

# **Costs and income support experiences for Pacific peoples who are disabled or have long-term health conditions**



**MINISTRY OF SOCIAL  
DEVELOPMENT**  
TE MANATŪ WHAKAHIATO ORA

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## **Disclaimer**

The discussion and conclusions reflect the views of the authors and do not necessarily reflect the views of advisors to the project or the position of the Ministry of Social Development.

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## Glossary of terms

**ACC Weekly Compensation** – a weekly payment made by the Accident Compensation Corporation (ACC) to people who are unable to work due to a personal injury. This contributes to lost income that would have otherwise been received from their paid employment if not for the period of incapacity caused by their injury. For more information: <https://www.acc.co.nz/im-injured/financial-support/weekly-compensation>

**‘Aiga** – family, including extended family.

**Akamanea** – to decorate, make beautiful.

**‘Akaruru** – to keep together, united.

**Child Disability Allowance** – a fortnightly payment from MSD made to the main carer of a child or young person with a serious disability. It is paid in recognition of the extra care and attention needed for that child. For more information: <https://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html>

**Carer Support** – a subsidy to reimburse some of the costs of engaging a support person to care and support a disabled person while the full-time carer has a break. It is provided by Whaikaha – Ministry of Disabled People and Health New Zealand – Te Whatu Ora. For more information: <https://www.whaikaha.govt.nz/support-and-services/carers-support-and-respite/carers-support>

**Disability** – any long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder the full and effective participation of disabled people in society on an equal basis for others.

**Disability Allowance** – a weekly payment from MSD for people who have regular, ongoing costs because of a disability. These could be visits to the doctor or hospital, medicines, extra clothing or travel. For more information: <https://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html>

**Individualised Funding** – self-directed funding from Whaikaha - Ministry of Disabled People that people can use to purchase disability supports. For more information: <https://www.whaikaha.govt.nz/assessments-and-funding/individualised-funding>

**Jobseeker Support** – a weekly payment from MSD that helps people while they are looking for work or can't work right now (e.g. due to a health condition). For more information: <https://www.workandincome.govt.nz/products/a-z-benefits/jobseeker-support.html>

**Koha** – gift, present, offering, donation, contribution.

**Long term health condition** – any ongoing, long term or recurring conditions that can have a significant impact on people's lives.

**Mana** – prestige, authority, control, power, influence, status, spiritual power, charisma –a supernatural force in a person, place or object.

**Meaalofa** – gift, present, offering, donation, contribution.

**O'ora** – giving of gifts.

**Supported Living Payment** – a weekly payment from MSD to help people who have, or are caring for someone with, a significant health condition, injury or disability. For more information:

<https://www.workandincome.govt.nz/products/a-z-benefits/supported-living-payment.html>

**Tagata** – person, people, peoples.

**Talanoa** – to talk, open and respectful discussion, a Pacific-specific qualitative approach to data collection.

**Tapu** – to be sacred, prohibited, restricted, set apart, forbidden, under *atua* protection.

**Temporary Additional Support** – a weekly payment from MSD that helps people who don't have enough money to cover their essential living costs. For more information: <https://www.workandincome.govt.nz/products/a-z-benefits/temporary-additional-support.html>

**Total Mobility** - Funded in partnership by local and central government, the Total Mobility scheme assists eligible people, with long-term impairments to access appropriate transport to meet their daily needs and enhance their community participation. This assistance is provided in the form of subsidised door to door transport services wherever scheme transport providers operate. For more information: <https://www.nzta.govt.nz/resources/total-mobility-scheme/total-mobility.html>

**Tuitui** – to lace, sew, thread on a string.

# Executive summary

## Background

Children in households with a disabled person are three times more likely to experience material hardship than children in households with no disabled people. They account for just over half of all children living in a household experiencing material hardship (Stats NZ, 2024). However, limited information is available on the costs faced by disabled people and people with long-term health conditions in Aotearoa New Zealand.

The Ministry of Social Development (MSD) commissioned research to build a better understanding of these costs and the circumstances of children in households with a disabled person or long-term health condition.

The research included three strands of qualitative research on income support, health- and disability-related costs, and material wellbeing for disabled people and people with long-term health conditions (hereafter 'health conditions'). The strands were Pacific peoples, Māori, and non-Māori, non-Pacific peoples.

Strands interviewing Māori and non-Māori, non-Pacific peoples were carried out by Katoa Ltd and Allen and Clarke and All is for All. These are reported on in Cram et al. (forthcoming) and Gray and Stratton (forthcoming).

This report presents the Pacific strand of that qualitative research.

Gathering the experiences of Pacific peoples is especially important because of the high rates of disability and health challenges among Pacific peoples and the high rates of hardship they experience (Wilson and McLeod, forthcoming).

## Methodology

Talanoa (in-depth interviews) were conducted with 16 Pacific peoples who are either disabled, have health conditions, or care for someone who is disabled or has health conditions. Not all were MSD clients. The talanoa were carried out in person or online to suit participants' availability and accessibility needs, and maximise their participation.

A Pacific research framework, the Tivaivai framework, was used to guide all phases of the study, including planning and scoping, data collection and analysis, report writing, sense-making, and presentation of findings. The Tivaivai framework uses a culturally grounded, collaborative, and reciprocal approach to engaging with Pacific communities and sharing their stories.

Questions that guided the research focused on:

- The direct costs associated with being disabled or having health conditions
- Unmet needs
- Indirect costs associated with being disabled or having health conditions

- Consequences of any additional costs and unmet needs
- Interrelationships between costs and people's situation and context
- Access to income support.

The Pacific peoples interviewed ranged from their 20's to their 70's in age. They included people identifying as Samoan, Tongan, Tokelauan, Niuean, Papuan, and Cook Islands Māori. Eleven were women and five were men. All lived in the Auckland or Wellington regions.

As a qualitative study, the results are intended to provide a deep understanding of participants' situations. The research complements work undertaken by Wilson and McLeod (forthcoming) to quantify the difference in income between households with children where someone had a disability and similar households where no one had a disability.

## Key findings

Key themes from the talanoa are as follows.

### Direct costs

#### **Most people reported a range of direct health- and disability-related costs**

The direct costs people talked about included the costs of medical appointments, rehabilitation and therapies, special food, equipment, furniture, clothing, shoes, extra home heating and transport costs.

For some, these costs were extensive. This was especially the case when mobility was affected, or there were costs associated with having a carer provide alternative or respite care.

Only two of the 16 participants said they had few health- and disability-related costs, or that their costs were manageable.

#### **Health- and disability-related transport costs were very high for some**

Transport to and from health appointments, as well as transport needed to manage life as a disabled person or a person with a health condition were key direct costs for some people.

Some disabled people and their carers had moved to help manage these costs (e.g., moving into the central city to reduce transport costs). For carers, the costs of getting their loved one to and from activities, church, and medical appointments could be considerable.

### **Direct costs could be hard to identify**

It was sometimes difficult for people to identify what costs were health- and disability-related costs, or what share of regular expenses such as power were health- and disability-related.

## **Unmet needs**

### **Some participants and/or those they cared for had a range of unmet health- and disability-related needs due to cost and affordability**

Income inadequacy and cost barriers meant some people could not afford the specific diet, regular health care, rehabilitation, or extra help around the house they knew would improve their health or help them manage their conditions or disabilities. Not having the financial resources to meet these needs had profound impacts on the health, wellbeing, and quality of life of some participants. For example, the expenses faced by one participant prevented them from making recommended modifications to their home.

### **There were other barriers to accessing needed supports**

Other barriers to accessing needed supports were the time, energy, knowledge, and advocacy required to gain access to treatments, funded equipment, and resources.

### **Limited availability of suitable and accessible housing was identified**

Several participants described having difficulty finding suitable housing that met their accessibility needs. In some cases, people had to make do with living in unsuitable housing, such as housing without adequate heating or housing that was not wheelchair accessible.

## **Indirect costs**

### **A common indirect cost was reduced paid employment and earnings**

Some disabled people and people with health conditions had managed to sustain or gain paid employment. Sometimes this was with support from 'aiga, pacific providers, and clinicians, or flexibility from employers.

However, a common theme was that being disabled or having health conditions, or caring for loved ones who were disabled or who had a health condition, disrupted opportunities to participate in paid employment.

Some were currently working part-time or doing voluntary work but wanted to work full-time. For others, ill-health or being disabled ruled out employment for now or permanently.

Carers had often been in paid employment and/or education before taking up their caring roles.



### **Carers balanced wellbeing gains from providing care against the financial costs of lost employment**

Carers often reflected on their cultural values when they talked about deciding to give up employment to care for their loved one. They were conscious of the economic penalty associated with choosing to care for their loved one over being in employment but prioritised the wellbeing gains for their disabled family member and the other members of their family.

### **Some disabled people and carers experienced costs to their own physical and mental health**

Some people talked about effects of health conditions and being disabled on their mental health, or that of the person they cared for.

There were indirect costs to carers that came with prioritising care of their loved ones. These included the stresses and strains of life as a carer, and the costs to their own wellbeing from not having the time and financial resources to take care of themselves. Some had experienced periods of burnout.

### **Another indirect cost was being unable to live independently**

Some disabled people and carers had lost the ability to live independently, without needing to be cared for, or needing to be a carer. Carers talked about supporting their loved ones to be as independent as they could be within this context. One participant living with 'aiga to save on costs talked about wanting to live on their own, to gain more independence.

