-1999)*. Donald Beasley Institute.

²⁵ Campbell, F. (2008), “Exploring Internalized Ableism Using Critical Race Theory”, *Disability & Society*, 23(2): 151–162. doi:10.1080/09687590701841190

²⁶ Goodley, D (2009). “Foreword”, in Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Aabledness*, London: Palgrave Macmillan, ix–xii.

²⁷ Wickenden M. (2023) Disability and other identities-how do they intersect? *Front Rehabil Sci.* 2023 Aug 10;4:1200386. doi: 10.3389/fresc.2023.1200386.

²⁸ Hosking, D. (2008) *Critical Disability Theory*. A paper presented at the 4th Biennial Disability Studies Conference, Lancaster University, UK, Sept. 2-4, 2008

8.3 Overall themes and implications

Participants' insights speak to the following common themes.

8.3.1 People are on the edge financially

The research found that half of participants – most of whom had been recruited from low- and middle-income households – said they had “just enough” to get by and most of the remainder said they had “not enough” or “not quite enough”. The implication of this is instability and a lack of capacity to absorb any unexpected shocks. When people can be easily tipped into financial insufficiency, this increases the risk that disabled people and people with health conditions find themselves in. Further, people were often incredibly grateful to receive the supports they did, in spite of the difficulties they experienced. This too, is a part of ableism. Ableism has made expectations low, and accordingly, people are often grateful even when their needs are not fully met. The implication of this is that disabled people accept insufficiencies. A part of meeting extra costs through improved income support, is supporting people to lift their horizons.

8.3.2 Many want to work

People often spoke about their desire to work, but there was an absence of suitable jobs, accommodations, or supporting infrastructure. Contributing to this was the fear of committing to working more, losing income support, and then having difficulty reapplying for support if they need to cut back on work at a later date. Working requires having the confidence to apply, getting there, and being able to use the bathroom during the day. It is feasible when people can avoid fatigue through rests, access the equipment they need and know they will be permitted to leave early if they need to deal with their own or their family member's health. We heard that many of these enabling conditions were lacking.

Many participants were attuned to how relying on income support impacted their life and opportunities and wanted something different. The implication of this is that the cohort was receiving income support because they were without the multi-faceted support they needed in order to succeed in the workplace.

8.3.3 Stigma

Some participants made it clear that they experienced stigma either as a beneficiary, disabled person, or both. This stigma could be internalised; it was expressed indirectly via the way people spoke about and justified their situation. This stigma results, at least in part, from how society reacts and responds to disability and beneficiary status. This implied that perception is a barrier. The weight of perception, and the loss of opportunity, time, and relationships it represents, is hard to measure, but is part of the experience of many participants. Further, an implication of stigma is that it can prevent people from obtaining the support they need. We heard, for example, people not wanting to identify with certain diagnoses and wishing they did not have to be identified as a beneficiary.

On the other side, some participants who did identify that they or their family member had a diagnosable condition, were then met by doubt on the part of healthcare and income support

providers. They experienced an opposite type of judgement, as people looking for support but not being seen as genuinely qualifying for it. This type of stigma was exemplified by the experiences of mothers who had been dismissed as “anxious” and treated like a nuisance for seeking help, before their child’s condition was ultimately confirmed.

8.3.4 Diagnosis

Participants relied on diagnosis to obtain financial and non-financial support. However, for many participants obtaining a diagnosis was a significant struggle due to the costs and time it could take. Most participants were very clear that the struggle to get a diagnosis, and a reliance on diagnosis, is a barrier due to the costs and time it can take. In many ways, the emphasis on a diagnosis reflects a Pākehā or Western value system; the need to give people labels in order to access supports is not a culturally sound way of operating for all. The implication of this is that people have to carry a label in order to get support, and some do not personally identify with this.

8.3.5 The system reinforces difficulty

Income support is available to provide a minimum level of support. Almost all income support payments are means tested and assessed based on family income and circumstances. We heard several examples of people who had to apply for subsidies only being allowed to access to the cheapest equipment available. This led to more physical discomfort, requiring more household labour to work around the limitations of the cheap washing machine for example, and more frequent replacement of things like glasses. In some ways, the income support system reinforces difficulty, by maintaining a cycle of reliance via a minimum of resources, rather than investing in those who need support so their social position can change.

Lastly, the migrant voice in this report is proportionally less, due to the sample. It is important to note that for those in the migrant sample, barriers to navigate, obtain and sustain support were more pronounced, partly due to unfamiliarity with the system of supports in New Zealand. This aligns with the preceding discussion.

8.3.6 Knowing the system and being able to self-navigate is central

People must become experts themselves, and the implication of this is significant opportunity costs, and burdens. People lose time, where they could be learning, developing, and contributing, because they are instead waiting in the call-line to speak to someone from MSD to advocate for something they are eligible for. Equalising access to support and employment requires consistent application and explanation of rules so people receive the supports they are entitled to without unnecessary struggle.

For every person we spoke to who could advocate, there was another who did not have the required skills or capacity. Accordingly, as long as receiving entitlements relies on one’s own knowledge of the system, people will miss out.

Many of the participants in this research were concerned about others who were in the same position as them or who were more vulnerable. It was clear from the way they spoke that they wanted the observations they recounted in these interviews to be used to help those in the community who had the most challenges. They wanted to know that work would be underway to ensure support and advice is provided fairly, including to those who do not already know the exact questions to ask.

Further, it is notable that in the sample a great deal of administrative burden falls to women and/ or mothers. Again, this situation reinforces known inequalities. If the goal is to reduce hardship among diverse people in New Zealand so they can equitably contribute to society, then society and government must continue efforts to make supports easier to access.

We thank every participant for their contributions to these insights.

Appendix A: Detail on research methods

Planning

Expert review

Prior to finalising the research plan, drafts were sent for review to an Expert Reference Group, modified following feedback, and then sent to MSD's Research Ethics Panel and Privacy Adviser for discussion and approval. Their recommendations were incorporated into the final methods as described in this report.

Sampling and recruitment

Sample requirements and strategy

The New Zealand Income Support Survey (NZISS) was a nationally representative survey of 1,852 participants aged 18-64 with low- or middle-incomes that made them potentially eligible for income support payments delivered by MSD or Inland Revenue. This survey was administered by Reach Aotearoa.

MSD identified potential participants from the NZISS sample frame. The *Allen + Clarke* team, in consultation with the MSD team, developed a process for prioritising subgroups of respondents to ensure the best chance of achieving the required sample. Members of the Reach Aotearoa team then made the first contact with potential participants.

After exhausting the samples provided by Reach Aotearoa without achieving the required numbers, it was agreed to extend the sample to include more disabled people not adequately covered in the NZISS sample, to be identified through direct recruitment. This direct recruitment utilised *All is for All's* contacts in disability communities, and resulted in four additional interviews.

Initially, the requirement from MSD was that the sample should include 40 people, of whom 20 should be migrants or New Zealanders of non-European ethnicities and the rest New Zealand European. Among this sample, different life situations, and definitions of whether participants or their dependents were disabled, were required, including the following suggested numbers:

- 4 participants with children receiving Child Disability Allowance (CDA)
- 4 participants with disabled children not receiving CDA
- 4 participants with children living in cold housing where parents say they don't have enough money (this was an attempt to find more children with other chronic health conditions, since this was not explicitly covered in the NZISS questions)
- 4 participants with children who are not their own

- 4 participants who responded to the survey on behalf of someone they care for
- 10 participants who say they identify as disabled, or are defined as disabled according to the WGES indicator²⁹
- 10 participants who did not say they are disabled and were not disabled according to the WGES indicator, but who say they have poor health or receive a health or disability related payment.

