

**In-depth study to understand costs and income support for
Tāngata Whaikaha Māori me o rātou whānau, and Māori
living with long-term health conditions**

A study by Katoa Ltd for the
Ministry of Social Development

FINAL REPORT

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Mihi

E ngā mana, e ngā reo,
Tēnā koutou katoa
He mihi whanui tēnei ki a koutou e awhi nei i tēnei kaupapa
He putanga tēnei mahi arotakenga nā koutou
Nō reira e rau rangatira ma
Tēnā koutou, tēnā koutou, tēnā koutou katoa.

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Personnel

The project leads were Fiona Cram, PhD; Anna Adcock, MA. Fiona and Anna also interviewed participants with the support of a team of whānau interviewers.

Advisors to the project were Deni Tipene, Helena Tuteao and Louise Were. Matua Ike Rakena and Huhana Hickey joined the advisory team as meaning makers and peer reviewers.

Whānau interviewers (who also advised and helped make meaning) were: Wendy Isaia, Fran Kawene, Arianna Nisa-Waller and Areta Ranginui Charlton.

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Glossary of Māori Words and Terms

Source. Moorfield (2024)

kāinga rua.....	second home
kāpo.....	blind
kotahitanga.....	unity and solidarity
kura	school
māmā	mother
manaakitanga.....	support, hospitality, care
Pākehā	New Zealander of European descent
rangatahi	young person, youth
rangatahi whaikaha Māori	disabled Māori youth
rohe	region, area
tamatāne	son
tamatāne whaikaha Māori	disabled Māori son
tangata whaikaha Māori	Māori with lived experience of disability (singular)
tāngata whaikaha Māori	Māori with lived experience of disability (plural)
tautoko.....	support
Te Ao Māori.....	the Māori world
te reo Māori	the Māori language
te Tiriti o Waitangi	Treaty of Waitangi
tikanga.....	correct procedure, traditional culture and protocols
tūrangawaewae	place where one has rights of residence and belonging through kinship and whakapapa
whakapapa	genealogy, ancestry
whānau	extended family
whānau hauā.....	whānau with experience of disability
Whānau Ora	Māori family wellness
whenua.....	land, territory, rivers, mountains

Abbreviations

ACC.....	Accident Compensation Commission
CRPD	Convention on the Rights of People with Disabilities
EGL	Enabling Good Lives
MSD	Ministry of Social Development
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UNDRIP.....	United Nations Declaration on the Rights of Indigenous Peoples

Executive summary and examples of experiences

In the second half of 2023 and into early 2024, Katoa Ltd interviewed 20 people – tāngata whaikaha Māori (disabled Māori), whānau of tangata whaikaha Māori, and/or Māori with long-term health conditions. The purpose of this study was to enquire into the health- and disability-related costs they faced, whether they were able to meet these costs, and their receipt of income support intended to assist with these costs. The people who took part were on low- or middle-incomes and aged between 23 and 63. The study was commissioned by the Ministry of Social Development (MSD) to help inform policy advice on ways to improve income support payments and reduce child poverty.

An overview of findings is provided below. Then, strengths and limitations are discussed. This is followed by examples of people's experiences developed from the research findings to illustrate the lived realities of the people we spoke with.

Most participants said they had 'not enough' or 'only just enough' money to meet their everyday needs

Only three of the 19 participants who responded to a question about how well their income met their everyday needs said they had enough money. Eight said they only just enough money and eight said they did not have enough money to meet their everyday needs.

Participants experienced a range of direct costs associated with being tāngata whaikaha Māori, whānau of tangata whaikaha, or Māori with a long-term health condition

Participants were asked about the direct out-of-pocket costs they faced. The direct costs which MSD was interested in included the additional health- and disability-related expenses associated with goods and services for day-to-day living (e.g., rent, health care, transportation, equipment, food).

People often found it difficult to attribute a portion of their direct costs to being tāngata whaikaha Māori, whānau of tangata whaikaha Māori, or having a long-term health condition as they considered their spending (or inability to afford) normal expenditure.

Some who were owner-occupiers or renting had additional housing costs because they needed to live in neighbourhoods close to shops and transportation and/or required housing that was dry and warm.

Direct costs of transport were associated with having to drive themselves or a whānau member to health appointments. Primary health care was a common direct cost, along with specialist health care when it had been sought out to speed up diagnoses needed to access disability funding.

Internet costs were high for whānau of tāngata whaikaha Māori as tamariki and rangatahi spent a lot of their time on their computers due to their impairments or health conditions. Direct costs of mobile phones were incurred so that parents could stay in touch with tamariki and rangatahi when they did go out.

Some people said their pet costs were associated with being tāngata whaikaha Māori or having long-term health conditions (e.g., a dog that was part of a participant's wellbeing plan).

Cost barriers led to a range of unmet needs associated with being tāngata whaikaha Māori, whānau of tangata whaikaha, or Māori with a long-term health conditions

We asked people if they had unmet needs and if so whether these unmet needs were due to cost and affordability, or due to other barriers. We also asked how people were compensating for any unmet needs.

Additional costs associated with being tāngata whaikaha or having a health condition, and/or participants' inability to engage fully in employment, meant that cost barriers and unaffordability were the biggest drivers of unmet needs.

The most flexibility people had in their budgets was what they spent on groceries. Food insecurity was evident for some. Some reported difficulty affording the healthy food or special diets they needed for themselves and/or their tamariki, and their increased reliance on cheaper, processed foods. This was likely to be adversely affecting whānau health and wellbeing.

People went without a range of other goods and resources because they could not afford them, with many forgoing home modifications, equipment, or housing that would better meet their needs. Many could not afford a personal allowance, special events, insurance, organised sports or fitness, clothing, dental care, holidays, or the setting aside of a contingency fund.

Walking, cycling and using public transport were alternatives to using taxis if people were unable to drive. However, these alternative transportation methods restricted their access to activities and education opportunities and were sometimes considered unsafe.

Most did not regularly visit whānau who lived elsewhere, or return back to their tribal homeplace if they lived some distance away. Some were not able to visit their marae even if it was close by because of costs associated with being disabled or having long-term health conditions. Visits were substituted with on-line solutions and travelling to see whānau was substituted with engaging with whānau who were close by.

Some had forgone streaming services due to their unaffordability, and at least one participant was worried that they would soon have to give up their internet service due to financial pressures. Being able to afford internet costs was key to connection and recreation for many.

While giving up full-time employment was a key indirect cost associated with being tāngata whaikaha Māori, whānau of tāngata whaikaha, or Māori with a long-term health condition, many whānau did not see this as a negative

We asked questions that explored indirect costs, costs of lost opportunities and any compensating strategies.

Those who had given up full-time employment to care for tamariki whaikaha did not see paid work as a lost opportunity. Rather, they were committed to being fully present to ensure their tamariki had the best opportunities to live good lives. The cost to the taxpayer of their decision was the income support and caregiver allowances they received, whereas the personal cost to them was the potential negative impacts on their own health and wellbeing (e.g., isolation, burnout). The potential benefits were better long-term health and wellbeing outcomes for their tamariki.

Some wanted support to find suitable and flexible employment that would work in with health- and disability-related needs

Those who wanted to work but felt constrained by whānau care obligations were making plans that involved whānau support and employer understanding and flexibility. Those who were thinking about work after their time as a carer were looking for formal support to help them prepare and access appropriate employment opportunities. As carers they had forgone paid employment as well as training and educational opportunities.

An important indirect cost for many was loss of connection with whānau and culture

As noted above, many had not travelled back to their tribal area and/or visited with whānau who lived elsewhere for a number of years because they could not afford to. Without the ability to maintain

these connections, an additional cost was potentially a diminished sense of cultural identity, belonging and psychological wellbeing.

Those who wanted to learn or revitalise their te reo Māori were confined to free courses or had to forgo this aspiration. This was a lost opportunity for participants to strengthen their connections with their cultural heritage. Missing out on this opportunity could, in turn, have negative impacts on their sense of self-worth.

The level of health- and disability-related costs, living arrangements, housing, and whānau support all influenced how people managed

We asked people questions that explored how their situation and the context they and their whānau lived in was inter-related with the costs they faced, and the consequences of any additional costs and unmet needs associated with being disabled or having a health condition.

Participants were diverse in their living arrangements. Some lived by themselves. Others lived in two-generation households and some lived in three-generation households.

If they had owned their house for some years or their whānau was helping them with mortgage payments, housing costs were generally low or offset by them having flatmates. If the direct costs associated with them being tāngata whaikaha Māori or having long-term health conditions were low, then they did not experience many financial pressures. If, however, their direct costs were high then they described their finances as tight.

Those who were renting their accommodation, regardless of the composition of their household, described rental costs as high and often on the rise. If they lived by themselves, their accommodation was usually small and this constrained their ability to host their whānau. For some, this did not prevent their grandchildren from staying at their place when they fell out of favour with their parents. The pressure of this on finances meant this could only be for a few nights.

Those in two-generation households – mothers looking after tamariki whaikaha – were financially literate and disciplined. They went without social opportunities, food, or paid employment so they could afford to be at home with their tamariki. They were also strong advocates for their tamariki, working to ensure they had access to the supports they needed.

Those in three-generation households were often reliant on whānau members for day-to-day support (e.g., looking after older whānau members, ensuring tamariki got to school), including being able to afford the rent. Financial pressures could lead them to look for paid employment, placing more reliance on other whānau members to stay at home and be caregivers. Whānau conflicts could leave people feeling trapped because of their inability to move out because of the unaffordability of rental accommodation in their area, and their reliance on the support of whānau members they had conflicts with.

Some participants could call on financial support from their whānau for housing, travelling back to their tribal area, and emergencies. Other options mentioned for financial support included their church and their children's school. For example, a kura fundraised so that tamariki could go on trips.

Half of participants reported receipt of a health- and disability-related main benefit and only three reported receipt of Disability Allowance

Ten participants reported receipt of one of main health- and disability-related benefits. Six received a Supported Living Payment because they were either a carer ($n=3$) or because their permanent disability severely restricted their capacity to work ($n=3$). Four received Jobseeker Support – Health Condition or Disability. In addition, two received Jobseeker Support – Work Ready and one received Sole Parent Support.

Few reported receipt of supplementary health- and disability-related payments and supports. Only three participants received the Disability Allowance. Two received a Child Disability Allowance, and three received Temporary Additional Support (TAS). None had accessed Home Modifications Funding.

While people were grateful for their income support payments, most receiving income support said they did not have enough money, or only had just enough money to meet their daily needs. Only two said they had enough money.

Some who were not accessing income support payments to help meet their costs either had tried to do so but had been told they were not eligible, or were going to apply. Some who had not applied or did not plan to apply were not aware of their potential eligibility, or appeared to misunderstand eligibility criteria. Four participants who were not in receipt of any income support were working.

Experiences with Work and Income were diverse. Some talked about the good treatment they received from their local office. Others talked about having to go through an advocate two or more times to qualify for a benefit. A unifying thread was that people wanted their whānau context to be understood by Work and Income and reflected in their income support package.

None of the participants took up the offer of a check by MSD of whether they were receiving their full-and-correct entitlements. This meant the study was not able to explore whether people's ability to meet additional costs could have been improved and unmet needs could have been reduced had they received all the income support they were entitled to. Receipt of Disability Allowance, in particular, appeared low given the costs and unmet needs that participants described.

Strengths and Limitations

Key strengths of this study were the Kaupapa Māori methodology, and the connection made with participants as all interviewers were Māori and many were whānau of tangata whaikaha Māori.

Because of the small sample, the findings may not necessarily be generalisable to the wider population of tāngata whaikaha Māori, whānau of tangata whaikaha Māori, and/or Māori with long-term health conditions. The study will not have captured the full diversity of experiences and views. It may under-state the costs borne by tāngata whaikaha Māori with high and complex needs as a result. Some whānau – mothers – in the present study were however able to speak about raising tamariki with high and complex needs.

While the participants were a broad range of ages, all but one was female. The experiences of tāne Māori (adult men) are therefore not well-represented. However, at least three of the female whānau in the present study were raising tāngata whaikaha Māori sons, and their input provided insights into the experiences of tāne Māori aged from 8 to 19 years.

Overall, the people we spoke with generously shared within the context of a 90-120 minute interview, with many also offering to help with other research. The resulting data is rich, providing insights into their finances, day-to-day lives, and often their history of experiences with Work and Income. The costs they described and their feedback on what they are missing out on because of affordability challenges may well resonate with other tangata whaikaha Māori, their whānau, and Māori with long-term conditions.

Examples of experiences of Tangata whaikaha Māori me o rātou whānau

This section presents four personas which give a sense of the circumstances participants described. Each persona is a composite profile drawing on multiple participants' kōrero. 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 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
- comments on what would help.

The personas are:

- Mārama – a working māmā managing her own long-term health conditions and supporting adult daughters who have health needs
- Kara – a māmā caring for tamariki needing extra attention
- Makere & Kahukura – a carer and her tangata whaikaha Māori daughter
- Mere – a grandmother adjusting to life after a stroke

Mārama – a working māmā managing her own long-term health conditions and supporting adult daughters who have health needs

Mārama and her husband live outside their tribal rohe, in a region that some of their mokopuna have whakapapa to. They had settled there shortly after getting married and had raised their three children – one boy and two girls – there. At 30 years of age their oldest daughter, Kiara, now works in another town and still needs a lot of support. Kiara was diagnosed with dyslexia when she was 9 years old, and she struggles with a lot of things. Mārama often advocates for her so she can get the assistance she needs. Her other daughter has a mental health condition and is reliant on Mārama to take her to her appointments, or just to be there for her if she has had a rough day.

Mārama describes herself as having experienced a lot of injuries and having had a lot of surgeries over her 53 years. She also lives with type 2 diabetes and suffers a lot from arthritis pain. There are foods she knows she should eat to try and manage her condition, and foods that she needs to avoid. She is trying to get a garden sorted so that they can grow some of their own fresh fruit and vegetables, but this has been slow going.

There have been times when Mārama was constantly going back and forth to the doctors, and she has a drawer full of pills that they prescribed her for her pain. Although her prescriptions are now free, she still finds it a stretch to cover her doctor's bills. She's also been reading that acupuncture might help with her pain, but it costs \$80 for each session, and she'd need to have at least two sessions a week.

Even so, she is still working part-time as a carer on the night shift at a local rest home. She can't afford not to work as she's not eligible for a benefit because of what her husband earns at his job. Their power bills are also high because if Mārama does not stay warm her body seizes up.

They are working on some alterations to their home so that it's easier for Mārama to get around. They had thought about asking MSD for help with some funding for these home modifications but in the end they decided there was no point asking as they thought they'd just get turned down because they were over the income threshold. Plus, the work they needed done would cost more than what MSD would give them.

The last time Mārama was able to travel to her tribal rohe was five years ago for her mother's tangi. She thought of this travel as a necessity rather than a 'cost'. She has not been able to afford to return since.

Extra direct costs

- Extra medical costs for primary care visits and medication, especially pain medication.
- Home modifications to improve accessibility for Mārama.
- Cost of power to keep their house warm, including an electric blanket for night-time warmth.
- Transport costs associated with supporting her daughter with her health needs.

Unmet costs

- Māmara would like to visit with her daughter who lives in another town and also take her mokopuna back to visit their tribal rohe. However, she cannot afford these visits.
- Mārama is unable to afford acupuncture sessions that could help alleviate her pain. Other therapies are also out of reach because of the cost.
- Mārama would love to have a spa bath installed in her home as soaking in hot water really helps to temporarily alleviate some of her pain.

Opportunity costs

- There are time and energy costs associated with supporting her adult daughters with their health needs.
- Mārama gets tired because of her work hours. If she did not have to work she would have more time and energy to support her daughters with what they need.
- Mārama's tiredness may impact on her own wellbeing as sleep deprivation is associated with type 2 diabetes and also exacerbates the impact of this long-term health condition.

Income support

- Mārama and her husband no longer go into Work and Income because they have been denied support in the past. They have given up on ever getting anything to help them with their living expenses and so Mārama has to continue to work.

Financially

- They have enough money to meet their daily living needs, but only because Mārama continues to work.

What would help

- *Support with pain management.* A pain management specialist would provide a more holistic assessment of Mārama's medication and therapeutic needs.

- *Financial support to access therapies.* Investment in Mārama's therapies would potentially enable her to continue to work and help her manage her long-term health conditions better.
- *Personalised consideration of Mārama's support needs.* Mārama and her husband's income puts her over the income thresholds for support. She therefore feels locked in to working long hours, in spite of her long-term health conditions. Case management would inform Mārama's decision-making about whether there is income support that would enable her to achieve a better balance of work and her health requirements.

Kara – a māmā caring for tamariki needing extra attention

Kara is a sole parent who is raising her two boys with support from her whānau. She lives in a three-bedroom Kainga Ora house on a sunny section, and they have a pet dog. Her youngest son, Haami, who is nearly 7 years old, is having problems paying attention at school. The school liaison person suggested to Kara that he may have ADHD and she is now waiting to get an appointment for him with a paediatrician. The wait time is long. When he was younger her son had had his eyes tested and they recommended glasses for him. Kara has not been able to afford to replace his first pair of glasses after he broke them.

Kara herself suffers from anxiety and works to control this by having a cold shower every morning. She also has essential oils and diffusers in her house and feels these help both her and her boys.

Kara doesn't work as she believes her children should be the priority in her life, especially her youngest who has always needed extra attention. Although money is tight, Kara makes sure her sons have enough to eat – often holding off eating her own evening meal so she can give them seconds from her plate if they are hungry after eating their own kai. Kara also tries to buy healthy food for her boys, but this is getting less and less affordable and she is finding that she having to get more processed food at the supermarket. This is a bit distressing for her as she notices the effect that even small changes in their diet have on her youngest son in particular.

She would love to take her boys back home to their tribal area, but this is simply unaffordable. Instead, they spend time with whānau who live close by and do things together that don't cost a lot, if anything. Kara has not visited with her mother – her boys' grandmother – in two years and misses her a lot.

Extra direct costs

- Extra cost of replacement clothing and shoes for her youngest son, as he either wears things out quickly or loses clothes more frequently than other kids.
- Paediatric appointment(s) to get a diagnosis for her youngest son will incur transport costs.

Unmet costs

- Cannot afford to go to a paediatrician privately so is waiting for an appointment after being referred by her GP.
- Cannot afford to travel back to her tribal area to visit with and have the support of her whānau there, in particular her mother.
- Cannot afford to buy the amount of healthy food she had been accustomed to purchasing.

Opportunity costs

- Kara would love to return to work at some stage, but currently she feels she needs to be at home for her sons. She had worked full-time up until her second son was born and she separated from the boys' father.

Income support

- Kara receives Sole Parent Support and is waiting on a diagnosis for Haami so she can claim other, disability-related, income support.

Financially

- Kara feels she has only just enough money to get by, but that it is getting harder and harder each week to make ends meet. It is difficult to save for emergencies or unplanned costs.

What would help

- *Support on her journey to obtain a diagnosis for her son.* Kara is very uncertain about what it will mean to get a diagnosis for her son. She is unsure what she should say to the paediatrician and whether a diagnosis will be a good thing or not for him.
- *More understanding from her local Work and Income office.* There have been times when money has been so tight that Kara has had to seek a food grant from Work and Income. She tries not to do this as she feels she is interrogated every time, including being asked if her whānau could help her.
- *Finding a way to travel home to visit with her mother.* There is no slack in Kara's budget that enables her to save for a holiday or to even put a little away each week for emergencies.

Makere & Kahukura – a carer and her tangata whaikaha Māori daughter

Makere's daughter, Kahukura, has lived as tangata whaikaha Māori from the day she was born some 23 years ago. Up until she was 18 years old Makere received a Child Disability Allowance to help her raise Kahukura. Now she's older, Kahukura receives a Supported Living Payment and a Disability Allowance. Her mother manages her money for her and gives pocket money each week that she can spend. Makere gets a Supported Living Payment as a carer for her father and has been told that she cannot get a second payment as a carer for Kahukura.

During all this time, Work and Income have never asked to meet Kahukura, they have only wanted proof that she has a disability. For a period when Kahukura received Jobseeker Support – Health Condition or Disability, Work and Income sent letters asking when she was going to go to work and notices that her benefit may be cut. Makere had to ring them many times to explain about Kahukura and how the nature of her disability meant she cannot work before she was granted Supported Living Payment. She has also had to ring them a few times to get them to update the address they send correspondence to.

Makere and Kahukura recently shifted into a larger rental house that can more easily accommodate their whānau. They live with Makere's son and other daughter, her father, and a mokopuna, as well as her partner. Work and Income gave them some help by paying their bond, but that was all they were offered. Their rent is very expensive and all the adults in the house contribute to paying it, including Kahukura.

