Carers' Strategy Action Plan Engagement

Summary of feedback relating to the draft Carers' Strategy Action Plan

September 2026

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA

Contents

Introduction

From 17 November 2025 to 12 March 2026, the Ministry of Social Development (MSD) ran a public consultation process, requesting feedback on the draft Carers' Strategy Action Plan (Action Plan) through a variety of forms.

We would like to thank all those people who made the effort to provide their feedback. Whether you completed the survey, sent in a submission, or joined a community workshop, your feedback was vital to this process. We would also like to thank the Carers Advisory Group, who were instrumental in the design and delivery of this consultation. The Carers Advisory Group members are:

Laurie Hilsgen	CEO of Carers NZ and Secretariat of the Carers Alliance
Catherine Hall	CEO, Alzheimers NZ and co-Chair of the Carers Alliance Executive Board
Wayne Naylor	CEO of Hospice New Zealand
Pania Tulia	Advisor to Young Carers NZ, former spokesperson, and Workforce Development Manager for Able Minds
Zandra Vaccarino	National Executive Officer of the New Zealand Down Syndrome Association
Jo Lambert	CEO of Stroke Aotearoa New Zealand
TOA Pacific	
Te Rina Ruru-Pelasio	Co-founder and Trustee of Unseen Heroes and Māori Development Manager at ABI Rehabilitation NZ
Fiona Perry	Community Liaison Co-ordinator at Yellow Brick Road
Lisa Martin	Director of Complex Care Group
Louise Judd	CEO of Continence NZ (acting)
Janine Stewart	General Manager for IHC and Co-Chair of the New Zealand Carers Alliance

Additionally, we give thanks to the following groups and organisations for their help in hosting community workshops or welcoming MSD staff to speak with their memberships:

Asian Network	Carers New Zealand	Complex Care Group
Disability Connect	E Tū Whānau	Family Leadership Alliance
I.Lead	Kaikaranga	National Beneficiary Advocate Consultative Group
National Council of Christian Social Services	Needs Assessment Service Co-ordination Association	NZ Dementia Foundation
New Zealand Down Syndrome Association	Pacific service providers	Pomare Taita Community Trust
Pou Tangata	Stroke Aotearoa New Zealand	Te Ao Marama Aotearoa Trust (TAMA Trust)
Unseen Heroes	Yellow Brick Road	

The contributions received were insightful, wide ranging, and provided significant value to this work. We have read and analysed all the feedback, and this summary presents the key themes and discussion areas from the consultation. While it was not possible to capture every comment, this document outlines a range of perspectives and includes specific examples from written submissions and workshops.

Background

Carers are family, whānau, aiga, and individuals, who provide care for someone close to them who needs additional assistance with their everyday living because of a disability, health condition, illness, or injury.

Almost 500,000 people identified as providing informal or unpaid care in the 2023 Census. However, the number is likely much higher, as many do not recognise themselves as a 'carer' because they view their role as an extension of their responsibilities to whānau, family or friends.

The New Zealand Carers' Strategy (the Carers' Strategy) was launched in 2008 in partnership with the NZ Carers Alliance (Carers Alliance). Its vision is to ensure that: "New Zealand Aotearoa, is a society that values individuals, families, whānau or aiga who support others who need help with their everyday living".

To date, the Carers' Strategy has been implemented through three multi-year Action Plans. These time-limited Action Plans contained actions that the Government would take to address key priorities identified by carers and government agencies. The latest Action Plan, Mahi Aroha Carers' Strategy Action Plan 2019-2023, expired in December 2023.

Since the start of 2025, government agencies, the Carers Alliance and the Carers Advisory Group have been involved in the development of a new Carers' Strategy Action Plan to better respond to ongoing and new challenges for carers. Cabinet approved the draft Action Plan in November 2025, and public consultation on the Action Plan ran from November 2025 to March 2026.

How we consulted

Public consultation on the draft Carers' Strategy Action Plan was designed in collaboration with government agencies, the Carers Alliance and the Carers Advisory Group. Consultation consisted of five distinct channels with the aim to reach as many carers, individuals and families as possible. Multiple, distinct channels for engagement allowed people to provide their feedback in the ways that best suited them and the time they had available.

For the purposes of this report, 'participant' includes any of those who provided feedback through one of the channels below.

Online public workshops

Five public, online sessions were held across the consultation period, and they were advertised on the MSD website and through Carers Alliance partners. These sessions were approximately 90 minutes and covered specific questions about the content of the draft Action Plan.

Community workshops

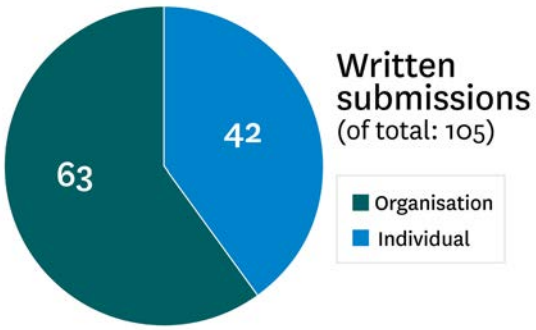
Representatives from the Carers Alliance and other community organisations hosted 16 sessions online and in person, engaging with their diverse memberships to ensure a wide range of carer perspectives were represented. Facilitators were supported with engagement materials and resources from MSD.

Targeted, online engagement workshops

MSD hosted 18 targeted online engagement sessions with organisations and advocates representing different groups of carers and members of the care community. These sessions focused on population groups, such as Māori, rainbow communities, and youth, as well as key interest groups such as researchers and academics, and Pacific service providers.

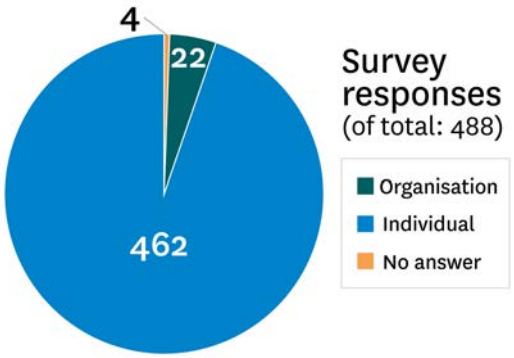
Written submissions

A total of 105 written submissions on the draft Action Plan were received during the consultation period. Forty-two (42) submissions were made by individual carers or community members who did not list an organisation, and the remaining 63 submissions were made on behalf of at least one organisation, network, association or other community group.



Online survey

An online survey was also available throughout the consultation period. The survey featured multi-choice questions about the draft Action Plan and its content. Four hundred eighty-eight (488) responses were received with 95 percent coming from individuals and the remaining 5 percent completing the survey on behalf of an organisation.



General feedback on the consultation process

During our consultation on the draft Action Plan, we received feedback on the consultation process, including how we engaged with people, who we did and did not speak to, and how the consultation was received in the broader context of caring in New Zealand and past consultations.

Some people expressed gratitude for our efforts to reach a broad range of carers and the care community. We saw particular enthusiasm from workshop groups who had not been engaged previously on caring, such as migrant carers and ethnic communities.