A detailed sampling strategy was developed by the *Allen + Clarke* team based on these specifications and the known characteristics of potential participants in the NZISS survey sample. This strategy prioritised sampling those of non-European ethnicities, in order to have the best chance of recruiting the required 20 non-European participants. This meant that all people of non-European ethnicities were firstly recruited in the three urban areas. In the Wellington and Dunedin areas, the sample included a majority of New Zealand European people, and in Auckland the first sample was completely people of non-European ethnicities. A second sample of people in more rural areas was identified to be recruited later, who were offered online interviews only. There were no people of non-European ethnicities living in these areas.

MSD used their survey datasets to find out how many participants with the required responses were potentially within the sample of those in the specified areas and open to being contacted. Ultimately there were 137 potential participant IDs identified for this study in the areas of interest.

Once the sample IDs had been generated, showing the numbers of potential participants in different situations, the potential sample was split into six subgroups (not including those with children not their own, as this was too difficult to screen for and was agreed as something that could be brought up during the interview if relevant), with target sample numbers adjusted as follows:

1. People who live with a child in a house that they cannot afford to keep adequately warm. Eligible to participate if they answer a screening question about health conditions for the child. Target: 6
2. People who answered on behalf of someone else. Target: 4
3. People identified as having a disability or health condition, and who do not have a disabled child/ receive CDA. Target: 16
4. People not in group 3 who said they have poor health or receive a health or disability payment. Target: 4
5. People who receive CDA. Target: 4

²⁹ Washington Group Enhanced Short Set, a set of survey questions for measuring disability in population statistics.

6. People who live with a child who has a disability but do not receive Child Disability Allowance (CDA). Target: 6

Recruitment approach: privacy considerations

Throughout the recruitment process, privacy requirements meant that each team (MSD, Reach, *Allen + Clarke*) had access to only part of the full record of information about each participant as follows.

- The MSD team had the ability to select potential participants for follow-on studies using de-identified information and NZISS survey responses, but were not to receive any identifiable information (names and contact information) of NZISS Panel members from Reach Aotearoa.
- The Reach Aotearoa team had access to all participants' contact details and NZISS survey responses (held separate from each other), but were not involved in decisions about which survey responses determined the list of IDs and the order in which they were to be called.
- The *Allen + Clarke* team knew from MSD the numbers of participants with certain responses, in order to design the sampling strategy and recruitment scripts, and was provided by Reach Aotearoa with contact details for those who agreed to be contacted, but did not have access to any participant's full ID details and NZISS survey responses.

To address the privacy requirements, MSD and *Allen + Clarke* teams jointly agreed a detailed description of why each list of potential participants had been selected and prioritised for sampling (that is, the characteristics seen as relevant and the rationale for calling certain groups first). We then agreed on the recruitment scripts that the Reach team were to use for each group, without Reach needing to know the full details of the participant's previous survey responses.

The MSD team generated a sample (or samples if specific sub-group targets need to be met) and sent the de-identified details for the sample to Reach. These details included the NZISS Household ID, Survey Number, and Meshblock variables for un-named groups of interest, and target numbers to recruit in each of those groups. This information was not shared with the *Allen + Clarke / All is for All* research team.

Participant contact information was transmitted securely from Reach to *Allen + Clarke* using password protected spreadsheets (passwords were communicated via separate text message); these details were then kept in a recruitment spreadsheet used by the *Allen + Clarke* team members responsible for recruitment.

All primary data collection materials (recording and transcripts) were stored on *Allen + Clarke's* secure server until the completion of the project. Participants' identifier numbers, but not their names or other contact details, were used on all transcripts and notes relating to their interview.

The MSD Project team drafted a process document on data storage and use; following review by their Privacy advisor the *Allen + Clarke* team wrote up further detailed processes for ensuring data security.

Recruitment process

The Reach team recontacted previous NZISS participants in the requested order, exhausting each subsample before moving on to the next. The team used screening and information scripts provided by the *Allen + Clarke* team, specific to each subgroup, to ascertain whether they were eligible to take part in this research. Those who were interested were later contacted via their preferred methods (call, text, email) by the *Allen + Clarke* team member who would be conducting their interview. They were provided with further information and, if interested, booked in times for the interview. Participants who did not respond were recontacted five times via all available methods, before being noted as not available to participate.

Modifications to recruitment strategy

Due to researcher availability and the barriers with recruiting sufficient ethnic representation in South Auckland, it was agreed that eligible participants from other areas around Auckland would also be called, and that interviews in these regions would be offered online or via phone only.

As the recruitment progressed, it became clear that Group 1 – designed to identify more children with chronic health conditions by calling those who reported being unable to heat their house in the previous survey and asking whether their child had health problems - was the most complicated to recruit (due to the amount of screening and uncertainty of eligibility) and was producing very few eligible responses. The recruitment process was longer and more costly than initially expected. After recruiting throughout July 2023 and with a top-up sample including rural areas in September, 30 interviews were completed representing 31 individual participants, but the full quota of 40 participants agreeing to be interviewed was still not able to be met.

The MSD team recognised the difficulties in reaching the recruitment targets using the NZISS, and the gaps in coverage (of people with different experiences of disability) identified by the MSD Ethics Panel and the ERG. They therefore agreed to alter the requirements to allow up to five participants (out of a reduced target of 35 rather than 40), with disabilities not adequately covered in the NZISS sample, to be recruited through direct recruitment. This direct recruitment utilised *All is for All's* contacts in disability communities, and resulted in four additional interviews. The research teams agreed that processing of data from these interviews should ensure that readers of the report could not identify which responses come from participants recruited via different means.

Final sample

Table A1 shows the overall targets and final numbers for whom interviews were achieved, in each subsample group.

Table A1. Sample targets and final numbers

Group	Target number/ potential from NZISS sample	Number recruited by Reach	Number completing an interview
1 (child in a cold house with health condition)	6/10	3 (not eligible for this study)	0
2 (carer/ answering on behalf of another)	4/8	1 (not eligible for this study)	5 (1 recruited as a carer, 4 answering as partner/ household member of person in group 3 or 4)
3 (answering for self, identified as disabled or having a health condition)	16/41	26	11 (includes 3 from alternative sample group)
4 (answering for self, not identified with health condition or disability but report poor health or receiving health/ disability payment)	4/8	6	7 (includes 1 from alternative sample group)
5&6 (child receiving CDA/ child with disability not receiving CDA)	4/6; 6/12	11	12 (including 1 initially recruited as a household member of an adult)
TOTAL		47	35

Interviewing

Interview piloting

The team developed interview schedules based on the research areas of enquiry. These included a list of structured questions about costs, with optional tables to fill in with dollar costs or comments. This part of the interview schedule was developed to get structured data on costs and some other questions if possible. The questions were edited and finalised following review by MSD disability advisers, the Māori and Pacific research teams in the wider project, Chinese and Indian contacts for cultural review, and disability sector contacts via *All is for All*. The questionnaire, attached in Appendix C, was the basis for a qualitative, semi-structured conversation in which topics would be covered as they arose, with allowance for the participant to decide which sections to focus most on.