Still things are tight in terms of their budget and Makere has had to forgo some insurance as well as dental visits and has tried to cut back on their grocery budget. Their grocery budget is the last place left now where they can make any savings, so now they live week to week and Makere tries to figure out how to juggle what needs to be paid for.

Their gym memberships have not yet been cut as going to the gym together is something that Makere and Kahukura enjoy, and it gets Kahukura out of the house and keeps her healthy. Makere also needs to go with Kahukura as she cannot go on her own, so she has used some of the income she receives as a carer to pay for her annual gym subscription.

Makere is thinking about returning to full-time work. If she does, Kahukura will take care of her grandfather during the day – a responsibility that she loves.

Extra direct costs

- Rent on a larger house so that their whānau can stay together and support Makere's father, mokopuna, and Kahukura.
- Gym membership for Makere and Kahukura so they can go to gym together and exercise. Kahukura cannot attend the gym by herself.

Unmet costs

- Their desire to eat healthy kai sometimes has to be set aside if there are other bills that need to be prioritised.
- Dental visits are unaffordable.
- Car insurance and the mechanical warranty for Makere's car have had to be stopped as they are no longer affordable. Yet her car is essential in terms of getting people to health appointments.

Opportunity costs

- Lost time in employment for Makere while she cares for her father and Kahukura.
- If Makere returns to work, Kahukura will stay at home to look after her grandfather. While she loves doing this, there may be opportunity costs to her of participating in other activities where she can interact with people.

Income support

- Kahukura receives a Supported Living Payment and a Disability Allowance.
- Makere receives a Supported Living Payment as carer for her elderly father.

Financially

- There is not enough money to met their everyday needs.

What would help

- *Supported Living Payment (Carer)*. As Makere cares for both Kahukura and her father it would be helpful financially if both carer roles were recognised and income support provided.
- *Employment coaching*. If Makere decides to return to work, Kahukura will be left to care for her grandfather during the day. While Kahukura loves doing this, she may also benefit from some form of limited and appropriate employment that sees her engaging regularly with others outside of her whānau. An employment coach may have other ideas / solutions that would see both Makere and Kahukura able to think about suitable, flexible employment.

Mere – a grandmother adjusting to life after a stroke

Mere is 56 and lives by herself in a one-bedroom, second story flat that she rents from a private landlord. The stairs she has to climb to reach her flat are difficult for her as a few years back she had a stroke and had to learn to walk and to talk all over again. She continues to suffer from fatigue and pain and has a lot of anxiety that she attributes to her memory loss from the stroke. She also feels frustrated because she lost a lot of her te reo Māori after the stroke. Mere describes every day as challenging, so she takes things one day at a time.

She misses being able to host whānau gatherings as there's not the room for them in the flat. Still, she has her mokopuna over to stay, and her partner sometimes sleeps over. Her landlord installed a heat pump in her flat because it's uninsulated and was very cold in the winter. This has made it more liveable, but now her rent has gone up – almost doubling in four years.

Extra direct costs

- Increasing cost of rent due to the heatpump going in – she needs to use the heatpump due to being in her home a lot after her stroke.

Unmet costs

- Mere's rent is becoming less affordable. It would also make sense for her to have accommodation that was more accessible, but this may come at a greater cost. She would also have to meet the costs of a move.

Opportunity costs

- Mere is losing out on time with her whānau, and on the opportunity to access support from her whānau.

Income support

- Mere is on a Supported Living Payment, and is in the process of applying for a Disability Allowance.

Financially

- She does not have enough money to meet her everyday needs.

What would help

- *Rehabilitation support.* Mere still requires support with her rehabilitation after her stroke, including culturally responsive support to strengthen her ability to speak te reo Māori.
- *Housing support.* Mere may be eligible for social housing and would need support to both find accommodation and to move into a new home.
- *More financial support.* Mere may be eligible for Accommodation Supplement as well as Disability Allowance. Proactive help from MSD to let Mere know about these payments and providing her with support to apply would improve her situation.

Introduction

This research explored with tāngata whaikaha Māori (disabled Māori), with whānau carers of tāngata whaikaha tamariki (disabled children), and with Māori with long-term health conditions the extra cost of the goods and services they access, what their unmet needs are, what trade-offs they are making, and the consequences of health- and disability-related costs for their lives. The research also explored whether tāngata whaikaha Māori, whānau of tāngata whaikaha Māori and/or Māori with long-term health conditions are receiving income support intended to help with health- and disability-related costs, and if not, why not.

The research was commissioned by the Ministry of Social Development (MSD) and is part of a wider work programme designed to build evidence that can inform MSD's policy advice. This includes advice on ways to improve income support for disabled people and people with long-term health conditions and ways to reduce child poverty. Dedicated Kaupapa Māori research was commissioned to provide insights into the intersection of disability and culture.

Māori and the impact of disability

Māori are more likely to be disabled¹ than non-Māori, with a rate of nearly one in four for Māori compared to less than one in six for non-Māori² (King, 2019). For Māori aged 45-64 years this rate increases to over two in five, while three in five Māori over 65 years of age are disabled. In addition, nearly half of young disabled Māori (0-14 years) have multiple impairment, with the likelihood of this experience increasing with age. Two-thirds of disabled Māori aged 65 years or over report multiple impairment (King, 2019).

In the ancient world of Te Ao Māori, being kāpo (blind) or having other impairment was seen as a tohu, a sign of greatness (Tikao et al., 2008). A lot has changed since that time, with Māori understandings of disability impacted by colonisation and the experiences of tāngata whaikaha Māori (disabled Māori) often resonating with intersecting forms of marginalisation and oppression (Ingham, et al., 2022). Colonisation has been described by Kingi and Bray (2000) as having a disabling effect on Māori.

Despite colonisation, Māori maintain and advocate for holistic understandings of disability, where the right of Māori to live well-rounded, whānau-centric, cultural lives is reinforced (Kaiwai & Allport, 2019; King, 2019; Ratima & Ratima, 2007). While recognising diverse realities, Huhana Hickey and Denise Wilson (2017) promote whānau hauā as an indigenous Māori perspective on disability. Whānau hauā acknowledges an holistic, spiritual, relational and collective Māori understanding of disability.

Metaphorically, whānau hauā signifies the wind that propels whānau with member(s) who have a disability ... Whānau Hauā is grounded in the collective whānau and individual members' experiences of someone with a disability ... Whānau hauā manage disability as part of their daily life rather than it being central to an individual's identity or everyday life (Hickey & Wilson, 2017, p. 86).

Maaka Tibble, a prominent kaumātua, founder of Kāpo Māori Aotearoa and an icon of the disability community, also gifted the kupu Māori 'tangata whaikaha' in 2015 to encompass all disabled people and their whānau who want their impairments/disabilities described in te reo Māori. Tangata whaikaha

¹ While the phrase 'lived experience of disability' is used by King in her report, this report generally uses the term 'disabled' which aligns with the social model of disability, or the te reo Māori 'tangata whaikaha Māori' gifted by Maaka Tibble. The gifting of this name is described below in this Introduction. To adhere to te reo Māori conventions, when we refer to more than one person, we will denote with the use of macrons i.e. tāngata.

² King (2019, p. 20) writes "[t]he proportion of Māori with lived experience of disability in 2013 was 23.9 per cent compared with 15.6 per cent for Non-Māori. For Māori males it was 25.7 per cent compared with 16 per cent for Non-Māori, and for Māori females it was 22.1 per cent compared with 15 per cent for Non-Māori."

is a strength-based description that, as defined by Maaka, means 'striving for enlightenment, striving for enrichment'.³

Costs of living

Participants contributing to a 2016 report on key issues for disabled people in New Zealand "pointed out that having a disability is seen as often creating extra costs which financially disadvantage people" (Office for Disability Issues, 2016, p. 8). Rare Disorders NZ has enquired about additional costs in its biennial survey, which 1,076 people responded to in 2023. Over half the respondents reported that the costs associated with their disorder were high, and over half said the costs were hard to manage. The costs included healthcare, rehabilitation, devices, dietary, and home care services (HealthiNZ, 2024). Mitra and colleagues (2017) undertook a systematic review of twenty studies internationally and found evidence that disabled individuals have sizeable additional costs, ranging from US\$1,170 to US\$6,952 per year. Higher costs were borne by those with more severe impairment, and by those living alone or in small households.

The impact of being disabled⁴ is also seen across a raft of inequalities, including home ownership, subjective wellbeing, household income (Stats NZ, 2020) and child poverty (Stats NZ, 2024). Tāngata whaikaha Māori are less likely than non-Māori to be in the labour force and, if they are in the labour force, they are more likely to be underutilised and experience unemployment (King, 2019), earn less on average if they are employed, and have lower average job satisfaction (Stats NZ, 2020). Tāngata whaikaha Māori may therefore require "additional resources to participate in society and achieve an adequate standard of living" (Wilkinson-Meyers et al., 2014, p. 1541). These resources include what they need to be Māori and to do Māori things in the course of their daily lives (Ingram et al., 2022). Good financial support can help tāngata whaikaha Māori and their whānau access the goods and services of a society that is so often designed to serve non-disabled people (Hickey & Wilson, 2017).

Income support

Many tāngata whaikaha Māori, whānau of tāngata whaikaha Māori, and Māori with long-term health conditions are reliant on the country's income support system, or on earnings-related support from the Accident Compensation Corporation (ACC) if tāngata whaikaha Māori are disabled because of a physical or work-related injury. ACC was founded in 1974 following a 1967 Royal Commission on workers' compensation, 'to deliver injury prevention initiatives and no-fault personal injury cover for everyone in New Zealand' (ACC, 2021, p. 6). The Accident Compensation Act 2001 puts a greater focus on prevention and rehabilitation, while successive amendments extended ACC coverage to all mental injuries from sexual violence that occurred before 1999 and support for people who self-harm. ACC is developing a new ACC pathway of kaupapa Māori health services. This pathway will provide whānau with new options for the health and rehabilitation services available to them (ACC, 2024). A key difference between ACC and the income support system is that ACC provides claimants who were employed at the time of injury with up to 80 percent of their anticipated earnings, aids and equipment, and transportation to medical and rehabilitation appointments.

The proposal of the 1967 Royal Commission was however for a social insurance scheme that helped people with impairment regardless of the cause of that impairment. Warren Forster (2022) writes that the shift away from this proposal has resulted in the inequitable provision of support for tāngata

³ We recognise that whaikaha is not language that everyone embraces. It has been criticised for reinforcing western biomedical models of disability and as not being an Indigenous concept. Its use in this report should not be interpreted as undermining people's right to self-identify and use the terms they feel describe them best.

⁴ We recognise the social model of disability; that is, a response "and resistance to the prevailing medical model and specifies that individuals have impairments but rather than the impairment disabling a person, the barriers created by an inaccessible society are the disability" (Office for Disability Issues, 2024).

whaikaha, most clearly evidenced in the higher levels of support through ACC versus the income support system operated by Work and Income.

The current system is incomplete, and it is causing harm. It works for some people, but for many, it doesn't work at all. People receive different standards of care, and different social and income support, habilitation and healthcare based on the cause of a person's impairment. Families are expected to pick up the costs of what people in Government choose not to provide (Forster, 2022, p. 5).

MSD's disability-related responsibilities include the provision of income supports (see below) and employment supports.

It is important to note that MSD has, and will continue to have, a role in the disability space. This contributes to MSD's focus on long-term social and economic development. Core parts of MSD's role include delivering supports and services for disabled people through the welfare system, administering disability-focused services and policy advice on disability issues (MSD, 2023, p. 15).

In the first half of the 2010's research into the experiences whānau and families had of accessing income support from the income support system highlighted the issues faced by some of those most in need of government support. This included the inadequacy of the level of financial assistance available to them, the overwhelming number of Work and Income staff and other government agencies they often had to engage with to get this support, the humiliation and judgement many experienced when asking for assistance, and their lack of awareness of what they were entitled to or the obligations they needed to meet in order to receive income support (Auckland City Mission, 2014; Baker et al., 2012; Cram et al., 2020; Pipi & Torrie, 2018).

Recently MSD has introduced three organisational shifts collectively known as Te Pae Tawhiti – Our Future (MSD, 2018; 2022). A goal of the first shift, Mana manaaki – a positive experience every time, is for people to “feel comfortable dealing with [MSD], be aware of all that is available to them and be confident they will receive it” (MSD, 2018, p. 21). The second shift, Kotahitanga – partnering for greater impact, sees MSD committed to strengthening its connections with partners to reduce social service access barriers for clients, whānau and families, and communities. The third shift, Kia takatū tātau – supporting long-term social and economic development, is about supporting clients to “acquire adaptable, flexible and transferrable skills” (MSD, 2018, p. 23) for a changing future work environment.

The mission of MSD's Māori strategy and action plan, Te Pae Tata – Te Rautaki Māori me te Mahere Mahi, is “to embed a Māori world view into our organisation that will honour our commitment as a Te Tiriti o Waitangi partner and prioritise the needs of whānau” (MSD, 2020, p. 7). The three shifts from Te Pae Tawhiti are reiterated within Te Pae Tata in terms of their enactment for Māori:

Key shift 1: *We will earn the respect and trust of Māori*

Key shift 2: *We will form genuine partnerships with Māori*

Key shift 3: *We will support Māori aspirations.*

MSD hosts Whaikaha | Ministry of Disabled People⁵ (MSD, 2023), which was established in the 2022 Budget to help drive an Enabling Good Lives (EGL) aligned transformation of the disability system. The focus of Whaikaha was instituted at its inception; namely, “to enhance the mana, and improve the lives of disabled people,” including tangata whaikaha having “control over how their personalised funding is used to meet their unique needs” (NZ Government, 2022). The EGL initiative, in turn, was developed in 2011 by members of the disability community. The vision of EGL is a future where “disabled people and their families will have greater choice and control over their lives and supports

⁵ Note that Whaikaha is operationally autonomous.

and make more use of natural and universally available supports” (Enabling Good Lives, 2023). In other words, the vision is about shifting authority away from ‘the system’ and vesting it with “disabled people and their families as experts in their own lives, and leaders in their lives and communities” (Whaikaha | Ministry of Disabled People, 2024). A principles-based approach (self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, relationship building) is at the heart of work to achieve this vision (Enabling Good Lives, 2024).

Also within MSD, Work and Income delivers income support payments. The practice statements in Work and Income’s client commitment statement are aligned with Te Pae Tawhiti; that is, “knowing (ka mohio ki a koe – know you) and supporting (ka tautoko i a koe – support you) clients, in collaboration with them (ka mahi tahi – with you)” (Work and Income, 2018).

Income support for tāngata whaikaha Māori and their whānau and/or carers to help them meet the costs of a disability or health condition includes the following payments (Graham, 2022). There are two main benefits for working-age people whose work capacity is impacted by a health condition or being disabled:

- Jobseeker Support – of up to \$353.46 per week after tax for a single person aged 25 or over without children when a health condition (or disability) prevents working or means they are working reduced hours.
- Supported Living Payment – of up to \$402.84 per week after tax for a single person aged 18 and over without children whose capacity to work is severely and permanently restricted due to disabilities, health conditions or injuries.

Supplementary assistance for people impacted by a health condition or being disabled includes:

- Disability Allowance (DA) – of up to \$78.60 per week for ongoing additional costs incurred by disabled people or people with a health condition likely to last six months or longer, who have income below the qualifying income threshold (e.g. \$823.31 per week for a single person from 1 April 2024). The rate of payment is based on recipient’s verified costs. DA can be paid for a child.
- Child Disability Allowance – of \$59.23 per week (non-taxable) for carers of a child with a serious disability likely to last 12 months or longer.

Supplementary assistance through Temporary Additional Support may also be available to those needing medical treatment, and those in hardship or facing essential disability costs they are unable to otherwise meet (Graham, 2022).

MSD has responsibility for a range of housing-related functions including:

- assessing eligibility for social housing and management of the social housing register
- payment of housing-related financial assistance
- providing support through contracted navigator services, integrated services case management and Housing Brokers who assist people to access sustainable private accommodation
- ensuring people with no other housing options are supported into emergency accommodation, usually motels.

The present research

The research described in this report explored the additional costs tāngata whaikaha Māori, whānau of tāngata whaikaha Māori and/or Māori with long-term health conditions experience, and whether they are receiving adequate income support to enable them to live good lives. The research aligned with Article 31 of the 2006 United Nations Convention on the Rights of Persons with Disabilities

(UNCRPD) (United Nations, 2023); namely, that “States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.”

Exploring the direct costs (i.e., out-of-pocket costs) of living with an impairment can be done in at least three ways: (i) comparing the actual costs of disabled people with non-disabled people, (ii) asking disabled people to estimate the additional met and unmet costs they have (the approach taken in our research), or (iii) estimating how much extra money a person with impairment would need to achieve the same level of wellbeing as someone without impairment (Mitra et al., 2017). While noting that quantifying extra costs can inform policy makers, Mitra and colleagues (2017) also called for more qualitative and participatory research into the consequences of the costs of disability, including the nature of unmet need. As Kingi and Bray (2000) reiterated, qualitative research allows people – in their research, Māori – to describe their concerns and contribute their lived experiences to understandings of disability. The present research sought these insights by setting the enquiry about direct costs within the context of a conversational interview and enquiry into people’s lived experiences.

Research questions

The research set out to answer the following questions:

What are the direct costs associated with being disabled or having health conditions?

Including 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.

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.

How are people compensating for unmet needs? This might include, for example, adapting their social situation, or having other ways of getting by to reduce the impact of unmet needs. It recognises resilience and ways that disabled people and those with health conditions, and their families and whānau, exert agency in the current system.

What are the indirect costs and costs of lost opportunities associated with being disabled or having health conditions, or compensating strategies? This may include forgone 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.

How is a person’s situation and the context they and their family or whānau live in inter-related with the costs they face? 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, mental distress.

Are tangata whaikaha Māori and Māori with long-term health conditions accessing income support payments that help with costs of health conditions and/or disability and, if not, why not? This is focussed on income support payments, noting that they could also be entitled to have the cost of equipment or home modifications covered via Ministry of Health or ACC and may not be accessing those entitlements.

In the next sections we describe our methodology – Kaupapa Māori disability-centred research – and study methods.

Methodology

In deciding the methodology for this study, we began from a foundation of Kaupapa Māori (by, with and for Māori) enquiry and looked to how other Māori researchers were undertaking their research with tāngata whaikaha Māori me ō rātou whānau, and Māori with long-term health conditions. We also bore in mind Donna Mertens (2018, p. 145) co-option of the term ‘universal design’ from architecture to describe research methodologies that are “accessible, inclusive, and usable by all people, including those with disabilities, chronic illnesses, or who use a language other than English” (including Sign Language users). Our methodological considerations therefore included using this universal design lens to identify how our Kaupapa Māori methodology should be tailored for this research.

To facilitate a Kaupapa Māori, disability-centred methodology for this project, the research team also included tāngata whaikaha Māori advisors and whānau advisors. We were familiar with the benefit system from our previous research, and some of the Māori mothers we had previously interviewed and/or their tamariki were disabled and/or had long-term health conditions (Cram et al., 2020, 2024). We had undertaken several Kaupapa Māori (by, with, and for Māori) qualitative health, social service, justice, education and housing research studies with Māori. Katoa Ltd had not, however, previously focused specifically on long-term health conditions and disabilities as a research kaupapa.⁶ For this reason, we had the following advisors:

- Deni Tipene (Te Āti Awa) is an Enrolled Nurse with 10 years of in-depth health experience who completed her Bachelor of Nursing Māori degree in 2023. She brought a wealth of lived experience from caring for a child with a disability and having a disability. Previously, she has been a participant in our research as a young wahine māmā.
- Helena Tuteao (Ngāti Mahuta) has lived experience of disability and 20 years' experience in a variety of roles in the disability sector. Since 2013 Helena has been on the Waikato Leadership Group of Enabling Good Lives, and currently works for My Life My Voice as a Community Capacity Builder Lead, prioritising investing in disabled people and communities.
- Louise Were (Ngāti Rongowhakaata, Ngāti Tūwharetoa) is a Māori evaluator who specialises in evaluation and policy analysis, with her professional background stretching across Māori, public health, disability, and community contexts. She has raised a daughter with a disability and strongly advocates for the disability communities.

During the finalisation of this report Dr Huhana Hickey (Ngāti Tāhinga, Whakatōhea) and Matua Ike Rakena (Waikato, Ngāti Whātua, Te Waiohū, Ngāi Tahu) joined us to peer review our report and support our meaning making.