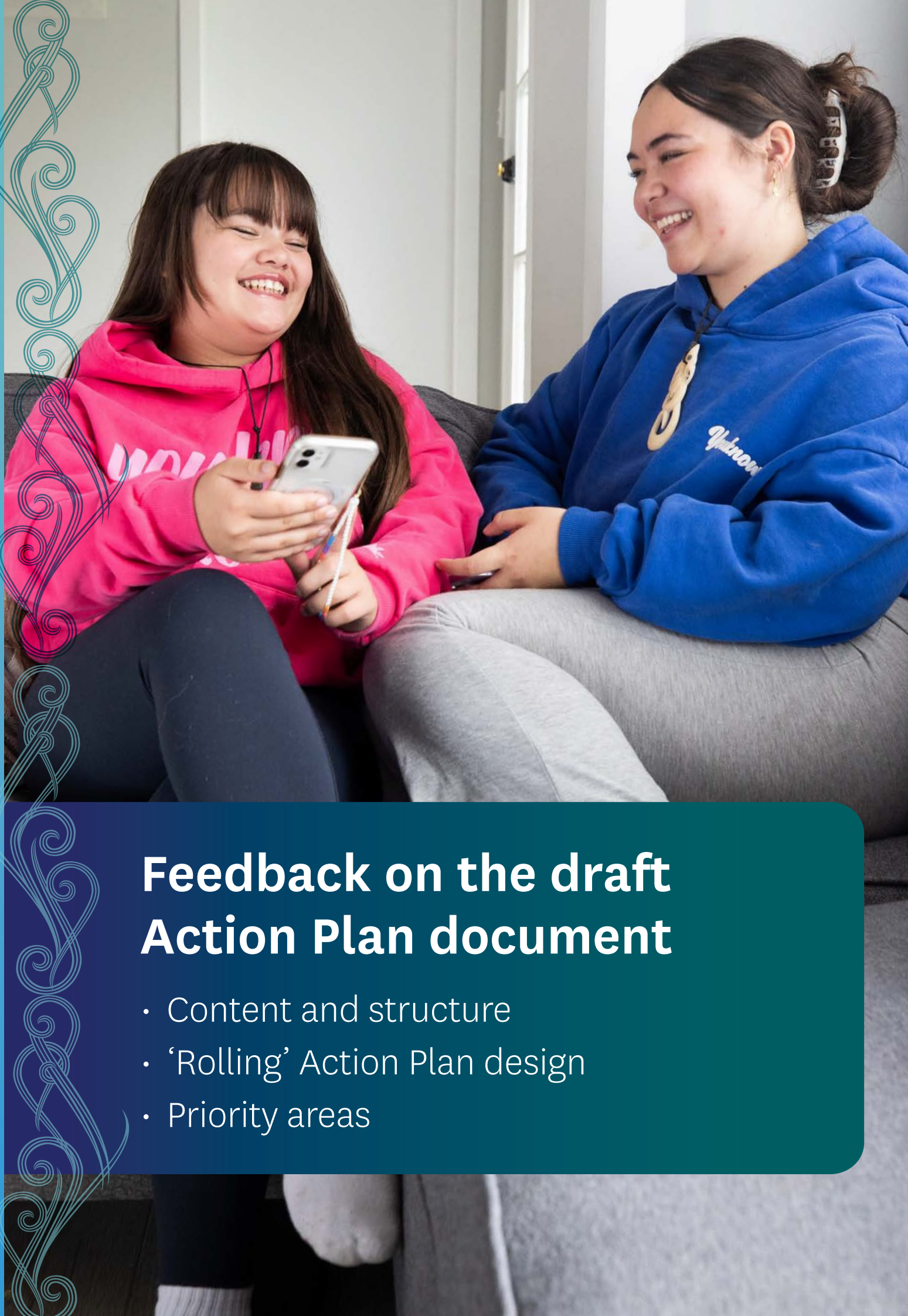
> "When carers, providers and advocacy groups are invited into the kōrero early, the result is more grounded, responsive and durable."
>
> – Written submission

Many people expressed disappointment that important perspectives would be missed during consultation. The primary reason given was that carers are often exhausted and time-poor due to their extensive responsibilities, limiting their ability to engage in workshops or prepare a submission. Groups who do not see themselves in this Action Plan, such as young carers, also may not have been engaged in this process.

In written submissions particularly, participants suggested that the engagement process was not enough. As well as groups being missed, participants suggested a co-design model with the community instead of engagement (also discussed in the governance section of this summary). Others saw the engagement as another lengthy government process, delaying more tangible actions for carers.

> "For 20 years I was so overwhelmed I lived in 30 min blocks just trying to get through days. Please seriously consider any feedback you get and realise that I would guestimate that 95% of those who's opinions matter the most cannot be reached..." – Written submission

Some participants discussed how the engagement was delivered in a wider context. Written submissions often commented on the importance of following Te Tiriti o Waitangi principles as a guide for consultation. Others said carers are facing a difficult climate at this time, mentioning government restructures, other engagements and policy changes that affect carers, and the fatigue many still feel following COVID-19.



Feedback on the draft Action Plan document

- Content and structure
- ‘Rolling’ Action Plan design
- Priority areas

Content and structure

Throughout the consultation, participants commented on the way the draft Action Plan was written and structured. This section captures their feedback in relation to terminology, language, and formatting, including the order of priority areas and immediate deliverables.

Key feedback: content and structure

- Carers are a complex group, and many do not identify with the label 'carer'.
- Some language choices were felt to be complicated, vague or tokenistic.
- Support for priority areas, but these should be ordered by importance.
- The Action Plan should clearly point out next steps and milestones.

Definition of carers

Generally, people liked that the draft Action Plan specifically mentioned unpaid carers, informal carers, and family/whānau carers. However, we heard that 'carer' is not the preferred term for everyone. Many see caring as an innate responsibility—or a shared, reciprocal role—rather than as a singular identity. This is especially true for young people, Māori and Pacific people, and those in other ethnic communities. The term 'carer' can also be associated with employment and not reflect existing family relationships.

> "Caring in our whānau comes from aroha and responsibility for each other. Because those responsibilities don't really end, it makes sense to have support that can continue and change as our needs change too."
>
> – Workshop attendee

To capture such a complex cohort, some people suggested the Action Plan should explicitly mention all the diverse groups it intends to include. Some stated that the definition of care went beyond support and incorporated culturally appropriate concepts like manaakitanga, whanaungatanga, aroha, and hauora.

General comments on content

Those who supported the content of the Action Plan said that the actions felt like appropriate first steps, and the key priority areas had been effectively identified and aligned with what carers said was most important.

> "The deliverables are appropriate starting points. Their effectiveness depends on implementation." – Written submission

The most common critique was that the Action Plan language was too soft, and the actions were exploratory rather than concrete and practical. Some people said that vague language, like "explore", "map", "consider", or "develop", risked making the Action Plan feel tokenistic. Others felt that mapping exercises should be foundational work for the government rather than taking up resourcing as part of an Action Plan intended to support carers.

Some participants recommended that the Action Plan should be more explicit about how and when deliverables will be achieved and who is responsible. They suggested firm measurements and accountability might balance their concerns that early actions were too exploratory, because they would see a date for moving forward into more practical actions. Others suggested new actions and proposed the government invest additional funding, which is covered in the 'Future actions' section on page 23.

> "For carers and whānau experiencing immediate and acute pressure, the absence of firm commitments risks reinforcing a pattern in which their needs are acknowledged in principle but not acted on in practice."
>
> – Written submission

Some people wanted to see more holistic views and broad frameworks applied to the Action Plan. We particularly heard support for including Te Tiriti o Waitangi/the Treaty of Waitangi (Te Tiriti o Waitangi), as the foundational document in New Zealand, and the Enabling Good Lives principles, which were created for disabled people and their whānau.

> "Te Tiriti feels like the elephant in the room when reading through this strategy." – Workshop attendee

Many people were worried about the complexity of the language in the draft Action Plan and were enthusiastic about the intention to create a plain English version and other translations wherever possible. This is seen as important for both the carers cohort and the people they care for.