The first two interviews were pilots with one conducted online and the other by phone (at the participants' convenience) in early August 2023. During these interviews the researchers told participants they were welcome to comment on any questions they needed explanation on, and noted any instances in which questions were hard to follow or in which the question order could be shifted so the conversation progressed more naturally. Researchers took notes on how the interviews had progressed, debriefed, and made slight edits to the order and priority of questions.

Following the pilot interviews and the initial in-person interviews, the teams agreed that it was more practical to fill in cost survey tables during the in-person interview process, but that when conducting interviews long distance (online or via a phone call) it was more feasible to discuss each type of potential cost as part of the ongoing conversation with the participants, and for the note taker to list statements about costs within the interview notes document.

Interview procedure

Participants were to initially be invited to in-person interviews, but as the project progressed it became clear that in some cases online interviewing would work better with the availability of participants (particularly parents) and research team members.

Overall, 16 interviews were conducted in person, 13 via video call (including one participant who related separate experiences and costs for two household members that they supported in different ways) and five by phone between 7 August and 13 November 2023. All interviews were conducted by a pair of researchers in which one would lead the questioning and one would take notes, interjecting to clarify or follow up on lines of questioning. Interviews took approximately 60 minutes, ranging from 30 to 100 minutes.

Consent forms (attached in Appendix B) were emailed in advance and then, if not completed in advance, filled in on the day. In several cases long-distance participants were uncomfortable with the technology required to sign digital documents so agreed to confirm consent via email or phone call.

In-person interviews were conducted in meeting venues booked in Dunedin and Wellington. For the online interviews, participants were sent a link to a MS Teams meeting at the agreed time and were emailed information in advance. Interviews were recorded and auto-transcribed if consent was given.

Participants received a \$100 supermarket voucher as koha in recognition of their contribution. This was first mentioned during recruitment and confirmed at the conclusion of the interview.

During the interviews, the researcher from *All is for All* took the first round of notes in a template document based on the questions, and emailed these to their partner researcher from *Allen + Clarke*, using only the participants' identifier number. These notes were then expanded on by the *Allen + Clarke* researcher using quotes from automated transcripts or audio recordings. In addition to quotes and summaries of responses, these notes contained situational information including the participants' employment, household, carer status, demographics, and notes on whether they were disabled, had a health condition or what combination of conditions and impairments they reported.

Information provided to participants

All participants were sent information sheets (attached in Appendix B). MSD produced versions of these in several alternative formats including an easy-read version.

The interview teams brought other information to share if relevant or requested. This includes brochures from MSD about different types of income support, contact details for advocates in the area who could help advise about benefit processes, and contact details for culturally-relevant support services in case of distress or other issues being brought up during the interview. In some cases the researchers discussed income support and disability support processes during the interview (this was particularly the case when the *All is for All* researcher had prior knowledge of these systems) or included further information in follow up emails, texts or in the envelope containing the voucher.

Data analysis

Data from the interviews were analysed in two main forms. Quotes were collected relating to each area of enquiry then coded thematically, in a collaborative process between team members, to ensure the key ideas were identified for reporting on. Participant characteristics and reporting of extra costs were collected in a spreadsheet. This information was analysed to produce basic demographic summaries, and to show the overall areas in which people most commonly discussed extra costs and the demographics of those who discussed them.

Thematic analysis

Given this project's aim of centring participants' reports of experiences and their meaning-making, the approach to coding could not be overly rigid or pre-planned. Therefore, data coding and identification of themes was undertaken in a reflexive manner. This approach acknowledges the researchers' active and emerging interpretation of patterns and meaning in the data. In this case where the coding involved multiple researchers, the "reliability" of coding is less important than achieving different and richer interpretation of meaning.³⁰

Once all interview notes had been collected, the lead researcher selected passages of text from all participants' notes relating to each area of enquiry to be reported on, then conducted an initial round of coding, noting themes or major ideas that each quote related to, and repeating themes if and when they recurred between quotes. Where relevant, the quotes were grouped by subgroup (i.e., type of disability or health condition, type of housing situation, type of employment situation). Once all excerpts were coded the team members read over the excerpts and codes, and identified which themes could be drawn out in the report to show the overall range of, and most notable, findings.

A sensemaking session, held with the MSD and Katoa³¹ research teams at the end of 2023, provided an opportunity to report on initial thematic ideas and to reflect on which were coming through the most strongly or were of most interest to discuss.

³⁰ Braun, V., Clarke, V.: Reflecting on reflexive thematic analysis. *Qual. Res. Sport Exerc. Health* 11(4), 589–597 (2019). <https://doi.org/10.1080/2159676X.2019.1628806>

Byrne, D. (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Qual Quant* 56, 1391–1412 (2022). <https://doi.org/10.1007/s11135-021-01182-y>

³¹ The research team conducting the concurrent Māori study.

Cost and demographic data analysis

The team used a summary spreadsheet to hold demographic and cost information for each participant. Demographics included ethnicity, perspective (i.e., whether responding as a parent, carer or support person, or about their own health or disability), the health and disability conditions that they or those they cared for had, location, housing situation, type of income support received, and employment status. Cost information included their view of how they were getting by financially, then a predetermined list of areas for possible extra expenditure due to health or disability, and comments elaborating on what they either currently spent or would like to spend if they were able to.

The information in the spreadsheet was used to produce basic demographic summaries, and to show the overall areas in which people most commonly discussed extra costs and the demographics of those who discussed them. It also showed the extent to which people were actually spending extra on certain things, versus those who were aware spending more might help (due to the existence of products and services and their needs for these) but were currently unable to.

Personas

As part of presenting the data, the research team was tasked with creating up to 10 persona profiles in the form of “vignettes”, or composite narratives, to illustrate the overall range of experiences that participants described. A vignette is a story based on research findings. By combining the accounts of multiple research participants into a single hypothetical profile, vignettes can protect anonymity while making the overall findings accessible to readers.³²

Once we had undertaken around two thirds of the interviews, the research team began drafting profiles representing people in situations that had come up more than once. Each team member who had been involved with interviews had an opportunity to add notes or suggestions about what participants had said that was relevant to each profile, and to suggest additional profile types, ensuring that all participants in the final sample were represented at least once throughout the vignette profiles. Some participants’ responses about their situation contributed to more than one vignette.

The first draft of vignettes focused on the experiences of a generalised group of people. Following the team’s reflections on the thematic analysis process and sensemaking discussion, the subsequent draft personified each “type” into the narratives referred to in the report as “personas”. These personas have a name and more specific details, including the

³² Gourlay, A., Mshana, G., Birdthistle, I, Bulugu, G., Zaba, B., & Urassa, M. (2014). Using vignettes in qualitative research to explore barriers and facilitating factors to the uptake of prevention of mother-to-child transmission services in rural Tanzania: a critical analysis. *BMC Med Res Methodol*, 14(21).

<https://doi.org/10.1186/1471-2288-14-21>

Johnston, O. (2023). Student voices that resonate – constructing composite narratives that represent students’ classroom experiences. *Qualitative Research*, 23(1), 108-124.