In addition to Fiona Cram and Anna Adcock, our research team consisted of four wāhine Māori who are whānau of tangata whaikaha: Areta Ranginui Charlton (Tūhoe, Ngāti Ruapani), Arianna Nisa-Waller (Ngāi Te Rangi, Ngāti Ranginui), Wendy Isaia (Ngāpuhi) and Fran Kewene (Waikato, Maniapoto).

A Kaupapa Māori methodology sees being Māori as normal, thereby avoiding a victim-blaming mentality and promoting a structural analysis (Cram, 2009; Smith, 2012). This resonates with disability-centred and disability-led methodologies championed within a social model of disability, which challenge deficit-based understandings of disability as solely related to an individual's impairment and enquire about the barriers to disabled people participating in society (Smiler et al., 2022). Like Kaupapa Māori inquiry, this methodological feature enables an enquiry to have a dual focus on the lived experiences of tāngata whaikaha Māori and their whānau, and on the structural barriers to tāngata whaikaha Māori living good lives (Smith, 2012). As Wyeth and colleagues (2021) explain in the protocol for their research with Māori about injury-related disability burden,

⁶ Although Fiona Cram was involved in writing Uia Tonutia, The Ministry of Health's 2011 Māori Disability Research Agenda.

the problem is not ‘being Māori’; instead, rather than locating the causes of inequities and adverse outcomes with the individual, system and structural biases are explicitly investigated (Wyeth et al., 2021, p. 4).

In their discussion of a Māori perspective on disability, Smiler, Stace and Sullivan (2022) write about the intersectional and dynamic experience of whānau hauā. Ingham and colleagues (2022, p. 1) also note the poorer outcomes that arise “because of the multiplicative impacts that occur from the many intersecting forms of oppressions with ableism and disablism.” When we considered issues of intersectionality we mainly sought to mitigate against the ‘double whammy’ of side-lining disability issues within Māori research and Māori issues within disability research (Collins et al., 2009). Our mitigation was a commitment to enabling the voices of tāngata whaikaha Māori, their whānau, and Māori with long-term health conditions to be heard (Ingham et al., 2022; Minister of Health, 2023b), including voices about how research should be undertaken. For example, key priorities identified by tāngata whaikaha Māori and their whānau are that research should:

look beyond impairment to quality of life; respect participants’ identity integrity; acknowledge the centrality of whānau; and take a holistic perspective with respect to disability (Ministry of Health, 2011, p. 2).

Our Kaupapa Māori methodology acknowledges whānau as the fundamental building block of Māori society (Smith, 1995). The key priorities above and Hickey’s scholarship reminded us to retain an holistic, intergenerational, quality of life approach when engaging tāngata whaikaha Māori, their whānau and Māori with long-term health conditions in our research. Jones et al. (2024) also encouraged tāngata whaikaha Māori in their research to share about the impacts of disability on their own lives as well as on the lives of whānau members. In addition, Smiler and colleagues (2022, p. 1147) write that research methodology should reveal “what living with disability mean[s] for disabled people themselves and their solutions for barrier removal.”

Many Kaupapa Māori researchers have co-designed their research methodology with tāngata whaikaha Māori, acknowledging that all parts of the research process are part of whakawhanaungatanga (Ingham et al., 2022; Smiler et al., 2022). This resonates with Cree scholar Shawn Wilson’s (2008) writing about research as ceremony, where relationships are forged and strengthened throughout – from the beginnings of research to the co-construction of meaning and the design of research products. Opportunities for co-design in the present research were however limited. Instead, we asked tāngata whaikaha Māori me ō rātou whānau, and Māori with long-term health conditions to talk with us about their lives in response to pre-determined questions and in the context of a government agency’s research aims. We therefore took care to fully inform potential participants about the nature of the research so they could decide whether to give their informed consent to be involved.⁷

Linda Smith describes how once the kaupapa of the research is tika (true) then the priority for researchers is to find the right methods and the right people (Smith, 2021). Most of the interviews for this research were carried out by two Māori interviewers, at least one of whom was whānau of tāngata whaikaha Māori. Our plan for this pairing of interviewers for some interviews, however, was disrupted by the loss of whānau members and the need for interviewers to attend to their own whānau priorities. To the extent allowed by the structured interview schedule, we also asked questions in a relaxed and conversational way (Keil & Elizabeth, 2017) to gain an understanding of participants’ everyday lives, their additional costs, and their receipt of income support. Tāngata whaikaha Māori and their whānau guided the pace of the interviews and provided information they considered relevant to the questions being asked.

⁷ The kaupapa of this research might be described as *with* tāngata whaikaha Māori me ō rātou whānau, undertaken *by* Māori and whānau researchers, but not designed *by* tāngata whaikaha Māori.

Engagement with participants was informed by the principles of a 'community-up' approach to researching with whānau (see Table 1). This is not unlike Jones and colleagues (2024) use of the 'Whānau Tuatahi Framework' (Jones et al., 2010) to inform the Kaupapa Māori methodology of their research with tāngata whaikaha Māori.

Ethics

The protocol for this research was reviewed by the MSD Research Ethics Panel. This included review of our adherence to the accessibility charter in recognition that MSD is the lead Crown Agent for the charter and a set of privacy protections (Appendix B). We also discussed the protocol with the Māori members of an Expert Reference Group formed by MSD to support this and other projects and formed our own Rōpū Kaitiaki of five tāngata whaikaha Māori and whānau advisors.

All research information and processes were flexible, easy to understand, and in plain language, including Easy Read and Easy Read te reo Māori. This was coordinated with and supported by MSD's Alternate Formats team.

The consent information provided to participants made it clear that some de-identified information would be provided to MSD, but at no time would MSD receive any information that identified the participants. A general Participant Information Sheet and Consent Form can be found in Appendix A.

All participants received a copy of information about support services in their local area. We also undertook a risk mitigation review and utilised a distress protocol (Appendix B). No participants became distressed or were assessed as being at risk.

MSD prepared an additional Information Sheet and Consent Form for participants, seeking their consent for their contact details to be provided to MSD following their interview so that participants could receive a check of whether they were receiving their full and correct entitlement to benefits and payments (Appendix C). This check was separate from the research project and no information from the research project was to be provided to MSD unless the participant decided to share this themselves. No participants took up the offer of this check, and so there was no follow-up with any participants about how they had found this entitlement review process.

Table 1. 'Community-up' approach to researching with whānau.

Cultural value	Research principle	Research practices
Aroha ki te tangata	Allow people to define their own space	We engaged in cultural 'rituals of encounter', guided by participants. Participants defined their space and meet on their own terms, including how they participated in the research and who supported them to do so. Whakawhanaungatanga enabled participants and researchers to make linkages and connections. We respected the fluidity and diversity of participants, including allowing them to self-identify (e.g., as Māori, as tangata whaikaha Māori).
He kanohi kitea	Be a face that is known	It is important for the researcher to be known, so at least one of the two interviewers had some link to the participants' Māori and/or disability community.
Titiro, whakarongo ...kōrero	Develop understanding to find a place from which to speak	Within the context of this enquiry, participants set the agenda for the research, including the pace at which it proceeded and decisions about: <ul style="list-style-type: none"> • What their story was • What they wanted to speak to • What the role of researchers was.
Manaaki ki te tangata	Share, host, and be generous	Participants' whānau were able to participate in the research. We provided the support, including interpretive support, desired by tāngata whaikaha Māori and their whānau. We took food to in-person interviews, and were clear that we did not expect to be fed. We provided a koha to participants and whānau who attended in support. Participants were able to move in and out of their [research] space (e.g., stand, sit, give the researchers a house tour).
Kia tūpatō	Be politically astute, culturally safe, and reflexive	We were cautious that participants were kept safe – that they were left in the same, or a better, space than before they engaged in the research. Many said they would be happy to be contacted about other research projects. Participants had the time and space to practice their own tikanga (e.g., karakia). Participants made their own decisions about following up with the benefit expert. If they were undecided, we followed up with them 4-5 days after the interview to give them time to think through their decision.
Kaua e takahia te mana o te tangata	Do not trample on the dignity of a person	To help ensure that the research journey was enjoyable and enlightening for participants, we: <ul style="list-style-type: none"> • Communicated with tāngata whaikaha Māori and their whānau about the research, including returning the transcript of their interview and sharing the findings and publications if they wanted to see these. • Acknowledged participants' ideas about the current research and about future research.
Kia māhaki	Remain humble	We were committed to remaining humble and seeking ways of gathering knowledge that were accessible, inclusive and usable by all people. We responded to any inquiries from tāngata whaikaha Māori and their whānau respectfully and thoughtfully, often seeking advice about income support from our MSD colleagues and providing this to participants. We answered questions (or sought out the knowledge) and shared our knowledge in response to requests. We sought to support tāngata whaikaha Māori and their whānau in their understanding and use of research findings.

Source. Adapted from Smith (2006, p.12, Diagram 1).

Method

Participants

The population of interest for the study was tāngata whaikaha Māori and Māori living with long-term health conditions (adults aged 18-64) with incomes that made them potentially eligible for income support payments, and Māori in the same age and income brackets who care for a child (aged under 18) or adult (including an adult child) who is tāngata whaikaha..

Selection and recruitment

The majority of participants were adults who had participated in MSD's 2022 New Zealand Income Support Survey (NZISS) (MSD, 2024) as a respondent or as someone who completed the survey on behalf of a respondent. The NZISS was administered by Reach Aotearoa and surveyed 18–64-year olds on low- and middle-incomes. The current study drew on the NZISS by re-contacting participants who had agreed to be approached about the possibility of answering other questions of interest to MSD. Potential participants were told a \$100 koha would be offered to participants in recognition of their contribution. More details of the selection and recruitment processes can be found in Appendix D.

The regions participants were selected from were Auckland (including Pukekohe, Awhitu and Puni), Taranaki (including New Plymouth, Waitara, Stratford, and wider rural Taranaki), Dunedin and Invercargill. Two participants who were recruited through this process were living in Hamilton at the time of their interview.

The goal was to recruit 20 participants from the cohort of eligible participants. In the event, 16 participants were recruited from the NZISS cohort. An additional four participants were selected and recruited through the research team's networks to increase the diversity of our participant sample. Invitations were issued to two tāngata whaikaha Māori and two whānau members. Three of these participants were in Auckland and one was in Hamilton.

Interview Overview

Participants were invited to be interviewed at a place and time convenient to them and given the option of an in-person or a telephone/Zoom interview.

Building rapport

At the start of the interview, time was taken to build rapport with participants. This involved introductions (whakawhanaungatanga), karakia (with participant agreement), giving an overview of the purpose of the research, reviewing the participant information and responding to any questions or concerns, and seeking participants' informed consent to be interviewed and for their information to be included in the study.

In setting the scene for the research we acknowledged that tāngata whaikaha Māori may well receive care and support from those they reside with and from whānau and friends outside their home, and that participants may also have whānau who are tangata whaikaha Māori. We explained, however, that the questions we were asking in the interview were about them (the person recruited), as it was their experience that MSD wanted to know about. At the same time, we let participants know they were most welcome to explain how things worked in their whānau if they felt it was important for us to know.

Rapport building and the early stages of the interview was an opportunity to hear from participants about how they identified with Māori culture and the language they used to describe impairments or health conditions that affected them and others, and their relationships with others. This helped guide

the language the interviewers used when asking the questions. Answers to some of the questions in the interview schedule were often provided within the context of establishing rapport, and any answers were acknowledged when the questions were asked (e.g., “You told us earlier...”). There was also a final, wrap-up question and check about whether there were other things participants felt we should have asked about.

The interview schedule is set out in Appendix H. This was structured around the following three areas of enquiry which grouped together the different research questions: ⁸

1. The participants’ situation and the housing and neighbourhood they and their whānau live in, and their participation in paid work and other activities.
2. The additional costs participants attributed to being disabled or having a health condition, having a disabled child or a child with a health condition, and compensating strategies.
3. Participants’ past and current benefit receipt and their experiences of claiming and/or not claiming income support payments.

More details on conduct of the interviews, piloting, recording and analysis can be found in Appendix D.

Limitations

Because of the small sample, the findings from this study may not necessarily be generalisable to the wider population of tāngata whaikaha Māori, whānau of tāngata whaikaha Māori, and/or Māori with long-term health conditions. The study will not have captured the diversity of experiences and views. A proposal by the researchers and MSD to boost the number of participants to 35 was not able to be delivered on because of budget constraints. Some limitations of this study were likely due to the need to use a pre-determined participant pool (see description of the NZISS above, Selection and recruitment and Appendix D).

While the participants were a broad range of ages, all but one was female. The experiences of tāne Māori (Māori men) are therefore not well-represented. As noted in the introduction, tāne Māori experience higher rates of disability than wāhine Māori (Māori women) (King, 2019). Tāne Māori are also nearly twice as likely than wāhine Māori (60.8% vs. 39.2%) to be allocated Ministry of Health disability support services, with this difference largely reflected in supports for 5-24 year olds (Ministry of Health, 2022). At least three of the female participants in the present study were raising tamatāne whaikaha Māori (disabled Māori sons), and their input provided insights into the experiences of young tāne Māori.

The small sample also limited the range of disability and long-term health conditions that participants had lived experience of. Most notably tāngata whaikaha Māori with high and complex needs were not well represented, so that the discussion of costs in this study probably under-states the costs borne by these tāngata whaikaha Māori (Mitra et al., 2017). Even so, the patterns of costs described here and the feedback on what they are missing out on because of affordability challenges may well resonate with other tāngata whaikaha Māori, their whānau, and Māori with long-term conditions.

⁸ 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 planned 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 no participants were interested in proceeding with this assessment.

Research participants

Eight interviews were undertaken with Māori mothers of tamariki or rangatahi who were tāngata whaikaha Māori (Table 2). One participant did not however identify her daughter as tangata whaikaha Māori. And one participant who had raised tāngata whaikaha tamariki who were now over 20 years of age was also caring for a younger tangata whaikaha tamatāne. The average age of these participants was 45.0 years (s.d.=9.1 years), while their children ranged in age from 6 to 31 years.

The 29 year old tangata whaikaha Māori daughter of one participant was present during the interview and one interviewer talked with her while the other interviewer talked with her mother. Both were included as participants in this research. The 10 year old daughter of another participant was also present during the interview and participated in the interview but was not included as a participant because of her age.

A further twelve interviews were conducted with tāngata whaikaha Māori and/or adults with long-term health conditions. One interviewee identified as having long-term health conditions and tangata whaikaha Māori, and another identified as having long-term health conditions and whānau of tangata whaikaha Māori. These participants ranged in age from 23 to 63 years, and had an average age of 45.8 years (s.d.=11.1 years). One identified as male and 11 identified as female.

Table 2. Overview of participants' lived experience

Identify	Description	N
Wh	Participants who identified solely as whānau of tangata whaikaha Māori	5
Wh + TWM	Participants who were whānau of tangata whaikaha Māori and also identified as tangata whaikaha Māori	2
long-term health conditions	Participants who identified solely as having long-term health condition/s	7
long-term health conditions + TWM	Participants who identified as having long-term health condition/s and as tangata whaikaha Māori	1
long-term health conditions + Wh	Participants who identified as having long-term health condition/s and as whānau of tangata whaikaha Māori	1
TWM	Participants who identified solely as tangata whaikaha Māori	3
Wh -	Participant who did not identify as whānau of tangata whaikaha Māori	1

Note. * TWM=tangata whaikaha Māori, Wh=whānau

Findings

Enquiry Area 1 – Participants’ situation and the housing and neighbourhood they and their whānau live in, and their participation in paid work and other activities

This first enquiry area provided a general description of participants’ housing, neighbourhood, work and activities. Health and/or disability was only touched upon here when it was raised by participants.

Housing

The majority of participants (N=14) lived in rental accommodation, owned by a private landlord (N=12). Many of those who were renting privately mentioned the increasing cost of their rent, with one saying their landlord “charged an arm and a leg” and put the rent up each year (also see Housing below, under Enquiry Area 2).

Six participants owned their own home. One of these participants was also renting as her and her husband were renovating their home. Another participant described how she contributed to paying the mortgage by finding flatmates to live with her in a house owned by her family.

I live in a three-bedroom. It's insulated and double-glazed. It's owned by my family and I contribute by way of finding people to live in the house and paying the mortgage. It was bought by my brothers who are a bit older than me. And I live in it to keep it tidy, to keep it landlarded. I'm in a very good situation...I've been very, very lucky – aged 20-29, long-term health conditions

One participant stayed in the basement garage of her mother’s owner-occupied house.

Table 3. Housing tenure

Tenure	Tangata Whaikaha Māori / Māori with Long-term Health Conditions	Whānau	Total
Private rental	7	5	12
Social rental	1	1	2
Homeowner	5	1	6
Other	0	1	1
Total	12*	8	20*

Note. Numbers do not sum because one participant was a homeowner who was currently renting while she and her husband renovated their home and so appears as both a private renter and homeowner.

Generally, participants’ houses were two- to three-bedrooms, sometimes with a cabin or other ancillary dwelling on-site. The exception was a four-generation whānau that had recently moved to a six-bedroom house so they had room for everyone.

A whānau participant said their whānau had been in the same house since their own mother was a baby. Others mentioned being in their accommodation anywhere from a year or so to 20 years or more.

We’ve been at the same house since my mum was a baby. So when my Nan and Granddad first moved to [this suburb] they bought the house for them and their five kids – no, three kids, that’s right. So mum was only six months, and mum is now 54 – aged 30-39, whānau

I’ve been here for 20 years, and I’ve got the same landlord who doesn’t do much but he’s never put my rent up – aged 50-59, whānau

Participants spoke about liking the things that made their home liveable; for example, a nice view, being close to work, being able to have pictures of whānau around, having air conditioning/a heat pump, being warm, and being on a single level. The increasing cost of rent and issues related to their housing (e.g., lack of accessibility, lack of insulation) were the most frequently mentioned housing challenges.

Sometimes I struggle because there's no railings outside, so I've got like these steps. Well, three steps to get into the lounge, and on the other side of the house I've got three steps and go through one door and then you go through another door. So, if I'm really bad [I can't] get up those steps even though. My legs are like, 'Nah! No, you're not doing anything today' – aged 50-59, long-term health conditions

Other challenges mentioned by individual participants included not being able to be spontaneous (e.g., accept invitations because of the need to make arrangements for her son), clashes with whānau members (see quote below), or just wanting to finish renovations and return to their own house. Five participants did not mention housing challenges.

What irks me the most is that I love my grandchildren and I treat them with kid gloves, and love them but [my daughter] doesn't do the same for [my adopted son], so it's become a little bit toxic. ... But it's so hard to find a rental. I'm stuck – aged 50-59, long-term health conditions & whānau

Participants suggestions for what might help with their housing challenges included more money, being able to get a mortgage to buy their own place, supports to make their house safer (e.g., handrails), being able to find tradespeople, and having ways to alleviate their loneliness. Of these, the alleviation of financial stress was the most common suggestion.

I was trying to get a mortgage, but I don't think I can and my credit rating is not the best – aged 50-59, long-term health conditions & whānau

Community – Neighbourhood

Two-thirds of the participants (N=13) said their neighbours were the best thing about the location of where they lived. Their neighbours, whether they were related to them or not, provided them with a sense of community and also a sense of safety. A whānau participant also commented on moving to a new community where the people were “so much nicer” to her, meaning less racist.

Here, where we are, we've got amazing neighbours. Not many places in [this city] you can leave your windows open at night. We're down a long driveway and our neighbours in front watch our place like hawks – aged 40-49, long-term health conditions

[My son's] made friends with a few of the neighbours. When he was catching the bus just down the road, this elderly lady [and him] got on really really well. It's a lovely neighbourhood and it's safe. There's been times I've gone out and I've left the house unlocked if [my daughter] doesn't have a key. Never had anything [go] missing in four years – aged 50-59, long-term health conditions & whānau

However, four participants said their neighbours were their biggest challenge. A whānau participant said that when she rebuffed a neighbour's advances, he threw broken glass over her fence and her dog had cut itself on it. She described how things had then escalated to her neighbour's whānau threatening her, leading her to ask Kāinga Ora to build her more secure fencing. When they refused, she wrote to the Kāinga Ora Minister and the fencing was then constructed. Another participant talked about having “a psycho” across the road while another described the difficulty of getting to know their neighbours.

Well, I think it's for me I find it a bit challenging getting to know my neighbours. ... my kids don't like one of the neighbors because they say that [this neighbour] looks right into our house. And

so I don't know what to make of that. ... they just stand outside on their lawn and stand there staring into our house. ...those little things remind me that being blind, I feel a bit more vulnerable. ... I don't want to shut my curtains 24/7 – aged 40-49, tangata whaikaha Māori

Some participants talked about liking their closeness to amenities (e.g., parks, supermarket) and the quietness of their neighbourhood.