Finally, participants suggested that language around carers should be forward-thinking, positive, and mana-enhancing. Carers did not want to be "people to feel sorry for", but they wanted to be seen for the hard work they do and the significant economic contribution they make to New Zealand.

> "The Draft Carers' Strategy Action Plan does not yet address the structural conditions that produce carer burnout, financial harm, and long-term system cost." – Written submission

Format

Participants supported the Action Plan being separated into key priority areas. However, some wanted to see each priority shifted to reflect its importance to carers, or a particular area specified as the top priority. Health and Wellbeing and then Financial Security were the issues of greatest importance.

A smaller number of participants mentioned that they or their communities found the draft Action Plan difficult to understand in its current form. They could not easily interpret the definitions of priority areas, deliverables, and actions. They wanted a clear structure designed to be understood by the community, which could point directly to next steps with milestones, timeframes, and accountable agencies listed.

The ‘rolling’ Action Plan design

Across all channels, feedback on the ‘rolling’ design of the Action Plan was largely supportive. Nearly 92% of participants to the survey agreed with the change to a rolling Action Plan to improve outcomes for carers over the short and long term. In submissions and workshops, the majority of participants also supported this but said that appropriate accountability measures would need to be implemented to ensure progress is made. Some of these participants also focused on the need for the Action Plan to be flexible and responsive, suggesting it could be reviewed and updated to address the changing needs of carers.

> “We think a rolling action plan is a good idea if the actions are measurable, have dates for achievement assigned and progress towards achievement is monitored regularly.” – Written submission

A small number opposed the rolling Action Plan design and raised specific concerns about what this would mean for carers and the success of actions. This group tended to have the view that this new structure was focused on removing, or reducing, government accountability.

> “Without fixed end-dates, there is a danger that actions could drift amidst changing political priorities.” – Written submission

Some participants raised questions about the impacts of political priorities on the continuity of the Action Plan. The concern for this group was that a new Government may not continue work on these actions and that political change could stall, or even reverse progress made through the Action Plan on key priority areas.

Other critiques were made of the term ‘rolling’. Some felt this implied ‘rolling on forever’ while others thought the term was “government speak” and that the Action Plan should contain text that was “simple and clear to everyone, including those who don’t have English as a first language.”

Priority area one: Recognition and appreciation

There was broad agreement on the Recognition and Appreciation priority area, as participants cited the need for carers to be recognised for the work that they do and their significant contribution to New Zealand's economy.

There was also wide agreement that, while important, this priority area should be secondary to the more urgent priorities of 'Health and Wellbeing' and 'Financial Security'. Issues such as respite and support services, in particular, were noted to be of higher importance. One workshop also wanted 'Recognition and Appreciation' to be renamed, as they thought the title did not make it obvious that it included navigation of supports and services or cultural safety.

Key feedback: Recognition and appreciation

- Low approval for Carers Appreciation Day, many see this as tokenistic.
- Eurocentric processes mean cultural safety is often lacking in services.
- Significant barriers prevent effective service access and navigation.
- A 'one size fits all' approach is not appropriate to carers as a diverse group.

Carers Appreciation Day

Of the Action Plan's nine immediate deliverables, the Carers Appreciation Day (Appreciation Day) received the most critical feedback. Survey respondents ranked an Appreciation Day as the least useful for carers, while feedback from workshops and written submissions suggested it be abandoned or progressed as a lower priority.

Many were not supportive of the Appreciation Day deliverable in any form, viewing it as a "pat on the back" and a way to "look good but do nothing". They strongly emphasised that focus should be on delivering tangible supports and services for carers as opposed to organising a day for carers.

> "I don't need an appreciation day to know what I do matters. I need to know that there is a safety net before I hit the ground."
>
> – Written submission

Some were supportive and gave feedback on how the day could be used to achieve meaningful change for carers. Similar to those who did not support an Appreciation Day, many in this group reiterated that an Appreciation Day needs to be accompanied by meaningful actions and commitments that lead to improved outcomes for carers. They saw opportunities for a day to:

- raise awareness for caring, particularly to improve visibility for specific groups of carers (e.g. young and migrant carers)
- reach those carers who do not self-identify
- circulate important information on carer wellbeing, and health and supports available to carers.

Cultural safety in the delivery and promotion of existing services

While most participants agreed that cultural safety is critical to both the carer and care recipient, there was a wide range of thoughts and opinions on how to ensure and improve cultural safety. The discussions often went in different directions, depending on the unique lived experience of the participant or the workshop group.

We heard from some that cultural safety should be an expected baseline for services. Many, however, told us that that current services and care processes tend to be Eurocentric and lack understanding for cultural needs.

> "I'm Māori but my son is Samoan, I have never had an experience where I have been able to access any services that are culturally appropriate to either one or both of us." – Workshop attendee

Many conversations focused on the importance of clearly defining "cultural safety" and doing this work in collaboration with iwi. Feedback insisted that the government must first understand what culturally safe services and practices look like before implementing any measures.

Other discussions focused on which groups to include in the work to improve cultural safety. For example, young carers have unique experiences of care and very different needs in terms of respite, or taking a break, as do carers from the Rainbow community. Many carers and care recipients also have multiple overlapping identities, further adding to their unique needs and priorities from cultural safety.

Some participants suggested building on existing expertise in the sector, much of which was underutilised. For these participants, better cultural safety was a matter of:

- tapping into the knowledge and expertise of culturally safe service providers who already operate in New Zealand and applying this more widely
- using existing and readily available key resources and social structures, such as community groups, Marae, schools, and churches
- utilising tikanga practices where they are also cultural appropriate to other non-Māori groups
- increased funding for interpreters and translation of documents into more languages.

Training was another common thread in discussions with many speaking of the need for more cultural safety training for frontline services. For example, one submission wanted professionals who understand Pacific values, family structures, and lived realities.

Another suggested implementing the Whānau Ora approach to better align with te ao Māori worldviews.

> "A revised action needs to focus on frontline services being culturally safe and centred around meeting the needs of carers and whānau, so that they feel supported in ways that affirm identity and whakapapa."
> – Written submission

Improving service access and navigation

Survey respondents ranked this as the most important of the three immediate deliverables under Recognition and Appreciation. This was confirmed in workshops and written submissions where many participants shared their challenges with access and navigation in the past. We heard that improving service access and navigation will require multiple options or "pathways" since different groups of carers have distinct needs (i.e. a one-size-fits-all model would not be appropriate). Differences in the type of impairment as well as the age, culture, identity, and geography of a carer or the care recipient, often determined what types of supports they could access or needed for their navigation journey.

> "Navigation is key, being able to talk to whānau about what to expect for themselves and their own health and wellbeing. One size does not fit all, one size fits one." – Workshop attendee

Differing needs for service access and navigation often led into discussions about the use of portals and websites. Those that were in favour of a website or portal often stressed that this would be most effective as a 'one stop shop', and it would need to clearly link to supports from different sectors, such as health, education, justice and disability.

Some participants expressed concerns about the digital divide, specifically citing that those who are less digitally literate, or live rurally with limited access, may not see benefits. Some participants also distrusted online content and the use of social media. It was stated that while the information can be provided online, it is critical that carers can also access real people for help with navigating.

> "It's like going to a bank and asking for a mortgage; you can read the bank's website but you need a mortgage broker to advise and guide you." – Written submission

Strengthening existing navigation pathways was another key theme amongst feedback. These participants spoke of refining current navigation processes and investing additional funding in the services that have a proven track record. One recommendation was widening the range of information formats to better support the diversity of carers. Existing initiatives that came up in discussion were Health Navigators, Enabling Good Lives Kaitūhono or Connectors, and funded social workers. Many also suggested investing in additional funding and resources in for General Practioners (GPs), Needs Assessment and Service Coordination (NASC), and community organisations that commonly make referrals to carers.