<https://doi.org/10.1177/14687941211016158>

factors (personal/ situational factors and those relating to their experiences with government systems) that helped people in these situations cope.

We have noted how many participants' interviews are referred to, to build each persona. In our initial draft, these included the participants' ID codes so we could check back on the interview notes to audit and edit each other's representation of their experiences and ensure that no persona was too heavily weighted towards one participant. The content of the personas relies on the participants' own interpretation of their situation. It also relies on the researchers' decisions about which details of which participants' lives to include to spread a representative range of situations across the personas.

Appendix B: Information and consent forms

Information and consent form for an in-depth study to understand extra costs and income support



About the study

This research aims to learn more about the extra costs people with health conditions and disabilities face, and find out whether they are receiving all the income support they should be getting from Work and Income to help with those costs. If you have a child or care for someone with a health condition or disability, we would like to know about their experiences as well.

Allen + Clarke and *All is for All* have been contracted by the Ministry of Social Development (MSD) to carry out the research.

You are invited to participate in this research because you indicated in your response to the New Zealand Income Support Survey that you could be willing to answer some more questions.

What does participation involve?

Your participation involves an interview about you and any people with health conditions and disabilities in your household who you care for. It asks about how life is for you, about the extra costs that come with health conditions and disability for you, income support payments, and things that affect you or members of your household in carrying out everyday activities.

If you agree to participate in this study, we will organise a 60 minute interview. We find interviews are best face to face, but can also do them online or over the phone (depending on what best works for you). We can construct the 60 minute interview to suit your accessibility needs, including for example with multiple small breaks. Interviews will include interpreters for NZ Sign Language and other languages, if this is needed for you.

We will be scheduling interviews from early August, and will arrange an accessible venue in your area where interviews can be conducted privately. The interview will be recorded with your consent.

The benefits of participation

Your participation will provide an opportunity to share your experiences about the costs you face, what works for you, and what could be improved with the income support system. We will report findings to MSD, who will use the information to inform new policies and processes. We value your contribution and you will be provided with a \$100 koha in recognition of your time.

How will my privacy be protected?

The information you provide us will be treated as confidential. All reports and presentations about this study will not include any information that could identify you or any member of your family. At no time will MSD receive information that identifies you or any member of your family either unless you provide explicit consent because you wish to know more about the income support payments you could get.

MSD will receive your responses to some questions so that they can better understand costs and whether people are getting the payments they need, but this information will not identify you or any member of your family. Only *Allen + Clarke* and All is for All staff will have access to the information and the audio files of your interview. We will delete your contact details after the research is finished, and will delete all files from your interview after 1 year. We are happy to provide you with a copy of your interview transcript notes as well as the final copy of the research. If you want to correct anything on the transcript after your interview, you can do so by contacting the Lead Researcher (XXXX) within 4 weeks of your interview.

Do I have to participate?

Your participation is entirely voluntary, and you do not have to participate in this research. If you choose to participate and then change your mind later, you can withdraw by contacting the Lead Researcher (XXXX) If you decide to withdraw, we will delete your information. Your withdrawal will not affect your current or future relations with the income support system, MSD or *Allen + Clarke*. The reporting from this project will be published in 2024.

Any questions?

If you have any further questions about the research, you can contact the Lead Researcher(XXXX).

What happens next?

If you agree to participate in this research, please fill out the below. We will collect the signed form from you before the interview. If you would like to receive a summary of the findings after the research is finished, you may list your email address.

After the interview, we will be conducting a second consent check with you if you would like to be referred to someone in the Regional Health and Disability Team at Work and Income who can organise a check whether you are receiving the correct funding and income support you should be getting from Work and Income to help with your costs.

Statement of consent: I agree to take part in the study

- I have read the information sheet about the In-depth Study to understand extra costs and income support for people with health conditions and disabilities.
- Questions I had about the study have been answered.
- I understand all my information and that of any other family member will be kept confidential and we will not be personally identified in any report.
- I understand that I can take part and not answer all of the questions, or withdraw completely at any time by contacting the Lead Researcher(XXXX), and that I will not be disadvantaged if I choose to do this.
- I understand that information I do provide will not be used to disadvantage me or any member of my family.
- I understand that MSD will receive my responses to some questions so that they can better understand costs and whether people are getting the payments they need, and that the information they receive will not identify me or any member of my family.
- I consent to take part in the research.

Signature _____ Date:

Printed name:

E-mail (optional) for findings:

Appendix C: Interview guide

Introduction

Thank you for meeting us today. We will begin by introducing ourselves (introduce team, mention interest in the subject area, include introductions for any interpreters or support people)

We are doing this research in order to advise the Ministry of Social Development, who want to know more about the extra costs disabled people and people with health conditions and disabilities face, and whether they receive income support from Work and Income that can help with those costs.

Just to confirm, whatever you say will be confidential. We will be reporting about the overall range of experiences that people tell us about, and we will not use your name or identifying details about you or anyone else you mention in the interview. Have you signed/ are you able to now sign the consent form? And do you have any questions for us about this?

There are a few parts to this interview. We would like to start by talking about your situation and the context of your life, including whether it is you, a child of yours, or a member of your household you are the carer for who has health and disability needs. Then we have some questions about:

- how health and disability needs affect the things you can do, including participation in paid employment and other activities
- accessibility and how you get by financially
- a survey about extra costs, and the types of income support you have received.

Which of those areas are you interested in talking about with us first?

You do not have to answer every question, and you can ask to stop or take a break at any time. Can you confirm that you are ok with us recording this interview? This is to help us take accurate notes. [If yes] Thank you, we will start now.

Section 1. Qualitative interview

Your situation and the context of your life

People

1. Who do you live with - What does your household look like?
 - a. *We want to understand who is included in your 'household' and what your definition of your 'household' is.*
2. As you know we are talking to people about issues relating to costs for health and disability needs. Can I just confirm, when you answer the questions, will it be:
 - about your own health or disability needs
 - as a parent or caregiver with a child aged under 18 with health or disability needs
 - as a carer for an adult who has health or disability needs
 - a combination of these [eg own and as a parent or caregiver or carer]?
3. [if self] – could you tell us a bit about the (health or disability) condition you are living with? How does it affect you?
4. [if child] – could you tell us a bit about the (health or disability) condition your child is living with? How does it affect them?
5. [if caring for adult] What is your relationship to that person [eg partner, child, parent]? Does anyone else help with the caring?
6. If you are comfortable, can you tell us a bit about what condition or conditions they are living with? How does it affect their daily life? [implied – how does it affect yours]
7. And are you a carer for a person with a disability or health condition who does not live in your household?

Place

8. Thinking about the place you are living in – what do you like about where you live?
 - a. *As commentary if needed:* Like for example is it warm and dry?
9. What are some of the things that are difficult about the place you are living in?
10. What is one thing that could help with the difficulties?
11. Thinking of the places and services in your community that you connect with - what are the things that work well for you?

- a. *As commentary if needed: Think about community services, schools and local health services like your GP.*

- 12. What are the things that do not work so well in your community?
- 13. What is one thing that could help improve this?

