



What we heard

Summary of submissions: *Mahi Aroha – Carers’ Strategy Action Plan 2019-2023*



MINISTRY OF SOCIAL
DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA



NEW ZEALAND
carers
ALLIANCE



Contents

Introduction	6
Who we heard from	9
Workshops	9
Survey	10
Submissions	15
Some of the stories we heard.....	16
Recognising.....	17
Recognition for their contribution	18
Recognition of the impacts of caring	19
Recognition and classification of different disabilities and conditions	20
Recognition needs to be accompanied by support	20
Navigating	29
Availability	39
Flexibility	40
Quality of respite care	42
Supporting	45
Balancing	57
General themes.....	63
Family violence and safety	63
Retirement income	64
Diversity of carers' needs	64
The design of the action plan	65
Keeping carers involved	66





How did we use the feedback we received? 67

- We expanded Actions 3 and 17 to address emerging issues..... 67
- We refined Actions 1, 9 and 14 to give them a more specific purpose..... 67
- We changed Action 2 to better reflect the views of respondents..... 67
- We merged Actions 7, 8, 11 and 12 to make the Action Plan clearer 68

Appendix 1:
Workshop rankings of support for Actions 69

Appendix 2:
Survey rankings of support for Actions 72





Introduction

In 2018, we asked carers what they needed to support them in their role. This information, together with feedback from carers on previous action plans, international and domestic research, and insights from the Carers Alliance, formed the basis of a discussion document - Mahi Aroha: Caring for the Carers, which set out the draft Carers’ Strategy Action Plan 2019-2023. This was organised under four focus areas (Recognising, Navigating, Supporting and Balancing) and contained 20 actions.

Throughout July and August 2019, we invited public consultation on the discussion document, which outlined our plans to better support people who are caring for someone with a disability, health condition, illness or injury. Consultation was primarily focused on hearing the voices of carers themselves, however we also received feedback from representatives of provider and advocacy organisations. What we heard during consultation, along with cross-agency engagement, resulted in *Mahi Aroha – Carers’ Strategy Action Plan 2019-2023 (Mahi Aroha)*.

During consultation, we wanted to hear from carers about whether we had got the Action Plan right – whether the actions reflected what mattered most to them, and if there were any issues that we had missed.

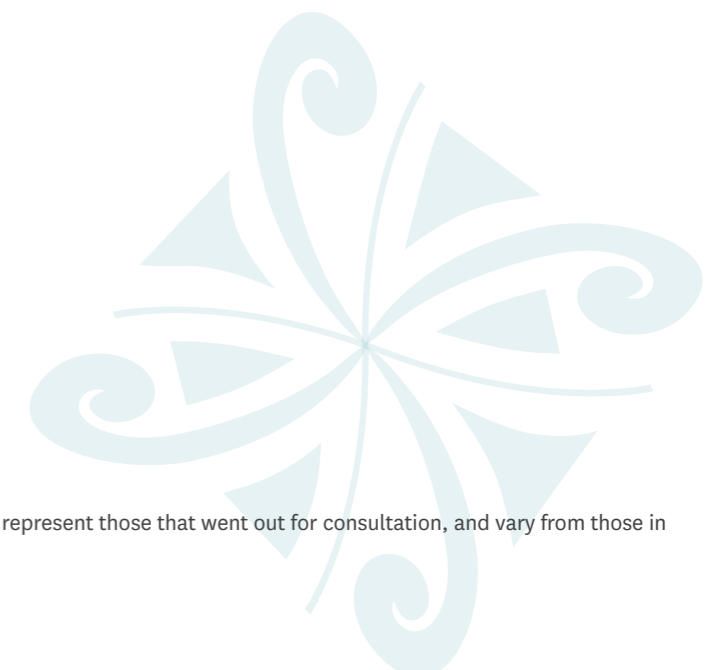
This document summarises what we heard as part of the 2019 consultation process. For each focus area and its related actions, we have summarised the key themes that emerged during consultation. We hope this will help to provide some insight into the feedback we received and the issues that carers face. However, we also recognise that carers’ experiences are made up of far more than a summary of submissions can provide. As such, we have also created a ‘Some of the stories we heard’ section on page nine to provide an insight into the lives of some of the people that contributed to this document.



The discussion document sought feedback on 20 proposed actions, as a result of the consultation the actions were revised to the 17 actions of *Mahi Aroha – Carers’ Strategy Action Plan 2019-2023*.¹ The final section of this document describes the key changes that were made as a result of the feedback we received.

Overall, feedback on the discussion document reinforced what we heard in the original consultation in 2018. Carers told us that caring could be a deeply rewarding experience. However, there were many ways in which caring was hard. Carers talked about the challenges of navigating the support system, of not feeling like their contribution was valued, and of not feeling like they could take a break when they needed it. As a result, actions that looked at financial support, enabled carers to take a break, and strengthened navigation, were strongly supported. Some new issues also emerged, which are addressed in the general themes section.

We would like to thank everyone who contributed their time and experiences to the consultation process. All the ideas, suggestions and stories we heard were invaluable in developing *Mahi Aroha*, and deepening our understanding of how we can work towards a society where carers feel recognised, valued and supported.



¹ The wording of the actions in this document represent those that went out for consultation, and vary from those in the completed Action Plan, *Mahi Aroha*.

Who we heard from

Consultation on the proposed action plan took place throughout July and August 2019. We used a range of approaches to reach out to carers, including an online survey, written submissions, workshops, hui and talanoa.

Workshops

The consultation process was developed by Ministry of Social Development (MSD) and the New Zealand Carers Alliance. An agreed meeting schedule set out a mixture of cities and towns around the country where workshops were organised. This was designed to capture a diverse range of carers, as well as return to the places we visited during our initial consultation in 2018. Facilitators were engaged to set and run the workshops, which mostly ran for two hours.

We worked with the New Zealand Carers Alliance to promote awareness and attendance at the workshops.

A total of 17 face-to-face workshops were held. A variety of sessions were offered in order to help carers feel welcome, safe, and encouraged to share their views and experiences. Eight workshops were open session, four were hui, four were talanoa and one was targeted specifically at Ethnic Communities.

As part of each workshop, participants went through the 20 proposed actions and selected the five actions they felt were the greatest priorities. The totalled results of this exercise are included as Appendix 1. Participants were also given the opportunity to discuss if there was anything they would like to change or if there was anything missing.



Survey

People could also participate in the consultation process through an online survey. The survey launched on 27 June 2019 and was promoted by the New Zealand Carers Alliance, in the SuperSeniors newsletter and on the MSD website. By the close of the survey, on 26 August 2019, 603 people had engaged with the survey.

The survey asked participants to reflect on the proposed action plan, with questions spread across the four focus areas: Recognising, Navigating, Supporting and Balancing. Participants were asked 'do these actions reflect what matters to you?' and provided with an option to indicate their level of agreement with each proposed action. The results from this part of the survey are included as Appendix 2.

Participants could elaborate on their response in the open comment boxes, which asked 'please tell us what you would change about this focus area or the actions', and 'is there anything else that you think might be more important than these actions?'. Participants also had the opportunity to describe how they saw themselves as 'carers', provide their overall view of the proposed action plan, and contribute any final comments. The last section provided participants with the option to answer demographic questions, such as gender, age, and nature of the care provided.

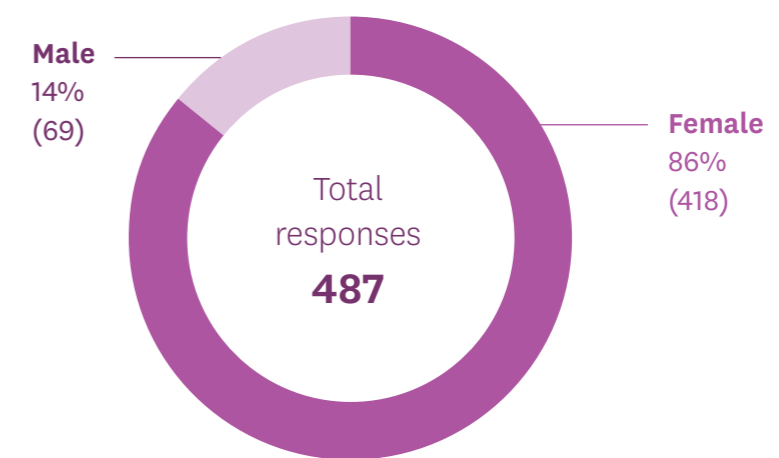
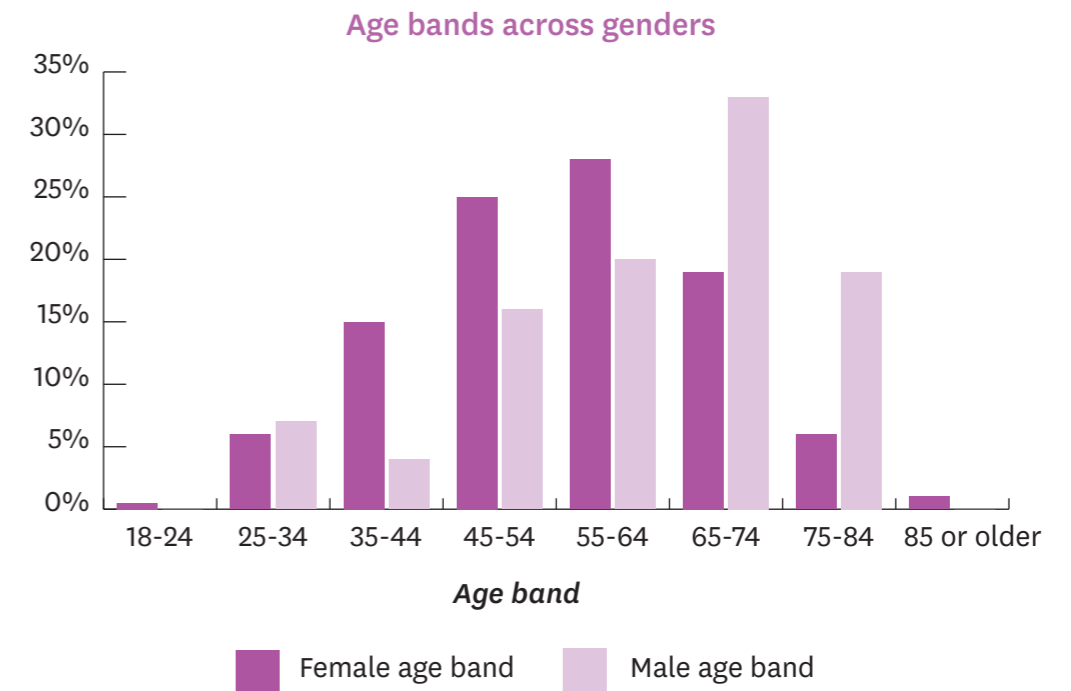
Information on the demographic profile of survey respondents is provided on the following page.



Age and gender

As the graph below shows, of those who provided demographic data, 86 percent were women, and 53 percent of women were in the age group 45-65.