Some participants, however, said that navigation is not the core issue and there simply are not enough services or supports. These people felt strongly that more navigation tools and information would not address barriers to eligibility or access and could in fact add to the backlog when the existing services receive too many referrals to handle. Specific barriers raised in discussion included available languages (e.g. English not a first language) and limited awareness about the term "carer" and the support available to carers. Many spoke about the lack of coordination between agencies and limited advocacy support. Others commented about the poor responsiveness of agencies, sharing they felt support services did not listen to what their needs were.

One key criticism raised on eligibility barriers was that government systems and processes should be strengths-based. It was felt that these systems can be particularly detrimental to outcomes for Māori whānau who want to protect the mana of their loved one but feel forced to engage in the deficit-based language that is required to access financial support.

> "When whānau are required to share high levels of detail about their whānau and living arrangement and needs and then are declined or granted less financial support than they thought they would receive – those whānau become distrustful and resentful. Which is fair enough. This needs to change." – Workshop attendee

Priority area two: Health and wellbeing

Health and Wellbeing was universally supported as a critical priority area for participants. Feedback often approved of the Action Plan's honest description of carer needs for support services, such as respite and the access barriers they face. The biggest focus of discussion in this area was on respite services.

Key feedback: Health and wellbeing

- Effective access to respite is the primary concern for carers in Health and Wellbeing.
- Barriers include geography, cultural safety, specialist care needs, and social or cultural stigma towards taking a break.
- Many feel that promotion and mapping of respite services will not resolve the lack of funded providers.
- Strong support for helping frontline professionals to improve referrals.

Promote respite and break options

National outreach to promote respite and break options was considered a priority deliverable by survey respondents with 70 percent selecting this option amongst their most important of the nine deliverables. This was reflected in workshops and written feedback, where participants stated that "all carers need respite or wellbeing breaks to sustain them" and that for carers to keep doing their critical work "...government and society need them to be resilient, well, and well-supported".

Conversations during the workshops revealed that participants perceived respite differently. For some, respite covers a variety of things that provide relief, rest and relaxation, but for others the term is strongly connected to formal institutions or services.

> "Respite can look very different for different people. Doesn't necessarily have to be the loved one going into care. It could be going to the gym or getting a massage to self-regulate." – Workshop attendee

In both workshops and written submissions, feedback on the promotion of respite often lead to discussion of service availability and existing access barriers. This was sometimes a product of geography or specific cultural safety needs for respite. Common examples included:

- carers being unable to access transport options to take their loved ones to respite
- a lack of comfort and confidence in the available options
- limited available in-home respite assistance
- challenges scheduling respite around unpredictable behaviour.

A common sentiment amongst this group was that promotion of existing services is insufficient when suitable respite services do not exist, are not funded, or cannot handle the demand. These comments often focused on specific groups of carers that are underserved by existing respite options.

In some instances, participants felt that this was due to funding or eligibility criteria while other participants felt that it was a case of insufficient expertise or facilities to provide care. These views were shared by carers of different groups, including cultural groups, those caring for people with specific conditions and disabilities, young carers, and carers of people with younger onset dementia who may go undiagnosed and then struggle to qualify for supports due to their age.

> "There may be no existing services for small groups in particular. That means the few carers that look after them will go unsupported and have no respite." – Workshop attendee

Familial duty and feelings of cultural responsibility were discussed as barriers to some carers taking a break. Many felt that this could be interpreted as ungrateful behaviour or putting their own interests ahead of the person they care for. This internal conflict was captured by one workshop attendee who said: "the idea of getting a break is like 'That was in your wedding vows, what do you need a break for?'". Many wanted work done to normalise and socialise the importance of taking a break from care, or to work on the unique barriers that prevent carers from reaching out for help.

While many barriers are highly complex, some community carer organisations said they could can be addressed through simple but high-impact solutions. One example given related to young carers accessing camps that provide valuable respite from responsibilities at home. Advocates told us how it can be as simple as providing the basics for children such as towels and blankets so that they can attend.

Establish a national picture of respite

Feedback on this immediate deliverable was generally favourable and reflected that the caring community often struggles to find complete and consistent information about available respite services and supports. In particular, there was interest in better public information on respite as a tangible outcome of this deliverable.

While discussing the utility of a national picture of respite and break options, some participants stressed that this would need to effectively capture smaller providers and not only the large, well-known organisations. In a similar vein, others suggested that this picture would need to include information on wait times, geographical distribution and accessibility. Others stressed that this picture should not just cover what is available but also demonstrate how respite is used by different people, as many carers are not aware of the different ways it can be utilised.

Participants commonly discussed the need for visibility of respite options both inside and outside of the home. There were two distinct groups of carers with opposite needs:

- For some, care delivered at home was unsuitable due to the additional costs for travel and accommodation when carers must find an alternative place to stay. This group needed care outside the home, which in some areas was not available.
- For others, respite delivered within the home was the only option and they could not explore residential care because the process of moving the person they cared for would create additional stress and work that outweighs the benefits of the respite.

There was much conversation about carers needing tangible support, not mapping exercises. Many thought that this information should already be available to government, and that a national picture will only have value if it leads to addressing the gaps by increasing and improving access to services.

> "What will government do with this information to improve respite when the challenges are lack of options in many areas; lack of investment in funding and facilities; and lack of delivery of solutions to meet the diversity of needs among carers and their respite preferences at all age points?" – Written submission

Expand community pathways to support referral from frontline professionals

This immediate deliverable was a strong focus for many throughout consultation and was also ranked highly by those who completed the survey. Feedback discussed the gaps in existing referral systems and the challenges faced by frontline professionals with making referrals. The most prominent theme in discussion was that there is a need for more information – both for frontline professionals at the point of referral and also for the community about the referral process itself.

> "We need solid referral mechanisms to support carers rather than relying on word of mouth and good will." – Written submission

Many agreed that the best solution to improve these referral pathways was working within the systems and organisations that already exist in the community. They suggested more focus on training and resources for frontline professionals in the community to enable them to provide effective referrals.

Some feedback focused on specific gaps in the existing referral networks. GPs and health professionals were discussed because in cases of physical health or disability it is often a formal assessment or diagnosis that leads to a caring role being recognised. Some participants, however, stated that GPs did not always have the relevant expertise to make an assessment or referral. Mental health conditions were discussed as one example where referral opportunities may be missed.

> "GPs aren't always the best at supporting whānau because they look at it from a medical professional view." – Workshop attendee

To best enable frontline professionals, GPs, and NASCs to improve referral pathways, participants provided several suggestions, including:

- ensure they have up to date information about recent respite changes so they can appropriately recommend/allocate services
- ensure they are aware of all relevant community supports to supplement allocations
- create joined-up diagnosis-to-support pathways that include identifying carers.

A critique that arose in some feedback was that this deliverable, and the Action Plan in general, "…does not mandate the necessary education for frontline professionals…". This view suggested that if there are no incentives and accountability measures in place for GPs, NASCs and other frontline professionals to upskill, then the work of learning and investigating options would remain with the carer.

Priority area three: Financial security

For many participants, Financial Security was identified as the most important of the three priority areas, and there was widespread support for including it as a priority. Carers shared how the loss of or reduced hours of employment and study can have both immediate and long-term impacts on their incomes, careers and savings, as well limiting their ability to participate in activities that support their wellbeing, such as respite, sports, clubs, social engagements, etc.