How health and disability needs affect the things you can do, including participation in paid employment and other activities

- 14. *(If Applicable)* Can you tell us if you are in paid employment?
 - a. Are you a contractor?
 - b. How many hours do you usually work per week?
 - c. do these hours vary at all?
 - d. do you feel you could work more hours than you currently do?
 - e. do you feel you would prefer to work less hours than you currently do?
- 15. *(If applicable)* If you're not in paid employment;
 - a. Would you like to be?
 - b. How many hours do you feel you could work?
- 16. *(If Applicable)* Is your partner in paid employment?
 - a. how many hours do they usually work per week?
 - b. do these hours vary at all?
- 17. Has the [disability, long-term condition, or mental distress – use their wording to name the condition] that you have told us about meant that anyone in your household works less than they would like to? (or doesn't work, or works in lower paid jobs?)
- 18. *(If applicable)* What is the impact for you and/or others in your household of this work situation?
- 19. *(If applicable)* What is one thing that could help you and/or others in your household access the type of employment you would prefer [paid employment, more hours work or a higher paying job?]
- 20. In the last twelve months have you missed work, education, training or has your child missed school due to the impact of disability or health conditions? (if yes, how often has this been happening?)

21. Can you tell us if there are any activities that you would like to participate in but do not, or participate less in, because of the [disability, long-term condition, or mental health condition] that is experienced by yourself/those in your household?
 - a. What are these activities?
 - b. why do you/ can you not participate?
22. (If applicable) Are there any activities your child does not participate in, or participates in less because of their [disability, long-term health condition, or mental health condition?]
 - a. examples include schooling, school trips, hobbies, sport and recreation, cultural activities, family get togethers and events, church activities and events, doing things with friends
 - b. why do they/ can they not participate?
23. (If applicable) Are there any activities that [adult household member you are talking about] does not participate in, or participates less because of the [disability, long-term condition, or mental health condition?] being experienced?
 - a. What are these activities?
 - b. Why do they/ can they not participate?
24. Are there any things you do to make it easier for you or your household members to participate in activities? (for example – get someone to help with caring, find venues that are accessible or cheaper...)
25. What is one thing that could help you and/or them participate more in activities?

Accessibility and how you get by financially

26. In the last 12 months have you been looking for somewhere to live and struggled to find an accessible option?
27. In the last 12 months have you had extra or unexpected costs due to inaccessibility?
 - a. For example, the costs of having to travel to a different restaurant because it better serves your dietary needs, or the cost of having to travel to a specific specialist doctor.
28. How do you get by financially?
29. If you can't afford something your household needs, what decisions have you made or tricks have you found to manage with your situation?
30. If you received an extra \$50 per week, what would you put that towards? If on top of that you received an another \$50 per week, what would you put that next \$50 towards?

Thank you for telling us about your experiences. We are next going to fill in a survey together about costs and income supports relating to health and disability needs. Would you like to take a break or have something to eat first?

Section 2 – survey

Survey on costs

1. How do you get by financially?
2. First of all I would like you to think about how well [your / you and your partner's **[combined]** total income meets your everyday needs, for things such as accommodation, food, clothing, and other necessities.

Would you say you have: not enough money, only just enough money, enough money, or more than enough money?

- ① Total income is the gross amount, before tax or anything else is taken out.

We're about to ask you a series of questions about costs that are additional costs associated with being disabled/having a disability/health conditions [guided by respondent situation and preference].

Examples of these are the special cost of accessible transport, additional costs related to accessible housing, or additional costs related to needing to maintain a particular diet. So, we are not asking about everything you spend, we are just asking about things that you feel you spend more on than you might otherwise, because of health or disability needs. We will show you [on screen or on paper] a list of things that people may have extra expenses for, and you just tell us as we go which of these you have extra costs for.

If you are not sure of the exact cost for something but feel you are spending more than you might without the health or disability situation, you could instead comment about the choices you make regarding spending on this.

If you have brought along information about your overall expenses, or would like to start by sharing what your main expenses are, we can fill in what you usually spend on things like rent, groceries, transport and power. [first form]

We have separated the different types of possible costs into weekly, monthly and more occasional costs.

[note if participant asks: we can shift something from eg weekly to monthly if they would find it easier to recall the cost in that area in a different timeframe – there are spaces in the tables for moving subjects to different time period tables, and we can recalculate after the interview]

If you are answering our questions as a carer for an adult who is disabled/has a disability/health conditions [guided by respondent situation and preference] and you help them by shopping and paying bills for them, we would like to hear about their costs.

(If applicable) Do you help the person you are caring for by shopping and paying bills for them?

Thinking about the following expenses on a weekly basis: do you/they have extra weekly costs due to you/your child/the person you care for being disabled/having a disability/health conditions [guided by respondent situation and preference] in any of these areas?

[read out the descriptor then the questions at the top of the survey table for each area; fill it in as they respond. If needed, fill out separate tables if eg responding for self and child]

RENT: Do you/they have to pay extra rent, mortgage payments, or board?

TRANSPORT: Do you/they have additional transport costs? [*Commentary if needed:* this includes extra costs for public transport, taxi/uber, petrol, WOF, car and bike repairs, regular car, bike repayments.]

FOOD: Do you/they have additional or special food costs? [*Note: meal replacement products like Ensure are a food not a supplement*]

MEDICATION/SUPPLEMENTS: Do you/they have additional or special medication and/or supplement costs?

PERSONAL CARE: Do you/they have extra weekly costs because of personal care needs? [*Commentary if needed:* this includes support for basic daily tasks and your daily living needs like food shopping, meal preparation and socialisation.]

EXERCISE: In a typical week, do you/they have additional or special sports and fitness costs?

PERSONAL ALLOWANCES: In a typical week, do you/they have additional or special personal allowances? [This might include: pocket-money, contributions or other payments made.]

CHILDCARE: *(If applicable to interviewee)* Do you have extra costs because of additional or special childcare for child/ren who are disabled/having a disability/health conditions [guided by respondent situation and preference]?

EDUCATION/ SCHOOL: *(If applicable to interviewee)* Do you have additional or special school or education costs for child/ren with a health condition or disability?

ADULT EDUCATION: *(If applicable to interviewee)* Do you/they have additional or special education costs?

OTHER: are there other areas where you have extra weekly costs?

We now want you to consider monthly costs: do you/they have extra monthly costs due to you/your child/the person you care for being disabled/having a disability/health conditions [guided by respondent situation and preference] in any of these areas?

[read out the descriptor then the questions at the top of the survey table for each area; fill it in as they respond]

INTERNET AND PHONE: Do you/they have extra broadband internet costs or mobile phone costs?

HOUSEHOLD SERVICES: Do you/they have costs for household services? [*Commentary if needed:* this includes extra costs for cleaners for example.]

MEDICAL: Do you/they have additional or special school costs for medical or health related needs? . [*Commentary if needed:* this includes additional costs of GP visits Ambulance fees, diabetes devices, glasses]

TREATMENT/THERAPIES: Do you/they have additional or special costs for treatment or therapies. [*Commentary if needed:* includes costs such as counselling, physiotherapy, osteopathy, gym, pool costs, yoga, equine therapy, special programmes for children i.e. music therapy.]

EVENTS: In a typical month, do you/they have additional or special activities or cultural event costs?

OTHER: are there other areas where you have extra monthly costs?

We're about to ask you a series of questions about costs you face that might happen less often but are still additional costs associated with disability and health conditions. When we ask whether there are any other barriers to getting what you need in these areas, this might include lack of accessibility, suitability, availability, and support services.