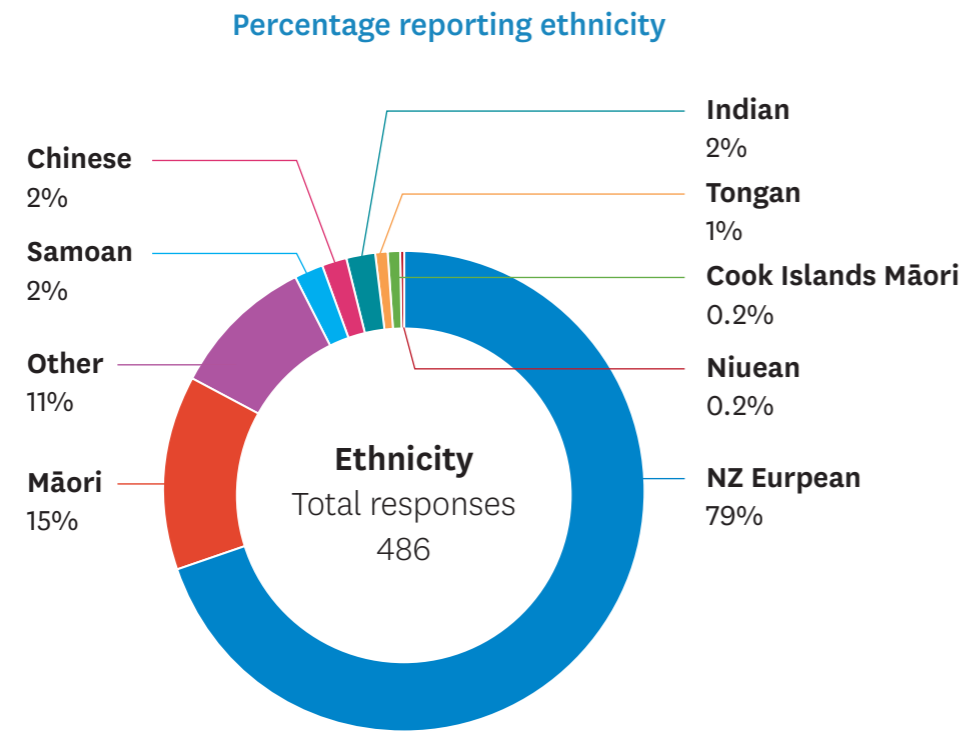
Young people (aged 18-24) were under-represented in the survey responses, making up only 0.5 percent of the female responses. No males in this age group responded.



Ethnicity

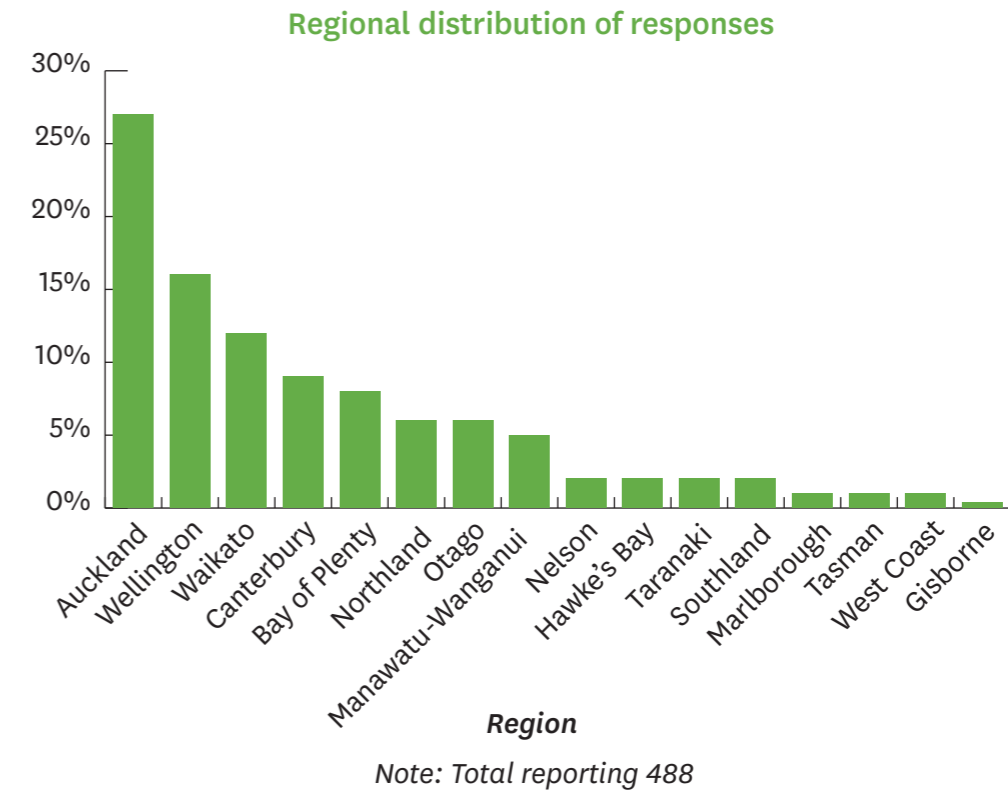
The majority (79 percent) of the respondents who provided ethnicity information identified as New Zealand European or Pākehā. Fifteen percent of respondents identified as Māori.

Respondents could opt to indicate more than one ethnicity.



Regional distribution

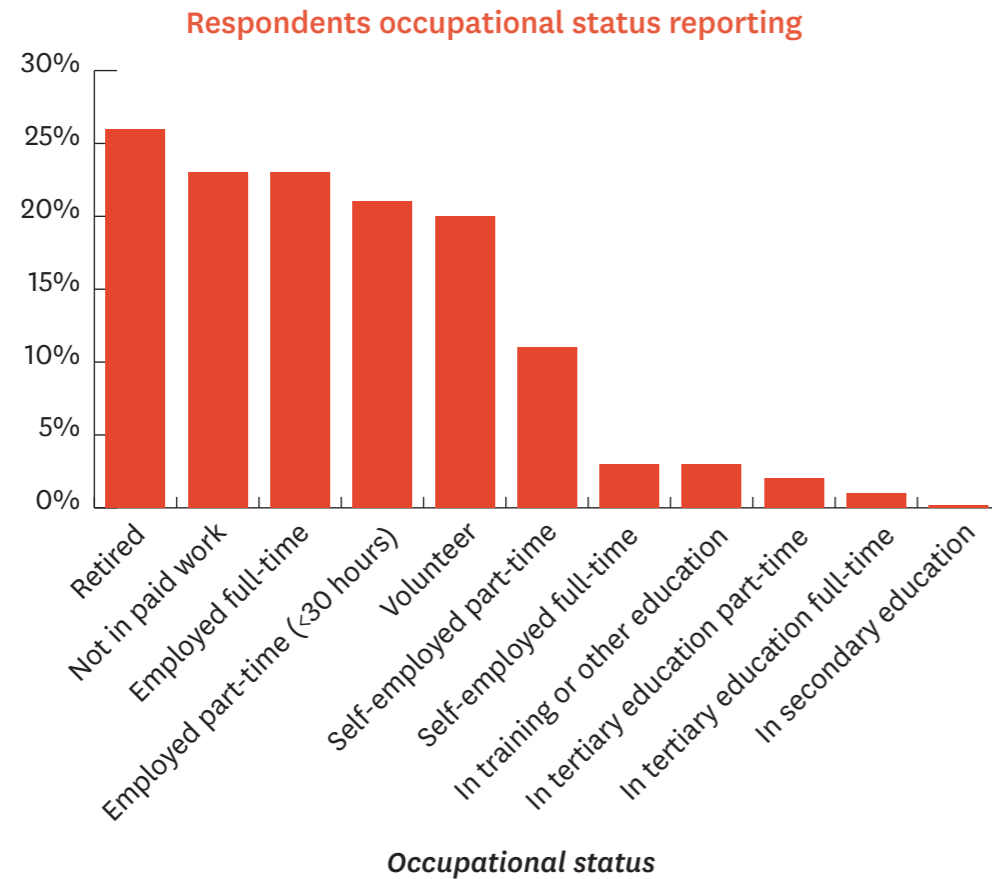
Sixty-five percent of the respondents who provided demographic data were from the four main regions (Auckland, Wellington, Waikato and Canterbury).



Occupational status

Just over a quarter of those who responded were retired. Respondents were able to indicate multiple occupational statuses. Fifty-eight percent reported being in some form of employment.

Just over 6 percent reported undertaking training or education.

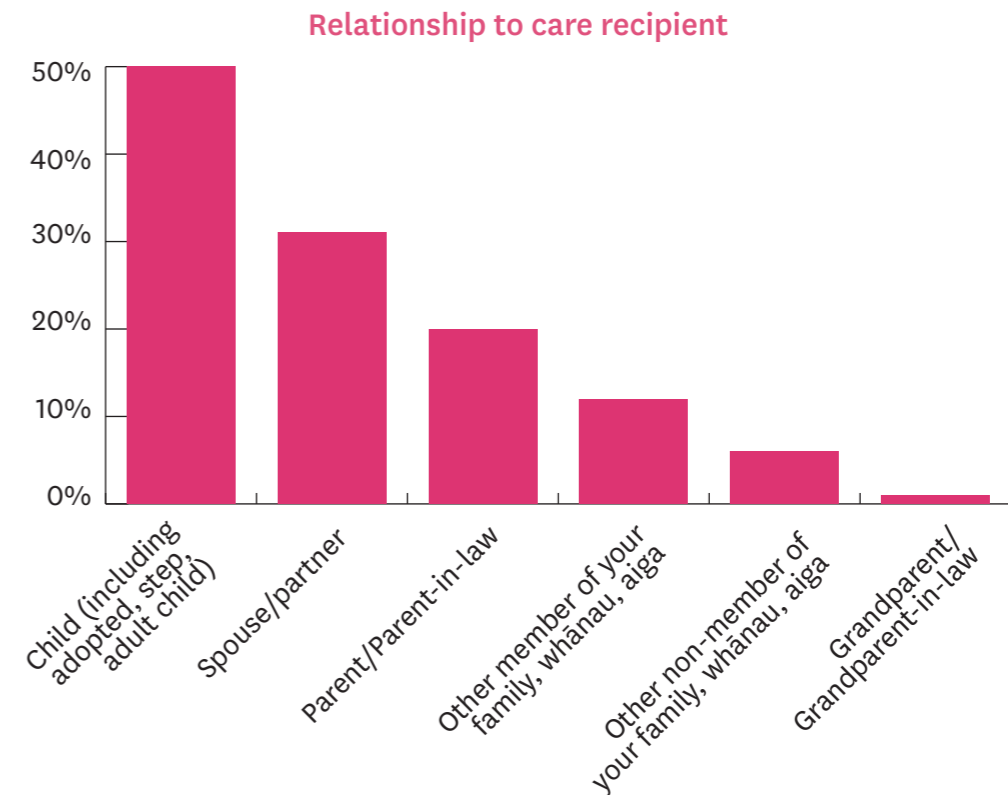


Occupational status
 Note: Total respondents 480

Relationship to care recipient

The majority of respondents were providing care to their child (including adult children).² A significant number were providing care to their spouse or partner (31%).