I must say it's got good parks; parks over there, we've got one there. ... and you could walk to town – aged 40-49, tangata whaikaha Māori

Other participants, by contrast, described their lack of access to amenities and the lack of quiet as challenging. The kinds of support a few participants wanted help with so they could overcome the challenges they experienced in their community included financial support to live somewhere else, security cameras, and the ability to take their tamariki with them to facilities (e.g., the gym).

Employment

Ten participants, including two whānau members with tamariki who were 10-11 years old, were in paid employment, working between 10 and 50 hours per week (average=35.9 hours per week).

Sometimes the nature of work with Māori is that you go wherever you're needed, so [the hours] can change, but usually I try to keep within a 40 hour week – Aged 20-29, long-term health conditions

I used to work more hours, but once I developed the rheumatoid arthritis I had to cut back on the hours, because I do domestic cleaning, and unfortunately it was just too much, so now I've gone down to about eight to ten hours – aged 50-59, long-term health conditions

Participants worked in healthcare, hospitality, education, social services, and businesses. The help they wanted with participating in paid employment included a more culturally responsive workplace, getting healthier themselves, being able to stop doing shiftwork, a larger workforce, and more money. Generally they also wanted Work and Income to be more responsive. One participant wanted the government to just look at their personal income rather than include their husband's income in the calculation of what they were entitled to.

If I didn't have to stress about going to work all the time and being the sole provider for me and [my 11 year old son], I think life would be a lot better. Life would be a lot calmer. We'd probably enjoy things a bit better and I wouldn't be stressed all the time – aged 50-59, long-term health conditions & whānau

I would love it if Work and Income, what it would look like if they were to put a EGL lens over what they do. I think it would look heaps different. ... like, how might Work and Income play a role in connecting communities rather than just working with people in isolation? Because...that would be beneficial to people and communities. ... I think that would be an essential element if they put on EGL lens over it, rather than [this being] just a far-fetched aspiration. ... And [staff] having disability awareness training – aged 40-49, tangata whaikaha Māori

Whānau members who were not in work said they were focussed on their tamariki, or were looking for employment now that their tamariki were older.

I committed myself to my children. If I was working full-time, there's no way I'd be able to keep my finger on the pulse of what's happening – aged 40-49, whānau

At the moment, [I'm looking for] part-time [work] because I haven't worked for so long. It's like I'm 16, I don't even know what I want to do. I'm not dumb. I could do something but you know, it's just finding what I'll be good at – aged 50-59, whānau

Whānau Activities

There was a wide range of activities that participants engaged in, with going to the beach, playing games (e.g., cards, outdoor ball games), and organising or attending whānau gatherings being common activities. Many of the activities participants mentioned were free or low cost. Named activities that incurred costs were gym attendance and other club membership.

You know, we have wānanga. We spend a lot of time with either of our whānau, whether it be singing, whether it be eating at the pools, at the beach, and then we also spend a lot of time at the marae – aged 40-49, long-term health conditions

I'll go to the beach, but I don't go swimming. I just sit on the beach and watch the husband fish or watch the kids play...I don't go for walks 'cause my knees and that bugger up. I don't do a lot of things – aged 50-59, long-term health conditions & whānau

The challenges participants faced with participating in whānau activities included pain, lack of ability or lack of courage to get out and about, feeling judged because of their size, and lack of money for petrol and/or for entry fees (e.g., to a pool). Being confined to home or to their neighbourhood was therefore often a combination of what they could physically do and what they could afford to do. These issues were reflected in what participants said would help with the challenges they faced.

I mean, maybe like a light exercise group or things like that, but then again, you see, because I don't know what my body's going to do, then I don't want to be in a position where I'm in trouble – aged 50-59, long-term health conditions

Sometimes if I get up at five o'clock in the morning, I used to get up and read and get a few things out of the way, and sometimes I can do that and other times I'll get up at five, and next minute you turn around and [my son's] right behind me going, "What are you doing?" It's like, I was hoping to sit down and have a cup of coffee and read for a bit or catch up on something else – aged 50-59, tangata whaikaha Māori & whānau

Enquiry Area 2 – The additional costs participants attributed to being disabled or having a health condition, having a disabled child or a child with a health condition, and compensating strategies.

The following section reports on the number of participants who talked about each of the cost areas. For many of the costs participants had not thought about what 'extra' they might be paying, so much of the reporting below focuses on their comments about affordability and trade-offs. The budget costings provided by participants are in Appendix I.

Housing

The average weekly cost of their rent or mortgage payments was around \$500 (for those who disclosed this cost). There was a wide variation in weekly rents / mortgage payments and a trend for those who owned their own home to have lower housing costs than those who were renting (average=\$258.13 vs. \$591.32 respectively), potentially because many had owned their homes for some years.

A participant with long-term health conditions described the extra rental cost she was paying because she needed a house that reduced her risk of an asthma attack by being warm, dry and free of allergens.

Yes, because if there is black mould, I wouldn't, I wouldn't be in there. I'm allergic to penicillin, as well. So all of that sort of thing. It's just not healthy for me. So I definitely wouldn't be looking at a place that was like that – aged 40-49, long-term health conditions

A tangata whaikaha Māori participant described her owner-occupied house as costing an additional \$100,000 because she needed to be close to a shopping centre and to bus routes so her children could get to their schools. She received the maximum Accommodation Supplement but said she felt uncomfortable having to share all her financial information with Work and Income in order to be eligible for this.

I feel...I don't get as much privacy as I like. Because things are so inaccessible I have to share information with other people. I don't get a choice about my privacy. ... It felt like there was a real power imbalance – aged 40-49, tangata whaikaha Māori

Two other participants made more general comments about paying too much rent because they wanted to be in multigenerational households. A whānau participant with long-term conditions said she was spending too much on rent because she needed to reciprocate childcare responsibilities with her daughter who she lived with, and also that moving would be difficult for her and her tangata whaikaha Māori whāngai son. The other whānau participant, who lived in a four-generation household, said she was “bawling my eyes out and freaking out” about the high cost of their rent (\$1,200 a week), with the solution being to split this rent with her tangata whaikaha Māori adult daughter.

Transport

For the seven participants who shared this information, their weekly transportation costs ranged from \$0 (as her employer paid her costs) to \$200. Only a few participants described themselves as paying extra travel costs, with the extra amount ranging from \$40 to \$100 per week. Two explained their extra costs as related to needing to either drive themselves or a whānau member somewhere.

I probably do, because I can't walk that far, so I probably spend more on getting closer to places and things like that...If I don't have to, I'll stay home sometimes, just so I'm saving the petrol...Well, today is a stay at home day. So, I've worked to get more money, and I'm not breaking my budget – aged 50-59, long-term health conditions

My daughter suffers from mental illness, so if she's got an appointment and she's having a rough day I take her to either [name of town] or [name of city] or wherever she needs to go – aged 50-59, long-term health conditions & whānau

When others said they were not paying extra transport costs, this appeared to be because they did not have the money to pay extra. Instead, they were walking, biking, taking public transport and/or not going out.

I got [my son] a bike so that he could bike to school and be independent but it's a fight and a battle to get him to bike to and from school – aged 40-49, long-term health conditions

And what it's resulted in is the kids can't do every single thing they'd like to, as I need to get them there. ... If they can't bus to where they need to get to then [the only option] is to taxi them and that gets quite expensive – aged 40-49, tangata whaikaha Māori

A participant with long-term health conditions spoke about spreading the word among her peers about how to get access to subsidised taxis through a community organisation. This meant that the cost of her getting out and about was affordable.

Having or not having money for petrol and/or for vehicle upkeep costs (e.g., warrant of fitness, registration, servicing) for those who owned a car, determined what they could or could not do. For example, the cost of travel was a barrier to going places for many participants, including travelling to see whānau and/or journeying back home to their tribal area. A participant with long-term health conditions for example, had not been able to engage in the cultural activities she wanted to because she could not afford the transportation costs.

Food

Six participants (three whānau with tangata whaikaha Māori tamariki, and three tangata whaikaha Māori / Māori with long-term conditions) disclosed their weekly food budgets. The three whānau were spending over twice as much on food, on average, than the three tangata whaikaha Māori / those with long-term conditions. This is perhaps not surprising given that whānau were feeding tāngata whaikaha tamariki and rangatahi with big appetites. As a māmā explained, her tangata whaikaha son was over six foot tall and ate a lot.

For many participants, their food budget was the only place they could still save money if they had to. However, it was hard for a tangata whaikaha Māori participant to do price comparisons and make savings as her support person did her grocery shopping. Others described how they had grown or gathered food in the past to save money on food, but were now unable because of their mobility issues or their work hours.

Well, you can only take it from food there's nowhere else to take it from. I can't take it from the power; I can't take it from the rent; I can't take it from the petrol; I can't take it from the clothing, from the doctors, from the gym, which is the only thing I've got, so it comes from the food. ... you just live week to week – aged 50-59, whānau

When the cost of food was an issue for whānau, some participants compromised on the quality of the food they were buying (e.g., less fresh food and more processed food items). This compromise was difficult for whānau participants as they believed less healthy food negatively impacted the health and wellbeing of their tāngata whaikaha tamariki. Other participants with long-term conditions said they were not able to afford food they had been told they should be eating or to fully avoid foods (e.g., gluten) they had been told they should not eat.

There are some foods that I've been told I should eat, but I can't afford them. Not a chance. ... More so whole foods and the fruit and veggies. Take off the tomatoes, tomatoes are no good for all my arthritis – aged 50-59, long-term health conditions & whānau

I'm gluten dairy free. Yes, all the food has to be gluten and dairy free, so that's a lot more expensive buying it – aged 50-59, long-term health conditions

Some whānau participants downplayed the importance of food for themselves as they sought to save money. A māmā said she might go without or eat after her tamariki. A tangata whaikaha Māori participant and a whānau participant said they were doing intermittent fasting to cut down on the amount of food they ate. Both reported being very happy with the weightloss they had experienced as a result.

I'm just not that interested in food at the moment and all it's been a couple of years, because I'll eat as much as I need to eat but you know, my kids will always like, they will always come first – aged 40-45, whānau

How much weight have you lost so far? I can't remember. Mum: Fifteen kilo. ... It's really easy, and it's the best thing I've ever done – aged 20-29, tangata whaikaha

Some participants said they were not shy to ask for help with putting food on the table; for example, asking their children's school for help, going to foodbanks, or seeking food grants from Work and Income.

Personal Care

The general feedback from participants was that they would love to spend money on themselves and personal care but they could not afford to. Three participants said they were paying extra for personal care because of disability or long-term health conditions. In two cases, participants were buying

essential oils to either help them navigate their way around their home (i.e., different smells for different rooms for a tangata whaikaha participant), or to help their tangata whaikaha son relax and focus. The third participant was spending the most each week on personal care, with this including her medicines and the cost of trips to the pharmacy to get them.

Three of those who mentioned their budget explicitly said it was \$0, and that they would love to be able to afford personal care items. Even though a tangata whaikaha Māori and whānau participant said \$0, she managed to save for a 'treat' every now and then, although she also noted that she had not had a haircut in four or so years.

Even sometimes and something simple like getting my eyelashes and eyebrows tinted; I can kind of manage that, but I have to squirrel money aside to go and do it. It's those kind of things that are completely out of budget; the nice moisturizers and things, can't do them - aged 50-59, tangata whaikaha Māori & whānau

Childcare

Two participants said they had childcare costs. A whānau participant was paying someone to get her son to school if she was working a morning shift and could not do this herself. This cost her \$30 a time and was sometimes up to three times a week and sometimes not needed in a week. She did not see this as an extra cost, instead emphasising the importance that the person transporting her tangata whaikaha son was trustworthy.

The second participant had recently received disability support funding from Taikura Trust that included \$30,000 for in-home support. She used this funding to pay for someone to care for her son during the school holidays if she had to be at university.

I was lucky enough to get somebody that could look after him for me. I had to pay them hugely for it...I paid forty dollars an hour for the lady that I had in, but that accommodated for her travelling from [her home] to here, and that also meant that if she wanted to take him on trips and stuff; rather than me having to apply for the expense afterwards – aged 50-59 years, tangata whaikaha Māori & whānau

School

While participants did not mention weekly costs for school, some mentioned costs for their school age children at the start of the year. These included uniforms, stationery, textbooks, and in one case a Chromebook which the tangata whaikaha Māori participant had not been able to shop around for. A mother said that she did not always pay school fees because school was supposed to be free.

A whānau participant described the trips and wānanga her tangata whaikaha Māori son had gone on when he was in the Māori Unit at his high school. They had only had to pay a little bit extra for these as the Unit "did a lot of fundraising." For another whānau participant, the attendance of her son at his school was only possible because the school funded a full-time teacher's aide. At the time of the interview, she was in dispute with the Ministry of Education about the eligibility of her son for Ministry funding.

[The school's] funded [a full-time teacher aide] themselves because [my son] doesn't get any teacher aide hours....[They] hire their own ed psyche privately as well, and few schools can afford to do that. They use I think the funding that they got from their international students and the fees that the international students are paying, but normally they use that for other resources within the school; they used that to pay for his teacher aide, and for the ed psych – aged 50-59, tangata whaikaha Māori & whānau

Adult Education

None of the participants mentioned details of spending on adult education, and one participant was explicit that the Māori language course she had done had been free.

Two participants talked about tertiary studies and the student loans that had to be taken out to cover costs. One (tangata whaikaha + whānau) knew there were scholarships she could probably apply for to cover the costs of her own study but said she was too busy to complete any applications. The other whānau participant described how her tangata whaikaha Māori son was now in his fifth and final year of study, completing a tertiary computing course after beginning scholarship-funded studies while he was at high school.

They're really good. So they promised that after the five years they are going to give them a job anyway, you know, whether it be through the Warehouse Group or IBM. We're very lucky he got into it. And out of all of the ones that went to it at college...he's only one still standing – aged 50-59, whānau.

Barriers to adult education mentioned by other participants included cost, lack of time, and not being able to find the training they wanted to do.

I wanted to go to night school with my stroke because I lost a lot of my spelling and reading abilities. I wanted to go back but the price was just too much and the time. I just haven't got the time. You know, doing night shift and then you've got to try and study during the day. I can't even keep up with the work that work gives me – aged 50-59, long-term health conditions

I thought about being a naturopath. I researched it the other day and I couldn't find anywhere in New Zealand that does the training. Not that I looked really hard but – aged 50-59, long-term health conditions & whānau

Fitness / Sport / Therapy

Only one participant discussed what she budgeted for mentoring and occupational therapy services for her tangata whaikaha Māori son.

I've had to do private occupational therapy, and that was six hundred dollars for the first visit and then a hundred and seventy dollars per visit after that ... At the moment, I'd say I'm doing mentoring services with [my son] once a week, and that works out about nine hundred dollars a month to have somebody come in and take him out into the community – aged 50-59, tangata whaikaha Māori & whānau

A whānau participant had used her carer support payment to pay for a gym subscription for her tangata whaikaha Māori daughter, as her daughter could not go to the gym on her own. She used a gym card to accompany her, saying "it's free for me."

The spin class... Everybody does it; I like listening to the music. So, when everyone stands up, I stand up; I get tired quickly, but I can do it – aged 20-29, tangata whaikaha Māori

Two participants said they had had gym memberships that had been good for their physical and mental health and wellbeing. However, they had had to cancel the memberships as they became unaffordable. A participant also mentioned that she did not do group activities but tried to engage in regular exercise in and around her neighbourhood.

Personal Allowance

The majority of participants had no money for a personal allowance, with many saying this was simply unaffordable. For others a personal allowance was an every-now-and-then item, when it was affordable. Only one tangata whaikaha Māori participant said she had a personal allowance that her mother gave her, as her mother explained,

I mean, so that's another cost. I mean, she's got to have something. I know, like with her benefit, I use that because I need it – aged 50-59, whānau

Another participant with long-term health conditions gave her daughter pocket money in exchange for her doing one hour of cleaning a week.

Pet Care

The money participants were spending on pet care was mostly on food, with some also factoring in veterinary care and medicines for their pets. Although a young participant with long-term health conditions described her dog as having many ailments, her dog was part of her wellness plan and she was willing to sacrifice her own needs to cover the costs of caring for it. Because of this she did think she was paying extra for the dog's care.

I can have a dog...she's my wee bestie. And it's nice to have her around and she's helped with the mental health stuff as well – aged 20-29, long-term health conditions

A participant with long-term health conditions also said that her two dogs and two cats gave her comfort and support, and enhanced her life. This was similar for another participant, although she was concerned that she would not be able to afford this for much longer as her rent had gone up.

He knows if I'm really struggling, like if I go up to the toilet he'll wait right outside the door for me, and he'll slowly walk down the hallway with me, and stuff like that. I mean, I can be sitting out the front, all that; dogs can go past, whatever, he won't leave my side – aged 40-49, long-term health conditions

Another participant also talked about her son having a cat that was very special to him.

Internet and Phone

Participants paid varying monthly amounts for internet and phone service. A participant was paying \$80 a month for internet so she could Facetime with her children and mokopuna. Another participant also explained her costs,

\$80 for phones and \$160 for internet. My husband and I watch a lot of the Māori channel. I like to watch my news. Plus doing our house up we've got to YouTube a lot of stuff – aged 50-59, long-term health conditions & whānau

When asked if she was spending less on this than she would like to, this participant responded that her phone was important,

I'm guessing I pay the same as anyone would. As long as I've got money on my phone to ring the doctors or change an appointment at the hospital or whatever I need to do. As long as I've got money on my phone, I don't care – aged 50-59, long-term health conditions & whānau

Two participants felt they were paying extra – one because of her son's computer activity and the other because she had to be able to contact her son by mobile phone, which she said cost her an additional \$20 a month. Another tangata whaikaha Māori participant also explained that having the internet was a necessity for her, "for accessing my smart speakers. I can talk to the kids from my speaker." She had also paid for her heat pump to be hooked up to WIFI so she could operate it from her mobile phone. At least one participant worried about losing her internet access because of affordability issues.

Household Services

The most commonly mentioned household service was power, with many participants setting aside / paying a weekly amount of between \$50-60 to cover their power costs. SkyTV was mentioned by a

couple of participants – one saying she was giving it up as she could not afford it anymore and another saying she only had it because her partner paid for it.

For a participant with long-term health conditions the power bill was high as their rental home was not insulated and she did not think it would pass a healthy homes check. It was important to her that the house was warm as her son spent a lot of time at home. Her daughter explained this,

But she does pay extra in power because if he doesn't have his alone time and he could put his headphones on and zone out into something, then things aren't going to go well – aged 30-39, whānau

Two participants paid extra for power because they needed to stay warm. Compared to other participants the cost of this for one was around an additional \$200 each month, which she said was affordable because she was working long hours. She had not made this calculation herself however,

Q: Do you have any idea how much extra that might cost to run? I wouldn't have a clue. For me, I've got to stay warm otherwise my body seizes up and then I can't move because I'm in pain, so we just keep the house warm so that I'm warm...If I'm warm then I'm mobile. We're looking at the cost of that – aged 50-59, long-term health conditions & whānau

Medical

Participants' medical costs varied greatly and only two stated that these costs were higher because they or their children were tāngata whaikaha Māori or living with long-term conditions. Those with children under 13 years of age were grateful that their medical care and prescriptions were free.

A participant with long-term health conditions was paying the highest amount mentioned by those who disclosed the cost of their care, and even then she said \$150 a month was the minimum she might pay. Two other participants said they paid regular amounts to their general practice to cover the costs of their visits.

So I don't have to worry about paying \$20 everytime I go... [\$5 a week] It mounts up every time... So long as I've got all my medication I'm fine – aged 60-69, long-term health conditions

A participant with long-term health conditions also had a Medic Alert alarm, with installment costs paid for by her church and Work and Income taking the subscription costs directly from her benefit.⁹

A whānau participant described occasions when her now 10 year-old daughter had been assessed but she had not followed through on their recommended treatment. While it could be inferred that this was because it was unaffordable for her, she did not explicitly state this.