Thinking about the following types of costs which might come less often:

EQUIPMENT: Do you/they have extra costs that are upfront, additional or special for the purchase of health and/or disability-related transport equipment? [*Commentary if needed: including wheelchair or mobility device, adapted vehicle.*]

INSURANCE: Do you/they have additional or special insurance costs (contents/car/home)?

CLOTHING: Do you/they have additional or special costs of clothes/shoes?

CONTENTS: Do you/they have costs that are additional or special costs of purchasing or replacing household contents? [*Examples of costs may include: a certain brand of washing machine, a certain bedroom suite.*]

DENTAL: Do you/they have additional or special dental costs?

HOLIDAY: In a typical year, do you/they have additional or special holiday costs?

CONTINGENCY: Do you/they have any one-off costs that are additional or special contingency amounts?

OTHER: are there other areas where you have extra one-off costs?

Income support payments you (or the person you care for) receive now or have received in the past

We're going to ask you a series of questions about the income support payments and disability allowance payments you have received from Work and Income in the past, or what income support you might be accessing now to help with a disability and/or health condition. We will quickly note which payments you are or are not receiving. If you have received or applied for some in the past but not now, we'll ask a bit more about how that has gone. Also, if you would like to know more about income support that is available, we have some information we can share at the end of the interview.

If you are answering our questions as a carer for an adult household member who is disabled/has a disability/health conditions and you help them with their income support payments, we would like to hear about their payments and your experiences helping them.

(If applicable) Do you help the person you are caring for with their income support payments?

[record the conversation while filling in the table]

[if pressed for time, just ask yes/ no questions]

1. *(If applicable)* Are you currently receiving the Disability Allowance (DA) for your own health and/or disability-related costs?
2. *(If applicable)* Are you or your partner receiving the DA for a child's health and/or disability-related costs?
3. *(If applicable)* Is the person you are caring for receiving the DA?
4. *(If applicable)* If you/they are not currently accessing the DA, have you applied for it in the past?
 - a. If so, how did you/they find applying for the payment?
 - b. If you/they received DA in the past but are not currently receiving why is that?
 - c. Do you/they think they might be able to get the DA but choose not to apply? If so why is that?
 - d. Do you think the person you are caring for might be entitled to DA but choose not to apply? If so, why is that?
5. *(If applicable)* Are you receiving Temporary Additional Support (TAS) for your own health and/or disability-related costs?
6. *(If applicable)* Are you or your partner receiving TAS for a child's (aged under 18) health and/or disability-related costs?

7. *(If applicable)* Is the person you are caring for receiving Temporary Additional Support (TAS) for their own health- and/or disability-related costs?
8. *(If applicable)* If you/they are not currently accessing the TAS, have you applied for it in the past?
 - a. If so, how did you find applying for the payment?
 - b. if you received TAS in the past but are not currently receiving why is that?
 - c. Do you think you might be entitled to TAS but choose not to apply? If so why is that?
 - d. Do you think the person you are caring for might be entitled to TAS but choose not to apply? If so, why is that?
9. *(If applicable)* Are you or your partner receiving Child Disability Allowance (CDA) for a child?
10. *(If applicable)* If you/they are not currently accessing the CDA, have you applied for it in the past?
 - a. If so, how did you find applying for the payment?
 - b. if you received CDA in the past but are not currently receiving why is that?
 - c. Do you think you might be entitled to CDA but choose not to apply? If so, why is that?
11. *(If applicable)* Are you currently receiving the Supported Living Payment (Carer) due to your caring role?
12. *(If applicable)* Is someone else in your household currently receiving the Supported Living Payment (Carer) due to your health condition or disability?
13. *(If applicable)* If you/they are not currently accessing Supported Living Payment (Carer), have you/they applied for it in the past?
 - a. If so, how did you/they find applying for the payment?
 - b. if you/they received Supported Living Payment (Carer), in the past but are not currently receiving why is that?
 - c. Do you/they think they might be able to get the Supported Living Payment (Carer), but choose not to apply? If so why is that?
14. In the last 12 months have you used any subsidies from MSD or other agencies to support modifications to your home?

- a. If not: are you aware there are subsidies?
15. Have you/ they received any other income support due to your/ their health or disability?

Final Questions:

We are just about finished the interview - thank you so much for your help.

1. Is there anything else you would like to share?
2. If you could change one thing that would make your situation better, what would it be?
3. Would you like to be referred to someone who can assess your eligibility for any other Work and Income benefits and allowances? If yes, I will show you the information about this now and we will discuss how they could contact you.
4. If you get this assessment done, we would like to call you back one more time in a few weeks, to ask how it went and whether you found out any changes to your benefits. Would that be ok?

Here is the information about the assessment; we will need to go through another consent form just to be sure you understand what is involved.

If this interview has brought up any concerns that you would like to discuss with someone, we have some contact details for community law advisors, beneficiary advocates and people who provide counselling support in your area. If any of these are of interest, here are some contact details.

Appendix D: Costs by category

Examples of medical and health appointments participants have received

GP or Doctor

Cost mentioned by

- 11 participants

Frequency range

- Variable, regular, often to every three months.

Specifics and cost

- At times GP/doctor was ballparked at \$0-100.00.
- Most frequently was specified at around \$20.00 but cost was not always stated.
- Non-resident migrants note paying full price for family members to see GP.

Therapies

Cost mentioned by

- 6 participants

Frequency range

- Regular (weekly, monthly, every few months). Some funded. If self-funded, often not as regular as needed due to costs.

Specifics and cost

- Physiotherapy and massage (costs vary), “The cost is a factor but it’s also a fatigue factor – would go more if it was not so tiring.”
- Osteo and acupuncture, “Only when can afford it”
- Osteo and physio \$35 each per month, partially subsidised by Work and Income
- Speech language therapist \$130 per session, paid by grandparents
- Physio and medical (cost unspecified), paid by workplace
- Mental wellbeing therapy, costs unspecified, Covered by ACC

Diagnostics

Cost mentioned by

- 3 participants

Frequency range

- One-off

Specifics and cost

- \$900 neurologist, \$400 additional eye exams to rule out additional health issues, \$500 heart scan. Paid for by mother for disabled adult daughter.
- Just under \$300 to see a private paediatrician for Tourette's Syndrome diagnosis. This was paid by family after less-specialised doctors in the public system dismissed them.
- Behavioural psychologist to assess for intellectual disabilities for \$2000, paid for by grandparents; parents could not afford.

Appointments requiring travel

Cost mentioned by

- 2 participants

Frequency range

- Variable

Specifics and cost

- Specialist appointments, \$150 a session in (next city over), meant to be every few weeks but actually every few months: barrier is cost and energy required for travel
- Traveling to/from Australia for medical visits.