Key feedback: Financial security

- Support for priority area but concerns around lack of funded solutions.
- Many are confused about what is available and agree that a clear picture of financial assistance is a good first step.
- Most agree that carers would benefit from skills recognition in some form as gaps in CVs are a common barrier to education and employment.
- Employers do not often offer supports for staff providing care however it was agreed by many that there are small or simple things that they can do.

"The financial impact is not theoretical — it is devastating. Giving up a high-income job to become a full-time carer is not a "choice." It is a necessity caused by limited support systems, unsafe or inaccessible schooling, and the lack of respite. The financial burdens of caregiving must be directly addressed." – Written submission

Develop a picture of available financial assistance

This immediate deliverable was considered the most important in the Action Plan with 85 percent of survey respondents ranking this amongst those they believed most useful for carers. In workshops and written feedback, many expressed their support for this immediate deliverable, citing a need to address the confusion and anxiety among carers who are frustrated at having to rely on personal networks to find out what support is available. For this group analysis was an appropriate first step towards addressing the issues faced by carers.

> "When I see 'develop a picture of available assistance' my first thought is: 'where are the gaps?' Begin with that question." – Workshop attendee

A large group was vocal that this deliverable did not go far enough. They argued that visibility would not solve the issue of funding shortfalls for providers and services, and they shared their stories and those of friends and whānau struggling with the process of being declined for support when they were in significant need. This group also questioned why a national picture of financial assistance had not been developed, given work has been ongoing on the Carers' Strategy since 2008.

> "We should already have this picture. The Carers' Strategy has been in place for seventeen years. Multiple Action Plans have been implemented. Research and reports have been commissioned. If we do not yet have a clear picture of what financial assistance is available and where the gaps are, that is itself an indictment of the strategy's execution — not a reason to start again from scratch."
>
> – Written submission

Participants suggested better utilising existing structures, particularly increasing funding to existing NGOs and proven service providers, while others promoted international models of financial support, such as the Carer Support Payment in Scotland. Others spoke of the informal networks that carers use to share information about accessing financial supports and how this often fills the gap when there are not clear resources and directions for what carers can get.

> "Carers are often very generous with information to other carers as they know it's hard to put all the pieces of carer information together."
>
> – Workshop attendee

Map potential pathways for carers

Many participants agreed that training and formal recognition for carers would be one appropriate pathway to financial security. This would also help to address "gendered disadvantage", where woman tend to do more care work, especially mothers caring for multiple generations at once.

> "I want to have a future and learn, but I also want to provide financial support for my children." – Workshop attendee

Carers described the transferrable skills they were developing through lived experience, including learning quickly with little support, conducting their own research, and experiences in highly regarded professional areas, such as health, education, legal systems, or finance. These skills, however, are not always formally recognised. This leads to difficulties in obtaining employment upon leaving a carer role and, therefore, contributes to individuals' financial insecurity. One written submission, for instance, described how their years spent caring for a family member did not count towards a post-secondary course's practical component because they had not worked with a trained supervisor.

Participants said it was important to create and promote employment pathways for carers that led to futures both inside and outside of the care sector. They suggested tangible products that could be "put in the gap on your CV." They also discussed NZQA recognised qualifications and cross-crediting towards further qualifications.

> "An NZQA framework qualification gives carers mana and opportunities for their future." – Written submission

Some participants raised that carers are a nuanced group and not all want a future in professional care. Some may have aspirations that fall outside of care, while others may not want to enter formal employment, especially older carers who have passed retirement age. These carers cautioned against framing available pathways as an expectation:

> "It must be framed as an opportunity not a pressure. People should know what is out there if they find themselves with capacity, but there should be no enforcement." – Workshop attendee

Develop understanding of supports provided by employers to carers

Less feedback was provided on this immediate deliverable than other areas, especially in written submissions. While most were highly supportive of work towards carer-friendly employment practices, the general feeling from participants was that supports available through employers were rare and often not well understood. As such, they questioned how much positive change could be achieved.

Participants spoke of their own experiences with finding flexible arrangements that allowed for them to work around their care schedules. With few options available, carers often are working in industries that have limited opportunities for career progression or advancement, which in turn has impacts on the person's immediate finances, longer-term earning potential, and retirement savings.

> "Most employers currently offer limited structured support for carers."
> – Written submission

While participants generally agreed that many employers would not take carer supports seriously without effective policy mechanisms and incentives, they differed on how to best achieve greater flexibility in the workplace.

- Some suggested financial support systems that allow individuals to balance caring and work or encouraging employers through tangible incentives.
- Others believed that employers should be responsible for understanding the care responsibilities of their staff and, accordingly, provide flexible arrangements and realistic workloads.

> "Many carers want to work, but they need the flexibility e.g. remote work options, flexible hours, employer education on the realities of caregiving." – Workshop attendee

There was also discussion of steps that employers can take to make a significant difference to carers in their workforces. Feedback provided examples of good employer practices, such as providing training opportunities to upskill or holding a role open to recognise the value of their staff when they leave for caring. There were also specific suggestions for how to improve employer supports for caring, such as a dedicated leave payment for new carers in the same way as parental leave is currently provided.

> "Could there be job protection for carers during intensive caring periods? Maybe incentives for employers who retain carers."
> – Workshop attendee

Additional perspectives and personal experiences were raised and discussed in the workshops. Below are four examples of key discussions points:

- Flexible working arrangements are often provided in a way that benefits the employer far more than the employees.
- The definition of 'family' that employers operate under for dependent leave and tangi should include chosen family, not just biological family.
- Carers end up having difficult and uncomfortable conversations with their employers about their role and situation to appeal to them for flexibility and accommodations, which they may still be denied.
- Some carers are not able to engage in work, education or training. These individuals still need financial security to get by day-to-day.

It was also suggested that the government should be targeting schools and universities to see how they are supporting carers. In the case of young carers, schools are often unaware of the carers in their population and do not know how to offer support to them. Universities, too, have a role to play in supporting student carers, who have an increased risk of not completing their studies and missing out on qualifications that may improve their chances of obtaining employment.

> "I'd like this to include education providers as well as employers. For example, I'd love to know what universities are doing to support carers." – Workshop attendee

Next steps

- Government accountability
- Future actions
- Working with communities

Government accountability

Feedback from consultation also focused on the mechanisms that are needed to ensure effective implementation of the Action Plan. Participants wanted to ensure that adequate first steps are taken to sustain the Action Plan's momentum and, that these initial actions would be delivered in a reasonable time. Feedback on government accountability measures often flowed out of discussion about the 'rolling' structure and the common concern that without an end date there would be a greater need to implement regular reviews and hold agencies accountable.

Key feedback: Government accountability

- Participants want effective governance systems in place with active input from carers and those with lived experience.
- Many asked for regular reviews and transparent reporting processes.
- Participants want to see active leadership and accountability from government agencies on the Action Plan and immediate deliverables.
- Implementation needs to build on these immediate deliverables and in-time deliver practical actions to address the key issues identified in the plan.

Governance

Feedback on governance focused on putting adequate governance arrangements in place to guarantee accountability, enable the effective delivery of actions, and improve alignment across government agencies. Accountability and enforcement were concerns for many who wanted to see agencies take a more active role than with previous Action Plans. Some of this group stated a need for mechanisms such as legislative backing, independent oversight and consequences for non-delivery.

Workshop attendees and written submissions frequently brought to our attention the importance of involving specific groups of carers and community partners in the governance process. Many suggested additional engagement and targeted representation from key population groups including Māori, Pacific, migrant communities, youth, disabled people and complex needs were considered critical to the governance process.