Some respondents were caring for more than one person, which is reflected in the percentage totals. Just over 12% of respondents were caring for two people and 3.5% of respondents were caring for three people or more people.



Relationship to care recipient
 Note: Total respondents 455

Submissions

The public were welcome to make an open written submission on the proposed action plan. Details were provided on the MSD website and promoted in workshops.

We received 24 submissions: 13 were from individual submitters, and nine from organisations. The majority were received by email.

² In the context of this work a carer is anyone who cares for a friend, family, whānau or aiga member with a disability, health condition, illness or injury.

Some of the stories we heard...

Everyone we spoke to told us how important it was to them to care for their loved one. But, caring can be hard. These are some of the stories we heard.

A carer told us that they were worried their spouse would have fallen over while they were at the consultation, because they weren’t home to look after them. They had come to tell us how hard their situation was. Their spouse wouldn’t let anyone else in the house, so they had no choice but to leave them on their own. They didn’t do this very often as their spouse would get angry if they went out too often. They couldn’t convince their spouse to go to respite and had no support.

A carer told us about using respite only once for their child, who had very high medical needs. They found a nurse to look after their child, however, when they got home the nurse said their child was too fragile to care for on her own and that she couldn’t do it again.

A parent told us their child had been excluded from school. They were very stressed, and while people had said they hoped there was help, no one had offered any. They didn’t know what they were going to do and felt completely alone.

A carer told us about the stress of dealing with their teenager when they became violent. They talked about the loneliness of having nobody to turn to who could understand the nature of their child’s disability and provide a safe, timely and appropriate response.

A parent of multiple disabled young people told us of the challenges of finding their way through the system to ensure the children received adequate services. They told us not to forget that no matter how hard it was, they loved the children and got great delight from being their parent. They said that they had become a different person – one who had to learn how to fight to get the support the children needed.

Recognising

Recognising is the first of four focus areas in *Mahi Aroha*. It aims to ensure that carers are recognised for the important work they do, and that their role is acknowledged by health professionals, employers and teachers.

Many respondents³ emphasised the importance of recognition. Some felt their roles as carers were not valued and that they had no voice. They asked to be trusted, supported and heard. Recognition was about being valued for their contribution to society, understood for what their role involves, and supported no matter who they were caring for.

“I think ‘recognising carers and their contributions’ is the most important and overarching action step. It implies [imminent action] and significant change for caregivers. Please press on with this.”

Submission

“Carers need to be listened to. And someone needs to listen to what’s not being said. Because there’s a lot.”

Workshop participant

“For me, it’s about recognition, trust, choice and – ultimately – empowerment.”

Workshop participant



³ Respondents is used in this document to broadly capture those that engaged with the consultation process, whether this was through responding to the online survey, writing a submission or attending a workshop.

Recognition for their contribution

When discussing recognition, a recurring theme was the perception that caring is not recognised as a legitimate job. Some carers referred to stigma and a perception that they were not contributing to society. Carers pointed out that, by taking on the caring role (whether by choice or expectation), carers were doing a job that would otherwise be carried out by a professional workforce.

“You’re not just a carer, you’re an educator, an advocate, a medical expert. You’re everything for that one person.”

Workshop participant

“I want people to see this as a job. We’re an insurance policy for the government. If we don’t do our job, it costs the country and government so much. We need to be seen and valued.”

Workshop participant

“Immediate action to support, fund more, and [ensure] that carers are acknowledged better than they are now, because they are saving the taxpayer tens and tens of millions of dollars caring for family members in their own home. Carers deserve more support, national awareness, funding and help.”

Survey respondent

“There is a real stigma of being on the benefit. Because people look at you like you’re not contributing, you’re lazy. You’re draining society.”

Hui participant

Respondents also highlighted that carers have deep expertise on the needs of the person or people they care for, but often do not feel that this knowledge or expertise is listened to.

“My wife is nonverbal. She lost her language because of a stroke. But I can talk to her and understand her. I read her body language and her eyes. We know our loved ones best.”

Hui participant

“Carers are the experts. That has to be recognised.”

Workshop

Recognition of the impacts of caring

Carers also expressed a desire for the impacts of caring to be recognised. Responses highlighted that some carers must give up their employment or other life activities to focus on providing care. For some carers, they are fully committed to providing care every day and throughout the day. This can have an impact on the wellbeing, self-esteem and health outcomes of carers.

“We give up so much, and as families you see yourself falling behind. You see other families racing ahead to places you’d love to be.”

Workshop participant

“Carers do not have the same rights as other citizens and are expected to forfeit careers/jobs/their health and wellbeing, to care for their disabled child.”

Survey respondent

One workshop participant also noted there was a lack of understanding of how people could help carers to manage these impacts, commenting:

“If I’m not valued, I have to constantly fight for help. People are saying ‘I hope you’re getting the help you need’, not ‘what can we do to help?’”

Workshop participant

Recognition and classification of different disabilities and conditions

Some respondents felt the specific disabilities of care recipients were not well recognised. Respondents noted that the way conditions were recognised and classified had an impact on the support carers received.

“If FASD [Fetal Alcohol Syndrome Disorder] was recognised as a disability, then those who care for them and adjust their daily lives and working lives to cater for their complex needs, could be recognised.”

Survey respondent

“With ME/CFS [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome] – half of our kids and adults are not even classed as having a disability because medical people do not understand the illness at all. They consider it to be a psychological problem. It is not, it is bio-physiological. We are a missing-in-action group of stressed out carers with no status nor financial support to keep our kids alive and functioning.”

Survey respondent

“Increase accessibility to include carers of chronically ill as well as disabled. Recognition of chronically ill, rather than just disabled people is needed, as so often support for families is not available due to diagnosis. This is despite the end needs being similar, and the role of the carer being the same.”

Survey respondent

Recognition needs to be accompanied by support

Another theme in the feedback was the notion that recognition needs to be coupled with support – or that support is a core part of achieving recognition. This was expressed in comments that noted financial support is one way that recognition could be shown, as it communicates to carers that their contribution is valued.

Value lifts people up and out of despair. There are many ways of expressing that carers are valued. It could be through societal acknowledgement (people often ask what she does and when she says ‘carer’ they say, ‘oh but what else?’) or government acknowledgement through payments (recognising caring as a real job).

Workshop feedback

“Recognition should not be a substitute for support.”

Survey respondent

Action 1

Exploring mechanisms, including legislation, to better recognise carers and their particular needs.

Respondents identified a range of benefits that greater recognition in legislation and policy could achieve. Some respondents noted that recognition in legislation was important to the action plan as a whole, helping to give a sense of accountability and commitment from the Government. Others recognised that legislative recognition could potentially be used as a mechanism to advance other action points or protect carers’ rights.

Legislation is needed to lock in implementation of the Carers’ Action Plan and not have it be a political football to ebb and flow with changing governments’ priorities.

Workshop feedback

“Legislation would give oomph to our lives, to our cause.”

Workshop participant

Legislation is a long-term goal with potentially big ramifications. It could address needs identified in other actions – eg funding for carers to stay at home, training/educational opportunities, social support opportunities, networking/integration across other government agencies.

Workshop feedback

Explore legislation to bring together a focus on carers, across the fragmented services, etc.

Workshop feedback

“Legislation brings accountability, it’s a guiding anchor. It brings agencies together and empowers carers. It would mean that we could go to the Ombudsmen. We would have rights.”

Workshop participant

“Once your children are 18, you’re no longer their legal guardian. But really, you will be their guardian for life. They will never be completely independent. There needs to be recognition of this, you need to be able to protect your adult children.”

Workshop participant

“Legislate to protect the rights of whānau carers as a vulnerable group”

Survey respondent

The role of policy was also a key theme, with some expressing that changes in policy were required to provide more support. In discussing the role of policy, respondents expressed the importance of including the perspective of carers in decisions. Some respondents highlighted that there needed to be more visibility of carers' experiences and avenues for their voices to be heard in government.

“I want, more than anything else, for policy to speak to the realities of the caring role. That means more people have to actually understand what is involved.”

Workshop participant

“Is advocacy the main weapon? How do we action any of this, and make our voices heard outside of this engagement process?”

Workshop participant

“Funders are unaware, as is government, of how reliant the system is on informal care. Because they don't pay for it, they don't see it. It's invisible. And there's no value placed on it”.

Workshop participant

Respondents also highlighted that defining caring would be helpful, as the responsibilities of caring can vary.

“I am a carer. But I also do my finances etc for my mother. I'm realising that's also caring. I think it's really important that we understand what caring is, what it means, and when it applies.”

Workshop participant

“Making it clear exactly who is considered as a carer, hours, disability level etc.”

Survey respondent

“Caring varies on different days and locations. There needs to be a NZ term which encompasses the rights, respect, responsibility of caring work.”

Survey respondent



Action 2

Develop and implement a national campaign to raise awareness of carers, including a National Carers’ Day.

The idea of a national campaign and a Carers’ Day was supported by most survey respondents and met with some positive feedback at the workshops. Respondents highlighted that awareness was needed, as the public often do not realise the challenges carers face, or do not recognise their contribution to society. Respondents expressed feeling misunderstood and undervalued:

“I would like someone to look at me and say ‘wow’, rather than look me up and down and say, ‘you’re worthless, start contributing to society.’”

Workshop participant

“People ask me if I work. Am I working at the moment? I never stop. But it’s not in an office, so they don’t think it counts.”

Workshop participant

Carers can feel they have no value, and as if they are constantly fighting. People are not aware what it’s like to support a disabled child full-time, there needs to be more awareness and public dialogue on carers.

Workshop feedback

The profile of carers needs to be lifted. A national campaign to promote awareness would be huge – society needs to understand what carers do and their stories.

Workshop feedback

Others noted the benefits raising awareness could have for carers, such as bringing carers together and normalising reaching out for help. Some submitters highlighted that more awareness was needed around certain types of conditions, such as learning disabilities, mental health and Fetal Alcohol Syndrome Disorder.

“We need promotion in our culture to make it ok for carers to ask for help and for people to understand that ‘many hands make light work’ and enrich the lives of the person and their carer.”

Submission

Submitters also had ideas for the implementation of an awareness campaign. One submitter suggested having a campaign around mental health for carers, and another proposed highlighting carers’ experiences through media releases with statistics and human-interest stories.

“Create a campaign around ‘Who is caring for the Carer?’”

Survey respondent

Who’s there as a face for mental health for carers? Maybe that could be the focus of a campaign?

Workshop feedback

However, some respondents saw other actions (such as reviewing financial support) as more of a priority. This was reinforced by sentiments that awareness would make little difference to carers’ day-to-day lives and the money spent on a campaign would be better off being distributed directly to carers. Some respondents noted that it was not public support that was needed, but rather support from the government.

“I think initiatives like the higher pay legislated for carers does more for them than a national campaign. It tells the community that they are valued.”

Survey respondent

The notion of a Carers’ Day had a mixed response. Some submitters highlighted that a national day risked being tokenistic, while others noted better support for carers was needed first, so that carers could have the time and energy to participate.

“In my opinion we have far too many national days already. They require the time and energy of those already most stretched, the carers. Better to skip that and focus on constructively bringing about payment for carers. This in itself will generate the most needed recognition that I face as a caregiver.”