## **The consequences of direct costs and unmet needs**

### **Health- and disability-related costs sometimes led to other needs not being met**

Health- and disability-related costs put pressure on families' budgets. There were times when they were unable to afford the basics, including food, petrol, and school uniforms.

For one participant, the strain of trying to meet health- and disability-related costs had affected their children's school attendance. For another, their children's ability to participate in extra-curricular activities was affected.

### **Most said their income was not enough or only just enough to meet their needs**

Of the 15 participants who gave answers to a question about income adequacy, five said their income was not enough and seven said their income was only just enough to meet their everyday needs. Only three said their income was enough and none said they had more than enough income.

### **People and their 'aiga often went without or made do**

Some people talked about making do with resignation. Others were just managing financially, but no longer had any financial buffer.

## **Interrelationships with context, compensating strategies and sources of support**

Aspects of people's situation and context helped to mitigate against their costs and the strain these caused.

### **Suitable and affordable housing and safe neighbourhoods made a positive difference for some**

Living in suitable housing made a significant difference in the day-to-day lives of some participants. Housing being warm, close to family, and affordable were important factors in determining how suitable participants found their housing to be.

The neighbourhood that they lived in also contributed to how people felt about their housing. It was important to participants that they felt safe and that their neighbourhood provided a sense of community.

### **Care, support, and advocacy provided by family members were key factors that helped people manage, compensate for, and share costs**

Participants expressed their gratitude for the care and support that they received from their families. Family members played key roles in helping secure needed treatment, resources, and equipment, sharing knowledge, and helping compensate for and share health and disability related costs.

Many received support with their daily living expenses, and more expensive items like travel for family events, from extended family.

Carers often advocated for resources on behalf of their loved ones. Some were aware that not all people in their community would have access to someone who could do this for them.

### **Churches and community involvement were important sources of connection and support, but there were associated costs**

Participants were active in their communities. Family and community events were a source of meaning and fulfilment. For some, restricted finances negatively affected their ability to contribute to and participate in these events.

Some participants volunteered in their communities for children's sports teams, schools, or through their church. This provided connection and happiness. People were passionate about the causes they volunteered for.

### **Faith was a source of strength**

Many people described how their faith enabled them to be thankful for what they had and provided a sense of purpose.

### **Other ways of getting by included using foodbanks and loan companies**

Some people mentioned using foodbanks and buying second-hand. One carer reported using loan companies and preferring this to trying to get extra help from Work and Income.

### **Disability support workers were central to managing for some**

Some participants had support workers to help with care. For those who could afford it, support workers were described as reducing the pressure on families.

Finding a suitable support worker could be difficult as they needed to be the right fit for the person they were caring for.

### **Some people expressed greater comfort with support they received from Pacific health and social service providers**

People mentioned travelling long distances to be able to access services from a Pacific health provider. One participant talked about the discomfort they had felt receiving services that were not tailored for Pacific peoples.

## **Accessing income support**

### **People's awareness and understanding of income support options to help with the direct and indirect costs of disability and health conditions varied**

Most participants were unaware of the different types of income support that could help with direct and indirect costs of disability and health conditions. There was also limited awareness of the range of agencies that could provide income support.

Some people were aware of income support but did not know how to access it or did not want to because of their previous experiences.

### **Some people had positive experiences applying for income support, others less so**

Experiences applying for income support were mixed. While some participants reported positive experiences, others found the experience stressful and confusing.

Some disabled people and people with health conditions felt that eligibility criteria meant they could not access income support they needed to manage their health-related costs.

Some participants also felt there could be a lack of clarity in communications about income support payments.

Having to repeatedly apply for income support when their needs were ongoing and had not changed was frustrating for some participants.

Several participants expressed their determination to move into work to reduce their reliance on income support, reduce their costs, and improve their wellbeing.

# Introduction

## Background

In Stats NZ's child poverty reporting, children in households with a disabled person are three times more likely to experience material hardship than children in households with no disabled people. They account for just over half of all children living in a household experiencing material hardship (Stats NZ, 2024).

In 2023, Ministry of Social Development (MSD) Policy commissioned research to provide a better understanding of the over-representation of children in households with a disabled person among those in material hardship. The intention was to build the evidence base for future policy advice on how to respond to these inequities.

MSD scoped and carried out the research in partnership with external researchers, and in close collaboration with the Child Wellbeing and Child Poverty Reduction Group, Whaikaha – the Ministry of Disabled People, and the Ministry for Pacific Peoples (MPP).

The research included:

- projects that looked in more depth at the Stats NZ material hardship data
- qualitative research that asked disabled people and people with long-term health conditions (hereafter 'health conditions'), or their carers, about their extra costs and income support receipt
- a project that looked at disabled people's awareness of, and experiences with, income support payments based on the New Zealand Income Support Survey.

## The present study

This report presents one of three parallel studies that formed the qualitative research component.

It provides findings from talanoa (in-depth interviews) with 16 Pacific peoples who are either disabled, have health conditions, or care for someone who is disabled or has health conditions.

Gathering the experiences of Pacific peoples is especially important because of the high rates of disability and health challenges among Pacific peoples and the high rates of hardship they experience. For example,

- of all Pacific children, 36 percent live in a household with a disabled person – this compares with 29 percent of children overall
- of Pacific children living in a household with a disabled person, 38 percent are in a household experiencing material hardship (defined as being

unable to afford six or more of 17 items that most people regard as essential) – this compares with a material hardship rate of 21 percent for children in households with a disabled person overall (Wilson and McLeod, forthcoming).

## Questions that guided the research

The research set out to answer the following questions:

**What are the direct costs associated with being disabled or having health conditions?** Direct costs we were interested in included any 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 any 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 any 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 sources of resilience and ways that disabled people and those with health conditions, and their families and whānau, might 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 might include forgone paid work, promotions, training, educational or social opportunities associated with being disabled or having a health condition or caring for others who are disabled or have a health condition.

**How is a person's situation and the context they and their family or 'aiga live in inter-related with any costs they face? What are the consequences of any additional costs and any unmet needs?** For example, do they have less money for day-to-day living costs, go without, have limited choices, have reduced participation and enjoyment, or experience mental distress?

**Are people accessing income support payments that help with costs of health conditions and/or disability and, if not, why not?** This question is focused on income support payments, noting that people could also be entitled to have the cost of equipment or home modifications covered via MSD, Whaikaha – Ministry of Disabled People, Ministry of Health, or ACC and may not be accessing those entitlements.

# Research framework and methods

The Tivaivai research framework was selected to guide the study, and talanoa (or komakoma in the Cook Islands Māori language) as the main qualitative data collection method. A talanoa is an extended form of in-depth interview that aims to ensure that a deep understanding of the experiences of participants is gained.

## The Tivaivai research framework

Tivaivai is a Cook Islands quilt of fabric that is artistically hand-stitched for the comfort of tagata (people). It is traditionally made by a group of women, who are supported by members of their families and the community.

A Tivaivai can also be a metaphor for a human life in the making. As the process is thorough and vigilant, every handling of the Tivaivai is like the handling of a child, a human life. Completion of the Tivaivai requires caution, and detailed and careful application of love, respect, humility, and service.

The Tivaivai research framework was developed by Teremoana Maua-Hodges in the late 1990s (Futter-Puati and Maua-Hodges, 2019).

This framework was used to guide the research process in the present study. The intention was to embed a Pacific worldview and provide an overlay for the study that protected what is therapeutic, healing, empowering, and inspirational for Pacific peoples.

The study followed the five phases of the Tivaivai research framework (Figure 1) that are described in more detail below.

**Figure 1: The five phases of the Tivaivai research framework**



### Phase 1: Akaruru te tivaivai – Gathering the materials – planning and scoping

In this phase, the research scope, questions, and materials were developed. This was undertaken collaboratively by:

- MPP
- MSD

- the Katoa team conducting a parallel study with Māori participants
- the Allen and Clarke and All is for All team conducting a parallel study with non-Māori, non-Pacific participants.

An Expert Reference Group was formed by MSD to support the qualitative research and the other projects in the work programme. Members were representatives from non-government and government sectors with experience of being disabled and/or expertise in health and disability policy and service delivery. Members of the Expert Reference Group reviewed and provided advice on the research scope, design, questions, and materials.

Research materials included Information Sheets and Consent Forms, and a Talanoa Guide. Versions that were developed collaboratively were adapted to be appropriate for Pacific participants. Cultural dimensions to the questions that had some commonality for Māori and Pacific peoples were jointly developed by the MPP and Katoa teams.

The Information Sheet and Consent Form are attached in Appendix 1. Easy Read versions of these materials were developed to be available where needed. This was coordinated with and supported by MSD's Alternate Formats team. The Talanoa Guide is attached in Appendix 2.

Advice on the study was sought from holders of knowledge of Pacific cultures and issues for disabled Pacific peoples. This was done by MSD after MPP's initial design work.

Advisors included:

- members of the Pacific and Community Capability Programmes team at MSD
- Fonotī Pati Peni Umaga (Queen's Service Medal), a member of the Pacific Disabled Community and the MSD Pacific Reference Group
- Dr Ofa Dewes, Director of the Langimālie Research Centre, Associate Investigator at the Maurice Wilkins Centre for Molecular Biodiscovery, and Senior Research Fellow at the University of Auckland's Centre of Methods and Policy Application in the Social Sciences.