> "Ensure a wide and representative range of carers are involved, particularly those who are less visible, less likely to advocate for themselves, or who have more complex needs." – Written submission

Many had strong views around the level at which key groups should be involved in the governance of the Action Plan with many participants suggesting closer collaboration between the Government and carers. Several submissions referenced the partnership model between MSD and the Carers Alliance as an example from which to build any future governance arrangement.

> "Engaging carers as equal partners shifts the approach from top-down decision-making to true co-design, resulting in more practical, effective, and sustainable outcomes." – Written submission

Monitoring and reporting

A key focus of monitoring and reporting was on accountability, in particular what "checks and balances" would be put in place to ensure consistent progress was being made on the 'rolling' Action Plan. People wanted to know more about review frequency, evaluation frameworks and data collection.

- Concerning review frequency, participants considered this critical for keeping the Action Plan's objectives relevant, for tracking progress, and for addressing any gaps, including identifying groups that may fall through the cracks.
- With respect to data collection, participants stated that identifying carers can be difficult and addressing this issue will require using clear indicators and a range of approaches to better identify and reach carers.

> "There is a lot of demographic shift in certain populations, for example the aging Pacific population. So we need to check in at regular intervals to make sure the plan is still fit-for-purpose." – Workshop attendee

Above all, participants wanted to know how the objectives would be measured and how the government would know if the Action Plan is working. They offered specific suggestions on measuring progress, including:

- clearly defined 12-, 24-, and 36-month milestones
- Cabinet-level annual reporting on carer outcomes
- public performance dashboards with measurable targets
- lead agencies listed against actions
- regular surveying of carers to gather input
- a formal review trigger if deliverables are not met within a defined timeframe
- independent oversight including carer representation.

Other considerations for implementation

Participants made it clear that they wanted implementation of the actions to be more practical over time. A common expectation was that scoping and mapping exercises must identify gaps but also feed into solutions to address these gaps. Participants wanted tangible steps taken toward the priority areas and to know that government agencies have detailed project plans to support the deliverables in the plan.

There was also discussion about how to best communicate changes to carers. The risk brought forward was that while communicating change to the community is critical, this can overwhelm carers when changes happen quickly and without enough warning.

Future actions

Participants offered a range of recommendations on potential future actions for the Action Plan, and the most common themes are described in the following paragraphs. Not all suggestions, however, are covered in detailed, but some other, notable recommendations included:

- establishing a Minister for Carers
- professional development for health professionals
- travel and accommodation support for rural carers
- automatic financial reassessment based on intensity of care
- a wellbeing screening tool for carers that helps prevent burnouts and crisis situations.

Navigation support role

A common recommendation was developing a navigation support system with funded support roles to assist new carers with understanding the supports and services available to them and navigating different government agencies. Participants suggested that health professionals could play an initial role, where, at the point of diagnosis, they refer families to a support worker or a wider programme that provides this service. Parent to Parent was praised as an example of how this navigation support can help carers, and many also spoke of informal community peer support networks that help them, such as online groups.

> "Having designated navigators will help carers access appropriate support pathways." – Written submission

Targeted mental health supports

Many people raised the need for targeted actions to support those who are caring for individuals with mental health conditions, pointing out that "for carers of people with mental illness, respite looks different from traditional models and is rarely recognised as such." We heard about the unique demands on these carers such as intensive emotional support, crisis management and safety monitoring.

Mental health supports for carers were also widely discussed with many participants agreeing that carers often put their mental wellbeing behind the needs of the person they care for. Recommendations included trauma informed counselling, dedicated peer support programmes for carers, and the introduction of formal assessments for carers in their own right to ensure their physical and mental health needs are recognised and addressed.

> "People need psychosocial support for mental wellbeing, include specific mention in the action plan. Access to physical care is easier than access to psychosocial services and support."
>
> – Workshop attendee

Kiwisaver contributions

Concerns over long-term and retirement savings was a significant area of discussion in financial security. Many people suggested that government contributions should be made to Kiwisaver when people pause their careers to provide full-time care. Participants frequently pointed out that due to the gendered nature of care, women have lower average retirement savings and less financial security later in life.

> "Providing carers with the annual KiwiSaver contribution if they have a 24/7 role is an important milestone that would deliver results across actions." – Written submission

Addressing system fragmentation

Participants sought greater coordination among agencies and between the Action Plan with other relevant strategies and work programmes.

- Many felt that the current caring landscape was too fragmented, with agencies having their own programmes and services in place despite supporting the same carers. This fragmented approach leads to duplication of efforts and navigation challenges. Participants thought this contributed to past Action Plans not being fully delivered.
- Various written submissions strongly stated the need to link the Action Plan with other government strategies and action plans to reduce duplication, while ensuring all activities build on or support one another. Other work programmes noted by participants included Disability Support Services (DSS), the New Zealand Disability Strategy, the Dementia Mate Wareware Action Plan, and the Rare Disorders Strategy.

> "We need to see the Ministries of Social Development, Disabled People, Health and Education working more collaboratively to improve services and support for disabled people and their carers." – Written submission

Revising The Guide for Carers

While some viewed The Guide for Carers as a useful resource, many noted that it had significant limitations, such as accessibility and prescriptive language. Several suggestions were made to improve the document and its reach, including:

- better distribution including to rural communities
- distribution to schools in an accessible format for children
- regular updating of content to align with system changes
- translation into more languages
- creating an additional shorter version that can be more easily translated and distributed
- rewriting the document in plain English, from the perspective of a carer
- releasing practical companion guides for common tasks, like returning equipment after someone has passed.

Practical support for everyday processes

Many participants asked for guidance and training for everyday processes of care. Participants suggestions included home-based coaching, help with sleep, toileting processes and behaviour regulation, and support for specific conditions. To deliver this support, some participants suggested a 24/7 helpline, and others recommended utilising the home and community sector. The need for practical support during transitional periods is demonstrated by a comment from one workshop attendee below:

> "I am thinking of the young people who relied on Special Education support while at a school age. When they turn 18, suddenly they are no longer getting this because they are no longer a child. But their need does not vanish on their birthday. Can we have more support for their carers in how to transition them to adult services?"
>
> – Workshop attendee

Future investment in financial supports

Many participants suggested investing in and expanding existing services that have a proven history of successful outcomes for carers, such as Permanent Caregiver Support and CareWise. Others recommended creating new services that target specific groups who frequently fall through the gaps in the current system. Women were often mentioned, as were ethnic minorities, rainbow carers, as well as specific groups of carers, including young carers and carers for those diagnosed with Young Onset Dementia. This group often had specific suggestions for future actions or priorities:

- Regarding Young Onset Dementia, a suggested targeted response was a working-age dementia stabilisation pathway to help households who may often face both the care recipient and the carer exiting the workforce in a short span of time without the opportunity to plan ahead.
- In the young carer space, advocates suggested targeting financial assistance at transport or digital services to help young people in low-income households.
- For Māori carers, there were calls for direct funding for Māori providers and Iwi organisations, who are best placed to provide culturally appropriate services.

> "I would like to see a link between financial supports and equity outcomes for groups of carers who are facing extra struggles. I'm talking Pacific, Māori carers, disabled carers, etc." – Workshop attendee

Working with communities

Throughout the consultation, many participants stressed the importance of ongoing engagement and the inclusion of carers and key organisations in the monitoring of the Action Plan. 'Transparency' and 'consistency' were key words that arose from this type of feedback, which was centred around maintaining the channel that has been opened through engagement on the draft Action Plan.