Submission

“A national Carers’ Day risks being tokenistic. Whoopee! We get a day. So what?”

Workshop feedback

“Having a Carers’ Day does not help when you are exhausted from the realities of looking after a loved one.”

Survey respondent

“National Carers’ Day – probably a good idea but in the future. Let’s get the basics right first.”

Submission

However, another respondent noted that a Carers’ Day could be a good opportunity to celebrate carers, generate solidarity and help them to feel important.

“A Carers’ Day would be nice. A celebration day, when we are recognised. When there can be sharing, laughing, talking and caring. We don’t expect anything, just to be appreciated, to feel important and valued. We don’t want anything else.”

Talanoa participant

Action 3

Better understand the needs of carers, particularly younger, older, Māori, and Pacific carers, as well as other hidden carers by creating a carer research fund.

There was some scepticism around the value of a research fund. As with a national campaign, some respondents felt it was not a good use of time and money, and other actions were more of a priority.

Others highlighted that a research fund was needed to get a better understanding of the issues carers face, including the economic and emotional impacts of caring. These insights could then be used to advance other goals.

“Identify the economic burden of parents who cannot work due to caregiving, and the emotional burden of being isolated in their homes.”

Survey respondent

“More emphasis on data and research to better understand the carer landscape.”

Survey respondent

“If you don’t know who we are and what we do, how do you decide on the budget, and what will be done with that money?”

Workshop participant

A recurring theme was that research should seek to capture the experiences of all carers, including groups that were not mentioned in the discussion document. This included those caring for someone with a mental/intellectual disability and those in remote locations.



Action 4

Improve information about carers by modifying existing data collection tools.

There was limited comment on Action 4 in both the survey and the workshops. As with Action 3, respondents noted that there are important knowledge gaps that improved data collection could help to fill. For example, data collection could help to get a better understanding of the financial challenges that carers face, as well as how caring intersects with the welfare system.

“There’s no intentional data collection. We don’t ask who carers are, how many there are, what challenges they face, what their financial impediments to getting support are...”

Workshop participant

Respondents noted the importance of having a clear purpose to data collection. It was emphasised that, to be worthwhile, data collection would need to be meaningfully used by government and community organisations.

“There’s no point having data if it’s not data that tells us what we need to know and allows us to make a change.”

Workshop participant

Action 5

Better support to include the voices of young carers in policy development, including through re-establishing a Young Carers’ Advisory Board.

This action was an area that received little feedback in the consultation process, particularly from young people themselves. As noted in the survey data demographics, only 0.5% of respondents to the survey were under 25.

Navigating

Navigating is the second of the four focus areas and focuses on supporting carers to access the assistance they are entitled to.

Navigation was an area that many respondents felt needed improving. There was a common sentiment that the burden is on the carer to 'do the work' in finding the support they are entitled to. This in turn placed extra stress and pressure on carers in an already challenging situation. Several respondents made the comment that caring was like having two jobs – one in caring for their loved one, and another in navigating the system. Many respondents said they wanted the support system to be simpler, more proactive and more transparent.

“This is a critically important area, the challenges for a family trying to find any information is massive. It desperately needs centralising and communication. It is so, so hard to find what you need and who can help. This should be the first priority! Clear policies and guidelines along with where to get help. Again, a centralised hub is key.”

Survey respondent

“It shouldn't be about me, who's burned out after 15 years of caring, having to go from place to place to find things and to keep being told. I'm burning out. I'm almost done. It should be them, they should be helping me.”

Workshop participant

“It's like there are two jobs – the caring and then the logistics. And they're both such a struggle.”

Workshop participant

Action 6

Working with carers, people receiving care, and relevant sectors and agencies to explore the benefit of a national approach to managing continence.

Feedback on this action varied, with some stating that support for continence had worked well for them, and others identifying it as a major concern. Some respondents indicated that the level of support for continence varied between regions.

“I did not realise the incontinence sector was not national. Canterbury has mostly worked well for us.”

Survey respondent

Respite and continence depend so much on where you are.

Workshop feedback

“Continence [is] not an issue – yet. Access does seem to be by postcode, our household is in a ‘lucky’ area.”

Survey respondent

Some spoke about the issues they had experienced with managing continence. These included delays in getting help and funding concerns.

“Continence issues have been a major cause of concern for us. We earn too much for the Disability Allowance, but continence products are only partially funded – there’s a limit to the number of nappies we can get daily... We need mattress protectors, bigger-sized washing machine drums, carpet shampoo, disposable gloves etc. Our decisions about places to go in public are limited by where we can safely toilet a full-grown teenager with severe disabilities.”

Survey respondent

“I support the idea of a national system for continence, but please be sure that this is individually assessed. We currently spend \$175 every six weeks topping up the diapers that our son requires, because the current funding is inadequate for his needs”.

Submission

“It is important that incontinence is dealt with in a caring and non-judgmental way as it is very embarrassing for the person involved... A single point of contact in each area with the ability to help with incontinence issues would be very helpful.”

Submission

Some respondents felt that other care needs also needed to be addressed.

“I agree we don’t get sufficient resourcing in this area but there are multiple areas in the caring area that need appropriate resourcing.”

Survey respondent

A few respondents also highlighted that it was important to consider early intervention and preventative approaches.

“I think ‘managing continence’ could become just managing continence products – there needs to be a focus in primary care on pelvic floor rehabilitation – especially post-pregnancy and post urology or gynaecology surgery. ‘Sopping up’ the problem is not useful – there needs to be an equal focus on pelvic floor fitness and rehabilitation – just as there is for falls prevention and lower limb fitness and balance.”

Survey respondent

“I suggest research is required to determine the extent of unmet need. to be imparted to people at an early stage, before they allow it to dominate their interactions with society”.

Submission

Action 7

Strengthen navigation across all parts of the care and support system (including health, welfare and ACC) to ensure carers receive available assistance.

Feedback on this action highlighted the importance of having easy to use, integrated systems, with clear pathways for finding support. Respondents raised concerns about complexity and fragmentation of the current system. Many comments indicated that it would be useful to have a single access point for support, with suggestions that this could be in the form of a ‘navigator’, a helpline, or regional carers’ resource centres. Others highlighted the need to have a clear understanding of their entitlement to support, the responsibilities of different government agencies and how they relate to each other.

“It would be great to have a diagram that shows the relationships between different agencies. When we first fell into this sector four years ago it was very difficult to get your head around the different providers, govt and private, and how they related to each other. So much information at a time you are already totally stressed by the health implications to your life and family.”

Survey respondent

“My son is so complex, his needs span various agencies. We spend so much time trying to navigate. and that includes advocating. There’s no one group that represents his needs.”

Workshop participant

“I believe the system needs to be simplified so that access and entitlement is clear, and rights-based.”

Survey respondent

Clear and transparent information about how to access support was a recurring theme in the feedback. Respondents noted that carers often did not know where to go or what to look for, and that information about support often emerged through word of mouth or chance encounters. The importance of agencies being proactive was emphasised, as carers were not necessarily aware of what that they were entitled to or how to find out.

Why do carers need to fight and keep retelling stories? [We should] be told about full entitlement from [the] beginning.

Hui feedback

“There is not easy access to information or the information is not clear. Families struggle with a disability and lack of information. It is the Government’s responsibility to approach families, especially immigrant families who do not know the NZ system.”

Survey respondent

Carers are too busy to keep up with policy changes and entitlements. The system should be proactive in approaching carers to check they are getting the support they need.

Workshop feedback

Another important aspect of navigating was ensuring that support was available at key times, such as when the person was first diagnosed, during a change of circumstances or when the person was grieving.

“I said goodbye to her in the morning, she went off to school. I got a call later to say she’s in a psychiatric hospital. That’s how it started, that’s how fast it was. How do you get your head around that?”

Talanoa participant

“We need more emphasis placed on induction – education, support and connections at the start, at the time of diagnosis.”

Workshop participant

“Grieving after you’ve lost the loved one you were caring for is a long process. But the way it’s treated, it’s like people think as soon as they’re gone, that’s it. You move on, you’re over it.”

Talanoa participant

Action 8

Improving engagement between people needing care, their carers, and supporting agencies.

Feedback on this action highlighted various ways in which engagement could be improved between people needing care, their carers and supporting agencies. Respondents highlighted that they wanted better customer service and a client-focused approach from services. This included the services carers interacted with having better understanding of a range of disabilities. The importance of being listened to, valued for their expertise and empathised with, was reiterated.

“A listening ear. Someone who has supported someone with the condition. Just to listen, encourage and show the way for families.”

Survey respondent

“For the person caring to be listened to, not be made to feel useless and over-dramatic.”

Survey respondent

“Why not get medical students to spend a day with a carer? Then at least the future GPs might actually understand what we do.”

Workshop participant

Some respondents highlighted the challenges that migrant and refugee carers face, including having to deal with language barriers, and different ways of understanding support and caring. These could add up to significant barriers to accessing support. Similarly, hui and talanoa participants highlighted the importance of cultural awareness from those they interacted with in the care and support system.

The medical field needs to recognise that we hold loved ones with such mana – they often see it as a disease and ask, ‘how long are you going to hold onto them for?’ They’re thinking in this Western way.

Hui feedback



A further theme was the importance of having pathways for support for carers themselves. Navigation was not just about finding support for the person they were caring for – it was also about finding support for their own health and wellbeing needs as carers. Some respondents expressed a desire to have a separate form of needs assessment specifically for carers.

“There needs to be a needs assessment for carers. They need to understand what a carer actually needs to be able to take a break and recharge, and what allows them to refuel.”

Workshop participant

“We ask GPs, ‘please interview carers separately’. If you ask a carer ‘are you coping ok?’, no one wants to admit that, actually no, they’re not. Especially in front of the person they’re caring for.”

Workshop participant

“There needs to be an ongoing assessment of the carer and the person being cared for.”

Talanoa participant

Respondents also noted the importance of a more holistic approach. Feedback suggested the support system should consider the carer-care recipient relationship, not just the medical conditions of care.

People’s lives are not a sum of personal cares and household management.

Workshop feedback

Action 9

Identifying whānau-centred tools and initiatives that provide culturally responsive approaches for Māori carers and their whānau.

Much of the feedback on this action emphasised the benefits of whānau-centred initiatives and why they were needed. Respondents highlighted that services often were not culturally safe and appropriate, and that this sometimes meant that carers did not receive adequate support. One hui participant expressed that Māori would continue to care from a Te Ao Māori perspective regardless, so it was a question of whether government would support them in that. Some respondents also highlighted that there was a need for Pacific-centred initiatives.

“Māori/Pacific Islanders/Asian culturally-responsive carer support. The existing home support (from MOH) [Ministry of Health] is very narrowly focused and doesn’t fit the cultural values of non-western communities. It is not about non-western communities not understanding what’s available. Rather, existing government-funded support is inadequate to meet our cultural needs.”

Survey respondent

Whānau-centred needs to be culturally ‘centred’ not just culturally ‘appropriate’ – see a lot of Māori families not getting the support they need.

Workshop feedback

“How can our systems shape to fit into whānau, not whānau shaping to fit into system?”