Planning for the three parallel qualitative studies was reviewed by the MSD Research Ethics Panel and Privacy Advisor.

## **Phase 2: Taomoumou te tivaivai – Tacking the tivaivai – data collection and analysis**

### *Data collection*

The Tivaivai framework reminds us that patterns, symbols, and designs for the quilt are a result of careful combination of the values and beliefs within those motifs. The lens of those stitching these must ensure the tapu and mana within these motifs are upheld.



For this research, a team comprising Tuli Mapuilesua and Dr 'Ana Koloto undertook the talanoa in May and early June 2024.

An exemption from part of the MSD code of conduct was granted to Tuli Mapuilesua as she was an MSD employee. This exemption meant that the following guarantees that were made to participants could be honoured:

- nothing that they said in the talanoa would affect any benefits they might receive or other income support payments like Working for Families
- what they said would be confidential to the research team.

Participants were recruited via Pacific community organisations. These included Pacific health providers, organisations representing disabled Pacific peoples, and Pacific churches.

Trusted representatives from these organisations were briefed on the purpose of the research and asked if they could reach out to members of the communities they served who might be interested in participating. This approach led to rapid recruitment which was important given time and budget constraints for the research.

To ensure a mix of ages and inclusion of disabled people, people with health conditions, and carers of people who were disabled or had health conditions, some guidance was given on the profile of people to approach. Although the intention was to have talanoa with working-age adults aged 18-64, three of the participants recruited were in their 70s. Two were carers for adult children who were disabled, and the other had a health condition.

Once an expression of interest in participating had been received, the research team shared the Information Sheet and Consent form with the potential participant. If that person was happy to proceed, a talanoa was scheduled.

Nine of the talanoa were online. Seven were in person. Online talanoa were via Zoom and were used when requested by participants. This was often because it suited their availability or accessibility needs and maximised their ability to participate. Most in-person talanoa were in a venue such as a community centre. Two were in people's homes. Staff safety risk assessments and mitigations based on MSD guidance for off-site visits were in place for each talanoa.

The beginning of the talanoa focused on getting to know the participants and making them feel comfortable. This stage is critically important in the Pacific context. It removed the barriers of power imbalance and encouraged participants to share. It gave researchers the confidence to ask questions in delicate and sensitive areas, such as finances and health.

Talanoa were audio recorded with the permission of participants. Recordings were transcribed (and in some cases translated from a Pacific language into English). Transcribers signed confidentiality agreements to protect participants' privacy (see Cram et al., forthcoming for the terms of this agreement).

At the conclusion of the interview, participants were asked if they would like to check whether they were receiving their full and correct entitlements from MSD<sup>1</sup>. An additional Information Sheet and Consent Form for participants wanting this check is attached in Appendix 3.

This check was separate from the research project and no information from the research project was to be provided to MSD staff carrying out the check unless the participant decided to share this themselves. Seven participants indicated that they would like to think about the offer of this check during the talanoa. Of these, one went on to complete the consent form and was referred for the check.

Participants in face-to-face talanoa received copies of information about income support payments and about health and social support services in their local area.

Following the talanoa, one interviewee sought advice on income support payments for a group of elders in their community. In the spirit of reciprocity, this was provided by a Tongan speaking MSD staff member and co-ordinated by Dr Koloto.

To recognise their contribution to the research, koha or meaalofa was provided to participants and members of their 'aiga who attended in support. This was in the form of a \$100 gift card for participants and a \$50 gift card for a support person. Food was brought by the interviewers to in-person talanoa as an expression of hospitality and appreciation. All participants were provided with the opportunity to request a copy of their talanoa transcript and to correct anything on the transcript after their talanoa. However, none of the participants took up this opportunity.

Average talanoa length was 50 minutes. The shortest talanoa was 30 minutes. The longest was 90 minutes. Following each talanoa, the interviewers had a debrief session. This provided an opportunity to discuss and reflect on the main points raised and assess whether changes to practice (e.g. how questions were asked) could be made to improve the information collected in the next talanoa.

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<sup>1</sup> There is a mutual obligation between clients and MSD. Clients are required to inform MSD of any changes in their circumstances that could affect their entitlement to assistance. Similarly, MSD must ensure that clients are receiving their correct entitlement based on the information provided by the client.

### *Analysis*

A reflexive thematic analysis process was used to analyse the talanoa transcripts (Braun and Clarke, 2006, 2012). This first involved the interviewers re-familiarising themselves with the data after the talanoa phase by re-listening to the participants' stories and journeys and re-reading talanoa transcripts. A summary of key messages of each participant's talanoa was developed with extracts of their talanoa to illustrate their story. Next, both interviewers identified codes (important features of the data) within participant responses to each interview question. Following this, codes were reviewed to begin to develop potential themes. Relevant data was organised according to the potential themes which were then checked against the coded data. Two additional members of the MSD Research and Evaluation team sense-checked the codes and themes against the transcripts. Finally, participant quotes that best highlighted the identified themes were selected to weave together into an analytic narrative.

### **Phase 3: Tuitui te tivaivai – Sewing the tivaivai – writing of the report**

Tuitui refers to the craft of stitching patterns and designs. In the context of this research, it involves stitching together the voices of the participants with accuracy, and in a way that tells their stories. These stories form the basis of this report.

Pacific peoples have histories of oral traditions, whereby storytelling and narratives are key to exploring multiple truths. These are stories about peoples' relationships with others, the environment, and with faith and God.

In the same vein, the writing of the report required careful selection of information and verbatim quotes to illustrate the themes from the talanoa.

In writing the report, all efforts were made to protect the identity of participants. All names provided alongside and within quotes are pseudonyms, and in some instances potentially identifying information has been removed. All participants were informed that reports and presentations about this study would not include any information that could identify them or any member of their family, but that their story may be recognisable to others that know them.

### **Phase 4: Akamanea te Tivaivai – Tidying the tivaivai – sense-making and peer review**

Akamanea is the final phase of beautifying the Tivaivai. For this research, this involved sense making workshops and peer review of the written report to ensure its robustness and coherence. Advisors and reviewers in these processes included or were from:

- MSD subject matter experts including the Pacific Reference Group
- the Ministry of Health

- Whaikaha
- Fonotī Pati Peni Umaga
- Dr Ofa Dewes.

## **Phase 5: 'O'Ora te Tivaivai - Gifting of the tivaivai – publication and presentations**

As is the norm in Pacific cultures, a celebration concludes a successful event. This is to acknowledge everyone involved in the Tivaivai making. In the context of this research, this involves publishing the report and sharing the findings with government agencies, participants, and community groups who will benefit from the information.

## **Strengths and limitations**

Key strengths of the study were the careful planning using the Tivaivai framework undertaken in collaboration with the MPP team, recruitment via trusted members of community organisations, and the interview team's lived experience of Pacific values and cultural understanding.

These features, combined with the ability of the interview team to connect with potential participants in the Tongan and Samoan languages, led to a smooth and positive recruitment experience and high rate of acceptance of the invitation to participate. As a result, findings from the talanoa offer rich insights into the experiences of a diverse sample of people. One participant chose for their talanoa to be conducted in Tongan and this was subsequently transcribed by one of the interviewers. All other participants chose for their talanoa to occur in English.

The research produced rich insights into experience of being disabled or living with health conditions. However, it only gathered the experiences of those involved and does not claim to represent the full diversity of experiences, challenges, and costs that disabled Pacific peoples and their carers face. Recruitment via Pacific community organisations may have led to a high representation of people connected to Pacific social services. This may have influenced some of the findings and conclusions. Although interviewers were empathetic and mana enhancing in their approach, neither was a disabled person. This may have influenced the depth of the talanoa.

A further limitation is that time and budget constraints prevented study materials being translated into a range of Pacific languages, to be able to respond to the language preferences of participants. These constraints also resulted in a different recruitment strategy being used for the Pacific study compared with the parallel studies focused on Māori and non-Māori, non-Pacific peoples. This affects the comparability of the samples across the studies.

The other studies mainly recruited participants as a selective follow-up to the New Zealand Income Support Survey of working-age people on low and middle incomes (Cram et al., forthcoming; Gray and Stratton, forthcoming). This resulted in a greater representation of people with disabled children aged under 18, and a younger age profile of adult participants in the parallel studies. Engagement with Pacific participants was voluntary, and due to the constraints of time and budget, uptake was low. As such the findings are only indicative and may not be representative of the different sub-groups of Pacific peoples or of the wider population of Pacific welfare recipients as not all participants were MSD clients.

## Research participants

Fifteen interviews were completed with 16 Pacific participants.

The lived experience of the Pacific participants was as follows:

- three were disabled people<sup>2</sup>
- eight were people with health conditions
- one was a carer for a disabled child aged under 18
- three were carers for disabled children aged 19-29
- four were carers for a relative who was not their child and who was disabled or had a health condition.<sup>3</sup>

Two participants were both a carer and affected by a health condition themselves. One participant was a carer for both their adult child and their partner.

The health conditions and disabilities mentioned as affecting participants, their children or partners, or the people they cared for included Autism Spectrum Disorder, anxiety, brain tumour, burnout, cancer, cerebral palsy, coeliac disease, diabetes, depression, Down syndrome, heart condition, being immunocompromised, mobility impairment, Parkinson's disease, spina bifida, spinal injury, stroke, and vision impairment.