> "Government must be collaborating with carers, Māori, Pacific, disability organisations, and NGOs on the development of immediate deliverables." – Written submission

Participants stressed that carers and communities will expect updates and actions to follow on from them sharing their lived experiences during engagement. They told us what they thought good ongoing work with communities should look like:

- Regular reporting directly back to key organisations, such as the Carers Alliance.
- Targeting gap areas for carers such as mental health by engaging with mental health services and relevant NGOs.
- Honouring and acknowledging the time and trust of carers and other participants of this consultation.

> "If something is put on the table, make sure that it is well supported and resourced. Consider the devastating impact on whānau when they have shared their thoughts and experiences, but when they ask for an update are told it is no longer going ahead." – Workshop attendee

A small group were concerned that engagement with carers would stop under a 'rolling' structure, as engagement with carers has historically occurred during the draft stage of a new Action Plan. It was important to this group that they continued to be actively involved in the process following the launch of the Action Plan.

Experiences with caring in New Zealand

- Issues and concerns with the current system
- The impact of caring on specific groups

Issues and concerns with the current system

Many people shared anecdotal evidence of caring in New Zealand and how the system, including government supports, impacted their lives. While their experiences have been captured previously in the report, this section provides a broad overview of carers' issues, concerns, and experiences with caring and the current system.

Key feedback: Experiences with caring in New Zealand

- Participants said caring for loved ones can be rewarding and important, but they also shared experiences which impacted their lives negatively.
- Many carers discussed the long-term impact of care on their personal lives, health and wellbeing and finances.
- Carers also discussed how the wider system, including government services, impacted them and compounded their challenges on a broad scale.

> "Strengthening these supports is essential to preventing burnout and enabling whānau to sustain their caring role safely and with dignity."
>
> – Written submission

Not feeling recognised

Many carers spoke positively about their experiences and said care was provided with love and was deeply appreciated. However, some carers said they were not recognised or appreciated in their day to day lives. They described their experiences as "deflating", "humiliating", "burned out", "silencing", "inferior", "socially isolating", "frightening", and "exhausting". Some characterised these emotions as "dehumanising" and stated that no one should be put in a situation where they feel like this on an ongoing basis.

Carers for people with mental health, invisible chronic illness, or rare conditions said that not being recognised directly affected their ability to care safely. Family and whānau carers, especially Māori whānau carers, described having a long history of caring where they provide important social and economic value without being acknowledged. Many carers said they must advocate for themselves, the people they care for, and their communities if they wanted to be recognised.

> "This role of caring is very isolating. People invite you to places you can't go and those friendships fade." – Workshop attendee

Lack of health and wellbeing support

Participants shared that caring can impact every aspect of health and wellbeing. Some carers struggled with disability, injury, or illness, which are exacerbated by the tasks they performed in their roles, such as lifting people regularly. Some said the compounding impact of stress, sleep disruption, and living in "survival mode" had put their mental health at risk. Many people said carers are at a high risk of burnout.

Some carers said that they struggle to find consistent support from health professionals. They shared stories where doctors, physiotherapists, and other professionals were inaccessible, temporary, or unsympathetic. They said it was difficult to know what support they were entitled to without targeted help with navigation.

Participants also stated that carers and their friends and family were trying to support one another with their mental health, but this led to increasing mutual distress. They further noted that while community connection is important, it does not replace professional intervention. However, when it came to accessing professional healthcare, many carers described only being able to seek help after a caring responsibility had finished or during occasional periods of respite.

Finally, people shared the long-term impacts of caring. Specifically, when the person someone is caring for moves into professional care or passes on, the carer still may be affected by the experience. Participants listed social isolation, grief, trauma, and poorer health as the most common impacts on their lives.

> "My intention is to care for my adult child as long as I am physically able to. If nothing changes, I fear that my physical ability to care will be shortened, and both my child and I will require outside support."
>
> – Written submission

Respite and taking a break

Many carers said that it was difficult to access appropriate respite or break options. They said respite could be sporadic, unreliable, not culturally appropriate, and it was often designed for aged care, which did not suit other situations. Some also said respite was too often being used to address emergency situations rather than as a preventative measure before a crisis.

Many carers shared they are left feeling like they have to take on their responsibility alone. They said that when looking after a loved one, it is difficult to ask for help or take a break without feeling guilty. Asking other family/whānau or friends could feel like placing too much pressure on an existing bond. Asking strangers, even professionals, could feel risky, uncertain, or unsafe. Those who care for people with rare conditions might even be the only experts in the country in the kind of care they need to provide and express concern that appropriate respite might not exist.

> "It often takes a crisis for people to acknowledge they need a break, and this can be seen as a failure in itself." – Workshop attendee

Education or employment

Time spent on caring responsibilities can isolate carers from education and employment opportunities. Carers shared that they have set aside personal goals, lost income, or never been able to use a degree that they earned. For young carers, they often missed formative years of schooling due to caring. They said they were labelled as "truant" or "disengaged" from education, but they wanted more support for balancing their complicated responsibilities.

Missing out on education and employment clearly impacted carers in the present day, as many carers noted they felt disconnected from their communities or from milestones that were "normal" for their peers. They also shared how caring affected their futures. When they finished caring responsibilities, they found it hard to return to the job market or they did not have KiwiSaver contributions they might otherwise have had.

> "There isn't a recognition of loss around carers having to leave their employment due to burn out and intensity of care. Many people end up having to leave the work force when they didn't want to."
>
> – Workshop attendee

Financial disadvantage

Participants explained the financial cost of caring put them at a disadvantage compared with others. This included money spent on transportation, medical expenses, therapy or counselling, specialist furniture, groceries, and housing. While some carers could apply for support from the government for caring expenses, these interventions could be difficult to access or require complex administrative effort.

The struggle to access traditional education and employment (discussed above) was one root of financial disadvantage for carers, impacting their ability to earn stable income. Some people had to work part time in order to care, or they had to leave their jobs to care full time, since they could not afford to pay for formal care. This created greater financial disadvantage because household expenses had increased but household income had decreased. Participants said that changes to employment were harder when a caring responsibility was an unexpected change, and some had to move house or sell important belongings in order to offer care.

Participants also mentioned that caring was not acknowledged financially as formal employment would be. Carers suffered from not having minimum wage, sick or holiday pay, and some did not understand their tax responsibilities.

> "How do we cope without having to sell the home?" – Workshop attendee

Government services and the disability system

Some carers expressed problems with the disability system, such as appropriate services not existing, services being "siloed" or failing to communicate with each other, agencies avoiding responsibility or being unresponsive, administrative burden on the client, and lack of flexibility. When carers were able to find the information or support they needed, this was often through their own effort, and it added to their exhaustion.

Carers also shared stories of staff who did not show compassion, breached privacy, or turned them away without explanation. In cases where bad experiences had already occurred, trust was eroded and returning to the system felt traumatising. This led to some carers avoiding support altogether.

Some carers said that structures for support were clearer when the care recipient was a child and became more complicated either when they left the school system, or when they turned 18 and were officially adults.

> "The challenges we face do not come from my children, but from systems that are not designed to meet the needs of neurodivergent families." – Written submission

The impact of caring on specific groups

We received significant feedback that related to varied, specific cohorts of carers. Many people asked the Action Plan to list these cohorts, where they could be identified. They were also concerned that carers with multiple intersectional identities would face unique risks and barriers. We note that the groups in this section are listed in no particular order and can often overlap.