Hui participant

“The values and the ways Pacific people live their lives are different. Let us use Te Whare [Tapa Whā] within our own system to uplift our own elderly. If we live our lives with those four pillars, with our own, our grandparents will feel empowered, uplifted, like they still have something to give, some purpose left.”

Talanoa participant

Some respondents at talanoa noted that Pacific people may not recognise themselves as carers, as caring was considered a normal part of family responsibility.

Pacific people like to look after their own family members at home. Family is the most important thing to Pacific people. It is not caring as a role, but an expected obligation as part of a family.

Talanoa feedback

Others highlighted some of the specific ways in which current approaches were not culturally safe and appropriate. For example, it was noted that the structure of services and funding models were often individualised, which conflicts with a whānau/aiga perspective. Feedback noted:

“That the Action Plan has the carer and their role within a whānau context. This means that the reality of whānau and whānau whānui are recognised and respected and that the Action Plan considers the presence of a family network being an advantage to the carer. This would also mean that support to all whānau members within the home is recognised and acknowledged by resourcing the group. This could be via payment and/or ensuring that the whole whānau has well-being structures around them”.

Submission

Support is not available to the wider family and is just for an individual. This is inconsistent with a Pacific way.

Talanoa feedback

“The system needs to be mindful of cultural appropriateness. My daughter can't give her father a bath, for example.”

Talanoa participant

“Care providers often put in place a support plan, but it's not appropriate. It doesn't suit us. We do things differently. Different things matter to us.”

Talanoa participant

Some respondents also highlighted that whānau-centred tools have value for all New Zealanders, not just Māori.

“I think whānau-centred tools and approaches are required for all not just Māori. I don't understand why there is a persistent differentiation in government on this. Māori models of health have a great deal of applicability to all.”

Survey respondent

“The whānau model is a perspective that all New Zealanders could benefit from – not an individual independent approach but a bringing together of community resources.”

Survey respondent

Action 10

Improve the quality, accessibility and equity of access to services across New Zealand to enable carers to take a break (including the flexible disability respite budgets – I Choose).

Respite and the ability to take a break was a major area of concern for respondents. It was the action that was most commonly identified as a high priority at the workshops and received a high degree of support from survey respondents (see Appendices 1 and 2).

Carers wanted the opportunity to take a break in a form that suited them – whether this be in a formal facility, their own home, or by taking a walk along the beach. Several respondents noted the importance of taking a break in allowing them to continue caring and be refreshed and alert in their role. Others shared stories that illustrated how crucial taking a break was to their mental health and wellbeing. Burn-out was a recurring theme, with some carers feeling like they only got help when they hit rock bottom.

“Taking a break is huge because, obviously, you're going to be a better carer if you are looking after yourself.”

Workshop participant

“I was encouraged to take a break. It wasn't until I took that break that I realised I'd been living with such high levels of stress and injuries.”

Workshop participant

“She's a good person, but there are times... What I need is time for myself. I need to recharge, start the cycle again so I can keep caring. If I don't have my time out, I will do harm to her and to myself.”

Workshop participant

Respondents also identified some key barriers that prevented them from taking a break as they needed. These included the availability of services, equity of access, affordability and the flexibility of current respite options.



Availability

Some respondents expressed feeling like they had few options for respite care. Respondents highlighted a range of reasons for this – for some, there was limited availability in their area, while for others there was not enough support for the specific condition that they were caring for. Some felt they could not rely on respite care being available when they needed it, as there was no overnight care, or care was dependent on the number of beds at their local rest home or hospice.

“In our case it is virtually impossible to access respite care. My spouse is on peritoneal dialysis and blind. No one else in the community is trained to perform the dialysis exchanges.”

Survey respondent

“I need help overnight. I can't be awake 24/7. I need in-home help. But no one I talk to can help. We care for these people all day, we can't be awake all night too. We need help!”

Talanoa participant

One respondent noted that there needed to be more information about the demand for respite care, so the appropriate level of support could be put in place to ensure availability. Others noted there was little point in being allocated respite if you cannot find an available service to use.

“How can you be allowed respite care, but you can't get it? There needs to be a proper system, so you can get it. And it needs to be when it works for you, is best for you, not when there's a bed...”

Workshop participant

“We need to get a handle on what is the actual demand for respite care – what I was saying before about intentional data. If we can demonstrate that what is available isn't enough, that is a step in the right direction.”

Workshop participant

Some feedback also highlighted that the options available weren't always appropriate, for example young people taking respite in rest homes.

“I just want us to say NO to young people going into old peoples' homes. It's not right. Maybe other families can help out... they already are. Just informally.”

Workshop participant

Flexibility

Respondents generally indicated support for more flexible use of funding. Flexibility recognised the diversity of carers' needs and would give them the autonomy to spend funds on what was best for them (whether this was a massage, a family holiday or a trampoline for a hyperactive child).

“I used to get all my 28 days' payment at once and keep it. Then, when nieces and nephews helped with care, I paid them money out of that lump fund. I got told that I couldn't do that, that money was solely for me to go away. They made me sound like a criminal, because I wasn't using it properly, according to their 'rules'.”

Talanoa participant

“Let us decide how we spend our money, what suits us. Islanders are so family focused, our way is different.”

Talanoa participant

“It's important to think about respite in creative ways which does not necessarily separate the carer and the person requiring care. This is especially so with relation to whānau and to Māori. How can we develop ways of people taking a break together? The one-dimensional view of respite, even if using flexible funding, provides limited outcomes.”

Survey respondent

“Reduce the emphasis on 'provided or contracted service' and move towards direct funding to carers so they can more often make their own arrangements. The I Choose proposal is a good start with this.”

Survey respondent

Another issue that was highlighted was the delay in being paid back for respite. Respondents felt that it was more appropriate for it to be paid in advance, as this minimised the financial stress of needing to find the money up front. Several respondents also felt that while it was good to be allocated respite, they could not afford to do anything with their time off.

“Make sure full-time carers have the ability to take time out which includes making funds able to do so. These people aren't earning money so therefore can't afford to go out.”

Survey respondent

“There's no point giving respite if I can only afford to sit at home.”

Survey respondent



Quality of respite care

For many respondents, a central issue preventing them from taking a break was the quality of respite care. Trust was fundamental, with respondents highlighting that you cannot truly take a break if you are still worried about your loved one and the quality of care that they are receiving. Some respondents highlighted that a lack of trust had prevented them from taking a break when they needed it.

“Respite isn’t respite when you put someone into care and they come back home twice as bad as they were before – like you have to put them into hospital...”

Workshop participant

For some respondents, this lack of trust stemmed from a perception that support workers were not always adequately trained. As one respondent noted, this creates risk for both the support worker and the person they are caring for.

“The system at the moment leaves paid carers vulnerable. They are being put in places they don’t have the training to be in.”

Workshop participant

“Improved respite care is a huge priority. Part of the issue is the workforce. There is no one trained to provide care. It’s all well and good to have kind people who are available, but this is a skilled, highly complex role.”

Workshop participant

Workforce is an issue for ensuring good respite care. A good substitute for the carer is needed, but the skills and capacity of the workforce often does not provide this. No one is responsible in government to lead workforce in the support sector. It is a growing need.

Workshop feedback

Some respondents had suggestions for how respite care could be better regulated to help improve quality and build trust. For example, one respondent suggested having a national database of professional carers, while another suggested developing a respite quality and outcomes framework for providers.

Several respondents highlighted the importance of ensuring that respite care was culturally safe and appropriate. This needed to occur at both the practical level of how care is carried out, as well as the conceptual level of how we talk about and frame our understanding of respite care.

“Our family members are often unwilling to go into respite. They don’t want to leave their homes. They want someone to come in who they can trust and who understands the way Pacific people do things.”

Talanoa participant

“We are aware that some of the words and acronyms used with the disability support system currently are jargon for most people. Māori whānau also experience these kupu and are somewhat alien to their own reality, ie terms such as Individualised Funding ‘I Choose’, which reflect an individualistic approach to carer support rather than being relevant for whānau. We encourage the creative use of language that is co-designed with whānau and that is translated into Te Reo as well as Pacific languages.”

Submission





Supporting

Supporting is Mahi Aroha's third focus area. It focuses on the supports the Government offers to carers, including financial support and carer wellbeing.

These were issues that received high levels of feedback in consultation. As shown in Appendices 1 and 2, reviewing the policy settings for financial support was rated as the second highest priority for workshop participants, and received a high level of support in the survey.

In addition to financial support, respondents talked about the importance of social connections, their place in the community, and for some, their spirituality. For example, spirituality, religion and prayer played an important role in the wellness of some Pacific family carers, helping them to cope with the challenges of their role. Other respondents noted the importance of holistic support, self-care strategies and the need to consider the 'whole person'.

"Self-care and wellbeing... that's what you need to be teaching. You need to teach carers how to do this and make sure they are addressing it."

Workshop participant

"One important aspect is 'Care for the Carers'. If not, there will be two people needing care and two more carers needed."

Submission

A recurring theme in the feedback was that carers were often so focused on the person they were caring for they neglected to look after themselves. Carers talked about experiences of stress, trauma and burn-out, with one respondent noting that carers don't have a wellbeing framework that sets out what it means to be well.

"Carers can be dangerously selfless. Their love is for the person they care for. Often they forget themselves."

Talanoa participant

"The body can live with a certain amount of stress, but I don't think people, even carers themselves, realise how much they live with. It's so far beyond 'normal' stress. You can only do that for so long before you just burn out."

Workshop participant

"Carers have complex psychological needs. There is real trauma here. Some people are clearly struggling with PTSD [Post-traumatic stress disorder]. And it's not being addressed."

Workshop participant

Respondents also mentioned wider factors that affected the support they needed. These included changes in family dynamics (for example, smaller households and increased female participation in the workforce), as well as the impacts of an ageing population.

Nowadays whānau are dispersed and not many left to share care or are older and need care themselves. Used to be that [there were] more whānau around and [they were] tighter in looking after each other. Not now.

Hui feedback

Action 11

Helping carers to access relevant information about the care role through improved language, formats and accessible tools.

Feedback on Action 11 highlighted the importance of information being provided in a range of formats, including online, print and radio, and in different languages. For some respondents, this made a big difference in how they accessed and engaged with the content.

“Languages are so important. How can you identify with information, and the subject of it, when you don’t understand it? When it’s not targeted at you?”

Talanoa participant

Ensure access to information is available for all populations, including through tools and languages. There is currently a lack of information for these groups.

Workshop feedback

“Electronic information will work for some, but hard copy information is essential for many people. There are also limits to people’s ability to access and operate online tools. Numerous care partners simply do not have the time or energy to engage with online planning tools.”

Submission

Respondents also highlighted the importance of local resources, networking and interpersonal connections.

“Which would you rather have – a document with correct ‘language, format and accessible tools’ or a human being who has the knowledge and the language to help you through? We need PEOPLE to help people, above and beyond the written framework.”

Survey respondent

“Networking is a crucial area because you often learn more from other carers than you do from the ‘professionals’. The trouble is people are so busy caregiving that they don’t have time to go to meetings.”