People interviewed ranged from their 20s to 70s in age. They included seven people identifying as Samoan, five identifying as Tongan, and one each identifying as Tokelauan, Niuean, Papuan, and Cook Island Māori. One of the participants identified with two of these ethnic groups.

Eleven of the participants were women and five were men. Nine lived in a household with children aged under 18. Ten lived in Auckland and six lived in the Wellington region.

Of the 16 participants (and/or the people they cared for), five currently received Disability Allowance and one received Temporary Additional Support. Two

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<sup>2</sup> Disability was classified in alignment with the United Nations Convention on the Rights of Persons with Disabilities, which defines a disability as any long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder the full and effective participation of disabled people in society on an equal basis with others.

<sup>3</sup> Note these counts do not sum to 16 because some participants had more than one lived experience (for example they were a carer and had a health condition themselves).

received New Zealand Superannuation, five received a main benefit (Supported Living Payment, Jobseeker Support, or Sole Parent Support), and one received ACC weekly compensation. Four reported receiving no income support payments. One of these had been receiving income support as a carer but payments have stopped with the shift to Individualised Funding.

## Findings

The following sections present the findings from the talanoa as they relate to the research questions. These are organised under the following headings:

- direct costs
- unmet needs
- indirect costs
- the consequences of direct costs and unmet needs
- interrelationships with context, compensating strategies and sources of support
- accessing income support.

Verbatim quotes from the talanoa are included to illustrate participants' experiences in their own voices, though some potentially identifying information has been removed.

### Direct costs

Participants were asked about the direct out-of-pocket costs they faced and which of these costs were disability-related or related to health conditions. 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).

Some of the direct costs identified by participants could be covered through public funding. However, participants were not always aware this support was available or faced barriers to access e.g. not meeting eligibility criteria.

### **Most people reported a range of direct health- and disability-related costs**

Some of the direct costs<sup>4</sup> people spoke about included:

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<sup>4</sup> While public funding is available to cover some of these costs, participants were not always aware this support was available or faced barriers to access e.g. not meeting eligibility criteria.



- costs of special food (e.g., for diets that were gluten free or met texture requirements)
- personal care (e.g., for podiatry and nail care following spinal injury or cancer treatment)
- special furniture, shoes, and clothing (e.g., where these were needed by those living with obesity or conditions that affected their mobility)
- equipment and equipment repairs (e.g., for wheelchairs, standing frames)
- extra home heating costs
- home modification costs
- fees for medical appointments
- extra transport costs.

Participants (disabled people and/or people with a health condition and their carers) described the various ways that these costs arose in their everyday lives.

He can't eat what we cook because he'll choke... So we have to make sure there's sushi, something different for the texture. That's just extra cost. (Moana)

[O]ne thing that I have at home is a standing frame. That's for me to stand. Hiring that is \$58 a week which is annoying, but it's helpful. I'm still in the works of trying to get a permanent standing frame donated to me. (Mele)

I pay \$100 a week on my power and gas because I have to have the heat at a certain temperature when it's cold... Since having that cancer medication my nails are very brittle so I like to go and get them looked after. (Alofa)

One father reported large one-off costs for replacing carpets and installing an air conditioner which were things recommended for his child's health needs.

When Pila was born that's one of the things that the doctor said to change our carpet because of his breathing... It took us about three years to save for a whole house carpet. (Tevita)

Costs were extensive for some participants. This was especially the case when mobility was affected, or there were costs associated with having a carer provide alternative or respite care.

Everything it's doubled... Everything changed. I didn't know that life would have been more costly. When I got into a wheelchair every little thing was now heightened. Our surroundings, how we travel, the time management. (Mele)

It's everything from dressing, everything has changed. Bibs, sipper cups, clothes, shoes. Care. If I need help to care for my mum I have to pay for

that. Sometimes they're really expensive, the agencies .... Last time they did six days for us and it cost, I'm pretty sure it was like \$1,500. Yes, a lot. (Leinani)

Only two participants (both with long term health conditions) said they had few health- and disability-related costs, or that their costs were manageable.

Medical is actually for free. We're enrolled with [health provider] in [area] and I don't pay much. I don't really pay for medication because ... I get that for free. (Fetu)

I know I'm paying extra because of my health condition, but it's not at a level that I'm worried about, concerned about. It's at a level that I can afford because I'm still working. (Togia)

## **Health- and disability-related transport costs were very high for some**

Transport to and from health appointments and transport needed to manage life as a disabled person or a person with a health condition were key direct costs for some people.

When we look back at our bank accounts and we look at the timeline of the statement, we see more transactions at the gas station than we do anywhere else. (Mele)

One participant with a vision impairment talked about choosing to live in the central city because otherwise the costs of transport were difficult to afford.

Definitely transport because I know a lot of people say catch the bus, catch the train. The problem is if I'm having to go anywhere that I haven't been to before I prefer to always Uber. Either way I still have to Uber especially if the bus isn't stopping near... That's where we've had to compromise. So, that we don't have to always rely on transport we can live in the city. (Tasi)

For those caring for a disabled family member, the costs of getting their loved one to and from activities, church, and medical appointments could be considerable.

[T]here's a [health condition] Pasifika Group that have exercises on Thursdays. I said to them it's just a bit much. We just need to calm down because it's so far and petrol is not cheap. Transport, I would say probably even \$200 a week, easy, to go back and forth. (Leinani)

One carer felt that their disabled son's weekly transportation cost could quickly mount up if he uses a taxi.

if the cost of taxi to town is \$100, total mobility covers the 80 per cent. So that \$80 leaves us \$20 so that's \$20 there, \$20 back. And that's every day. And then if he doesn't go by taxi, I take him.

For two of the carers, donated mobility vans were life changing.

I don't owe the money for the van because the van just a blessing come from the government. (Penina)

...I said to them I had the total mobility card. When they gave me the quote I just really couldn't believe it. I thought maybe that's without the subsidy. It was, from memory, \$190 one way... We have a mobility vehicle now and we're able to use that. We don't need those services. It's still a lot, \$200 a week for petrol but it's not as much as one trip, \$380 for one trip. (Leinani)

## **Direct costs could be hard to identify**

As with the parallel studies interviewing Māori (Cram et al., forthcoming) and non-Māori, non-Pacific peoples (Gray and Stratton, forthcoming), participants came to this research talking about their own "normal".

As a result, they could not necessarily separate their health- and disability-related costs from their regular household expenses. For this reason, it was not possible to put a dollar value on the total health- and disability-related costs people had.

It is also possible that some participants may have referred to costs that were not necessarily out-of-pocket costs because these were being met by 'aiga (see below), or by ACC, Individualised Funding, or Disability Allowance.

## **Unmet needs**

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.

## **Some participants and/or those they cared for had a range of unmet health- and disability-related needs due to cost and affordability**

Income inadequacy and cost barriers meant that some people could not afford the healthy diet, physical exercise, regular health care, or extra help around the house they knew would improve their health or help them manage their disability or condition.

There are medical things that I should be buying for me to take supplements and that, but I can't afford it. You know, there are things that are out there that can strengthen my legs or strengthen my bones, but I just can't afford it, so I don't bother .... I just simply can't afford a carer. That would make my life easier. A carer to come and, you know,

maybe look after my kids or cook my kids a meal while I'm resting my swollen feet. But I just can't afford it. I can't. (Mele)

If things were affordable then we would be able to overcome those challenges, be able to eat healthier, be able to exercise more. Even just for walking shoes, you've got to have the right shoes to be able to walk. (Manuia)

Carers were often unable to afford all the supports they knew their loved ones needed.

[W]e take him to get a massage maybe every month ... and that's \$80 a month. But he needs it like every week because his muscles are – they stiffen because he doesn't move it. I massage him, his legs and I have a oil there, the ginger what gets into his bones. I'll try anything. We can't afford to do the massage every week. So I try and do all this. (Moana)

## **There were other barriers to accessing needed supports**

Other barriers to accessing needed supports were the time, energy, knowledge, and advocacy required to gain access to needed treatments, funded equipment, and resources.

I think [the biggest challenge was] just the pushing. Pushing for his needs and trying to correct and put everything in place before anything happens to me. I just want to make sure he has everything before we get too old. (Moana)

Where mobility was affected, many different items of equipment were needed. These were hard to afford without financial support. One carer talked about the challenges she had trying to get funded equipment.

At first it was very hard. Thank goodness she was still able to walk a little bit. Now, not so much. At that time we didn't really have anything but a walking frame... From the rehab came the extra supports that we came home with. We were able to get it. I thought to myself, I thought studying was hard because I've done the Bachelors, I've done the Masters. I thought that was hard. Nothing harder than this kind of thing, to try and get help. (Leinani)

## Limited availability of suitable and accessible housing was identified

Several participants described having difficulty finding suitable and affordable housing that met their accessibility needs.<sup>5</sup> In some cases, people had to make do living in unsuitable housing, such as housing without adequate heating or housing that was not wheelchair accessible. Those who were renting were unable to make necessary housing modifications to meet their needs.

One carer described being given short notice by their landlord that they had to move out of a house their family was comfortable in, and then being unable to find a new rental that was accessible.