Also when she was young her eyes were tested, but I didn't go and carry on through it because they said that she had a certain... I can't even remember. I think she was only about three or four when we first did it. Then took her to Specsavers to do the proper test. I didn't follow through with getting her glasses. They recommended glasses for her but she was very anti-glasses and didn't want to – aged 30-39, whānau

Another participant's experience was almost the opposite, where after three years of her son being engaged with a paediatrician, the paediatrician told her he could not do anything further for her son and that he was closing his file. Another whānau participant had to fight for tertiary health services to stay engaged with her son after the Covid-19 lockdowns. She paid \$700 for an initial private paediatric consultation in order to find a pathway forward,

Yes, seven hundred dollars, and I'm on a benefit, so you can just imagine. ... One consult seven hundred dollars. That's the initial one, and then the follow-up ones were about three hundred dollars a pop. [The specialist] was really good because he got all of [my son's] stuff

⁹ She may have been in receipt of a Disability Allowance, which would cover this cost, although she did not explicitly say so.

from the hospital, and had a good look through it, and I got the initial consultation with him and we went through, "Okay, this is what we're going to do, I've seen this before." He was really cool; he actually looked at the child and saw the child then the ailment, which is how you want somebody to see it, not the child with the ailment, and that was really good – aged 50-59, tangata whaikaha Māori & whānau

Special Events

Participants said they could not really afford special events. This included trips back to their tribal rohe for celebrations and other occasions like tangi.

It depends on what it is, plus my family, my parents are on superannuation, and my kids are on a benefit as well, so we don't really go out much because we can't really afford to – aged 50-59, long-term health conditions

Even travelling to see her mother in another city was out of the question for a participant, and she said she had not visited her mother for at least two years. Another participant's experience was similar,

I would like to just go up North and see my mother. I haven't seen my mother in a few years. Just to go and see my mum would be cool. Or even my siblings...the last time I saw them was about four years ago...I would love to see my siblings, but it is what it is and can't afford it, so we just don't – aged 50-59, long-term health conditions & whānau

Another participant's special event was a church convention in Auckland once a year and members of the congregation paid her expenses.

Equipment

A participant with long-term health conditions talked about the price of the hypoallergenic pillows and blankets she needed to purchase every few months.

I think I have equipment. I have to get special blankets and pillows that hold dust mites...We'll say \$200 for replacing pillows and getting hypo-allergenic things that don't make me allergic...it does make a massive difference. Even since the allergies are in my airways it makes a big difference to the sinus infections too – aged 20-29, long-term conditions

A whānau participant described the additional \$200 she had to borrow to top-up the \$1,000 her tangata whaikaha son was eligible for through Studylink for a computer, when the cheapest one that met the specifications he needed was \$1200. While this was a study expense, it can also be considered a cost related to disability as her son spent a large amount of his time on the computer.

A whānau participant's father lived in the household with her and her daughter, but she had not needed to install any special equipment for him or for her daughter. Her father being in good health and her daughter keen to take care of him were part of the reasons why this participant was thinking about returning to work.

He's very independent, so I'm very lucky there. The only reason why I thought, "Oh well, go back to work" is because now that Dad's been discharged from the hospital, I will have a lot more time. I don't mind the odd day off work, and I'm sure my job wouldn't, to get Dad to his three monthly GP, and grab his meds. So, I'm sort of excited to go back, sort of – aged 50-59, whānau

A participant with long-term health conditions, on the other hand, had paid for rails to be installed in her bathroom to help her get in and out of the bath. She had asked Work and Income about support for this but they had turned her down. Another participant had bought a secondhand rail, and one had

installed a temporary rail solution while she was awaiting a bathroom renovation to make things more accessible for her.

We do have a shower, but it's in a shub, which I sort of struggle to get in and out of because of my knees, but we are putting in a bigger shower with a sliding door, so I don't have to climb over it. We are doing that, and we're putting a seat in there. ... at the moment I've got a suction handrail to help me get in and out of the shower because of the shub, but once we get rid of the shub and just have a walk-in shower, hopefully, well I know I won't need the handrail – aged 50-59, long-term health conditions & whānau

Insurance

Many participants simply stated that they could not afford insurance. This included car insurance for some – while they wished they could afford it, they said they could not. A participant had found that Work and Income made some allowance for house insurance but not for contents insurance or for vehicle insurance. This was also another participant's experience.

It doesn't matter; you're damned if you do, and you're damned if you don't. Like the insurers I have to have as part of the terms and conditions, car insurance. WINZ, "Nah, we don't do car insurance." I said, "But I still have to pay for it." I have to take it out of the food because that's the only place to take it from – aged 50-59, whānau

A participant who reported paying the largest amount for insurance described how her payments had gone up again and she was still trying to get some insurance for her husband.

That's on house contents and vehicles, and then my funeral insurance is only like, I think I pay \$20 a fortnight. But we do have more insurances to sort out when my husband and I get the same days off – aged 50-59, long-term health conditions & whānau

Three other participants had insurance. One said she had basic life insurance and also car insurance that she needed to have while she was paying it off. She thought she might maintain this once the car had been paid for because it might be more affordable then. She could not, however, afford contents insurance. Another participant also had life insurance and car insurance and was able to afford contents insurance, while the third participant had recently gotten health insurance that covered her for vision, dental and health.

Clothing

The clothing costs mentioned by participants included school uniforms, shoes for their tamariki, and clothing generally. A whānau participant mentioned that her son had to decide what the priority was – data or clothing – because if they could not afford it beyond his clothing allowance, they would have to go without.

Just mainly his clothes as he's getting older, you know? When he was at the last few years of college and everyone else's gears, you know, had the nice gears, so he'd want that as well. You know, stuff like that – aged 50-59, whānau

For another whānau participant, the choice was between her eating and being able to afford to get her boys shoes when they needed them.

I don't eat much - I spend all my money on my boys clothes and shoes. I don't even care, as long as I've got coffee and lemon I'm good, and fruit...I will go out and buy shoes for them and miss out on food because...when they say to me, "Mum, my shoes." "What about your shoes?" "I think I need some more." Look at his shoes. And then I'll just make that determination – aged 40-49, whānau

This was a frequent issue for this participant's tangata whaikaha Māori son who in addition to growing, dragged his feet and wore out his shoes more quickly than his twin brother because of his condition. When they grew out of shoes that were still in good condition, their mother donated them to the boys' school, for other tamariki whose whānau could not afford to get them shoes. She tried not to ask Work and Income for support very often because she had found they would say they only just gave her a grant and that she should ask her family or her neighbours for support.

Buying shoes for her son was also an expense for another participant, largely because her tangata whaikaha Māori son would lose his shoes. She also described how difficult it was to get through to Work and Income to ask about a clothing grant for her son,

You've got to apply for something online, and it tells you to ring the 0800 number. Their portal's not user-friendly. For instance, if you wanted to apply for something, and you could put in, "I want to apply for this." Upload the request and get say maybe somebody to call you back to say, "We've seen you've got this." It just says, "Please call us on 0800." Rather than just putting in the application and then having it sit in the portal, and then somebody will email you back or ring you, and say, "I see that you've put this in. Yes, we can do that for you, or no, we can't." It just tells you to ring the 0800 number, and you ring the 0800 number, and if you're not in the queue before eight o'clock in the morning your phone call doesn't get answered – aged 50-59, tangata whaikaha Māori & whānau

A participant with long-term health conditions was also spending money on shoes but for herself. She said she needed to buy two pairs of work shoes each year at around \$130-\$160 a pair in order to prevent more pain. Options that others mentioned for buying clothing for themselves were to go to secondhand stores or to only buy bras and underwear and then only if they were needed. As two participants had been losing weight, one had been passing her clothes on to the other who, in turn, passed her too-big clothes on to another relation.

All her clothes, mum's TV; she's going to give it to me, so I've already got heaps of her clothes – aged 20-29, tangata whaikaha Māori

Household Contents

A whānau participant had gone without so she could afford the fridge-freezer she wanted. She said the ones that Work and Income had offered her were not practical. In a similar vein, another whānau participant said she saved up to afford good furniture that would last, because her mother, father and her nan had instilled in her that "you get what you pay for." Others described how they were making do with what they had.

I need to replace, or do something with my range, because I have three rings that overheat, and the two sides the ones that don't work, so its been put off and put off and put off; but we did get it fixed previously. My daughter's husband got an electrician in that was supposed to replace the thermostats in them, but they've all gone again, so I don't know what thermostat was put in – aged 50-59, long-term health conditions

Dental

Many participants were not spending any money on dental care. Other expenses were seen as a higher priority. It was only their tamariki who were entitled to free dental care who were being seen regularly by a dental care practitioner. A whānau participant now worried for her tangata whaikaha Māori son who had aged out of free dental care. She said he had beautiful teeth but now he did not have a dentist.

While a participant's son had free dental care, she herself had needed \$1,200 worth of dental work recently. Likewise, another participant needed \$2,700 worth of dental work but did not know if she would ever be able to afford it. Others tried to access Work and Income funding (sometimes

unsuccessfully) for dental care, accessed cheap care options available to them because they had a Community Services Card, or went without and hoped for the best. A whānau participant had pulled out one of her aching teeth herself because it was “pretty loose.” She had also gotten false teeth through Work and Income.

*I got some falsies which I hate, and that cost five and a half thousand dollars, and I hate them, and I don't even have full dentures. They made me run around; I think I got four quotes in the end. Not two, four, “Nah, all of those are far too high, go to this place they're way cheaper.” I said, “You've already got the quote for them I gave it to you.” “Oh, I didn't think it'd be that dear.” ... It doesn't matter if it's plastic and cellotaped to your teeth if it's cheaper you're having that. So, you have to do all of these little things under the table to get the things you actually really need. These aren't wants; I don't want to look pretty; I need f***en teeth – aged 50-59, whānau*

Holidays

One participant mentioned a holiday budget, saying at a push she tried to put aside \$400 a year for a holiday. Another participant was only able to travel home with her sons at Christmas time because her sister helped with her costs and when they got there their accommodation was free.

I wouldn't say my family's wealthy, but they own their own properties...My sister's a teacher, so she doesn't have a mortgage because she paid her mortgage off years ago...and so, she's like, don't worry about anything sis; you just come up here. So food, accommodation, everything's covered, even gas – aged 40-49, whānau

Two participants saved so they could take holidays visiting with whānau who lived in another part of the country. One's gripe was that visiting within New Zealand was more expensive than taking a holiday in Australia.

Our trips, most of the time, are down south [to see whānau]. We have to work to save for our trips. As much as we'd like to go to Rome and Rarotonga, most of our trips are down south [to visit with whānau] – aged 40-49, long-term health conditions

A tangata whaikaha Māori participant was saving for a trip to Brisbane to visit with her aunt, uncle and cousins.

I'm saving money; we've got pocket money, because I'm going to have a holiday in Brisbane with aunty [name] and my uncle [name] and my cousins next year. ... I've already got money in my money tin because I'm going to go clothes shopping, and I'm going away for two weeks – aged 20-29, tangata whaikaha Māori

A whānau participant tried to take her whānau camping every year. However other participants said that holidays were unaffordable, saying things like “those days are gone” or that they normally did not go anywhere.

Contingency

When she thought about contingency costs, a participant said that occasionally she would have \$20-\$30 that she would use to pay someone to do some cleaning or to stay the night if she felt unwell and was worried about being alone. Two participants had a contingency saved. It was a contingency that had seen one get through breast cancer treatment. Other participants did not have contingency funds, although some were able to call on their whānau for help if they were desperate.

Income Adequacy

Only three of the 19 participants who responded to a question about whether their income was enough to meet their everyday needs said they had enough money. Eight said they only just enough

money, although their income did not cover everything they would like to have (e.g., insurance, transportation). The remaining eight participants said they did not have enough money to meet their everyday needs. Some participant comments are provided in Table 4.

Table 4. Income meeting everyday needs x comments

Rating	Comments
Not enough money	<p>If we had no job, I think we would be able to manage like a month and a half without being paid. And that's with our savings. So yeah, no, not enough. – aged 40-49, long-term health conditions</p> <p>Because of the price of everything. Food. I go, "Oh man, is that what I've got left." – aged 60-69, long-term health conditions</p>
Only just enough money	<p>Just scraping by, but I've just been used to scraping by so it's like nothing unusual – aged 50-59, whānau</p> <p>It depends on how you want to look at the concept. I would say because of the way I budget, I have just enough money to get through, because basically it pays for your basic bills, and that's it, and doesn't pay for anything else. If I didn't pay my insurance I'd probably have enough money – aged 50-59, tangata whaikaha Māori & whānau</p> <p>It's still a bit under, because I have to rely on public transport - Ubers and taxis can be quite expensive, especially if I want to travel at night. It's just that safety thing – aged 40-49, tangata whaikaha Māori</p>
Enough money	<p>Enough money with me working two jobs and my husband working, but if I give up one job we're gonna find it tough. In all honesty that's not going to be very far away – aged 50-59, long-term health conditions & whānau</p>

Enquiry Area 3 – Participants' past and current benefit receipt and their experiences of claiming and/or not claiming income support payments.

Supported Living Payment

Six participants said they received a Supported Living Payment – three because they were looking after someone who required full-time care and three because their permanent disability severely restricted in their capacity to work.

Because I'm totally blind, it's not income tested...I get [carer support] through Enabling Good Lives and Disability Support Services – aged 40-49, tangata whaikaha Māori

A participant with severe long-term health conditions had only recently learned from Workbridge that she could get the Supported Living Payment, whereas she said that this information had not been forthcoming from Work and Income when she enquired. Rather, Work and Income had told her that on her previous Jobseeker Support she would need to work 30 hours a week, which she had told them was impossible given her long-term health conditions.

One of the participants who received the Supported Living Payment as a full-time carer said she had to try for this payment three times through an advocate before Work and Income agreed she was eligible for it. Another participant said she could not receive a Supported Living Payment (Carer) payment for looking after her tangata whaikaha daughter because she was already receiving this payment for looking after her father.

WINZ, I'm already getting upset because they're just so frustrating to work with about anything. You'll have to fight and fight and fight and fight until somebody listens, and I don't do well. I've had to do that all my life; not just MSD, but services for her, but now that she's older and because I'm on a carers benefit for dad, I couldn't have that for [my daughter], so they put her on the sickness. They told me I wasn't allowed to have two benefits of the same – aged 50-59, whānau

Other participants who were potentially eligible for the Supported Living Payment as a carer had not applied for it because they did not know about the payment or thought they were ineligible for it.

No, no because I adopted him, so legally he's my child – aged 50-59 years, whānau

Jobseeker Support – Health Condition or Disability

Four participants received Jobseeker Support – Health Condition or Disability. A tangata whaikaha participant said he was on Jobseeker Support with added funding to cover health and transport costs so he could attend a methadone programme (so it is assumed he was on Jobseeker Support – Health Condition or Disability and possibly Disability Allowance). Another participant with long-term conditions had recently switched from Jobseeker Support (although it is not known if she was on Jobseeker Support – Health Condition or Disability) to a Supported Living Payment and Disability Allowance.

In addition, two participants received Jobseeker Support – Work Ready and one received Sole Parent Support.

Disability Allowance

Only three participants said they currently received a Disability Allowance. An additional four participants said they had received the Disability Allowance sometime in the past but were no longer eligible as their circumstances had changed (e.g., their son had turned 18 and had become eligible in his own right).

I have had a Disability Allowance before when I was a student to help again pay for just those general consistent medications. It was a very small amount, but it really did help – aged 20-29, long-term health conditions

A participant, whose son was now at university, had been told by by Work and Income that as her son was on Studylink he was not eligible for a Disability Allowance through them. However, she had not been told in a way she understood that he had to now apply for a Disability Allowance through Studylink.

Some participants who were not in receipt of a Disability Allowance said they needed to apply for it or had applied for it and did not qualify. One participant said she was not eligible for a Disability Allowance because her husband earned too much whereas other participants were in employment and possibly also earning too much.

We don't qualify. My husband earns too much, apparently. ... We did apply once when my husband got laid off at the sawmill, and because I was working, he was entitled to \$46 a week. Well, stick that up your f'ing backside, and that's why he took this farming job, because what the hell was \$46 going to do? – aged 50-59, long-term health conditions & whānau

Some whānau participants needed a diagnosis for their child so they would be eligible for a Disability Allowance or simply thought they would not be eligible because of their understandings of disability.

I thought I didn't have to. It was me not knowing what I was allowed. For me, that generic thought of disabilities was like just physical – aged 30-39, whānau

Child Disability Allowance

Only two participants said they currently received a Child Disability Allowance. One participant talked about the abrupt end to the Child Disability Allowance when her son turned 18. Another said they never qualified for it, and another was in the process of getting a diagnosis for her son before applying.

One of those currently in receipt of a Child Disability Allowance said she had gone through a drawn out process getting a diagnosis for her tangata whaikaha Māori son. The other participant described the process of applying for this support as “very tedious” as she said that even though her son had a lifelong disability it still had to be signed off by a doctor once a year to confirm that he still had it.

In terms of whether or not the Child Disability Allowance helped them financially, a participant was grateful but said,

You've just got to be very smart with your money, like the Child Disability Allowance helps a little bit, but in terms of my budget; I have to be very strict. I just can't flip off and go down the road to the restaurants and go have dinner or go buy a big bottle of wine or anything like that if you feel like it, because you can't afford it – aged 50-59, tangata whaikaha Māori & whānau

Home Modifications

No participants had applied for or received House Modification Funding (for which income and asset tests are administered by Work and Income). Some reasons for not applying for this funding centred round participants' potentially inaccurate assumptions about their ineligibility, including participants thinking they were ineligible because they were living in a rental or because their disability was not visible. In addition, a participant said they were making modifications themselves, while another assumed they would be turned down because they were working and therefore over the income threshold for funding.

In all honesty they'll turn us down, and I know that. I don't even have to go to them. They will automatically turn us down and I know this. They're so busy helping all the unemployed that

people like me and others, we'll get declined. Why? Because we're working. We earn over the threshold – aged 50-59, long-term health conditions & whānau

They wouldn't even help me get a handle to put over my bath, so I had something to support myself, or would help me with a raised toilet seat – aged 40-49, tangata whaikaha Māori & long-term health conditions

Temporary Additional Support (TAS)

Only three participants said they received TAS. One participant (aged 50-59, tangata whaikaha Māori & whanau) had been turned down and was unsuccessful appealing this through an advocate. She said, "They said no, and even the advocate said no, I wouldn't get it."

A participant who had received TAS said it had been taken away because of a change in the eligibility rules. They were finding it hard because this had left them down \$80 a week.

Not easy. What can I say, I had to adjust. There was nothing else I could do. Some weeks I have, you know, say up to \$50 a week for food because you kind of rein the money in a bit, you know, what's going where. Then some weeks we don't have anything because there's other bills that have to come out. What happens on those weeks where is no money because of other bills? You survive with what's in the cupboards – aged 30-39, whānau

Responses to the offer of a full-and-correct entitlement check from MSD

None of the participants took up the offer of a check by MSD of whether they were receiving their full-and-correct entitlements. This meant the study was not able to explore whether people's ability to meet additional costs could have been improved had they received all the income support they were entitled to. Receipt of Disability Allowance, in particular, appeared low given the costs and unmet needs that participants described.

Three different general reasons were given for not taking up the offer. The first was that they either had a good relationship with their local Work and Income Office and/or they thought everything was 'sorted' and did not want to talk to Work and Income. Either way, they were happy with what they were receiving.

They're really cool...and I have such respect for the manager...he listens – aged 40-49, whanau

The second reason given was that they had no time for Work and Income, with some saying they would prefer to seek advice elsewhere. The third reason given was that they did not think there was a chance that Work and Income would give them any additional support because they were not eligible. They knew this because they had already applied by themselves or through an advocate. Some who had not applied or did not plan to apply were not aware of their potential eligibility, or appeared to misunderstand eligibility criteria.

Discussion

The purpose of this study was to enquire into the additional costs borne by tāngata whaikaha Māori and their whānau and by Māori with long-term conditions, and whether they are able to meet these costs. Unmet needs were identified, along with shortfalls in the income support participants were or were not receiving. We gained insight into what people were forgoing and what trade-offs they were making. In addition to costs, this discussion looks at the implications of unmet need across a spectrum of goods and resources that provide nourishment and hope as well as cultural sustenance and vitality. Before this, however, we touch briefly on the notion of ‘additional costs’ in the framing of this research.

Questioning about ‘additional costs’ was critiqued by advisors to the study and often difficult for participants to answer

This study’s enquiry into the ‘additional costs’ of impairment was one of the first things that drew criticism from advisors from the tāngata whaikaha Māori community. The implication of this enquiry was that there were ‘normal’ costs, and then costs on top of this that were somehow not ‘normal’ but rather imposed by impairment or by having whānau members with a lived experience of impairment. This was seen as counter to the social model of disability that focuses on societal barriers that lead to disablement, and rights-based models that focus on inclusion and independence (King, 2021). Feedback from the public consultation on the 2023 Disability Survey, for example, suggested that a language of ‘unmet need’, or barriers or difficulties accessing resources, and of having limited or inadequate options may be more appropriate (Stats NZ, 2022).