Survey respondent

Others commented on the need to have relevant training, tailored to different needs and levels of caring experience.

“Make training relevant, don’t pull together a carers 101 for dummies training. By the time people are requiring supports the majority will have been caring in their sleep they have been doing it so long.”

Survey respondent

“I need help desperately to train me to cope with my [husband with dementia]. I have no idea how to live with him anymore and even though a support worker comes 5 hours a week – how am I supposed to interact with him the rest of the time!”

Survey respondent

Respondents also emphasised the need to recognise the financial and time constraints that carers have. Some respondents questioned if training was necessary given their experience, as well as where they would find the free time/money for a professional carer while they trained. One respondent stated that “carers do not have the time or energy to look and read information that may be available”, while others suggested that training should be free to encourage carers to attend.

“I can’t get any time off from caring, how would I attend training? And even when I had ‘qualified’ carers coming to care for my young adult, I still had to train them. I am even less able to attend outside ‘work’.”

Survey respondent

“We need to stop focusing so much on formal qualifications for carers. I think QBE is more important – Qualified By Experience. That’s more important. You can’t teach things like empathy in a classroom.”

Workshop participant

Some respondents had suggestions for the kind of content they would like to see in a training programme. A few respondents mentioned it would be beneficial to have training for those looking after someone with a disability, while others suggested first aid training and workshops on end-of-life care. Some feedback also indicated that if formal training was to be provided, it should focus on developing practical skills, rather than grading and assignments. As one survey respondent put it:

“Avoid at all costs any requirement for carers to be qualified. Most family carers intrinsically know from experience how to care for their loved one. Any training should focus on expanding their knowledge not trying to ‘quantify’ their ability with a grading.”

Survey respondent

Action 12

Update *A Guide for Carers* to ensure it is relevant for the different carer groups.

Action 12 received relatively little response, however, respondents did have some suggestions for how the Guide could be improved. A few respondents noted that there needed to be more of a focus on local resources, with one commenting that the Guide “assumes national consistency, but that that was not what you got”. Others highlighted that the guide could be more user friendly, as well as culturally safe and appropriate:

“For the resource for carers, this needs to include the voice of carers and include tips and tricks. I find some resources are too wordy and perhaps might be better developed as brochures that apply to different population groups with fewer words. From carers that I talk with, they speak of being overwhelmed when too much written information is provided as they are often trying to assimilate large amounts of information in a short amount of time.”

Survey respondent

Carers Guide is useful, but migrants have different concepts of support and how to access it and interact with government agencies. They need to rely on a person to help them understand and navigate supports available. This is both a language issue and how the information is presented.

Workshop feedback

Respondents also highlighted that just as important as updating the Guide was ensuring that it was well publicised. For example, one respondent suggested the Guide should be handed out by GPs at the beginning of the carer moving into their new role.

Some respondents also noted that they would rather have information provided face-to-face, such as through having a carers’ centre or through networking with other carers.

Action 13

Development of pathways to support young carers and their family and whānau to access the support they need.

As with Action 5, feedback on this action was limited by the fact that few young carers took part in the consultation process. However, there was feedback from the wider public that showed strong support for this action. Respondents acknowledged the impact that caring could have on young people and wanted to ensure that they were supported.

“I started doing this when I was in my 30s. It hit me like a tonne of bricks. I got clinical depression. To think there are 16-year olds, that there are 14-year olds who are barely legal to earn 10 dollars an hour as a babysitter doing this... That got me. We have to support them.”

Workshop participant

“Young carers have that brain plasticity. Life hasn’t beaten them down yet. They can still be something, go somewhere. We have to make sure they can do that.”

Workshop participant

“Surely young people are entitled to have opportunities and a career?”

Survey respondent

Some feedback was critical of the fact that financial support for carers did not extend to younger family members such as siblings.

“My daughter can’t get respite payments because she lives in the same house and is a sibling. She knows her brother best, she’s the only other person who can care for him. Even when we left someone else in charge, so we could have a break, she still had to be there.”

Workshop participant

“Many parents complain that the siblings, at teenage age, aren’t allowed to be paid to care for their sibling. This seems ludicrous to me as the sibling is far more likely to give the client the best care and knows the client than anyone outside the family. I think this rule could change.”

Survey respondent

“Pay siblings who are best carers and do above and beyond.”

Survey respondent

Action 14

Develop and implement initiatives to preserve and grow social networks, supports and connections for older carers and carers of older people.

Social connection was a common theme in the feedback received. It was noted that carers of all ages and at all stages of life can become socially isolated as the result of the time and intensity of commitment involved in a caring role.

“I get the groceries on Wednesday morning, I do a tai chi class Thursday morning. That's it. The rest of the time, I'm hovering. He's falling over all the time. I'm absolutely isolated.”

Workshop participant

“Networks that do not leave you feeling alone and isolated... one of the hardest things to come to grips with on this dementia journey is loneliness and isolation.”

Survey respondent

One workshop participant highlighted that social isolation could be made worse by the attitude and behaviours of other people, who may feel awkward and/or do not know how to behave around the person being cared for (particularly where there is communication and/or behaviour issues). Friends could end up becoming distant to the carer and/or the person being cared for, as the stigma associated with the care recipient was shared and experienced by the carer.

“You lose all your friends. People who have been good friends aren't so keen to come and visit anymore. They don't know how to deal with our situation.”

Workshop participant

Carers talked about the high value they placed on having connections with other carers, both virtually on social media (for example, Facebook) and physically (for example, meeting up regularly). Respondents highlighted that it was important that sources of regular connection were promoted and supported.

“Parent2parent meets once a month for coffee. It's great. It's a break, it's support.”

Workshop participant

“Why does there need to be something wrong with a person being cared for before someone will come and visit? They need regular check-ins and visits, even just for a cup of tea, a chat, someone painting their nails. The difference that makes is huge.”

Talanoa participant

“I would love a group chat, with a coffee and some kai, once a month. That would bring me so much joy.”

Talanoa participant

“Local, exceptional carers are mobilising, engaging and supporting each other. How do you support them?”

Workshop participant

For some carers, transport was a barrier to maintaining social connectedness. In regional and rural areas, access to public transport or any cost-effective alternative transport could be a barrier for older carers who could no longer drive. Another commented on the challenges of visiting others when living in an isolated area:

“We have the lowest population density and such a large area. If we can't go somewhere and meet others, we are so isolated. We have a strong bond, but physically, it's so hard.”

Workshop participant

Some carers also suggested there should be more peer support training, where relationships are facilitated with someone who has a shared lived experience of caring and can offer practical support.

Action 15

Responding to the Mental Health and Addiction Inquiry recommendations for families and whānau carers of people requiring mental health and addiction support.

Feedback on this action reiterated the importance of recognising and supporting the carers of people with mental health and addiction needs. One respondent said they felt like the family carers of those with mental health issues were not heard in the Government Inquiry into Mental Health and Addiction, as there seemed to be a focus on the professional workforce. Others highlighted that the Inquiry needed to recognise a broader range of conditions, such as FASD.

Some respondents stated the difficulties they had experienced with accessing support. One respondent noted they were encouraged to reach out, however, when they did so, there was no support available. Inadequate support for the person being cared for had consequences for carers, as it meant the need to provide support was passed on to them. For example, one workshop participant shared that when they could not access support living in a rural area, they ended up doing a lot of intensive, 24-hour, one-on-one care – something that would not occur in a hospital because the load would be spread between different people in shifts. Similarly, a survey respondent stated:

“Currently there is very little recognition of those supporting a loved one with mental health issues. We are left with the full burden when they are not unwell enough to be hospitalised.”

Survey respondent

Others highlighted the need for the response to the Government Inquiry into Mental Health and Addiction to be culturally inclusive. For example, it was suggested that Māori healers could help to address mental health from a Māori worldview.

Action 16

Funded Family Care policy change.

Respondents mentioned they would like to see more detail around the changes being proposed for Funded Family Care. Some were unsure of how Funded Family Care would affect other employment opportunities. Others currently receiving Funded Family Care worried about how the changes would impact the support they get.

“Funded Family Care policies need changing – but what to? The question wasn’t specific.”

Survey respondent

“Clarify how/what the funded family care [changes] recently announced will look like, the eligibility criteria, work possibilities whilst receiving funding.”

Survey respondent

“Changes to this policy are welcomed, with the provisos that it should include very clear guidelines on who is eligible, monitoring of the quality of care, provision for respite and split care between family and funded care.”

Submission

Some respondents also highlighted the limitations of using the 40-hour work week as a framework, as the nature of the care role often demanded more than that.

“Recently announced changes to FFC are a major step in the right direction but the question of how much payment in total is worked out is still a major problem. Thinking outside the square is needed so we don’t have a stopwatch on specific tasks. This is a big part of the insulting and demeaning system people objected to so strongly. Going outside the purchasing framework into a system that makes a payment to the carer in recognition of the total commitment they make without linking this to outputs. It could also be set to include respite support funds.”

Survey respondent

“40 hours is not enough for 24/7 carers.”

Workshop participant

Action 17

Review policy settings for financial supports for carers.

Financial supports was a major area of concern for respondents. Many respondents felt that current levels of financial supports were inadequate and needed to be increased. Some expressed feeling like they were financially penalised by taking on a caring role, particularly as it often meant they needed to withdraw from other sources of paid work. Financial pressures were further compounded by the multitude of medications and appointments, the need to travel for regular appointments, and the need to purchase specialised equipment. For some respondents, their financial position contributed to feelings of shame and stress.

“We shouldn’t be driving people into despair and poverty because they love their family.”

Workshop participant

“We need to be paid more. If we don’t do it someone else has to.”

Survey respondent

“Oh, how I would love to have some financial relief to cope with my caring love and ongoing grief.”

Survey respondent

Respondents also highlighted that equity of access to funding was an issue. Respondents mentioned there were inconsistencies in the funding provided by different agencies, across regions and between different disabilities/conditions. Some respondents also criticised aspects of the eligibility criteria for support.

“Income testing is wrong. I was separated from my husband, so was caring as a single adult. I got \$300 per week. Then my husband came back, and I get nothing. Because his income counts against me.”

Talanoa participant

“Carers Benefit is currently not paid to the spouse or partner even though it is the same essential service paid to a non-relative. This needs to change!”

Submission

For those receiving financial assistance, there was a common sentiment that caring was a job and should be treated as such, with a fair wage and the same rights as other employees. Some felt there was a stigma around being on a benefit and that financial support should recognise caring as work.

“Why can’t we be paid as if this is a job, rather than being paid with a benefit? It’s a 24/7 job.”

Talanoa participant

Some respondents expressed support for individualised funding, noting that it would empower carers to seek out and invest in what they felt was best for them. Others had alternative suggestions for how financial supports could be improved, with ideas such as a tax rebate or support during the grieving period.

“Financial empowerment. Having choice and flexibility, rather than rigid rules and silos”.

Workshop participant

“Flexible carer funding depending on geographic location – ie, it is more expensive to live in Auckland.”

Survey respondent

Action 18

Consider a carer payment to support carer wellbeing.

Respondents generally supported the idea of a carer payment, noting that it acknowledged that their wellbeing was also important.