I applied non-stop all the time trying to get as much, you know, looking at lots of viewings. I didn't realise until we were basically two days, we'd run out of time to get out of the house that we are really struggling to find another rental... We narrowed it down to there were main things that we found that we weren't successful in our tenancy applications was one, I think the access for Farani, his wheelchair. Just the accessibility seemed to be a problem and two, I believe that when they looked at our income they thought these people are on benefits. No thanks. It's too hard.

They're not going to be able to pay their rent. (Vai)

Another participant who was a wheelchair user described having a series of rented homes while on the waiting list for a Kāinga Ora home, none of which was accessible. The family had finally moved into a home that met more of her accessibility needs, including a ramp, but they were finding the rent very expensive.

Since 2019, so every single property we've been at we've never had a ramp installed at our house. My husband has always just bumped

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<sup>5</sup> MSD can provide a variety of housing related support for people including:

- assessing eligibility for social housing
- management of the social housing register
- payment of housing-related financial assistance
- ensuring people with no other housing options are supported into emergency housing
- providing support to those in emergency housing through contracted navigator services, integrated services case management
- Housing Brokers who assist people to access sustainable private accommodation
- Ready to Rent programmes developing skills and knowledge needed to secure and maintain a private rental.

[moved] me and my chair in and out of the house. Everywhere we go it's always been that way. (Mele)

One older participant with a heart condition had stable Kāinga Ora housing which was no longer suitable, as it was two storey and they could not manage the stairs anymore.

Others had previously lived in housing that made their health condition or disability more difficult to manage, such as housing that was old and without heating. Moving into a warm and dry house led to improvements in health.

We're renting at the moment. We live in a three-bedroom home. We moved here about two years, just over two years ago. We were in a home that [had] a shared driveway but also the room that me and my husband were in there was no heating or no aircon, that sort of thing. We resorted to windows in summer, opening the windows in summer but in the cold it wasn't anything that the mould could evaporate in. (Manuia)

In order for me to get a better quality out of life I had to go into private renting into new builds to actually understand the difference between Kāinga Ora homes that have been around for ages that I've been living in and suffering and getting sick left, right and centre, to move into a new build where I'm hardly sick but just trying to manage the health issues. (Alofa)

## Indirect costs

The talanoa explored whether people had experienced indirect costs as a result of being disabled or having a health condition, or caring for others who are disabled or have a health condition.

### **A common indirect cost was reduced paid employment and earnings**

Peoples' employment experiences had varied. Some disabled people and people with health conditions had managed to sustain or gain paid employment. Sometimes this was with support from family and clinicians, or flexibility from employers.

For me it's been good, mainly because of my support structure. I have a very good family support. My doctor and clinicians also give me good support and that helps me. It gives me confidence to carry on working on a daily basis knowing that they will be there for me if I need them. (Togia)

Work is great in allowing me to work from home if I have to which is an added bonus. Some companies I don't know if they would have that understanding. It also helps when you've got an Islander who is a team leader, as a manager. I think that's when it helps out a lot as well. (Manuia)

They gave me advanced leave and I used up all my sick leave, I used up all my annual leave, so they tried to find ways to... they took me off as a [occupation] so I became just an [occupation] and I did it on the phone. So that was a great relief for me because I was thinking, if I get sick, I can't work, I can't help my family with our girls, buy our food, so it's only one income. (Amiri)

I do the nine to five, but it's not fixed hours, like I could be working from home. Sometimes I can't always make it into office. Because I only started at [workplace] this year, it's helped a lot. It has helped a lot. I guess it did have to take for me to get a job for me to finally live a bit more comfortable now rather than before. (Mele)

However, a common theme was that being disabled or having health conditions, or caring for loved ones who were disabled or who had a health condition, was associated with disrupted paid employment.

I was working 20 hours. I started off with 20 hours and then when I got unwell last year I cut it right back to four hours. Then I got given the clearance that for now it's okay. I get contract work when I can because I know that my shoes are coming up and then the car registration and warrant. (Alofa)

For one young woman, adjusting to becoming disabled had led to a break in paid employment. She was currently working part-time but wanting to work full-time.

In 2018 I lost a lot of my vision, and it affected my confidence to work. Luckily [in] 2018 my contract for my job at the time was coming to an end and so I wanted to take a year off to readjust to this new way of looking at life because I had lost more vision. When I got ready to come back to work Covid hit so then I had to re-evaluate if I should go back to work again. It's taken me about four, almost five years to really feel confident to go back to work, which I started last year. (Tasi)

The mother of one disabled young person talked about how he had worked to gain a qualification and paid employment but needed to take breaks from being employed.

He was born with [health condition]... He has a degree in [degree] and he's non-verbal... He has that mentality that he can do anything if he puts his mind to it. He's just finished a cadetship [in occupation]. He was doing that for a year. He's just full on. At the moment, he's on a break. He's just resting. He hibernates in winter because it's too cold for him. So he's just looking for jobs at the moment. (Moana)

For some, ill-health or being disabled ruled out employment.

Sefulu couldn't work because she had a [health event] and she had her medical certificate from the doctor sent in once a year now. And mine

comes in also and as I said, I was waiting for my operation so we're on the waiting list. (Tino)

One neurodiverse participant was doing full-time voluntary work and hoping this would lead to full-time work and greater financial stability as her child got older.

Ever since I've started working here it's kind of changed my whole outlook and attitude on people and the way that they do things and the way they interact and everything that goes on in the workplace. It's kind of changed my perspective. I've had this health condition since I was 16 or 17 and now I'm 35 so I've had it for a long time... The support I have here is good from [workplace], and Ofa, my aunty, she has helped me along the way... If I was to come into work full time which is my goal, long term goal, and then to help my mum pay for the water bill, also the power bill, mortgage and clothes for my son, especially for him. It all adds up. (Fetu)

Carers had been in paid employment and/or education before taking up their caring roles.

I was working and studying before being in this role. So, 2022 I came into the role of carer for my mum. (Leinani)

First, for me to stop working was the reason for Pila. To help Pila and whatever stuff that he needs at home, at school, school activities. I have to turn up if he goes to swimming. If he goes camping. I need to be there because I understand. (Tevita)

One carer was being paid via Individualised Funding as a full-time carer for her mother. She pointed out that this funding covered only a fraction of the time she was providing care.

[T]he amount of hours it just doesn't match because they've said 24 hours for seven days that she needs care but then they only help us for 42. It just doesn't match. My family are just like oh my gosh. They see the amount of hours because the thing is with my Mum it's not just during the day. It's also at night. (Leinani)

## **Carers balanced wellbeing gains from them providing care against the financial costs of lost employment**

The carers often reflected on their cultural values when they talked about deciding to give up employment to care for their loved one. They were conscious of the economic penalty, but prioritised the wellbeing gains for their disabled family member and the other members of their family over their individual gains from employment.

[They] recommended that she go into a home but as you know with our families and our parents she really didn't want to do that and we didn't want to just take her and be like let's just carry on with our lives. That's



the other thing. People do tell me you can get more money if you're working because you went and studied, you might as well go and work to be able to pay for these things. I know that I am losing out as well while I'm being home on the money that I could get to be able to look after my family and look after all Mum's needs. At the same time there is no one really to be here with her 24/7 so I've had to make that choice to just be like we're going to have to live with less so that I can be here to make sure. To be honest I've seen such a change in her care since I've decided to make it my full-time job. Like I said, the falling. She's no longer costing the system. (Leinani)

He doesn't get really sick now. Less hospital now, less ambulance. Because he was really sick, and my wife was back at work. She studies, my daughter studies so we decided for me to stay at home and look after him. It was stressed out for everybody because if he was sick and I'm at work and my daughter had to pull out of school sometimes to come and then sometime my wife, they take turns. It was stressful for them. (Tevita)

If Rosa gets sick you don't understand what kind of sick she has. Only me I understand and I understand about all the situations for her because I am the mum. (Penina)

## **Carers experienced costs to their own physical and mental health**

There were indirect costs to carers that came with prioritising care of their loved ones. These included the stresses and strains of life as a carer, and the costs to their own wellbeing from not having the time and financial resources to take care of themselves.

To be honest, I used to exercise a lot. I used to eat healthy a lot but it's changed a lot since I became a carer. (Leinani)

Sorry, I'm just so bad, every time. That's why my family goes "Don't let her speak," because I just cry. (Moana)

Some had experienced periods of burnout which affected their physical and mental wellbeing.

[E]specially in the tough times when I was feeling exhausted, totally burnt out and I was almost like I can't do this anymore, I had to realise if I don't look after myself then who's going to look after Farani? People would say that to me and I was like, "Yes, yes, yes, yes." But I wasn't doing it, like putting it into practice. I wasn't having my own time where I could have time for myself, just looking after myself as well. Just getting enough rest for myself, eating well, doing things that make me happy. (Vai)

## **Mental health was affected for some disabled people and people with health conditions**

Some participants talked about effects of being disabled or having a health condition on their mental health, or that of the person they cared for. Mental health struggles were often related to a loss of independence or feeling like they were a burden on those caring for them.

My biggest challenge was my mental battle. That was the greatest challenge. My second challenge was my financial battle. (Amiri)

[A]t the moment he's fighting with his demons mentally. So we have to make sure he's mentally okay. (Moana)

## **Another indirect cost was being unable to live independently**

Some disabled people and carers in the study had lost the ability to live independently because they required support or provided care at all times.

My husband comes at lunch time to feed him and then I come after school. He's an adult now and still we still have to shower him. (Moana)

Carers talked about supporting their loved ones to be as independent as they could be within this context.