In addition, a Māori worldview of disability is grounded in interdependence and collectivism whereas even rights-based or social models of disability frame impairment as an individual experience (King, 2021). Whānau Hauā (Hickey & Wilson, 2017) captures the experiences of disabled Māori. As described by Kirsten Smiler and colleagues,

Whānau Hauā...focuses on whānau as an intergenerational and independent kinship group where the disabled individuals and their whānau bear the burden of impairment and societal discrimination, and the challenge to facilitate ‘balance’ (equity and equality) is a collective responsibility for disabled individuals, their whānau and wider society (Smiler et al., 2022, p. 1156).

The language of whānau ‘unmet need’ because of structural barriers to accessing resources that formed part of the enquiry was therefore more appropriate for Māori. As King (2021, p. 17) notes, none of the culturally informed Māori models of identity and disability “appear to have been applied by the Crown with regard to the use of appropriate approaches to health and wellbeing of Māori with lived experience of disability.” Moreover, some of the payments in relation to which MSD was seeking better evidence (Disability Allowance in particular), are framed in terms of providing compensation for additional costs. So, it should not be surprising that a framing of ‘additional costs’ was used in the commissioning of the current research.

On the whole, our research participants did not have a bad reaction to questions about ‘additional costs’ and they all used a whānau-centric framing to contextualise these costs. For some, this included consideration of how whānau contributed to them being able to meet their costs, while for others it was about them not being able to visit in-person with their whānau because they could not afford the travel costs. While many shared details of their budgets and the restrictions on their spending, it was still difficult for participants to give a precise amount that was ‘additional’ from what they might spend in the absence of impairment. What was easiest for participants to report was the things they were not spending anything on because they could not afford to (for example, dental care, insurance). In other words, they could identify their unmet need and explain that it was just not within

their budget. Most participants had little to no budget leeway for an allowance or special events that cost money. Personal care was only explicitly talked about by two participants – one who had a support worker and one who was paid as a support worker for a whānau member. Individualised funding (Whaikaha, 2024a) was also being received by one māmā so she could purchase the support services she and her rangatahi whaikaha needed. Other participants talked more generally about their lack of any budget for personal care items, explaining that they had no need for things for themselves and bought only essential items (e.g., sanitary products).

Participants sometimes also explained workarounds, with perhaps the most profound being a participant who had pulled out their own tooth because a dentist visit was not affordable. While others said they could not afford regular dentist visits, they were grateful if their rangatahi still qualified for free treatment and downplayed their own oral health. Their lack of funds for oral health care is not surprising given that cost is the most common barrier to oral health care reported by Māori.

“Preventative, restorative, or rehabilitative dental care is accessible to the affluent but often unattainable to those less well-off” (Robson, et al., 2011, p. 9). This lack of access to oral health care puts participants at risk of poorer overall health and wellbeing outcomes.

The importance of oral health cannot be overstated for physical, emotional, psychological, and socioeconomic well-being, not only at the individual level but also at the interpersonal (e.g., family, friends), community, and societal levels. Disparities in oral health care are differences that are both unnecessary and avoidable and also considered unfair and unjust (Northridge et al., 2020, p. 513).

Housing and transport were the most common areas that prompted them to think through and calculate their additional costs

For example, many knew what it cost in terms of additional petrol for them to get themselves and/or whānau members to doctors’ appointments. Some had also consciously decided to pay extra to rent a house that was warm and well-ventilated, and/or well-located. However, even if participants had found rental accommodation that suited them, it was often reported to be increasingly out of their budget as landlords instituted rent hikes in response to, or sometimes in the absence of, modifications (e.g., heat pump) to make their accommodation more livable and compliant with Healthy Homes standards (Tenancy Services, 2024). Homeowning participants were able to name the premium they had paid for a good house that was well-located; for example, an additional \$100,000 to be close to school bus routes and a shopping centre. These requirements also made it virtually impossible for this particular participant to move home to their tūrangawaewae because they would not have close access to public transport or a shopping centre. Some homeowning participants knew that where they lived was beyond their budget and only possible because they and/or their whānau had bought a house years ago, or their home was subsidised by their whānau.

Good housing – close to work, family, transport, and services – has been stressed by other tāngata whaikaha Māori talking about their human rights, participation, and poverty. For some of those interviewed by the Convention Coalition (2015), a lack of suitable housing negatively impacted their feelings of independence. This lack of suitable housing for tāngata whaikaha and their whānau was also highlighted during the Covid-19 lockdowns. The Human Rights Commission (2022, p. 29) noted “expectations that people isolate in their homes also assumes housing is warm and dry and safe, which is not the case for all disabled people and their whānau.” This confirmed findings from the 2018 NZ Disability Survey, that disabled people are more likely to report that their homes are damp and hard to heat, and too small for disabled children (Stats NZ, 2020). With warm, comfortable and accessible housing in short supply, unsuitable housing has been a long-standing issue that impacts on the social lives and productivity of disabled people and their whānau (Saville-Smith et al., 2007). In addition, Saville-Smith and colleagues warn,

Focusing only on an individual's need for an accessible dwelling does not meet the needs of disabled people for accessible communities, social and work environments (Saville-Smith et al., 2007, p. ii).

The neighbourhoods people reside in are therefore also foundational to their wellbeing. Most of the participants in the present study were positive about their neighbourhood. As in other research, their satisfaction was based on the desirability of the neighbourhood and its proximity to services and areas of interest as well as their assessment of the friendliness of their neighbours and of neighbourhood safety more generally (Wongbumru & Dewancker, 2016; van der Pas, et al., 2015). In describing the indicator used to measure sense of neighbourhood, the authors of *He Topu Ora* write,

Within te ao Māori, manaakitanga (support, hospitality and care), tautoko (support), and kotahitanga (unity and solidarity) are important values to have within a community of any form. Within a neighbourhood, this might mean checking on an elderly neighbour, participating in neighbourhood groups (for example neighbourhood watch), or interacting with people from your neighbourhood (Canterbury Wellbeing Index, 2023, p. 3).

Often neighbours engaged with participants and also kept an eye on things, and participants reciprocated this. Reciprocity also took other forms, for example asking their children's school for help (e.g., with food) while also donating good shoes that no longer fitted their own children to the school so the school could pass them on to other rangatahi. One participant noted the friendliness of their new neighbourhood and more affluent, mostly Pākehā and Asian community, compared to the poorer mostly Māori and Pacific communities they had previously lived in. However, other tāngata whaikaha Māori have noted that having good neighbours can be the case regardless of the ethnic composition of the neighbourhood (Higgins et al., 2010). Whānau activities and recreation also often centred around their neighbourhood, or were other things that were free, like a trip to the beach, or that could be saved up for (e.g., a weekend camping).

Problems still arose for some with neighbours or in their neighbourhood, which participants either dealt with (e.g., an aggressive neighbour) or simply accepted (e.g., weird neighbours, cars racing). This aligns with findings from the 2018 General Social Survey. Apart from harassment and gang activity, disabled people who responded to the survey did not report a higher number of other problems (noisy neighbours or loud parties, vandalism and graffiti, burglary, break-ins or theft, people being drunk in a public place, dangerous driving, or an increase in crime in the last year) than non-disabled people (Stats NZ, 2020). While their neighbourhood problems may have restricted participants' comfort about going out at night (Stats NZ, 2020), this was not specifically asked about in the present study. The impression was that participants were mostly staying at home because they could not afford to go out, even if they were keen to engage with adult education opportunities (e.g., learning te reo Māori) or to socialise. Socialising was also difficult for those with tāngata whaikaha tamariki as it could be hard for them to find people who were both willing and able to look after their tamariki. A qualitative study by Wilkinson-Meyers et al. (2014) of barriers and costs associated with disability also found an unmet need for support outside the home so that tāngata whaikaha could socialise.

Participants were also getting to services at little to no cost as they often walked or used public transport. This suited many while others still had to drive out of their immediate neighbourhood to go to work or to attend appointments, and one participant described how a reliance on public transport had restricted her tangata whaikaha Māori adult son's tertiary course options. The impact of poverty on Māori education attainment was also described by Barry et al. (2017), with these authors noting the flow-on impacts of this for people's future income, standard of living and psychosocial wellbeing.

Many of the participants in the present study described their distance from their whānau and the unaffordability of visiting them

Feedback on the 2023 Disability Survey (Stats NZ, 2022) about neighbourhood and community included the importance of asking after people's proximity to their extended family. Distance from whānau and the unaffordability of visiting them meant that many of the participants in this study had not been back to their tribal area or seen close whānau members (e.g., their mother) for some time. Definitions of transport disadvantage often remain confined to the mismatch between transport and the location of, for example, learning and work, healthcare, local activities and shopping. Even using this narrow definition, tāngata whaikaha – and tāngata whaikaha Māori especially – spend a disproportionate amount of their income on transport (Doran et al., 2022). As noted above, participants in the present study were clear about the additional transport costs of getting themselves or their whānau members to healthcare. The distinct Māori patterns of transport that include visits with whānau and cultural sites and accessing cultural activities often go unrecognised, including the additional time that needs to be spent planning, negotiating with and arranging support people, and budgeting for the costs involved (Disability Resource Centre, 2010; Raerino et al., 2013). The inability to even contemplate such visiting because of financial constraints is part of a wider picture of transport-based exclusion, whereby “disabled Māori are far less likely than others to have access to the transport that would enable them to meet their cultural needs” (Doran et al., 2022, p. 7).

For many of the tāngata whaikaha Māori in Jones et al.'s (2024) research, being disabled had created barriers to them connecting with things Māori. This then has a detrimental impact of people's sense of belonging and their wellbeing (Centre for Health, Activity, and Rehabilitation Research, 2014).

For Māori, traditional links to their whakapapa (ancestry), whenua (the land, rivers, and mountains) and tikanga (traditional culture and protocols) are expressed as important elements of their culture and identity. Participants reflected that they had retained a sense of primary self-identity as Māori, and their lived experience of disability had in many cases undermined their practical exposure to their own culture and compromised their ability to draw on their cultural connections within te ao Māori, which can compound disability or even be disabling in its own ways (Ingham, et al., 2022, p. 7).

Those who did manage to visit or travel to distant whānau and tribal home places described how this was only possible because of whānau financial support for them to do so. A tāngata whaikaha Māori participant, who was the day after our interview heading back to live in her tūrangawaewae with her teenage daughter, had the financial support of her brothers and had made this decision in spite of the stability of her job and accommodation. The pull of her tūrangawaewae was also strong enough for her to ride out her anxiety disorder so that she could make and fulfill plans to return home. The impact on the wellbeing of those who do not have support to visit or shift home can be negative. Barry et al. (2017) described how Māori isolation from whānau and wider cultural connections could lead to social exclusion and cultural dissociation, which in turn exacerbate the impacts of poverty. They write,

It has been suggested from the literature that strategies for moving out of poverty include maintaining cultural identity for spiritual and social fulfilment while adopting western economic opportunity. Others have recommended the re-institution of traditional whānau structure as a mechanism of nurturing well-being by contributing to cultural identity, and enhancing a sense of belonging (Barry, et al., 2017, pp. 43-4).

In both these options described by Barry et al. (2017), the pathway to prosperity for Māori is whānau-centric and culturally responsive rather than purely economic. It may, however, be presumptive to assume that people only find these pathways within their tribal rohe. Many Māori living away from their ancestral territory make strong connections where their kāinga rua, or second home, is located (Cram, 2020; Williams, 2015).

Food insecurity experienced by some is likely to adversely affect whānau health and wellbeing

Food insecurity was evident in some participants homes where growing or older children and/or a large number of whānau members needed to be fed. The trade-off was for adults to not eat as much and explain this as a lack of interest in food or as a carefully chosen diet on which they were happy to be losing weight. However, rangatahi know when their parents are concerned about food insecurity. Half of the rangatahi Māori with disabilities or chronic conditions who responded to the Youth19 survey reported food insecurity (compared to 23 percent of Pākehā respondents with a disability or chronic condition) (Youth19, 2021). Ministry of Health data for 2022/23 highlight the food insecurity experienced by disabled 5-14 year olds, with over a third living in “households where food runs out often or sometimes in the past year”. In addition, in 2021/22 one in four (24.1%) tamariki Māori aged 0-14 years were impacted by food insecurity, with this increasing to one in three (35.1%) in 2022/23 (Ministry of Health, 2024).

Other studies have reported on the shame and guilt Māori feel about food scarcity (e.g., ThinkPlace in collaboration with Auckland City Mission, 2014). However, making an assumption of guilt or shame for the participants in this study may be unwarranted given they were very open about other aspects of their lives that brought them either pride or shame; for example, not knowing how to cover their rent costs. They were not ashamed about not having enough food and/or having to seek out assistance with food. As in other research (e.g., Barry, et al., 2017), food was the item in their budget where they could still make savings, whereas their rent, power and internet were fixed costs. Where food insecurity seemed to hit hardest was in the inability of participants to buy healthy food for themselves and their whānau, with some reporting they reluctantly and increasingly purchased processed food or non-specialty (e.g., non-gluten free) items that their health practitioner had told them to avoid. Being unable to comply with dietary restrictions will impact participants’ health and wellbeing immediately, while in the longer-term ultra-processed food has been linked to a number of adverse health outcomes, including cardiometabolic and mental disorders and mortality (Lane et al., 2023). By saving where they can, in their food budget, participants are potentially risking the health of themselves and their whānau.

Similar food insecurity restrictions were not explicitly described by participants when it came to looking after their pets, although their pet food costs were low. Their pets were described as being members of their whānau, and as essential comfort and security for either themselves and/or their children. King and Cormack (2022), found that pets are a part of a nurturing environment for mokopuna Māori (aged 6-13 years) and confirm that they are often considered as whānau. They write, “being healthy was associated with being happy. For mokopuna, this included happy whānau, being with friends, playing with pets, and spending time outside in the sunshine” (King & Cormack, 2022, p. 384). So, these pets were akin to companion animals. Recipients of Disability Allowance have suggested that their care should be provided for in their disability payments (Welfare Expert Advisory Group, 2018).

Being able to meet the costs of access to the internet was important to participants, particularly those with rangatahi whaikaha

Regular costs such as their rent or mortgage, mobile phones, and internet were paid regularly by participants, along with many paying regular contributions to costs that might vary (e.g., power) or to cover costs that they knew would come up regularly (e.g., GP visits). They therefore managed their budgets by knowing what was coming out of their weekly income. Among these costs an internet connection was a priority for whānau with older tamariki and rangatahi. Rangatahi whaikaha were described as spending a lot of their time on the internet, often playing games or in one case doing coursework. This importance of the internet for young disabled adults has also been noted by

Disability Connect (2021). Older participants also described the importance of the internet, including their access to streaming services and information. A big concern for those under increased financial pressure was that they may have to forgo the internet and they could not see how they would manage in its absence. Gassin (2019) also highlights this concern for tāngata whaikaha Māori. As described by StatsNZ in their discussion about measuring inequality for disabled New Zealanders,

Access to telecommunications systems such as cell phones, landlines, and the internet allows people to communicate with the world outside their home, facilitates social contact and access to information, and is fundamental to contemporary life. It also provides a means for communication in an emergency, or when support is urgently needed (Stats NZ, 2020, p. 14).

Unsurprisingly, low access to the internet has been associated with lower subjective wellbeing (Minister of Health, 2023a).

Healthcare costs, particularly those for children, were prioritised; affordability and sometimes transport barriers could make accessing healthcare difficult

It is also well known that Māori, and especially tāngata whaikaha Māori, face barriers to accessing healthcare (Minister of Health, 2023b). Although healthcare costs were prioritised by participants, there was wide variation in what these costs were and the parents of tāngata whaikaha Māori generally talked more about attending to their children's health needs than their own. In the case of their tamariki, some participants' costs included accessing private health care so they could get a diagnosis or other evidence they could use to advocate for more financial support. Parents did not talk about skipping healthcare when their children needed it. While 45 percent of rangatahi Māori with disabilities or chronic conditions who responded to the Youth19 survey said they had forgone healthcare in the previous 12 months, their experience may well have pre-dated the expansion of free GP visits for under-14 year olds that was implemented from the end of 2018 (NZ Government, 2024). By mid-June 2020 nearly all Community Service Card holders and their children were enrolled in a primary care practice that offered free visits for children up to the age of 14 and lower cost visits for 14-17 year olds (Department of the Prime Minister and Cabinet, 2024; Health New Zealand, 2024).

Ten percent of the rangatahi Māori with disabilities or chronic conditions responding to the Youth19 survey also reported experiences of discrimination by healthcare providers (Youth19, 2021). Hector Kaiwai and Tanya Allport (2019) query the responsiveness of healthcare practitioners and the healthcare system to tāngata whaikaha Māori, based on statistics that show disease is the leading cause of impairment for Māori adults, and that Māori are at more risk than non-Māori of impairment following hospitalisation. Even so, participants in this study talked only about affordability and sometimes about transport barriers to accessing healthcare, and only mentioned discrimination in some of their feedback about Work and Income. Strategically, affordability and transport barriers are seen as 'social exclusion' and 'income and employment' determinants of health and access to healthcare (Minister of Health, 2023a). They might also be described as "competing responsibilities and commitments" (Bourke et al., 2023, p. 3), whereby participants were spending their limited budgets on other priorities. The Centre (2010) found that financial support and transport were part of a wider packet of resources (information, education, advocacy) that assisted tāngata whaikaha Māori to access good, responsive healthcare. In addition,

Being unable to afford healthcare was another concern and disabling factor for many participants and their whānau, with some suggesting that they had not accessed health care they knew they needed because of the perceived cost associated with receiving treatment (The Centre, 2010, p. 61).

Participants wanted their whānau context to be understood by Work and Income and reflected in their income support

In the third and last part of their interview, participants were invited to share with us the income support they were receiving, or had received in the past, and their experiences with applying to Work and Income for this support. Some who were working had spent times in their lives on income support, while others who were currently on income support wanted to transition into work even if they were currently in carer roles. Their experiences with Work and Income were diverse, from talking about the good treatment they received from their local office through to having to go through an advocate two or more times to try and qualify for a benefit. A uniting thread across participants was that they wanted their whānau context to be understood by Work and Income and reflected in their income support package. For some this included support to gain employment while for others it included support so they did not have to work as much. What they were asking for is what the Waikato Enabling Good Lives demonstration project has shown is possible; namely, an approach that is holistic, person-centred, strengths-based, and gives people options (Were, 2016, 2017). In the meantime, none wanted to avail themselves of a full-and-correct entitlement check.

Conclusion

In September 2008 New Zealand ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). Article 1 of CRPD states “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” The CRPD aligns well with the outcomes sought by Whānau Ora (Te Puni Kōkiri, 2022) and confirms the rights of tāngata whaikaha Māori and their whānau to Whānau Ora (Table 5). This system of human rights prohibits discrimination against tāngata whaikaha Māori (Forster, 2022). Of particular interest to the present study is the economic security outcome sought by Whānau Ora and CRPD Article 28 which speaks to the rights to social protection and an adequate standard of living (see Boxed section below).

With the insights it has provided into the chronic hardship of many participants, this study indicates that Article 28 of CRPD is not being fulfilled for them. Participants described years of getting by with virtually no leeway in their budgets for personal care items, discretionary spending, sustaining cultural practices and connections, or having an emergency fund. Whānau support came by way of housing provision, childcare assistance, food parcels, and day-to-day or emergency top-ups. Only one participant talked about the financial assistance she also received from her employer. When whānau and other supports were not available, and often when they were, participants were not forecasting any positive change or financial relief on their horizon.

The UN Committee that met in 2022 to assess New Zealand’s progress in implementing the CRPD commended the formation of Whaikaha | Ministry of Disabled People, and the development of Enabling Good Lives. New Zealand was also invited by the Committee to enshrine the right of tāngata whaikaha Māori to self-determination in legislation and policy, consistent with the obligations of te Tiriti o Waitangi and the UN Declaration of the Rights of Indigenous Peoples (UNDRIP) (Office of the Minister for Disability Issues, 2023).¹⁰ As a country we are therefore on a pathway to enabling the good lives and whānau ora of tāngata whaikaha Māori, their whānau, and Māori with long-term health conditions. However, we still have a ‘gap’ to close in terms of the income support people receive and the income support needed to enable them to live good, culturally enriched and enlightened lives.

¹⁰ UNDRIP reinforces the human rights of Indigenous peoples, along with our rights to self-determination, and was ratified by the New Zealand Government in April 2010.

