

**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 – Summary**

A study by Katoa Ltd for the Ministry of Social Development, June 2024

# Overview

In mid-2023 to early 2024, Katoa Ltd interviewed 20 people. These people were 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 ask about 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.

Key strengths of the study were the Kaupapa Māori methodology, and the connection made between Māori participants and the Māori interview team.

There were some limits to the study. The study could only speak with 20 people; all but one participant was wāhine Māori (adult Māori women). That is a small number, and the study did not capture a wide range of experiences and views, especially from people with significant impairment and tāne Māori (adult Māori men). However, some mothers were able to speak about raising tamariki (children) with high and complex needs.

At least three of the wāhine Māori in the study were raising tāngata whaikaha Māori sons. Their input provided insights into the experiences of young tāne Māori within their whānau.

People generously shared their experiences and the resulting data was rich. The costs they described and feedback on what they are missing out on because of affordability challenges may well be similar to the experiences of other tangata whaikaha Māori, their whānau, and Māori with long-term conditions.

# Key Findings

## Most people interviewed said they had ‘not enough’ or ‘only just enough’ money to meet their everyday needs

Eight participants said they only just enough money, eight said they did not have enough money, with the remainder saying they have enough money to meet their everyday needs. 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 their direct costs were high, then they described their finances as tight.

## Cost barriers led to a range of unmet needs

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 healthy food or special diets they needed for themselves and/or their tamariki. They had to rely more on cheaper, processed foods. This was likely to be adversely affecting whānau health and wellbeing.

**There are some foods that I’ve been told I should eat, but I can’t afford them. Not a chance.**

People went without a range of other goods and resources because they could not afford them. Many went without 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 options limited their access to activities, education opportunities, and were sometimes considered unsafe.

**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**.

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.

## People experienced a range of direct health and disability-related costs

People often found it difficult to say how much of their direct costs were related to being tāngata whaikaha Māori, whānau of tāngata whaikaha Māori, or having a long-term health condition. They considered their spending (or inability to afford) normal for them.

Some participants 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 linked 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 was needed to speed up diagnoses to access disability funding.

**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.**

Internet costs were high for whānau of tāngata whaikaha Māori tamariki and rangatahi (teenagers and young adults) 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 their tamariki and rangatahi. Some had gone without streaming services due to their unaffordability.

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

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.

## Employment

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.

Those who had given up full-time employment to care for tamariki whaikaha did not see this as a negative. They were committed to being fully present to ensure their tamariki had the best opportunities to live good lives. 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 were thinking about work after their time as a carer were looking for formal support to help them prepare for and access appropriate employment opportunities.

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

Many respondents 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 could be a diminished sense of cultural identity, belonging and psychological wellbeing.

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.

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. In turn, this could have negative impacts on their sense of self-worth.

## Housing and whānau support

Participants where diverse in their living arrangements.

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.

Those who were renting shared that rental costs were high and often on the rise. If they lived by themselves, their accommodation was usually small, and that made it hard to host their whānau.

I’ve got 29 grandchildren. Sometimes I get them come here and “Can I stay the night, Nan?” [I have to say] “No. Go home.”

Those in two-generation households – mothers looking after tamariki whaikaha – managed their money very well. 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. Financial pressures could lead them to look for paid employment, placing more reliance on other whānau members to stay at home and be caregivers. Due to the high costs of rental accommodation, whānau conflicts could leave people feeling trapped because they could not afford to move out and relied on the support of whānau.

Some participants could call on financial support from their whānau. Other financial support options included their church and their children’s school. For example, a kura (school) fundraised so that tamariki could go on trips.

## Access to and experiences of income support from Work and Income

Most participants reported receiving a main benefit, usually Supported Living Payment or Jobseeker Support – Health Condition or Disability. Three reported receipt of Disability Allowance.

Some who were not accessing income support payments 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.

Experiences with Work and Income were mixed. Some said they received good treatment from their local office. Others had to use an advocate two or more times to qualify for a benefit. 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 was because they felt they were receiving the right income support or did not want to risk being found to have a debt or not eligible for something they are already receiving. Therefore, this study could not explore if people’s ability to meet additional costs could have been improved and unmet needs reduced, if participants were receiving all their entitlements. Receipt of Disability Allowance appeared low given the costs and unmet needs that participants described.

## Further reading

To see the full report, ‘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’, go here: <https://www.msd.govt.nz/>kecis

**End of information | 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 – Summary**

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