He's got a mind of maybe a seven-year-old and we've just got to watch him because he runs. If he wants to go out and play, he'll just take off and play. Take off, open the door and run. We've got to make sure that it's safe for him. We're getting there. We're trying to make it so it's safe for him so that he can do the things that he needs to do without mum and dad being there all the time. He's learning to be independent, but he needs a lot of supervision. (Sia & Mose)

Sometimes people see disabled people and they talk to them as if you know, like they can't hear so they start yelling. They don't mean to. Sometimes they just think this is the way but sometimes I have to explain to them in a nice way, gentle way, you just have to say to Farani this or it's okay, he can do it himself. You don't have to automatically assume that he can't cut his meal or something on the plate, that kind of thing. It's little things. Sometimes it's just educating others. (Vai)

One participant living with 'aiga to save on costs thought that living alone would be better for her own and her 'aiga's wellbeing.

Now I'm living with my daughter in a new build but also finding that as I get a bit older and get a bit more I suppose anxious and things it's better off that I have my own whare. I was just talking to my girls that I will have to probably look at moving out and moving into my own place for my own holistic wellbeing and for theirs too. I never want to expose them

to any unwellness and things but my nine-year-old grandson said that he would give up school and stay at home with me. Yes. I have a lot of support but financially we're just trying to make things work as a family. (Alofa)

## The consequences of direct costs and unmet needs

The talanoa explored the effects of any direct costs and unmet needs associated with health and disability on people and their 'aiga.

### Health- and disability-related costs sometimes led to other needs not being met

One participant explained how costs resulting from her spinal injury had put pressure on her family's budget. This had sometimes meant that they would get into arrears with their power bill, or essential clothing and food could not be purchased for her children. In the past, this had flow on effects on the children's school attendance.

Sometimes my husband would pay for my [wheelchair] tyres to get pumped because it would flatten so we we'd have to pay for a technician to come out and fix the wheelchair. We would have those and that would be our power bill money gone for the week or gone for the month simply to just spend on a technician to come out and fix my wheelchair... [E]very time I called for help from Work and Income, they just declined it because my husband's income was okay...

There was a week where my son stayed home because we hadn't gotten him a school jumper and it was too cold for him to go. So, he just stayed home until we got the school jumper and then we sent him to school. Sometimes it can be the little things for us. The kids stay home because there's no food or there's no lunch. I know my kids went through that last year when I wasn't working. (Mele)

For this participant, although getting full-time work herself had improved the family's income, they still struggled to buy the basics.

[T]o get to the point where you both work full-time jobs and you're still short of money to buy milk. That's a huge issue. That's such a huge issue. We should be living comfortably but my husband and I still are not. Even with all the support that we get from our families. (Mele)

Another participant with a long term health condition talked about the impact that costs had on her ability to manage financially.

Having to go to budgeting and things I start to learn a bit more about how to manage your money a bit more wisely, but it hasn't helped with the expense of living with a disability. (Alofa)

Carers described the difficulties they had affording things for themselves or their families.

[I]t's hard because it's just like I said before it's one income at the moment... hopefully it's not a long-term thing. If Pila gets better and better so I can go back to work but at the moment we're struggling. I'm not going to lie to you guys, we are struggling with things at home. (Tevita)

My youngest is 16. They do want to do extracurricular. They do want to do piano lessons and whatever kind of lessons. I'm thinking to myself does the school have it for free? I'm thinking there's no way I can pay for that. (Leinani)

## **Most people said their income was not enough and only just enough to meet their needs**

People were asked if their income was not enough, only just enough, enough, or more than enough or to meet their everyday needs. Fifteen of the participants gave answers to this question:

- five said their income was not enough
- seven said their income was only just enough
- three said their income was enough
- none said they had more than enough income.

## **People and their 'aiga often went without or made do**

Some of the people we spoke with talked about making do with some resignation.

Once you take out bits and pieces from there, there's not much left over until the next week. So you become in situations like some of us where we live from week to week with what we need to do with our pay. (Togia)

It doesn't match up in terms of financial expenses and sometimes that can be a burden and sometimes I just look at ways of being able to afford it. I don't like to ask my children because they have four and five children each. We're lucky that we're Islanders even though we're born in New Zealand, but we were raised with our parents and grandparents we can afford to make things happen and just make those little sacrifices. (Alofa)

I guess in terms of all the things that I've mentioned that want to happen in this house with my Mum, there are days when it's a bit of a hardship. (Leinani)

Others were just managing financially, but no longer had any financial buffer.

It's different from when we lived in [place name] because we had some money that we could use to cover extra things like church things or fa`alavelave, or whatever, family stuff. Now that we're here it's different. We really don't have savings left and so it would be more of a struggle and we have to be more careful with budgeting... I guess now I would say we're okay but if there were any other extra things that happened like if someone in our family passed away or if something happened, like if our car broke down and we had no car for a while that would be really difficult. (Vai)

## **Interrelationships with context, compensating strategies and sources of support**

We explored how people's situations and the context they and their 'aiga lived in were inter-related with the costs they face and the ways they coped.

### **Suitable and affordable housing and safe neighbourhoods made a positive difference for some**

Living in suitable housing made a significant difference in the day-to-day lives of some participants. Housing being warm, living close to family, and affordability of housing were important factors in determining how suitable participants found their housing to be.

We are in a social house that's taken care of by Kāinga Ora and we have a two-storey - I think it can be called an apartment or a two-storey house. For me it's quite good because overall the rent is affordable for us, but also with the second level, I get good exercise going up and down, up and down. But our house is comfortable, it's warm, and it suits our purpose as well. (Togia)

Oh, we own the house. It's four bedrooms. It's warm. It's better than our other house we owned in [place name]. It was cold. We searched everywhere to be close to my mum and the [workplace] for my husband and the motorway for me. We bought it when Salu finished his degree so we're not in town. Because we stayed in town to be close to Salu's schooling. So now that we're here, it's so much better, I think. (Moana)

The neighbourhood that they lived in also contributed to how people felt about their housing. It was important to participants that they felt safe and that their neighbourhood provided a sense of community.

I've got a great neighbourhood. Very busy at times. The thing I like about this is that we've got our own space. It's spacious for us. I don't have to park my car very far and walk a mile to get home if I was to park out on the road. Also, just for safety. If I was to work from home I'm able to close the gate and just have that peace of mind. (Manuia)

The neighbourhood is really good. We looked for a house down a driveway for Salu safety wise. The neighbours are lovely. We've got two Samoan families and they're lovely. They always look out for us. (Moana)

## **Churches and community involvement were important sources of connection and support**

Participants were active in their communities as it was important for them to maintain their connections with their 'aiga and with their church community. Some of the church and 'aiga activities participants talked about attending were youth groups, family birthdays, and weddings.

Tuesday and Thursday is rugby. Wednesday we go to [sports club] and my son we have youth group. Even though it's a youth group it's a youth group of the kids and the older generation as well, it's just the new community coming together. That's us and then we get involved in church activities. We've just finished [Niue] White Sunday two weeks ago. (Manuia)

One carer described the high importance her mother placed on family and community events as a source of meaning and fulfilment.

We do have a lot of family birthdays and weddings. All those kind of things they still want to go to. There is a birthday on Friday, this Friday. A 70<sup>th</sup> that my mum would like to go to because it's her cousin. (Leinani)

Some participants volunteered in their communities for children's sports teams, schools, or through their church. This provided connection and happiness as participants were passionate about the causes they volunteered for.

I manage my son's rugby team... I've also mentioned to them that I'm not the healthiest of all people and I don't really want to be taking on a responsibility if my health is going to become a factor. I've managed to rope one of the other mums to come on board and co-manage the team with me and she's been fantastic... That's rugby and also [role] for [school]. We also get involved with the school events, Language Weeks, get involved there. (Manuia)

Yes. I do a lot of volunteer work for the church. That's just in terms of projects for the community. A lot of times I just connect people because I also know some health professionals... courses for the elderly. I just do that kind of thing. (Leinani)

## **Faith was a source of strength**

Participants described how their faith enabled them to be thankful for what they had and provided a sense of purpose.

E lagona a e lē lava ae what can we do? [I feel it is not enough but what can we do?] It's what we get to go on, and just live on. Pray to God that He helps us with stuff. And I'm sure there are other people worse off than us who needs more help. Be thankful with what we have. That's what we say. Just be thankful for what we have each day. (Sefulu)

Honestly, in so many ways I just can't give God enough thanks and glory for everything that's happened. I believe there's a reason. I know that God's not finished with us. When Farani and I are talking when he's down or something I'll be like, "Look, if God had finished with us, you wouldn't have made it out of that operating theatre. You would not be here today. There's a reason why you're still here. God's not finished with us. We've got work to do still. Who knows what that will look like but we're still living it. God has plans for us so praise God. I know we've learnt to be grateful for the little things like hey, the sun is shining or it's nice and warm in this room. We've got a lovely warm hot shower or just anything. It's just like you really do end up seeing all the blessings and you really do count your blessings. (Vai)

### **Care, support, and advocacy provided by family members were key factors that helped people manage, compensate for, and share costs**

The care and support of their families helped disabled people and people with health conditions through struggles with their health. Participants expressed their gratitude for this.