Table 5. Whānau Ora and the interconnections with Enabling Good Lives, UNDRIP and UNCRPD (Whānau Ora Interface Group, personal communication, June 20, 2023)

Whānau Ora Outcomes	EGL Principles	UNDRIP Standards	CRPD Articles
Whānau are self-managing and empowered leaders	Self-determination	Self-determination 3, 4, 5	Self-direction Clauses N and O in the Preamble
Whānau are leading healthy lifestyles	Beginning Early	Health 24	Health, Article 25 Habitation, Article 26
Whānau are participating fully in society	Person Centred	Equality 2	Equality, Article 5 Awareness raising, Article 8 Living independently and being involved in the community, Article 19 General obligations – human rights and fundamental freedoms
Whānau are confidently participating in Te Ao Māori	Mana enhancing	Indigeneity, culture; language 9, 11, 13	Participation in cultural life, recreation, leisure, and sport, Article 30
Whānau are economically secure and successfully involved in wealth creation	Ordinary life outcomes	Improvement in socio-economic conditions 21	Adequate standard of living and social protection, Article 28
Whānau are cohesive, resilient, and nurturing	Mana Enhancing	Indigeneity, culture; health 9, 11, 24	Protecting the integrity of the person, Article 17 Living independently and being included in the community, Article 19 Respect for home and family, Article 23
Whānau are responsible stewards of their living and natural environments	Ordinary life outcomes	Relationship to their land, 25	Participation in cultural life, recreation, leisure, and sport, Article 30

CRPD Article 28 – Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
 - a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
 - b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
 - c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
 - d) To ensure access by persons with disabilities to public housing programmes;
 - e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Mitra and colleagues (2017, p. 480) write, “public support programs are not sufficiently taking into account the extra costs associated with disability” and recommend a tailored approach for calculating and responding to the “sizable and heterogeneous disability costs” evidenced by research. While a tailored approach to disability support for tāngata whaikaha Māori, whānau and Māori with long-term health conditions may ultimately be needed, our research shows that a universal increase in income support would alleviate immediate hardship for many of the low- and middle-income tāngata whaikaha Māori interviewed.

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Appendices



Appendix A. Participant information sheet and consent form

In-depth study to understand extra costs and income support for Tāngata Whaikaha Māori me ō rātou whānau, and Māori living with Long-Term Conditions 2023

Participant Information

Tēnā koe

This is an invitation to be part of a study that will inform the Ministry of Social Development's policy advice related to the income support system.

The study is being carried out by Katoa Ltd, a Kaupapa Māori (by, with and for Māori) research and evaluation company led by Fiona Cram. The Māori researcher team and advisors includes tāngata whaikaha Māori (Māori with lived experience of disability) and those with lived experience of supporting tāngata whaikaha Māori as whānau.

The study is being funded by the Ministry of Social Development (MSD).

What is the study about?

The study aims to learn more about the extra costs Tāngata Whaikaha Māori, Māori living with long-term health conditions, and their whānau or carers 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.

Who's being invited to take part in this study?

We're inviting 35 tāngata whaikaha Māori, Māori with children with disabilities or health conditions, and Māori who are a carer for an adult with disabilities or health conditions to be part of the study. All these people completed the New Zealand Income Support Survey and said they would be happy to be contacted to talk further.

You have been contacted by Reach Aotearoa about permission for them to pass your name and contact details on to us.

What will I be asked about?

If you agree to being interviewed, we will ask you about:

- Who you share your home with, your housing, your community, your work (if you work) and your other activities,
- The additional costs you have because of a disability and/or a long-term condition, and
- Your access to income support.

Why would I want to be involved?

What you have to say about your experiences will help MSD plan changes to Work and Income and the income support system. You may not benefit directly from any changes, but they will hopefully make a difference to other tāngata whaikaha Māori and whānau Māori who require income support.

How long will the interview take?

You'll be interviewed in-person, unless you prefer to be interviewed on-line (Zoom) or over the phone. The interview will take around 60 minutes.

If we talk in-person, we can meet at a place where you feel most comfortable (for example, your home, your office, at the offices of a service provider you use). It's up to you where we talk. You can also have a whānau member and/or a support person with you when you're interviewed.

We value your contribution and you will be provided with a \$100 koha in recognition of your time. There is also a koha of \$50 for a support person.

Do I have to be involved in the study?

You do not have to be involved in this study. Declining this invitation to be interviewed will not impact the services or support you receive from Work and Income or MSD.

Do I have to answer every question?

No, just tell me if you'd rather not answer a question. And if you don't quite get what a question means, just tell us and I'll have another go at asking it.

If in the month after we talk, you change your mind about being involved in this project, just let us know and we'll delete our interview with you from our files.

Your withdrawal will not affect your current or future relations with the income support system, MSD, or Katoa Ltd.

What will happen with what I say?

We'll be writing a report for MSD based on what people tell us. This will include common themes or things that lots of people talk about as well as interesting ideas that might come from only one or two people. You won't be identified in this report.

We can send you a summary of the research when it's completed so that you'll know what has gone back to MSD from this research. The reporting from this project will be published in 2024.

Will what I say be confidential?

We will not be reporting anything back to MSD or Work and Income that identifies you or anyone else personally. If, during our talk, you want to say something 'off the record' just tell me, and I'll stop recording.

The things you talk about in the interview will be kept confidential by us. Anything that identifies you personally will be stored securely. The recording of your interview will be transcribed but your name won't be put on this transcript. The person who does the transcribing will sign a confidentiality agreement, and then only the research team will have access to this transcript.

We are happy to provide you with a copy of your interview transcript 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 Fiona Cram (fionac@katoa.net.nz) within four weeks of receiving the transcript of your interview.

The research team will do all they can to ensure that you will not be able to be identified in published reports. Any identifying information you provide during the interview, such as your name, will be replaced by codes, or pseudonyms. However, your story may be recognizable to others such as friends with whom you have shared your stories.

We will keep your interview recording and the transcript secure for 6 years, after which time they will be destroyed.

What if I still have questions about the research?

Please ask me any questions you still have. If you want to reach me, my contact details are:

<i>Name of interviewer</i>	<i>Mobile / phone number</i>	<i>Email address</i>

What happens next?

If you agree to participate in this research, please fill out the consent form 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.



KATOA LTD.

Fiona Cram, PhD, Director

PO Box 105611
Auckland City, Auckland
Aotearoa New Zealand

☎ 021 774690
✉ fionac@katoa.net.nz

Kia ora! We really appreciate you taking the time to consider being part of this research.

When we finish talking, I'd like to leave you with a small koha, as a thank you for taking the time to share with me.



In-depth study to understand extra costs and income support for Tāngata Whaikaha Māori me ō rātou whānau, and Māori living with Long-Term Conditions 2023

Research Consent Form

I have read the information sheet about the study to understand extra costs and income support for Tāngata Whaikaha Māori (Māori with lived experience of disability), Māori living with long-term conditions, and their whānau or carers.

Questions I had about the study have been answered.

I understand all my information and that of any other family and whānau members 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 by contacting the Lead Researcher Fiona Cram by email (fionac@katoa.net.nz) in the next month, 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 or whānau.

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 whānau.

I consent to take part in the research. Please check the boxes that apply:

Consents

- ☐ I consent to take part in the research.
- ☐ I agree to our talk being audio-recorded.

Requesting a copy of the interview transcript

- ☐ I'd like a copy of my interview transcript.

Requesting a copy of the report summary

- ☐ I'd like a copy of the project report summary.

Where would you like things sent to – an email and/or a physical address:

My name is: _____ Today's date: _____

Signed: _____

Appendix B. Research interview and distress protocol, risk and mitigation strategy, and privacy

Research interview and distress protocol

The following protocol outlines the actions of the interviewer if, during the course of the interview, a participant exhibits acute distress or safety concerns.

Adapted from Draucker et al. (2009 p. 348, Fig. 2)

Indications of Distress ¹	Follow-up Questions	Participant Behaviour/ Responses	Acute distress or safety concern? (Y/N)	Imminent danger? (Y/N)
Participant indicates they are experiencing a high level of stress or emotional distress, OR exhibit behaviours that suggest interview is too stressful (e.g., uncontrolled crying, incoherent speech)	<ol style="list-style-type: none"> 1. Stop the interview 2. Offer support and allow the participant(s) time to 3. Ask about their ability to continue: <ul style="list-style-type: none"> • Do you feel able to go on? 4. Determine if the person is experiencing acute emotional distress beyond what would normally be expected in an interview about a sensitive topic 			
Participant indicates they are thinking of hurting themselves	<ol style="list-style-type: none"> 1. Stop the interview 2. Express concern and conduct a safety assessment: <ul style="list-style-type: none"> • Are you thinking about suicide or ending your life? 3. Determine if the person is an imminent danger to self 			
Participant indicates they are thinking of hurting others	<ol style="list-style-type: none"> 1. Stop the interview 2. Express concern and conduct a safety assessment: <ul style="list-style-type: none"> • Are you thinking about harming someone? Who? 3. Determine if the person is an imminent danger to others 			

Note. Need to include signs of distress shown by all members of whānau participating in the interview.

Actions for interviewer

1. If a participant's distress reflects an emotional response reflective of what would be expected in an interview about a sensitive topic, offer support and extend the opportunity to: (a) stop the interview; (b) regroup; (c) continue.
2. If a participant's distress reflects **acute emotional distress or a safety concern beyond what would be expected in an interview about a sensitive topic, but NOT imminent danger**, take the following actions:
 - Encourage the participant / whānau to contact their GP, existing counsellor or call 1737 (<https://1737.org.nz/>)

- Encourage the participant / whānau to contact their kaumatua or counsellor OR *study kaumatua or counsellor* for follow-up.
- Provide the participant / whānau with *study kaumatua or counsellor's* contract details, and the number of the emergency department at hospital. And encourage the participant to call either if he/she experiences increased distress in the hours/days following the interview.
- Indicate that, with the participant's / whānau permission, the *study kaumatua or counsellor* will contact him/her/them the next day to see if they are okay.
- Notify the *study kaumatua or counsellor* and Principal Investigator of the recommendations given to the participant/whānau.

3. If the distress of a participant/whānau reflects **imminent danger**, take the following actions:

- Call 111 and ask for Police, or if there is an accident, ask for Ambulance
- Unless arrangements can be made for the participant to be transported to the emergency room by a family member.
- Indicate that, with the participant's / whānau permission, the *study kaumatua or counsellor* will contact him/her/them the next day to see if they are okay.

Immediately notify *study kaumatua or counsellor* and the Principal Investigator.

Risk and mitigation strategy

Risks identified and risk mitigation strategies were as follows.

RISK	MITIGATION
Tāngata Whaikaha Māori who participate may feel uncomfortable talking to researchers that are not disabled themselves.	Where non-disabled researchers engaged with tāngata whaikaha Māori, the whakawhanaungatanga process was utilised to support hearing the participants views regarding who would interview them. Supplementing information provided during the initial recruitment call about the members of the Katoa team, time was spent building trusting relationships to build a sense of trust and comfort in the process and team. Interviewers generally worked in pairs, with at least one interviewer being whānau of tāngata whaikaha Māori.
Inquiry into benefit receipt would be seen as a knowledge test	Participants were assured that it was not a test and that what they could recall is exactly what we would like to know. We will encourage participants to refer to the benefit booklet they received when they did the New Zealand Income Support Survey. We carried extra copies of this with us in case they have misplaced their original copy, as well as other MSD information about the types of financial assistance they offer and how to access these.
Inquiry into benefit receipt may potentially uncover benefit fraud	Information shared within the context of the research was treated as strictly confidential by the research team, including if instances of fraud were shared. Participants were also be assured that the interviewers are not connected with MSD and were unlikely to recognise fraud or probe for evidence of it. This should not prevent them from talking about it themselves though, in the knowledge that any conversation about fraud would remain confidential. Participants were also given the option of recording devices being turned off if they wished to discuss fraud or other potentially sensitive topics 'off the record'.
Participants may not see the value in contributing their	Reassurance was given to participants that the study was instigated by MSD, for the purpose of finding out their views and advocating for policy action based on the evidence collected from them. Also other agencies

RISK	MITIGATION
views to a study about income support	<p>such as Whaikaha are keen to hear and learn about the experiences of tānanga whaikaha Māori, Māori living with long-term health conditions, and their whānau and carers. Although we could make no guarantees that policy would change as a result of the study, we assured participants of our track record working with our MSD research colleagues, including their commitment to and success in advocating for the amendment of income support policies. Ultimately the decision to amend income support policies often rests with Ministers.</p> <p>All participants have indicated in their response to the NZISS that they were willing to participate in follow-up studies, so we anticipated that this risk would be low. We were, however, unable to contact a small number of potential participants whose names were passed on to us by Reach.</p>
Participants may feel uncomfortable talking to a researcher without support	<p>Participants were encouraged to bring whatever support they need to the interview, and that the researchers would be more than happy to talk with them and their whānau if that was their preference.</p> <p>Sharing with participants that any supporters would also receive a koha has, in past studies, encouraged participants to seek out support (e.g., with childminding in the E Hine study).</p>
Participants may feel uncomfortable talking with researchers they do not know	<p>Time was spent with participants (and their support people) establishing or building connectivity/whanaungatanga, with the interviews conducted in a place and at a pace that participants were comfortable with. In addition, one of the two researchers was someone from the tāngata whaikaha Māori me ō rātou whānau communities and therefore more knowable / connected to them and their experiences.</p>
Participants may become distressed during the interview if they have experienced or are currently experiencing sad or traumatic life events	<p>A distress protocol was followed during interviews whereby the researcher pauses and inquires whether participants wish to continue with the interview if they seemed distressed, and checks to see if there's anyone the researcher can contact to provide them with support.</p> <p>No participants were assessed by the interviewers as distressed during their interview.</p> <p>All participants were left with a list of local support organisations.</p>
Researchers' safety may be compromised if interviews are conducted in participants' homes	<p>Researchers completed a shared register of when and where they were conducting interviews, with check-in arrangements (at the completion of an interview) made between researchers in the team.</p> <p>Most interviews were undertaken by two interviewers so that no interviewer was visiting a home by themselves. When some interviews in Taranaki had to be conducted by a single researcher due to bereavement, the researcher maintained mobile contact with the lead researcher, letting her know when each interview had been completed.</p>

Privacy

All personal information gathered in this research has been protected to uphold the obligations set out in the principles of the Privacy Act 2020.

The information collected was confidential to the research team, and subcontractors were required to sign a confidentiality form (Appendix G).

Interview recordings were transcribed by a reputable transcription firm, ATS (Audio Transcription & Secretarial Services, Leanne Miller, CEO). Katoa Ltd has used this firm in the past and have had no breaches of confidentiality. They were also asked to sign a confidentiality agreement (Appendix G).

Prior to analysis interview transcripts and any other research materials were de-identified. This includes the removal of all identifying information (e.g., names, addresses, birth dates, etc.). Contact lists, transcripts, audio-recordings, etc. were stored in password protected Dropbox Cloud storage and on one local desktop computer that is also password protected, in Fiona's office. Fiona also password protected individual files so even if storage protections were bypassed, the files themselves were password protected. Passwords were held in 1Password which is accessible by fingerprint or facial recognition. The passwords for files were shared with the research team when necessary, via text messaging.

Information will be held for six years and we informed participants of this in the Participant Information sheet (Appendix A).

Appendix C. Information sheet and consent form for full-and-correct entitlement check

Information and consent form for a check of whether you are getting full and correct income support from Work and Income¹¹

If you would like to check you are getting full and correct income support from Work and Income, (whether you could get more support or whether you are being overpaid), we can refer you to Work and Income who can organise this for you. At the same time, if you would like free independent legal or benefit advice about checking your supports, we will give you the details of services in your area.

If you have questions about what a check of full and correct entitlement involves, you can call the Work and Income general enquiries team on: 0800 559 009 between Monday to Friday, 7am – 6pm. You are not required to give your name and client number. You can also use the online tool: Check what you might get (msd.govt.nz) - <https://check.msd.govt.nz/>.

What to expect

If you agree to be referred for this check, we will need the following details from you:

- Your name, contact telephone number and email address, and the address of where you live.
- If you want the check for someone you care for, we need to know their name and whether you are their MSD authorised agent.

We will send those details to a dedicated team at Work and Income. They will then organise for your local Work and Income Service Centre to get in touch with you to set up an appointment time.

If after today you decide not to go ahead with the check of support, just let them know that when they get in touch.

If you do want to go ahead, MSD can book a phone or face to face appointment at a time that suits you. If you need any communication supports like a NZ Sign Language interpreter that can be arranged. Let them know what suits you best.

Appointments will probably take around 20-30 minutes of your time.

At the appointment, the case manager will enter your details into their system. They will ask you about your situation and check whether you are getting everything you're entitled to.

If they find that you could be getting more support than what you are getting now, they will make those changes by going through their usual process. To get the extra support, you might need to provide some extra details or supporting documents, like receipts for your health and disability related costs or information from your regular general practitioner (GP) or GP practice.

If they find that you are getting more support than you should be, then they will need to put this right. Your payments may decrease, and you may have to repay some money.

If you are caring for a person and you are their authorised agent, the case manager can do this check for them. If you are caring for a person and they need an authorised agent but this has not yet been set up, the case manager can talk through with you how to get this underway.

Taking part is optional

¹¹ Note that this is not presented here in the larger text and format it was given to participants in. This version is for content only.

It is your choice whether you have this check or not. Nothing will change with your payments, or payments for a person you care for, if you decide not to take part.

If you choose to have the check, the research team would like to have another interview with you 3-4 weeks later to ask how you got on and what the experience was like. This interview is optional too. We can do it by phone or by using Zoom.

If you agree to the check and the interview, we can include your experiences in a report to the Ministry of Social Development that will help them improve their service to you and other New Zealanders.

Statement of consent for a Work and Income check of support

I agree to be referred to Work and Income for a check of whether I am (or someone I care for is) getting full and correct income support from Work and Income. I have had what to expect explained to me.

- Questions I had have been answered.
- If have further questions I can contact MSD or a benefit advisory for further information.
- I understand that my (their) details listed below will be entered into the Work and Income system.
- I understand that I (they) could receive more or less income support as a result of the check.
- I understand if I share my experiences of the check, this will be included in a report to MSD, and that the information they receive will not identify me or any member of my whānau.

Signature _____

Date _____

Your name _____

Contact telephone number _____

Email address _____

Residential address _____

If the check of support is for someone you care for and are their authorised agent:

Their name _____

Are you their authorised agent? Yes / No / Unsure

Consent for us to contact you for another interview

I agree that the research team can contact me for a telephone or Zoom interview in 3-4 weeks' time to ask about my experiences of having this check completed.

Yes / No

Signature _____ Date _____

Appendix D. Further details on methods

Selection and recruitment

Participants were selected to be invited to participate based on their responses to selected questions in the NZISS. These included questions relating to health, disability, health- and disability-related benefit receipt, and children cared for. Selection was stratified by family type.

The recruitment process confirmed eligibility by asking if the respondent, their child, or someone they are a carer for was Māori and was disabled or had a long-term health condition (inclusive of mental health conditions) that limited their ability to carry out everyday activities or meant they had extra costs. The recruiter was Māori.

Reach Aotearoa had delivered the NZISS and made the initial approach to the selected potential study participants and asked if they were interested in participating in the current study, and if so whether they were happy for their contact details to be shared with the Katoa research team. Potential participants were told a \$100 koha would be provided to participants in recognition of their contribution.

MSD in collaboration with the research team developed scripts for Reach Aotearoa to use to describe the study and seek consent for sharing of contact details. Details about the Katoa research and advisory team were also be shared with potential participants.

When the Katoa team got in touch with potential participants who agreed to being contacted they provided more information about the study, offered the opportunity for people to ask any questions, confirmed whether they would like to go ahead with scheduling an interview, and discussed their accessibility needs. Those who agreed to have an interview scheduled were sent the information sheet and consent form in advance (in a form that is accessible for them) (Appendix A), together with an outline of what the interview would cover.

An acknowledged limitation is that the limitations in the original survey in its inclusiveness flow through to this study. The NZISS:

- was a nationwide household survey with random selection of the areas and households to include and up to 10 attempts at contact,
- involved face-to-face interviews (or virtual interviews if preferred) with those in the selected households who met the age and income criteria,
- included provision for an interpreter if required,
- did not include provision of survey information in alternate formats, and
- included provision 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 where a selected respondent was unable to provide consent themselves (with the exception of a self-report section which was not administered – this section included the questions about health and disability and ethnic group).

The NZISS did not include the provision of survey information in alternate formats, and no other provisions were made to engage people with diverse communication needs (beyond sign language). This means the NZISS 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 meant that participants' agreement to being in the initial survey and to be contacted for further research also introduced some potential for self-selection and non-response bias.