Examples of medical and healthcare appointments participants would like to access

Mental wellbeing support

Mentioned by

- 5 participants

Specifics and cost

- Trauma therapy
- Art therapy
- Private psychologist - \$1200
- “Gold standard” therapy for adolescent and coaching for family; \$200 fortnightly, inaccessible through public health system
- Counselling, \$75 per hour if not accessed via EAP from work

Physical and movement therapies

Mentioned by

- 5 participants

Specifics and cost

- Massage therapy, mirimiri, swimming – could spend over \$100 monthly if had it
- Private Occupational Therapist: One appointment through school/govt but unlikely to get a follow-up
- Physiotherapy – mentioned by 3, sometimes partially subsidised by ACC but still need to afford the top up fee

Eye/ vision specialists

Mentioned by

- 2 participants

Specifics and cost

- Need to check or replace glasses, but eye specialists are expensive
- Private specialist: “I’m uncertain that they’d take me. That would be very expensive – most of my friends who have recommended private specialists get funded through ACC or similar”

Medications and health equipment accessed by participants

Funded medication

Mentioned by

- 14 participants

Specifics and cost

- None, following policy change to remove prescription fees, also EGL

Unfunded medication

Mentioned by

- 6 participants – current spending; 3 with unmet needs

Specifics and cost

- Monthly costs: \$10, \$15, \$20, \$28, \$40; occasional over-the-counter

Supplements and vitamins

Mentioned by

- 3 participants currently taking them, 6 who would like to afford more

Diabetes monitoring

Mentioned by

- 3 participants

Specifics and cost

- \$150 on Dexascans
- \$230 monthly for basic child continuous glucose monitor (CGM) - Costs all of CDA
- \$50 extra fortnightly because not fully subsidised

Medications and health equipment participants would like to afford**Unfunded medication**

Unmet need

- “Have spent \$175 a week but stopped recently as cannot afford”
- Would prefer the unfunded option but cannot afford it (\$30 monthly)
- New migraine drug, not funded by PHARMAC yet (\$800 monthly)

Supplements and vitamins

Unmet need

- “Micronutrients due to child’s condition; \$200 monthly, not covered”
- Probiotics for gut problems
- Several notes on wanting to spend more on these products

Diabetes monitoring

Unmet need

- \$380 for easier-to-use child CGM. Insulin pumps also unaffordable.

Accessibility aids and equipment

Mobility aids

Mentioned by

- 7 participants

Specifics and cost

- Mobility scooter maintenance costs: \$300/\$400 for a service every couple of years
- Canes for mobility, once or twice a year for a new cane, \$50-\$100
- Orthotics/insoles replaced annually for 2 participants – only initial appointment funded
- Wheelchair, funded by Access Able
- Crutches, lent by hospitals to 2 participants

Canes/ Glasses for low vision

Mentioned by

- 6 participants

Specifics, funding, cost and unmet need

- Cane replacement approx. \$90 plus \$36 for ceramic tip; required by 3 participants, some funded some not
- Prescription sunglasses, \$6-700.00, got help from Work and Income
- \$1200 for glasses for disabled young adult, that will likely only last 2 years – “they just get battered”, more durable glasses aren’t funded
- Government paid for cheapest glasses, but sensory issues means they need scratch-proof, flexible and comfortable pieces

Learning support

Mentioned by

- 3 participants

Specifics and cost

- \$50 for an ergonomic pencil/pen pack – set of 10 pencil grips. Fidget toys, batteries.
- University-funded note-taking support

Other once-mentioned equipment

Specifics, funding, cost and unmet need

- Hearing aids: \$10 per week to pay Work and Income back for loan
- Neuromodulator: \$600 AUD, reoccurring cost of gel pads. Applied, not yet accessed
- Adapters to administer medication/ supplements

Dental care

Dental care

Mentioned by

- 14 participants

Unmet need

- 10 participants mentioned concerns about dental care, wishing to get more dental care but being unable to afford it

Annual dental costs

- 3 participants quoted \$190, \$400, \$300 (for several appointments at the dental school)

Subsidised or loaned costs

- Had a dental cost of \$2500. WINZ paid this and participant repays WINZ \$26 per week. Current outstanding amount at time of interview was \$1692
- "I got my wisdom teeth out through the hospital. I was not looking forward to that bill, so I went to my GP and he was like, oh, you've got a community services card. So we can do it through the hospital."
- Received funding for a dental emergency
- Work and Income have lent money/ subsidised dentures (\$1500)
- Work and Income paid for dentist; she has to pay it back

Food

Extra food costs due to health or neurodivergence

Cost mentioned by

- 10 participants

Specifics and cost

- \$50 weekly extra food costs due to daughter's tastes- important daughter is eating as she is underweight. Have to cut back spending on other core food items.
- "certain food he won't eat... most of the time we just make it work, hard to know what's 'extra' as always just adjusting as we go"
- Extra \$50 p/w on food due to children's autism leading them to be picky regarding food. Food waste per week is high. Could easily spend a total of \$300-\$350 p/w on food for 3 people but budgets \$150
- Son will only eat from New World, food cooked fresh. \$100 extra. Doesn't factor in petrol and time.
- low carb and speciality foods are more expensive; hard to define exact amount extra being spent -trying to maintain a balanced normal diet overall
- \$75 extra per week, expensive catering to medical needs
- \$15 grocery delivery fee for when feeling unwell, mentioned by 3
- Extra \$80-100 weekly

Wishes for more affordable food costs

Cost mentioned by

- 14 participants

Specifics and cost

- More fruit/ vegetables, healthier foods, fresh meat, better variety of foods to meet all tastes, ability to store enough food to not run out
- Many comments on increasing cost of food

Clothing

Extra clothing costs due to wear and tear, health needs, and neurodiversity

Cost mentioned by

- 8 participants

Specifics and cost

- Sensory issues leading to the purchase of more expensive clothing items that meet these needs.
 - One participant stated they needed to purchase a specific school jacket to accommodate these needs of their child, which was priced close to \$300
 - \$60 on socks (*hard to quantify Nike socks, \$30 for 3 pairs*)
- Experiencing frequent wear and tear to clothing
 - Trackpants wearing through at the knees after a couple of wears. Extra \$30p/wk
 - Constant washing of clothing results in faster deterioration (stated going through 3-5 shirts a day)
- Often needs to purchase new shoes due to children losing them
- Need to purchase clothing that can accommodate health issues (for example, latex allergy, which restricts options)

Wishes for more accessibility to clothing

Cost mentioned by

- 7 participants

Specifics and cost

- Would like to spend more to be able to access better suited clothing
 - Received clothing grant from Work and Income (\$150) which stated would cover a jacket and shirt for their child if they were "*lucky*". Stated they need to save to purchase these "*expensive things*" which are a requirement for meeting the needs of their child
- Extra money would go towards replacing items for children such as shoes and school uniforms

Household contents

Household contents costs

Cost mentioned by

- 3 participants

Specifics and cost

- Annual electric blanket testing \$35
- Around \$4000 spent on a new bed
 - Specific bed and couch mentioned by another interviewee (all whiteware and furniture needed for specific health needs related to disability costed \$5000 in total over last 5 years)
- \$20-\$90 on smart light bulbs yearly (compared to \$2-\$6)
- Repayments to WINZ for replacement washing machine

Wish to afford household contents

Cost mentioned by

- 5 participants

Specifics and cost

- Kitchen equipment for people with vision impairments (adult-safe kitchen knives, kitchen scales etc.)
- Small exercise equipment such as Swiss ball, yoga mat, etc.
- Chest freezer
- \$1650 for laptop

Bills**Phone and internet**

Cost mentioned by

- 6 participants

Specifics and cost

- Unlimited broadband as “children use a lot”
- \$60. Have to have a specific provider due to location. Internet is a need as it provides access to socialising
- An extra \$30 - \$35 a month for child to have a phone
- \$20 extra on internet as being home a lot increases time spent online
- \$80 - \$180 current spend amounts mentioned by others