I've been here for a while and my mum came with me, so she's been my key helper. I went through depression and just been through a whole roller coaster. Then I got married and I moved back home to be with my mum. She can support me. Now I'm here with my son. (Fetu)

Getting used to it, it took me a while when I came out of hospital. I was grateful to have family support and it took me a while to do things on my own. (Manuia)

Family members also played key roles in helping compensate for and share the health and disability-related costs.

So quite a lot of our budget for our food and our rent, we had to readjust that budget for the petrol all the way from South Auckland all the way to town [for oncology hospital appointments]. Yeah. We struggled with transport and sometimes I would ask my family if they can help us. (Amiri)

My daughter will just say, "Mum, I bought this for you." (Leinani)

For one disabled person, family members and flatmates provided moral and practical support, and helped keep costs lower than they would be otherwise.

I live with my sister who I rely on a lot but because she also has the same [disability] as me she can relate to the struggles I go through. With our flatmates that we live with they're [Pacific Island ethnicity]. Being Pacific Island, we cohabitate really well together. (Tasi)

Although some of the young adults had their own income at times, their parents, who were their carers, often subsidised their costs.

[I]f he needs it we have to buy it. (Moana)

Family members also played key roles in helping secure needed treatment, resources and equipment and often advocated for resources on behalf of their loved ones. Some were aware that not all people in their community would have access to someone who could do this for them.

I feel for our people because I'm thinking to myself if this is me who can speak English imagine our people who struggle to communicate their needs... I spent a lot of time researching and talking and ringing around and communicating with GP and so many people. So many health professionals. (Leinani)

Some disabled people and people with health conditions talked about how their own self-advocacy and determination had helped them manage.

They gave me the wheelchair and I was like, "Okay, I'll take it." Then I just carried on with life, I never stopped. I didn't stop to be like, "Oh, how is this going to work?" I just made it work. (Mele)

## **Other ways of getting by included using foodbanks and loan companies**

When people talked about ways they got by, some mentioned using foodbanks and second-hand shops.

[W]e try to find some food bank that would give us – we found a place that will let us monthly. (Tino)

One carer reported using loan companies and preferring this instead of trying to get extra help from Work and Income.

I receive just the pension. That's all. I'm not getting money from other thing. I don't force Rosa for money but she's grown up, you know? She puts \$150 in my account because she knows I do everything and then my pension is not enough, my pension. It's coming down. Then I pay that, my bills that come and I pay my loan to the [finance company]. Sometimes if the car is damaged I am shy to go to ask at the Work & Income. That's why I go there and have a loan. I know the interest is going up, but there apply now and I get now. (Penina)



## **Disability support workers were key to managing for some participants**

Some participants had support workers to help with care. For those who could afford it, support workers were described as relieving and reducing the pressure on families.

Finding a suitable support worker could be difficult as they needed to be the right fit for the person they were caring for. A couple caring for their disabled son described their experience of having a support worker who got on well with him.

I guess it would be like if somebody could be around to look after Antonio. It's always tricky. That one is not just a funding issue. That's also finding the right person. You're probably both aware that trying to find carers is really difficult...we use [company name] as our agency but they're always struggling to find people. For Antonio we need somebody very special. We're lucky we get some Carer Support days. We use Sia's cousin usually because he knows Antonio and Antonio gets on really well with him. When we get back he's like, "Oh you're back." Then Salesi goes and for the next two hours he'll be like, "Salesi. Salesi. I want Salesi." They get on really well which is good. He does need somebody. He doesn't want to be with mum and dad all the time. It's like 24 hours he's with mum (Sia & Mose)

## **Some people expressed greater comfort with support they received from Pacific health and social service providers**

One carer travelled long distances to access services from a Pacific health provider for her mother.

They just want to go there because they're able to really connect with everyone there and they know people there. They're like, "Hello. How was Church." They go to Church in a different branch. They know a lot of them there, so they prefer to go there. That's another cost when we have to go to the doctor.

Another participant talked about discomfort they had felt receiving services that were not tailored for Pacific peoples.

[T]they gave me a lot of numbers you know, "These people will support you and all of that, you will get the support from these people". So I had the first support but then I felt that the palagi, pākehā nurse when she saw me, I don't know. Maybe it's just ... she looked at me, Oh, you're brown. So, what I heard is they'll do anything for you but that was the end ... only one or two phone calls and that was it. (Amiri)

## **Accessing income support**

Questions in the talanoa explored participants' awareness of income support and experiences of accessing income support.

## **Awareness and understanding of income support that can help with the costs of disability and health conditions was variable**

Some participants were unaware of different types of income support from MSD and other agencies that could help with the direct costs of disability and health conditions. Two participants described being aware of Disability Allowance, but not knowing what other support might be available to them.

We have no idea what's available for us, for him. It was only the Disability Allowance that we knew about and at that time, it was just too much for me to go fill out the forms. Maybe one time when I went, it was means tested. How much does my husband make? I don't know if it still is. It's just in the 'too hard' basket for me. (Moana)

All I knew was that there was Disability Allowance, like from Work and Income. I didn't know there's like fundings or all these other things that I was eligible for. I didn't know any of that because I never had anyone explain it. I don't know if it was who was working at the time, but I know for a fact no one sat me down and explained that this, and this, and this happens. I guess when you are put in a wheelchair, everyone who you come across they automatically think that you already know how the disability world works. Like where the money and stuff are, but to me, I didn't know. (Mele)

One of the participants had recently found out about other support, like the Ministry of Health Carer Support subsidy and additional help from Work and Income for things like power bills, from a Pacific community provider.

As well as it took for me to come into [workplace] to finally realise that there are these things called carer subsidy. A few of these things that I was going about with before, last year and previous years, I've been doing it wrongly. It was just not having the knowledge of a lot of things that I could have saved money on. Like I didn't know that if we were behind in our power bill also that I could turn to Work and Income for, like, arrears. I didn't know those things. Those little things like that. We would have a lot of arrears because sometimes it would get too much for my husband. (Mele)

## **Some people had positive experiences applying for income support, others had less positive experiences**

Participants receiving income support were generally appreciative of the support they received.

[Work and Income] is actually my best friend. I mean I'm so blessed and humbled to have the opportunity that they support me through all this. (Alofa)

One carer had initially felt shame at asking for help but had become more confident to ask for support when they needed it.

It's been a learning curve. Before I never had to go to [Work and Income] to ask for any help. When we first moved here, I did have the sense of like shame. It's like we have to go there and ask about this for money and stuff and I did have this sense of real shame having to ask for help. But then after a while it's like okay, we have no choice because if we don't ask, we're not going to be able to pay. (Vai)

Experiences applying for income support were mixed. One carer, who also had a health condition, described usually having positive experiences when seeking help from Work and Income, but that there was inconsistency depending on which staff member they spoke with.

There are people who are very experienced, they know, but when we get to somebody who's new, the last person that we went to didn't know but pretty much they know their stuff. They were helpful. They do things for us. We have no problem with it. (Tino)

Some disabled people and people with health conditions felt that eligibility criteria meant they could not access income support they needed to manage their health-related costs.

When you get all your resources, get the information that you require, that they require, and you get let down I feel that is enough for me to say that I don't want to pursue that with them anymore. Yes. That's when they said that we were not eligible. I wasn't eligible because the income was too high so I didn't pursue it any further... I don't think I would ever resort to going back to Work & Income. (Manuia)

I think one thing that was frustrating is that despite me being a disability, because everything with me as a disabled person now is twice of what an average able person has. But when we go to Work and Income with that, they don't take that into consideration. I'm still bunched with my husband. So, what my husband earns is what I'm eligible for and that's it. They don't understand that when you have a disability you have your own needs that are twice the amount of what we can live off with my husband. Yes, and I thought that was quite unfair because everything that I needed like if I needed extra support for my wheels or something, it will have to be paid off from my husband's pay but he doesn't get a pay increase so he'll have to work double shifts just to cover these little costs. Like me going to the gym for my hydrotherapy, my water walks. (Mele)

Back in the day when I was made redundant from my job with [employer], I did go to seek assistance from Work and Income and the process of getting that done is terrible. It's just terrible. It's almost like you have to beg and crawl on the ground and ask for assistance, and we Pasifika people are very proud. I said to myself I would never go through that again, never, and that's what I decided. I hope they've changed the way they do things at Work and Income because some of our people are just missing out on some assistance for whatever reason and some people I don't think deserve to get some assistance as well, so it's a balancing act. (Togia)

Some participants felt there could be a lack of clarity in communications about income support payments. One carer who also had a health condition described having his benefit cancelled and not knowing why.

We did and they stop it, I don't know why. ... but it wasn't that much. The last letter that I got, we have to let them know before the 60 days' up or six months or whatever, that we're going to respond back but why did they cut it back? All I got the letter was, they cut that back because some other things was – so I don't know what other things they cancelled of our benefit. I send them a respond and see why. (Tino)

Having to repeatedly apply for income support when their needs were ongoing and had not changed was frustrating for some participants.

The last time we tried was six years ago. I think once and then by the time he got it, and then received it, and then maybe three months later we had to apply again. I just think for me mentally, it's just too stressful. (Moana)

It's very stressful. I don't know if their system has changed but before this year, every three months I had to fill in forms to basically reapply for additional support. You get the standard Disability Allowance and then for me I'm entitled to this extra support [Temporary Additional Support - disability exception]... In order for that to continue I have to apply every three months which is really annoying. My vision impairment is not getting better any time soon. (Tasi)

Several participants expressed their determination to move into work and felt this would help them to better manage their costs and improve their wellbeing.