“The action step of a ‘Carer supplement’ is incredibly thoughtful! It would be wonderful to know that some money could be used specifically for my very own well-being, not only the wellbeing of my son.”

Submission

“Having a carer wellbeing payment would be lovely. That’s the type of stuff you give up. I just want to go for a walk on the beach. I wake up in the morning, and I take a deep breath, and think, I have to keep doing this for 30 years.”

Workshop participant

“Our family is really struggling because the care of our son takes so much time that I’m limited in how many hours I can work. Have a decent carer payment for myself would make a huge difference in our family life.”

Survey respondent

“Carers to receive payment for their wellbeing eg counselling or breaks away. All support seems targeted to the individual with needs, but no support to the family who bears the brunt of supporting these individuals. The effect on family is huge, emotionally, financially and physically.”

Survey respondent

Respondents noted that a carer payment could help in a range of ways, highlighting that it could be used for counselling and mental wellbeing, household tasks and respite/breaks away. As one respondent expressed:

“When I lived in Australia I received a carers allowance - not means tested and I could spend as best as I thought fit which enabled me to afford frozen meals, go away for short breaks, and hire a gardener. I am really financially struggling in NZ.”

Survey respondent

Some respondents noted there might be issues with how a carer payment was distributed within the family. For example, one respondent predicted that carers would simply end up spending the money on their care recipient. Another questioned how a carer payment would work in a household with multiple people providing care:

“There are fishhooks. What happens when more than one person provides care? I can see people getting really unhappy and it being a source of further tension in a house if there are some family members who are helping with care but not seeing any money. How do you decide how to divide money up fairly? And once it has been divided up, how much will individual people actually end up getting?”

Workshop participant

Another theme was the importance of flexibility and choice in how a carer payment was paid, with respondents noting this could be annually or in smaller, regular amounts.





Balancing

As the final focus area in *Mahi Aroha*, balancing focuses on supporting carers who want to balance paid work, study and other opportunities with caring.

Many carers welcomed the idea of improved support in this area and talked about barriers they faced in study or work. Feedback also noted that balancing should be understood in a broader context as other actions in the plan (such as respite and financial support) were crucial to being able to balance study and work. Carers needed time, energy and money to be able to work or study.

“These focus areas will only work if the carer can have the luxury of free time to study, or seek employment, if currently a full-time unpaid carer.”

Survey respondent

“Further training and employment is a nice idea, but who cares for the family member while the caregiver studies or works outside the home? Paying strangers to be caregivers is more expensive than paying family members. And currently, very few family members get paid for caregiving.”

Survey respondent

Action 19

Launch the Carers New Zealand CareWise initiative, including work to expand promotion of flexible working arrangements.

Respondents generally expressed support for this action. They highlighted that flexible, carer-friendly workplace policies could assist in two key ways: in helping them to return to work, and in making work itself more manageable.

Respondents noted that support for entering the workforce was needed both when they were in their caring role, as well as when their caring duties finished. Some respondents talked about the difficulties of transitioning back into the workforce after long periods of caring full-time.

“We need our employers to be more aware. To be more lenient and let us work from home, have flexible hours. They need to allow the person caring to keep working while they care. Once the person being cared for has passed away, the carers' employability has reduced. It's so hard for them to start again and re-enter the workforce.”

Talanoa participant

“You have your baby, you go from working to nothing. It's 22 years down the track before I can think about working again.”

Workshop participant

“I have been unable to resume work as a qualified psychologist due to caring for disabled children. Education supports and flexible respite funding would help me return to the workforce.”

Survey respondent

“Is there an agency to get carers and ex-carers into work?”

Survey respondent

Respondents also noted the importance of support from employers and awareness within the workplace. Some respondents talked about the challenges they faced in working while they were carers, such as needing to take extra time off or leave work unexpectedly. To accommodate this, several respondents suggested that having some form of additional paid leave would be helpful.

“I’m in the middle of the week, I’ve got two jobs on the go, and I get called about my kid. If I say to my boss, ‘I have to go – I might be back, I might not’... that doesn’t go down well. And if I’m doing it two, maybe three times a week...”

Workshop participant

“You have paid parental leave, maybe there could be paid parental care leave. Maybe that could happen around diagnosis time especially. Leave is particularly an issue for women. Women work now, they can’t just stay at home”.

Workshop participant

“What about a government subsidy that would go to an employer, so when you do have to be away, you have some coverage. I can’t do my job properly now, I’m split into so many bits.”

Workshop participant

“Sick leave needs to be addressed for caregivers who have school age children who become ill. I have used all my leave (9 days) on my son. Nothing left for myself! Mental health leave would also be helpful in order to recharge.”

Survey respondent

Others expressed gratitude for the flexibility they had received from their employer, noting the difference it made in balancing care and work responsibilities.

“For the government to promote flexible working hours, that would be great. It would help more of us to get back into the workforce. I can do one day a week and my employer is really supportive and flexible. But I know not everyone is like that.”

Workshop participant

“I work full time and couldn’t do this if my employer wasn’t sympathetic and gave me options like flexible work.”

Survey respondent

Other respondents highlighted that employment was unrealistic for them unless adequate support was available.

“You can only balance employment and/or study with caring, if you get regular respite breaks. There needs to be a balance between balancing employment and/or study with caring AND with respite. ‘Balancing’ caring with employment is already a double-job life. That is not sustainable for health and wellbeing, without adequate respite.”

Survey respondent

“Caring responsibilities are so comprehensive, and help has not kept pace with need. What this means is that employment is an unrealistic fantasy unless I can take my loved one with me. Despite a wide range of workplace qualifications and experience, unless an alternative caring service is made available, work can never realistically be incorporated into any day (or night). This is my reality.”

Survey respondent



Action 20

Developing carer skills and learning through formal training programmes that credit care experience, and to support further training or employment.

Positive feedback on this action highlighted the benefits of further education and learning new skills. Some respondents mentioned there were skills they wanted to develop, but they had not been able to due to the commitment of caring.

“You want to do things that aren't necessarily in your skill set, you want to branch out from what you've done before. The thought of 25 weeks of part time study... it would take six years.”

Workshop participant

“We need to go on courses, learn skills and upskill. I need to update my computer training.”

Talanoa participant

Respondents noted there needed to be support systems, such as respite, in place for carers before they could pursue their study interests. Some noted that courses could be too regimented for the typical carer, who needed more flexibility than other learners.

“Having somewhere to take the person being cared for while the carer has work or study. Day care for the people who can't be left at home alone.”

Survey respondent

“Having a list of people willing to care for your child while I studied would be excellent.”

Survey respondent

Respondents were generally supportive of having their caring experience recognised through a qualification, although not all wanted to work in the health sector and wanted support to transfer their skills. One talanoa participant shared that after three years caring and being out of work, prospective employers did not value or recognise the skills from, and time spent, caring. This made it harder to recover from their loss and transition out of carer role. Other survey respondents stated:

“Free training, and with small credits too. Carers families have more skills that are not recognised as a qualification.”

Survey respondent

“Provide qualifications to carers so it becomes a worthy occupation.”

Survey respondent

Feedback also highlighted that we were not clear enough in the intent of this action, which is focused on supporting carers to pursue interests ie study and training outside their care role. Many respondents interpreted this action as being about training to support carers to do their care role, which is covered in Action 11. To clarify this, we included feedback about carer training under Action 11.





General themes

There were some themes that did not relate to a specific action or cut across the action plan as a whole. These are discussed in the section below.

Family violence and safety

An issue that emerged during consultation was that of family violence and safety. Some respondents were managing very complex care situations and reported sometimes feeling afraid in the presence of the person they were caring for.

“I’ve had times where I’ve had to lock myself out of the house. Because I just need to have space. I’m scared of what will happen to me, and to him if we’re in the same house at these times.”

Workshop participant

“I am scared for the future. My son is a teenager now, but what happens when he becomes a fully-grown man? He’ll still have the mental age of a child, and need care, but his physical strength... That scares me.”

Workshop participant

Respondents also expressed feeling like there was nowhere to go for help or sufficient support for complex family contexts.

“My son is 15 and he hits me regularly. He’s very aggressive. If I was a wife and my husband was hitting me, there would be support.”

Workshop participant

“It’s so demeaning being hit by your own child. The shame. And you can’t do anything about it. You’re their parent, your job is to protect them. You can’t report them. But even when you get to absolute breaking point and you have to call someone before you do something, or something happens to you, no one can help. There’s no ability, no capacity, nobody.”

Workshop participant

“I’ve had to pull the car over on the motorway and just get out for a time out. You love your child, so much, and they’re good kids, but it’s just... you really can’t understand what it means to live with this. And there’s no support. To even talk about it is just taboo.”

Workshop participant

There was a sense of invisibility about the violence that carers experienced, with a perceived lack of avenues for it to be identified and addressed. Respondents highlighted the importance of carers’ health and safety being asked about and considered, along with the person being cared for.

“Violence against carers is a truly invisible crime.”

Workshop participant

“Violence is a problem. Often, it’s violence from a care recipient towards their carer. It’s not recognised. It could be picked up during a care assessment, but that (assessment) would need a lot more behind it. For instance, it doesn’t assess the carers’ dental state, obesity, violence, psychiatric condition of the carer... These things could all be identified and flagged, but there’s no money to actually address them.”

Workshop participant

Retirement income

Another recurring theme that emerged in the feedback was the loss of retirement income. By leaving their job to care for someone, carers were no longer contributing to savings for their retirement, such as in KiwiSaver, creating insecurity about what would happen when they reached older age.

“I haven’t been able to work while I’ve been caring. I don’t have any income, any KiwiSaver. I think there should be a KiwiSaver payment for younger carers who can’t work.”

Workshop participant

“I don’t have any KiwiSaver. I had to leave my job to care for my husband. I have no savings. What happens when we get to retirement age?”

Hui participant

“Everything I have saved for my retirement has gone. Every day I am just going deeper into the mire, and it worries me sick, and I think about my future with fear and dread.”

Submission

Diversity of carers’ needs

Several respondents emphasised that carers’ needs were diverse, and it was important to avoid a ‘one size fits all’ approach. Carer experiences differ due to a range of factors, including culture and ethnicity, their location and the disability or condition that they were caring for. For example, one submitter highlighted that caring for someone with Multiple Sclerosis presented particular challenges because the age of diagnosis is usually within people’s most productive working years. Others noted that caring for a person with a chronic condition had different challenges from caring for a person

with a long-term impairment, and that caring for someone with a learning disability was different from caring for someone with a physical disability. Carers could also be supporting family members with co-occurring conditions or caring for more than one person at a time. Respondents indicated that it was important to take the diversity of carer needs into consideration when developing and implementing the action plan.

“Flexibility, and understanding that everybody is different, even within their different cultures, and what works for one, may not work for another. The strategies themselves therefore need to be adaptable too.”

Survey respondent

“Every person is different, and the needs are therefore never the same. Listen.”

Survey respondent

“The whole system needs to be tailored more to recognising that everyone in care is different, and they have diverse needs.”