Power

Cost mentioned by

- 3 participants

Specifics and cost

- Higher power bills due to needing to use a clothes dryer as unable to utilise washing line
- Higher power usage due to being up throughout the night

Preferred spending on bills

Cost mentioned by

- 5 participants (no specifics)

Transport

Transport

Cost mentioned by

- 20 participants

Specifics and cost

- Travel to and from hospital appointments are a large cost, with some interviewees living rurally and have monthly appointments
- \$25 a week on fuel as child's school is 57km away, and though therapy is funded, travel is not
- Unable to afford costs for public transport, resulting in walking to the GP
- Extra \$50 every 2-3 weeks on petrol
- \$15 or more a week extra to attend AOD meetings
- \$70 weekly for petrol and \$220 annual WOF and Service costs

Preferred spending on transport

Cost mentioned by

- 14 participants

Specifics and cost

- Petrol and car maintenance and/or WOFs (one interviewee needs an engine replacement with that cost rising from \$7k to \$21k)
- Would prefer to be spending more but unable due to mental barriers (concerned of illness and safety regarding public transport)
- \$50 - \$100 extra could be used for petrol or food
- Extra would be spent on more frequent visits to the doctor

Housing

Rent/Mortgage

Cost mentioned by

- 13 participants

Specifics and cost

- Rent increase through City Council, increased to \$448 from \$300.
- \$170 for a room, power, food
- All DA payment goes to supported care accommodation
- Increase in mortgage from \$340 to \$400
- One interviewee stated they pay at least an extra \$100 (no other amount stated)

Preferred spending on housing

Cost mentioned by

- 7 participants

Specifics and cost

- Considered moving into a smaller apartment but not easy to find financially
- Other interviewees stated the same, with some needing to move into a location that is single story and has no stairs as this is an accessibility issue
- An interviewee stated they would like to spend more- but unable to yet. Feel this may change when they move off the benefit and onto ACC, while partner then starts working
- Would like to move to a better location ‘...would compromise on quality for location.’
- An interviewee stated they could possibly be living somewhere cheaper but then would lose family support

Insurance

Insurance

Cost mentioned by

- 9 participants

Specifics and cost

- \$57 a fortnight, basic cover – took out insurance to cover likely family health needs, but it does not cover everything needed
- Higher contents insurance than usual (higher premiums) due to breakages caused by behavioural outbreaks
- Car insurance but stopped rental insurance due to costs
- \$20 a week towards car and contents insurance
- One interviewee claimed they are unable to get insurance due to police charges (they can but stated the excess would be \$10,000)
- \$800 excess payments after a flood. This increased insurance rates

Preferred spending on insurance

Cost mentioned by

- 7 participants

Specifics and cost

- Interviewees who would like to spend on insurance would be after coverage for medical, rental, and contents insurance. Unable to afford due to costs.
- One interviewee's mode of transport was stolen (ebike) and was unable to replace as unable to afford insurance

Maintenance services**Garden service**

Cost mentioned by

- 3 participants

Specifics and cost

- \$60 fortnightly for lawns as no one in the house can mow
- \$80 a week in the summer to get lawns mowed
- \$210 monthly on lawn service

Household services needed

Cost mentioned by

- 9 participants

Specifics and cost

- Stove/oven repairs. Council landlords don't respond to maintenance promptly
- Would like a cleaner but unable to afford/does not qualify for support
- Gardener and/or external house cleaner due to not being able to do this work themselves due to chronic fatigue

Exercise**Exercise**

Cost mentioned by

- 5 participants

Specifics and cost

- Minimal exercise options such as walking outside, limited exercises, free activities such as playing sport at school etc.

Preferred exercise options

Cost mentioned by

- 14 participants

Specifics and cost

- Yoga specifically for blind people
- Gym to help with arthritis
- Aqua aerobics and swimming (\$40 ticket for the season).
- Gymnastics and boxing for children (used to take these activities up but now live too far away)
- Would like to see a personal trainer to help with exercises that don't trigger migraines
- Access to swimming which helps with mood (and exercise) but cost is a barrier

Personal Care**Current personal care costs**

Cost mentioned by

- 7 participants

Specifics and cost

- \$15 on groceries delivered once or twice a month
- \$300 a year on new linen, not provided at care home
- An interviewee meets a person from Blind and Low Vision at St Johns to do mobility training (funded) but hard to motivate them to travel that far

Preferred spending on personal care

Cost mentioned by

- 4 participants

Specifics and cost

- Would like to be able to spend on things such as haircuts and therapy

Adult education

Adult education preferred spending

Cost mentioned by

- 8 participants

Specifics and cost

- Want to address professional registration lapsing
- Looking for ways to access uni as facing barriers such as petrol costs as well as facing mobility issues (getting in and out of a car, wanting to avoid walking to uni)
- Would like to take up a 1 year diploma
- Want to spend more time on education but lack of staff times are a barrier to participate
- Taken free online education at home but want to move to paid courses which are expensive
- Vocational training through ACC. Have not had any follow up regarding this

Childcare and education

Childcare spending

Cost mentioned by

- 3 participants

Specifics and cost

- \$21 a week on afterschool care
- Occasional spending on activities for child (no amount stated)

Preferred spending on childcare and education

Cost mentioned by

- 4 participants

Specifics and cost

- Would like to pay for occasional childcare so parents can have a break
- Expecting costs to rise when child starts school
- Would like to have a tutor for their child. Unsure on costs but think this could roughly be \$100 a week

Events and holidays

Events

Cost mentioned by

- 3 participants

Specifics and cost

- Local Cosmopolitan Club for indoor bowls and a few drinks. Van (taxi or club vehicle) brings them home
- An interviewee takes part in community events, sometimes as a volunteer, so costs are paid

Preferred spending on events

Cost mentioned by

- 5 participants

Specifics and cost

- Would like to attend more events/socialise more without worrying about costs

Holidays

Cost mentioned by

- 3 participants

Specifics and cost

- \$1000 once a year. This is the full cost to visit family in Auckland
- Only get cheap flights which limits flexibility

Preferred spending on holidays

Cost mentioned by

- 5 participants

Specifics and cost

- Would like to have the option but cost and comfort are a barrier
- Want to be able to travel more and do more social activities

Contingencies and other costs

Current contingency costs

Cost mentioned by

- 3 participants

Specifics and cost

- Currently able to save about \$30 a week
- Trying to save for dental care and “bigger things”. About \$20 a week

Preferred spending on contingencies

Cost mentioned by

- 4 participants

Specifics and cost

- Would like to save more money for unexpected expenses but unable to. Living week to week. Saving is difficult

Current “other” costs

Cost mentioned by

- 3 participants

Specifics and cost

- \$10 for polydent for dentures
- \$20 a week, sometimes \$40 for personal allowance (coffee/tenpin bowling/swimming)

Preferred spending on other costs

Cost mentioned by

- 3 participants

Specifics and cost

- Make sure they have enough for cannabis and cigarettes. Accessing CBD oil that does not contain THC is difficult to access and expensive.
- Be able to contribute during special events such as birthdays etc.
- Seeing a sex worker for occasional company.



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All is for V7