Just really the single mum benefit and this childcare subsidy. Accommodation supplement as well and that's it. I think I enquired for accommodation. Yes. So, that's it from [Work and Income]. I like to earn my own income. I don't want to stay on that forever so that's my goal. (Fetu)

Despite me having a disability and being in a wheelchair, I needed to get over that hurdle that just because I'm in a wheelchair doesn't mean that I can't get out there and find me a job. (Mele)

One disabled person felt that increased flexibility of income support could help with the transition to employment.

Last year I was really sad because I thought I could keep the whole amount if I got a 20-hour job and they said no, you have to work 15 hours in order to not get it cut... because I'm working 20 hours, I basically got maybe \$100 or more less than what I would normally get every week. I wish there was a different method for them cutting people off in that way... I just think the whole system needs a refresher. There needs to be a more innovative way of making sure that the person with a disability, all their needs are met. (Tasi)

## Implications

In this study, 16 Pacific peoples participated in talanoa about the health- and disability-related costs they and their 'aiga faced, whether they were able to meet these costs, and their receipt of income support intended to assist with these costs.

Most of the talanoa participants had direct costs related to health conditions or disability. For some, these costs were very high. People spoke of ways that health-and disability-related costs had flow-on effects on their ability to afford other essential items. Participants also reported indirect costs such as reduced employment and earnings, and loss of independence. Many reported hardships that they and their families had experienced and most said that their income was not enough or only just enough to meet their everyday needs.

The experiences and insights that were generously shared by talanoa participants can help inform improvements in income and other supports for Pacific disabled people, Pacific people with health conditions, and their carers. These improvements may include:

- **Increasing awareness of the range of supports available and how to access these.** While some participants were confident they were receiving the support they were entitled to, others had limited confidence in their engagements with government agencies, little awareness of available supports and how to access them, or were reluctant to seek assistance because of negative experiences in the past.
- **Reviewing eligibility criteria for some income supports.** Several participants found themselves ineligible for income support even when their health-and disability-related costs were causing hardship to them and their children. Participants in the parallel studies with Māori (Cram et al., forthcoming) and non-Māori, non-Pacific (Gray and Stratten, forthcoming) had similar experiences.
- **Supporting disabled Pacific peoples, those with health conditions, and their carers into suitable employment.** Several participants expressed a desire to find suitable work and earn their own income. However, finding work that was appropriate for their circumstances could be a challenge and working more hours had led to a reduction in income for one participant receiving Supported Living Payment.
- **Making it easier for Pacific disabled people, people with health conditions and their carers to navigate the system of available supports.** Participants, particularly carers, spoke of challenges accessing supports from across the system, including equipment, therapies, and rehabilitative supports. Clear and culturally responsive communication about supports available, who is eligible, and how to access these could ensure that

more Pacific peoples receive the supports they are entitled to without unnecessary struggle.

- **Increasing the availability of Pacific providers in the community.**

Some of the talanoa participants expressed greater comfort with Pacific health and social service providers. These providers understood their circumstances, were non-judgemental, and helped them to access income and health supports they were entitled to. However, not all participants were in contact with Pacific providers or were able to access their services. Increasing the availability of Pacific providers in the community could help to increase awareness of and access to income and other supports among Pacific peoples who are disabled and/or have long-term health conditions.

## References

- Braun, V., and V. Clarke. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3 (2): 77–101. doi:10.1191/1478088706qp063oa.
- Braun, V., and V. Clarke. (2012). Thematic Analysis. In H Cooper (Ed.), *APA Handbook of Research Methods in Psychology Vol. 2: Research Designs* (pp. 57–71). APA books.
- Cram et al. [Forthcoming]. *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*. Ministry of Social Development.
- Futter-Puati, D., & Maua-Hodges, T. (2019). Stitching tivaevae: a Cook Islands research method. *AlterNative: An International Journal of Indigenous Peoples*, 15(2), 140-149. <https://doi.org/10.1177/1177180119836788>
- Gray, R. & Stratton, G. [Forthcoming]. *Extra costs and income support experiences for disabled people and people with long-term health conditions*. Ministry of Social Development.
- Stats NZ. (2024). *Child poverty statistics: Year ended June 2023*. <https://www.stats.govt.nz/information-releases/child-poverty-statistics-year-ended-june-2023/>
- Wilson, M., and McLeod, K. (forthcoming). *Material hardship of children in households with a disabled person*. Ministry of Social Development.



# Appendix 1: Information and consent forms for talanoa

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

### Warm Pacific greetings

This is an invitation to be part of research that will inform policy advice related to the income support system.

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

The Ministry of Social Development (MSD) is carrying out the research. The interviewers are xxxx from the MSD Research and Evaluation team and xxxx, an independent researcher.

### What does participation involve?

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

If you agree to participate in this study, we will organise a 60 minute talanoa. We find talanoa are best face to face, but we can also do them online or over the phone (depending on what best works for you). We can organise the talanoa to suit your accessibility needs, including for example taking breaks.

We will be scheduling the talanoa in May. The talanoa will be recorded with your consent.

## **The benefits of participation**

Your participation will provide an opportunity to share your experiences about the costs you face, what works for you, and what could be improved with the income support system. We will report findings to MSD, who will use the information to inform new policies and processes.

We value your contribution and you will be provided with a \$100 koha in recognition of your time. If you would like a support person with you at the talanoa, they will be provided with a \$50 koha.

## **How will my privacy be protected?**

The information you provide us will be treated as confidential. All reports and presentations about this study will not include any information that could identify you or any member of your family.

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.

What you say will not affect any benefits you might receive or other income support payments like Working for Families.

What you say will be confidential to the research team. Only the research team will have access to the information and the audio files of your talanoa. We will delete your contact details as soon as they are no longer needed. We will delete all files from your talanoa after 1 year.

We are happy to provide you with a copy of your talanoa transcript as well as the final copy of the research. If you want to correct anything on the transcript after your talanoa, you can do so by contacting the Lead Researcher xxxx at [xxxx@msd.govt.nz](mailto:xxxx@msd.govt.nz) within 4 weeks of your talanoa.

## **Do I have to participate?**

Your participation is entirely voluntary, and you do not have to participate in this research. If you choose to participate and then change your mind

later, you can withdraw by contacting the Lead researcher xxxx at [xxxx@msd.govt.nz](mailto:xxxx@msd.govt.nz). If you decide to withdraw, we will delete your information. Your withdrawal will not affect your current or future relations with the income support system or MSD. The reporting from this project will be published in 2025.

### **Any questions?**

If you have further questions about the research, you can contact xxxx at [xxxx@msd.govt.nz](mailto:xxxx@msd.govt.nz) or xxxx at [xxxx@gmail.com](mailto:xxxx@gmail.com).

### **What happens next?**

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

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

- I have read the information sheet about the In-depth Study to understand extra costs and income support for people with health conditions and disabilities.
- Questions I had about the study have been answered.
- I understand all my information and that of any other family member will be kept confidential and we will not be personally identified in any report.
- I understand that I can take part and not answer all of the questions, or withdraw completely at any time by contacting xxxx at [xxxx@msd.govt.nz](mailto:xxxx@msd.govt.nz), and that I will not be disadvantaged if I choose to do this.
- I understand that information I do provide will not be used to disadvantage me or any member of my family.
- I understand that information I do provide will not affect income support payments received by me or any member of my family.
- I consent to take part in the research.
- I agree to our talk being audio-recorded.

**If requesting a copy of the talanoa transcript**

- I'd like a copy of my talanoa transcript.

**If requesting a copy of the report summary**

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

**Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

**Printed name** \_\_\_\_\_

**E-mail (optional) for findings and/or transcript**

## Appendix 2: Talanoa Schedule

Within the context of talanoa, the researchers had conversations with participants around the following topic areas.

### Enquiry Area 1

#### Topic 1. Household and 'aiga 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:
  - disabled and/or a person with a long-term health condition,
  - a parent with a child who is disabled and/or has a long-term health condition,
  - a carer for a member of your 'aiga/someone who is disabled and/or has 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)
  - your experience of disability or health condition (e.g., (nature, severity, variability, duration), or
  - having a child who is disabled and/or has a long-term health condition
  - 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 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 'aiga do?
14. How does [disability or health condition or caring responsibilities] affect the activities you and your 'aiga do?
15. [if there are activities they don't participate in or participate in less because of [a disability or health condition or caring responsibilities]], What are the activities that are affected?
16. 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 D)*

*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 D (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 E contains overview of 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 power, gas, 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. Is debt a problem for you or your 'aiga? If yes, how does that affect you?
25. Finally, how do you get by? What decisions have you made, or ways 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 Allowance**

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. Are you receiving any other benefits or payments? (if so which ones)
28. (If applicable) Is the person you are carer for receiving any other benefits or payments? (if so which ones)
29. In the last 12 months have you used any subsidies or payments from the Ministry of Social Development – MSD – or other agencies to support modifications to your home? If not, Are you aware there are subsidies for home modifications?

**Enquiry Area 4. Final comments**

We're coming to the end of our talanoa 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**

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

## Appendix 3: Information and consent forms 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 Income**

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/)) - <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, Work and Income 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**

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.

### **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 advisor 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.

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

\_\_\_\_\_