Workshop participant

The design of the action plan

Some respondents had suggestions for how the actions could be re-ordered. For example, two respondents felt that ‘Supporting’ should go first, as they felt that this was the highest priority.

“Good stuff here. As focus priorities go [navigation] should be second after ‘Supporting’. The actions are good ones. The list could be re-ordered better. 7, 10, 8, 9, 6.”

Survey respondent

Other respondents commented that there was overlap between some of the actions and suggested they be merged. For example, one workshop participant noted that Action 13 and 14 could be combined, as although they targeted different demographic groups, they were both about supporting carers in opportunities and connections outside of caring.

Not unexpectedly, carers said they wanted to see what was discussed in the plan result in tangible outcomes. Some respondents highlighted the urgency of the plan and stressed the importance of actions being implemented.

“Keep investments in carers practical. Listen to what they want. Fund what makes a difference day to day.”

Survey respondent

“Please do something soon.”

Survey respondent

“I would actually action these ideas - not just talk about it”.

Talanoa participant

Keeping carers involved

Some respondents said they would like to continue to be involved and updated on the progress of the action plan. They emphasised the importance of active communication, including around how changes would be implemented.

“Please check in with carers on a regular basis. We learn much of what help is available by chance often following major struggles.”

Survey respondent

“Ask carers what they need. Listen and act.”

Survey respondent

“Keep in touch to let us know how this is going!”

Survey respondent



How did we use the feedback we received?

We expanded Actions 3 and 17 to address emerging issues

Following feedback from some carers on family violence and abuse, we have expanded Action 3 – Better understand the needs of carers by creating a carer research fund – to include a plan to undertake some preliminary research into the incidence and impact of family violence towards carers. We intend that this research will be used to advance further action in this area.

Another issue identified in consultation was the lack of financial security for carers as they move into retirement. This is something that will now be taken into consideration as part of Action 17 – Review policy settings for financial support for carers.

We refined Actions 1, 9 and 14 to give them a more specific purpose

After listening to what carers told us, we have changed Actions 1, 9 and 14 so they are tied to more specific, measurable outcomes.

For Action 1, consultation feedback helped to provide us with a clearer understanding of what recognition means for carers and, therefore, what we want to achieve (for carers to be recognised as a distinct group with specific needs and whose contribution is valued). These outcomes are now directly mentioned in Action 1.

For similar reasons, we also changed Action 14. The new wording in the action plan clarifies what we aim to achieve – for carers to be able to participate in social networks, have opportunities to keep up relationships and to enjoy interests outside of their caring role.

In response to feedback from talanoa, we refined Action 9 to include aiga-centred tools and initiatives.

We changed Action 2 to better reflect the views of respondents

In response to feedback that questioned the value of a National Carers' Day, we will begin this action by exploring the best ways to raise awareness of carers, how they can be supported and ensure they know the supports and services they are eligible for.

We merged Actions 7, 8, 11 and 12 to make the Action Plan clearer

Overlap between some of the actions was identified during the consultation process, particularly between Actions 7 and 8. Feedback highlighted, for example, that strengthened navigation around the system (Action 7) is greatly facilitated by proactive and transparent engagement from agencies (Action 8).

We also found that Actions 11 and 12 were more closely aligned with the navigating area, as being able to access relevant information in a suitable format was identified as being key to successfully navigating the system.

To address these issues, we have refined and merged Actions 7, 8, 11 and 12 in the final action plan (now action 2.2). This will allow us to have a more joined-up, integrated view of what strengthened navigation looks like and how carers are supported to access assistance for themselves and those they care for.



Appendix 1: Workshop rankings of support for Actions

This table shows the results of the group exercise used at the workshops during the July and August 2019 consultation. Groups of participants were asked to rank their ‘top five’ or highest priority actions. The results were totalled to form the table below.

Rank	Action and focus area	Number of groups selecting the action as a priority
1	Improve the quality, accessibility and equity of access to services across New Zealand to enable carers to take a break (including the Flexible Disability Respite Budgets – I Choose) Navigating	28
2	Review policy settings for financial supports for carers Supporting	24
3	Strengthen navigation across all parts of the care and support system (including health, welfare and ACC) to ensure carers receive available assistance Navigating	22
4	Consider a payment to support carer wellbeing Supporting	19
5	Exploring mechanisms including legislation to better recognise carers and their particular needs Recognising	14
6	Improving engagement between people needing care, their carers, and supporting agencies Navigating	13
7	Policy change to Funded Family Care Supporting	11

Rank	Action and focus area	Number of groups selecting the action as a priority
8	Develop and implement initiatives to preserve and grow social networks, supports and connections for older carers and carers of older people Supporting	11
9	Responding to the Mental Health and Addiction Inquiry recommendations for families and whānau carers of people requiring mental health and addictions support Supporting	9
10	Launch the Carers NZ Carewise initiative, including work to expand promotion of flexible working arrangements Balancing	8
11	Developing carer skills and learning through enabling access to formal training programmes that credit care experience and lead to further training or employment opportunities Balancing	6
12	Improve information about carers through modifying existing data collection tools Recognising	5
13	Development of pathways to support young carers and their family and whānau to access the support they need Supporting	5
14	Helping carers to access relevant information about the care role through improved language, formats and accessible tools Supporting	5
15	Better understand the needs of carers, particularly young, older, Māori, and Pacific carers, as well as other hidden carers by creating a carer research fund Recognising	5

Rank	Action and focus area	Number of groups selecting the action as a priority
16	Develop a national campaign to raise awareness of carers, including a National Carers’ Day Recognising	4
17	Identifying whānau-centred tools and initiatives that provide culturally responsive approaches for Māori carers and their whānau Navigating	4
18	Update the resource A Guide for Carers to ensure it is relevant for the different carer groups Supporting	4
19	Working with carers, people receiving care and relevant sectors and agencies to explore the benefit of a national approach to managing continence Navigating	3
20	Better support to include the voices of young carers in policy development, including through re-establishing a Young Carer Advisory Board Recognising	2

Appendix 2:

Survey rankings of support for Actions

This table show the results of the online survey, which asked respondents to indicate the extent to which the actions represented what mattered to them.

Action	Survey percentage by response category					
	Yes definitely	Yes somewhat	Not sure or not applicable	Not really	Not at all	(blank)
1. Explore ways to better recognise carers and their particular needs, such as legislation	63.7%	25.2%	4.8%	4.1%	1.2%	1.0%
2. Develop a national campaign to raise awareness of carers, including a National Carers’ Day	42.1%	29.4%	8.6%	14.6%	4.1%	1.2%
3. Better understand the needs of carers, particularly young, older, Māori, and Pacific carers, as well as other hidden carers by creating a carer research fund	46.9%	29.4%	10.6%	8.8%	2.8%	1.5%
4. Improve information about carers by modifying existing data collection tools	44.3%	32.8%	11.8%	7.8%	1.2%	2.2%
5. Better include the voices of young carers (25 years and under) in policy development through a re-established Young Carers Advisory Board	35.5%	29.7%	20.6%	9.6%	2.7%	2.0%
6. Work with carers, people receiving care, and relevant sectors and agencies to explore the benefit of a national approach to managing continence	43.2%	31.4%	12.8%	5.5%	2.5%	4.6%

Action	Survey percentage by response category					
	Yes definitely	Yes somewhat	Not sure or not applicable	Not really	Not at all	(blank)
7. Strengthen navigation across all parts of the care and support system (including health, welfare and ACC) to ensure carers receive available assistance	77.6%	14.4%	1.6%	1.6%	0.9%	3.9%
8. Improve engagement between people needing care, their carers, and supporting agencies eg resources for teachers, health workers and case managers	70.3%	21.3%	1.6%	2.5%	0.5%	3.7%
9. Identify whānau-centred tools and initiatives that provide culturally responsive approaches for Māori carers and their whānau	41.0%	22.6%	21.5%	6.0%	4.1%	4.8%
10. Improve the quality, accessibility and equity of access to services across New Zealand to enable carers to take a break (including the flexible disability respite budgets – I Choose)	78.9%	12.3%	2.1%	1.8%	0.5%	4.4%
11. Help carers to access relevant information about the care role through improved language, formats, and accessible tools	48.0%	33.7%	6.0%	4.6%	1.2%	6.4%
12. Update A Guide for Carers to ensure it is relevant for the different carer groups	52.8%	27.9%	5.9%	5.9%	1.1%	6.6%
13. Develop pathways to support young carers and their family and whānau to access the support they need	52.4%	25.2%	9.2%	5.2%	0.7%	7.3%

Survey percentage by response category

Action	Yes definitely	Yes somewhat	Not sure or not applicable	Not really	Not at all	(blank)
14. Develop and implement initiatives to preserve and grow social networks, support, and connections for older carers and carers of older people	60.0%	22.6%	7.1%	3.2%	0.7%	6.4%
15. Respond to the Mental Health and Addiction Inquiry recommendations for families and whānau carers of people requiring mental health and addiction support	55.2%	19.0%	13.1%	4.6%	1.4%	6.6%
16. Change Funded Family Care policies	59.5%	15.5%	16.7%	1.1%	0.2%	7.1%
17. Review policy settings for financial support for carers	74.1%	14.2%	4.3%	0.5%	0.2%	6.7%
18. Consider a carer payment to support carer wellbeing	74.2%	14.0%	3.6%	0.9%	0.7%	6.6%
19. Launch the Carers New Zealand CareWise initiative, including work to expand promotion of flexible working arrangements	46.9%	26.3%	13.7%	2.5%	2.3%	8.3%
20. Develop carer skills and learning through formal training programmes that credit care experience, and support further training or employment opportunities	48.1%	26.6%	10.8%	4.6%	2.0%	7.8%

Acknowledgements

We want to thank all the submitters, survey respondents, workshop, talanoa and hui attendees who provided input on the discussion document and proposed Carers’ Strategy Action Plan 2019-2023.

Disclaimer

The views and opinions expressed in this report are made by submitters, survey respondents and attendees at workshops, hui and talanoa held by the Ministry of Social Development. While the Ministry of Social Development has made every effort to ensure that the information in this report is reliable, it takes no responsibility for any errors or omissions in the information contained in this report.

All the photographs used in this publication are of carers. The views expressed and the quotes in this publication are not linked to and should not be ascribed to any particular carer in the photographs.

Publishing details

This work is licensed under the Creative Commons Attribution 3.0 New Zealand licence. In essence, you are free to copy, distribute and adapt the work, as long as you attribute the work to the Crown and abide by the other licence terms.

To view a copy of this licence, visit <http://creativecommons.org/licenses/by/3.0/nz/>. Please note that no departmental or governmental emblem, logo or Coat of Arms may be used in any way which infringes any provision of the Flags, Emblems, and Names Protection Act 1981. Attribution to the Crown should be in written form and not by reproduction of any such emblem, logo or Coat of Arms.

Published December 2019

Ministry of Social Development
PO Box 1556
Wellington 6140
New Zealand

Telephone: +64 4 916 3300
Facsimile: +64 4 918 0099

Email: info@msd.govt.nz
Web: www.msd.govt.nz

ISBN: 978-0-473-50678-0 (print)
ISBN: 978-0-473-50679-7 (online)



New Zealand Government