Interviews

If participants wanted an in-person interview, they were asked where they would like this interview to take place (e.g., in their home, at a support organisation). Most participants chose to be interviewed in their home, with one participant choosing to be interviewed at her work place. Participants were told that there was a koha budgeted for any support people, so they should feel free to invite one or two support people to their interview if they wanted to. Kai was taken by the interview team to the in-person hui, but it was signalled to participants that the researchers did not expect to be served the kai (as it was for their cupboards). At many of the interviews, researchers were offered a hot drink and at a few interviews participants also offered snacks.

We budgeted for two researchers doing the interviews, so we were able to include an interviewer from the participants' community / someone with a similar or related disability or health experience. Taking a team approach to the interview process, also allowed for an interviewer to remain 'present' with the participant/s, while another focused on listening and note taking. While we were responsive to participants' feedback on who they would like at the interview, all participants were happy to be interviewed by the two researchers we suggested. All subcontracted interviewers completed confidentiality agreements (Appendix G).

Interpreter services

Participants were asked if they required interpreter services (e.g., New Zealand sign languages, spoken language) and told that the research team would meet the cost of these services. None of the participants requested interpreter services.

Piloting

In order to achieve a conversational 'feel' in the interviews and test the understandability and flow of the interview schedule, two of our advisors were individually engaged in mock interviews and provided feedback on the consent and interview process, including the questions asked (e.g., whether they understood the questions and were able to answer them, whether the way they were asked was good for them more generally). Only minor revisions of the interview schedule were needed in response to their feedback, with members of the Rōpū Kaitiaki asked to check these revisions before participant interviews begin.

Ending the Interview

At the end of the interviews, participants were thanked and reminded about the process of the research that happens once everyone had been interviewed.

All participants received a \$100 voucher of their choice (e.g. supermarket or The Warehouse) per interview as a thank you/koha for their involvement in the research. If they had a support person at their interview, the support person received a \$50 koha voucher. Participants were also asked if they would like to receive a copy of the research summary and, if they did, the best way for them to receive this (e.g., electronic or hard copy) was noted down.

Invitation to follow-up interview

Participants who wanted to complete a full-and-correct entitlement check with a MSD benefit expert were to be invited to a second interview with the research team three to four weeks after that assessment. However, none of our participants wanted to pursue the option of the entitlement check.

Recording of data

The interviews were audio-recorded with participant consent. In addition, a database for the recording of interview responses were developed (in Excel). Participant responses were noted during the

interview and entered into the database after the interview, from the notes and the audio-recording. For the survey of additional costs, printed tables were filled in by the researchers at the time of the interview. Appendix E provides example tables for responses to Enquiry Area 2. Handwritten notes and audio-recordings were stored in a locked cabinet in Fiona Cram's office and accessible only by her. The database was password protected and stored in a Dropbox folder that was only accessible to members of the research team.

Analysis

The audio-recordings of the interviews were transcribed verbatim for analysis, and participants requesting a copy of their transcript were sent it. What then happened to the transcripts varied for the three areas of enquiry.

Enquiry Area 1: The participants' situation and the housing and neighbourhood they and their whānau live in, and their participation in paid work and other activities

Responses were analysed individually and then collectively by the research team using reflexive thematic analysis, which is a relational process – a dialogue between data, theory and interpretation (Braun & Clarke, 2019, 2020). Reflexive thematic analysis acknowledges the subjective, contextual and interpretive work of qualitative data analysis. We also engaged with our Rōpū Kaitiaki to provide input into and oversight of the analysis and reporting processes.

Enquiry Area 2: The additional costs participants attributed to being disabled or having a health condition, having a disabled child or a child with a health condition, and compensating strategies. Participant responses about monetary costs were aggregated for tāngata whaikaha Māori, carers of adult participants, and carers of children. Qualitative data collected were analysed using the same process as described for area of enquiry 1.

Enquiry Area 3: Participants' past and current benefit receipt and their experiences of claiming and/or not claiming income support payments. Participants' responses about receipt of income support were aggregated for tāngata whaikaha Māori, carers of adult participants, and carers of children. Qualitative data collected (e.g., about applying for income support, experiences of Work and Income) were analysed using the same process as described for area of enquiry 1.

Examples of experiences

Examples were developed to demonstrate the range of experiences and costs. These examples are single narratives about hypothetical people drawing on at least two of the participants' stories. This protected the anonymity of participants while presenting lived experiences in ways that are accessible to a wider audience.

Appendix E. Enquiry Area 2 – Data collection tables (separate sets for each participant)

Weekly costs	Cost (if they want to disclose)	Do you think you're paying extra? Y/N	<i>If yes</i> How much extra do you think you're paying?	If you spend less on this than you'd like to, is affordability a barrier?	If you spend less on this than you'd like to, are there other barriers?	Comments
Rent / Mortgage						
Transport						
Food						
Personal care						
Childcare						
School						
Adult education						
Fitness / Sports						
Personal allowance						
Pet care						

Monthly costs	Cost (if they want to disclose)	Do you think you're paying extra? Y/N	<i>If yes</i> How much extra do you think you're paying?	If you spend less on this than you'd like to, is affordability a barrier?	If you spend less on this than you'd like to, are there other barriers?	Comments
Internet and phone						
Household services , including firewood, additional heating or cooling, and subscriptions such as Netflix						
Medical						
Special events						

Other costs	Cost (if they want to disclose)	Do you think you're paying extra? Y/N	<i>If yes</i> How much extra do you think you're paying?	If you spend less on this than you'd like to, is affordability a barrier?	If you spend less on this than you'd like to, are there other barriers?	Comments
Equipment						
Insurance						
Clothing						
Contents						
Dental						
Holiday(s)						
Contingency						

Appendix F. Enquiry Area 2 – Potential Māori cultural elements

Inquiry area	Potential Māori cultural elements
RENT, MORTGAGE PAYMENTS, OR BOARD	Location, design (tikanga), manaaki, whanaungatanga – size ¹²
TRANSPORT	Additional / transport costs associated with maintenance of relational links with whānau and tūrangawaewae e.g. rental, lease or purchase of a van to accommodation travel as a whānau
FOOD	Kai Māori – If they eat kai Māori, do they feel they have additional costs obtaining this kai? Maara kai: planting and growing own kai
PERSONAL CARE This includes support for basic daily tasks and your daily living needs like food shopping, meal preparation and socialisation.]	Culturally competent care, e.g., practice tikanga and kawa, speak te reo Māori, support other cultural and spiritual practices such as karakia, pure Mirimiri, rongoā, healing, whitiwhiti kōrero Costs associated with work Costs associated with strengthening capability (tikanga, te reo Māori, whakapapa)
CHILDCARE	Accessing Kōhanga Reo, including engaging appropriate supports (e.g. teacher aide/inclusive learning support Accessing te reo Māori, mātauranga Māori within early childhood settings Accessing te reo Māori sign language learning Accessing te reo Māori closed captioning Whānau supported to learn about the impact of colonisation for Māori and tāngata whaikaha Māori
SCHOOL	Accessing Kura Kaupapa Māori, including engaging appropriate supports (e.g. teacher aide/inclusive learning support Accessing te reo Māori, mātauranga Māori within kura kaupapa Māori settings Accessing te reo Māori sign language learning Accessing te reo Māori closed captioning Whānau supported to learn about the impact of colonisation for Māori and tāngata whaikaha Māori
ADULT EDUCATION	Accessing wānanga or other Māori education / learning options, including personal supports and equipment to support inclusion and participation., Accessing te reo Māori, mātauranga Māori within adult education setting Accessing te reo Māori sign language learning Accessing te reo Māori closed captioning Whānau supported to learn about the impact of colonisation for Māori and tāngata whaikaha Māori
INTERNET AND PHONE	Accessing Māori tv and radio Assistive Communication devices, training to support use, and the use of te reo Māori application and language voice over
HOUSEHOLD SERVICES	Also costs beyond the household (e.g., be able to support on papa kāinga, marae)

¹² A larger house may mean a larger household and more informal care-giving and transportation support that reduces costs (Mittra et al., 2017)

Inquiry area	Potential Māori cultural elements
MEDICAL CARE	Accessing culturally competent care Whānau and friends' costs covered to support during medical care and hospital stays Mirimiri, rongoā, healing, whitiwhiti korero for tāngata whaikaha and for whānau
EQUIPMENT	Support and equipment to enable access to te taiao, marae and other hāpori spaces, holidays and events Assistive Communication devices, and the use of te reo Māori application and language voice over
INSURANCE	Accessing insurance options for taonga Māori
CLOTHING	Obtaining Māori branded clothing or other display taonga
HOUSEHOLD CONTENTS	Also costs beyond the household
DENTAL CARE	Accessing culturally competent care Whānau and friends' costs covered to support during care
FITNESS	Accessing culturally competent provider Access personal trainer or other person to enable access (e.g., support in the pool or at the gym)
PERSONAL ALLOWANCES	Tangi, wider whānau expenses / contributions to expenses, remittances Accessing te reo Māori, mātauranga Māori, kapa haka Accessing te reo Māori sign language learning Accessing te reo Māori closed captioning Connect with kaumātua for guidance and support Mirimiri, rongoā, healing, Whitiwhiti korero
EVENTS: special activities or cultural event costs	Maintenance of relational links with whānau and whenua-tūrangawaewae Strengthening place-based mātauranga Kaitiakitanga obligations Mahinga kai (hunting, gathering) Acquisition of tā moko, moko kauae Learning about the impact of colonisation for Māori and tāngata whaikaha Māori
HOLIDAY	Size of whānau rōpū travelling together
CONTINGENCY	For attending tangi – provision of koha, access to equipment if travelling away to marae or other areas (e.g., hospital bed, hoist, ramps, beach mobility chair)

Appendix G. Confidentiality agreements

For subcontractor, intermediary or research assistant

Project title: *In-depth study to understand extra costs and income support for Tāngata Whaikaha Māori 2023*

Project lead: *Dr Fiona Cram, Katoa Ltd*

Project funder: *Ministry of Social Development*

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the Consent Forms, tapes, or interview notes can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Signature :

Name :

Contact Details:

.....
.....
.....
.....

Date:

Approved by the Ministry of Social Development

Note: The subcontractor, intermediary or research assistant should retain a copy of this form.

For someone transcribing data or checking the auto-transcription of interview data, e.g., audio-tapes of interviews.

Project title: In-depth study to understand extra costs and income support for Tāngata Whaikaha Māori 2023

Researcher: Dr Fiona Cram, Katoa Ltd

Funder: Ministry of Social Development

As a transcriber of this research, I, _____, understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this non-disclosure agreement.

I, _____, agree not to share any information on these recordings with anyone except the Researcher of this project. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I, _____, agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) with anyone other than the Researcher.
2. Take reasonable technical and non-technical measures to keep all research information in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) secure while it is in my possession.
3. Take reasonable technical and non-technical measures to maintain the security of any storage device (e.g. laptop and desktop PC, Mac, USB stick, etc.) that host the said research information.
4. Not keep the research information in any third party cloud storage service, unless the files are in encrypted format and this is agreed by the researcher.
5. Return all research information in any form or format (e.g. WAV files, VOB files, CDs, transcripts, physical copy, etc.) to the Researcher, in a secure method, when I have completed the transcription tasks.
6. After consulting with the Researcher, securely erase or destroy all research information in any form or format regarding this research project that is not returnable to the researcher (e.g. information stored on my computer hard drive).
7. Inform the Researcher if we are aware of, or suspect there might be, a data breach while the data are within our own, or our subcontractor's storage systems. (This is particularly an obligation under the upcoming General Data Protection Regulation.)

Transcriber's signature :

Transcriber's name :

Date:

Appendix H. Interview schedule

Within the context of conversational interviews (see above), the researchers asked participants the following questions.

Enquiry Area 1

Topic 1. Household and whānau health and disability

These first questions are about you.

1. **Check in that we're all on the same page** - When we talked to you about being involved in this research you said you identify as:
 - a. tangata whaikaha Māori and/or Māori with a long-term health condition,
 - b. Māori and with a child who is tangata whaikaha and/or has a long-term health condition, Māori and a carer for a whānau member/someone who is tangata whaikaha and/or with a long-term health condition

Is that your understanding as well?
2. Do you feel comfortable telling us a little bit more about yourself? *(as appropriate)*
 - a. your experience of disability or health condition (e.g., (nature, severity, variability, duration), or
 - b. having a child who is tangata whaikaha and/or has a long-term health condition
 - c. your responsibilities as a carer?

Topic 2. Housing

These next questions are about housing.

3. How would you describe the place you're currently living in? – for example, the number of bedrooms, age and condition of the accommodation, tenure (e.g., renting, owner-occupied)
4. What are some of the things you like about this place?
5. What are the things about the place you live that you find challenging or difficult in relation to your disability or long-term condition?
6. Is there one thing that could help with these difficulties?

Topic 3. Neighbourhood – community

7. What are the things you like about the neighbourhood or community you're living in?
8. What are the things about this neighbourhood or community that you find challenging or difficult in relation to your disability or long-term condition?
9. Is there one thing that could help with these difficulties?

Topic 4. Paid work

Let's talk a bit now about your mahi, your paid work.

10. Are you in paid work or contracted work? *If yes* How many hours do you work in a typical week? Does this change from week to week?
11. Do you work less than you want to because [name of their disability or health condition and/or the caregiving role they have previously mentioned]?
12. Is there one thing that would make it easier for you to work the hours that you'd like to?

Topic 5: Other activities

These next questions are about activities.

13. What sorts of activities do you and your whānau do?
14. Are there activities you don't participate in or participate in less because of [a disability or health condition or caring responsibilities]? If yes, What are those activities?
15. Is there one thing that would make it easier for you to participate in activities?

Enquiry Area 2: The type and dollar value of costs for respondents

This next set of questions asks you to think about the extra costs of things and whether you feel that you / the person you are carer for pay extra because [you/your child/the person you are carer for [is disabled or a long-term health condition]].

Carer screening question As a carer for a disabled adult or an adult living with a long-term health conditions [guided by respondent situation and preference] do you help them by organising their bills and shopping for them? If you do, we'd like to hear about their costs.

The questions for each expense are similar: (also see prompts in data collection tables, Appendix E)

- Do you think you/they are paying extra for _____ ?
- If yes, How much extra do you think you/ they are paying?
- Do you/they spend less on _____ than you/they would like to? If yes, what prevents you/them from spending more?

The data collection tables that were used are in Appendix E (there were separate versions of these for each person that extra costs are reported for). Hard copies of these tables were filled in during the interview, as the questions are asked.

Appendix F contains overview of Māori cultural components in the cost areas. These will inform the interviewers of potential costs to inquire about. They will also be shared with participants as a potential prompt about costs.

Weekly costs

Let's start with weekly costs. We appreciate that costs can be different if we have a 'good' or a 'not so good' week. How would it be helpful to think about your week? If it's helpful you can also tell me about your costs and we can talk about whether you/they might be paying extra because [you/your child/the person you are carer for [is disabled or has a long-term health condition]].

1. Rent / Mortgage
2. Transport
3. Food
4. Personal care
5. Childcare
6. School
7. Adult education
8. Fitness / Sport
9. Personal allowance
10. Pet care

Monthly costs

Let's move on to monthly costs. Again, if it's helpful you can tell me about your costs for a 'good' or a 'not so good' week, and we can talk about whether you might be paying extra because [you/your child/the person you are carer for [is disabled or has a long-term health condition]].

11. Internet and phone
12. Household services, including firewood, additional heating or cooling, and subscriptions such as Netflix
13. Medical care
14. Special events

Less frequent costs

Let's move on to less frequent costs. Again, if it's helpful you can tell me your costs and we can talk about whether you might be paying extra because [you/your child/the person you are carer for [is disabled or has a long-term health condition]].

15. Equipment and housing modifications
16. Insurance
17. Clothing
18. Household contents
19. Dental care
20. Holiday(s)
21. Other one-off costs

Final questions in this enquiry area

22. Are there any other regular or less frequent extra costs I haven't asked about?
23. 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.
24. Finally, how do you get by? What decisions have you made, or tricks have you found to manage with your current situation?

Enquiry Area 3: Selected income support

This next set of questions is about income support.

Carer screening question As a carer for an adult disabled person, or lives with a long-term health condition [guided by respondent situation and preference] do you help them applying for and renewing income support from Work and Income. If you do, we'd like to hear about their income support payments.

The questions are about whether you've/they've applied for and received any of four different types of support. If you want to, you can also tell us what it was like applying for support. The questions are similar for each of the types of support.

Disability Allowance

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 carer for receiving the DA?
4. *(If applicable, skip if running out of time)* If you/they are not currently accessing the DA, have you applied for it in the past?
5. If so, how did you/they find applying for the payment?
6. If you/they received DA in the past but are not currently receiving it now, why is that?
7. Do you/they think they might be able to get the DA but choose not to apply? If so, why is that?
8. Do you think the person you are caring for might be entitled to DA but choose not to apply? If so, why is that?

Temporary Additional Support (TAS)

9. *(If applicable)* Are you receiving Temporary Additional Support (TAS) for your own health and/or disability-related costs?
10. *(If applicable)* Are you or your partner receiving TAS for a child's (aged under 18) health and/or disability-related costs?
11. *(If applicable)* Is the person you are carer for receiving Temporary Additional Support (TAS) for their own health- and/or disability-related costs?
12. *(If applicable skip if running out of time)* If you/they are not currently accessing the TAS, have you applied for it in the past?
13. If so, how did you find applying for the payment?
14. If you received TAS in the past but are not currently receiving it, why is that?
15. Do you think you might be entitled to TAS but choose not to apply? If so, why is that?
16. Do you think the person you are caring for might be entitled to TAS but choose not to apply? If so, why is that?

Child Disability

17. *(If applicable)* Are you or your partner receiving Child Disability Allowance (CDA) for a child?
18. If so, how did you find applying for the payment?
19. If you have not received CDA, or have in the past but are not currently receiving, why is that?
20. Do you think you might be entitled to CDA but choose not to apply? If so, why is that?

Supported Living Payment (Carer)

21. *(If applicable)* Are you currently receiving the Supported Living Payment (Carer) due to your caring role?
22. *(If applicable)* Is someone else in your household currently receiving the Supported Living Payment (Carer) due to your health condition or disability?
23. *(If applicable, skip if running out of time)* If you/they are not currently accessing Supported Living Payment (Carer), have you/they applied for it in the past?
24. If so, how did you/they find applying for the payment?

25. If you/they have not received Supported Living Payment (Carer), or have in the past but are not currently receiving why is that?
26. 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?

When supports have been asked about.

27. In the last 12 months have you used any subsidies from the Ministry of Social Development – MSD – or other agencies to support modifications to your home? *If not*, Are you aware there are subsidies?

Enquiry Area 4. Final comments

We're coming to the end of the interview and I just want to give you a moment to tell me anything else that you feel it's important I know, especially if there's something else I should have asked about but didn't.

Invitation for full-and correct entitlement assessment and follow-up interview for Enquiry Area 3

Would you like to be referred to someone at Work and Income who can check whether you [and/or the person you are carer for] are getting full and correct benefits and allowances from them?

If yes, I will show you the information about this now and we will discuss how they could contact you.

The MSD invitation was shared with them and their consent for their contact details to be passed on to MSD was collected if they are wanting to do this.

If you agree to go ahead, we will invite you to a quick follow-up interview to see how that went and whether it turned out that you [and/or the person you are carer for] qualify for a different amount of support you are getting now.

Appendix I. Overview of participant costs

Area	Number of participants mentioning these costs	Range	Average	Standard deviation
Housing (per week)	15	\$68.50-\$1200	\$502.50	\$318.27
Transport (per week)	7	\$0-\$200	\$80.36	\$74.43
Food (per week)	6	\$50-\$400	\$204.17	\$135.44
Personal care (per week)	5	\$0.00-\$125	\$31.67	\$54.13
Childcare (per week)	1	\$30		
School (per week)	0			
Adult Education (per week)	0			
Fitness / Sport / Therapy (per week)	1	\$246.92		
Personal allowance (per week)	0			
Pet care (per week)	6	\$10.-\$80	\$35.32	\$28.02
Internet and phone (per month)	11	\$20-\$240	\$109.55	\$72.24
Household services (per month)	11	\$15-\$430	\$228.66	\$137.59
Medical (per month)	6	\$15-\$150	\$65.06	\$51.32
Special events (per month)	0			
Equipment (occasional)	2	\$10-\$200	\$105.00	\$134.35
Insurance (occasional)	6	\$24.00-\$184.62	\$94.10	\$55.51
Clothing (occasional)	4	\$200-\$600	\$410.00	\$201.25
Household contents (occasional)	1		\$1200	
Dental (occasional)	0			
Holidays (occasional)	1		\$400	
Contingency (occasional)	1		\$25	