Key feedback: The impact of caring on specific groups

- Many specific groups mentioned the need for targeted interventions which considered their place in a wider societal context rather than applying a one-size-fits-all approach to every cohort of carers.

> "Carers are not a homogenous group. Māori carers, Pacific carers, young carers, older carers, disabled carers, rural carers, and those supporting people with complex needs face different barriers and opportunities, and for many caregivers, several of these factors apply at once."
>
> – Written submission

Disabled carers and carers with health conditions

Many carers mentioned they were navigating their own health or care needs (e.g., a disability, long-term health condition) while they cared for someone else. This situation was especially common for family and community carers who supported people with disabilities, neurodivergences, or mental illnesses. One suggestion was that disabled carers and carers with health conditions might be considered in a joint needs assessment along with the people they care for.

People also asked us to consider carers who develop health conditions as a result of caring. This included impacts on mental health like anxiety and chronic stress, or physical impacts like osteoarthritis and injuries from lifting and carrying.

> "Parents of neurodivergent children, many of whom are themselves neurodivergent, represent a high-intensity population."
>
> – Written submission

Māori carers

Māori carers were mentioned throughout the engagement included rangatahi, tāngata whaikaha Māori, and Takatāpui Māori, who experience multiple interacting disadvantages. Māori people said they were less likely to identify as "carers" because caring is a family responsibility and supporting the whānau, including elders, is a natural role for many people.

When it came to the content of the draft Action Plan, Māori carers wanted to see how Te Ao Māori and Te Tiriti were being considered and see Māori needs addressed specifically. They said Māori carers should be able to see they are included and entitled to support.

Participants also mentioned key strengths in how Māori communities care for one another and the value they provide to New Zealand. One was that informal and family care from your own community is culturally safe care.

Another was that family care enables communities to prevent tāngata whaikaha Māori from being isolated or entering state care, which is already a higher risk for Māori people compared with the general population.

> "A one-size-fits-all approach removes us Māori from the realities in our communities." – Workshop attendee

Older carers

Participants told us that increasing numbers of older carers are experiencing the detrimental effects that can accompany aging and, as a result, also need support for their own health and care needs. We heard that the Action Plan should consider this future state when planning ahead.

Some people told us that older carers do not need pathways to employment or further study, but they do need practical support in the immediate future. They are likely to experience financial disadvantage due to not having KiwiSaver or because caring costs did not allow them to save money for retirement. The idea of a joint needs assessment was raised in this space as well as in feedback on disabled carers.

> "Carers are aging too, and they can't continue forever." – Written submission

Other ethnic communities

Carers from other ethnic communities, who represented many different cultural backgrounds, shared with us some general trends. For example, similar to Māori they are less likely to identify as "carers" due to cultural norms that view caring as a family responsibility. Some faced barriers to accessing information, especially those with immigrant or refugee backgrounds who do not speak English as a first language. Carers from other ethnic communities supported efforts to make the Action Plan accessible in other languages and to make services culturally safe.

> "Having interpreters and translation lets people understand your plan better, because they may not have the literacy in English."
> – Workshop attendee

Pacific carers

Similar to other groups, we heard that a majority lens does not capture the cultural complexity of Pacific carers. Participants mentioned that Pacific carers should be approached as a diverse population with multiple cultures rather than a homogenous group.

We also heard that many Pacific people do not identify with the label of 'carer' because this is simply their accepted role in the family. A formal view of caring might create tension or shame because it would be seen as treating their family like work. This perspective may result in Pacific people not realising the Action Plan or carer supports are meant for them unless they are addressed directly. This can compound disadvantage.

> "As Pacific people, being a carer can be set in place long before our family members become sick and need us. It is your role in the family."
> – Workshop attendee

Rainbow, LGBTQIA+, and Takatāpui carers

Carers in Rainbow or LGBTQIA+ and Takatāpui communities stated that they would like to be identified as a key cohort in the Action Plan. They shared that they are statistically likely to be in unpaid work, including caring, and likely to have lived experience with disability. Rainbow carers asked that the definition of 'family' carers should explicitly include chosen family, as this caring relationship is common for the rainbow community. They also said that cultural safety should include consideration of unique Rainbow culture, including where it overlaps with other cultural identities.

> "It should be very clear that the definition of family includes chosen family, because we don't want any risk that they are not acknowledged or included because they are so specifically important to our community." – Workshop attendee

Rural and isolated carers

We heard about barriers for rural and isolated carers, including those who are digitally isolated. Carers in this cohort can face long travel times, difficulty finding relevant information, limited local services and health providers, and limited access to respite. It can also be more difficult to find culturally targeted services in smaller populations.

> "It's a lot harder to access any of these things living in the country, if you don't have a computer or aren't good on it, it makes it a whole lot harder." – Workshop attendee

Supporting people with complex needs

When caring for people with complex needs, carers often deal with unique stressors, such as high intensity situations, unpredictability, trauma, Child-to-Parent Violence and Abuse (CPVA), and emotional exhaustion. Support can be difficult to find if health professionals are not familiar with particular needs and carers become singular experts and advocates.

We heard that people wanted to see specific consideration of carers who support people with mental health or neurodiversity needs, rare conditions, or those who are undiagnosed. The needs mentioned under this section included: Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Pathological Demand Avoidance (PDA), anxiety, depression, eating disorders, chronic illness, intellectual and developmental disabilities, long-term effects of stroke, Dementia, Young Onset Dementia (YOD), Foetal Alcohol Spectrum Disorder (FASD), Cerebral Palsy, cancer, and Prader-Willi syndrome.

> "When you look after someone with rare or complex needs in such a small country, you might become the only expert in their care."
> – Workshop attendee

Women carers

Many people we engaged with spoke about it being more common for women to be carers, especially mothers. They linked this to gender expectations and societal inequity. Caring can compound financial disadvantage for women in the long term, as women carers remain out of paid employment, have limited work opportunities if they finish caring, and limited finances at retirement age. Participants suggested targeted measures to address female carers' lifetime earnings as a pay equity concern.

> "The default carer is often the mother or the daughter."
> – Workshop attendee

Young carers

Participants said that young carers, especially those caring for their siblings, have unique needs that should be addressed. They often miss out on education or employment opportunities that can impact their short- and long-term prospects. Written submissions included research showing that young carers would benefit from holistic support that integrates education, health and mental health, and transitions to adulthood.

In one workshop, there was a call for better data collection to identify young carers. There was also support for government agencies, schools, and health professionals being made aware that they might be working with young carers and creating proactive strategies to help them.

> "These young carers are sacrificing their own childhoods through no fault of their own." – Workshop attendee

Concluding comments

For four months, thousands of people shared their stories, experiences, ideas, and thoughts about caring in New Zealand and the Carers' Strategy Action Plan. We are immensely grateful for the time people invested in this process and to the support we had from the caring community to make this consultation possible.

The discussion in workshops and in written submissions frequently spoke to the intensely demanding role of caring and the significant challenges that carers face to find and access support. What we heard was not just opinions on the content of the draft Action Plan, it was also a unique set of personal stories from people who have had significant and/or ongoing interactions with the New Zealand care system. We heard about the issues that carers face, the cultural and social dynamics of caring, and the distinct groups of carers that make up this informal care workforce.

While there was support for many of the specifics of the draft Action Plan, there was also a majority of voices that wanted to see more tangible actions. Feedback was often intently focused on what we can do to make a real difference in the lives of this crucial group who every day give so much for the people they love and provide so much value to New Zealand.

This feedback has been critical to setting the scene of caring in New Zealand. With this document, we hope we have provided an accurate summary of what was said. A true and detailed picture of this consultation is critical both to inform future work on the Carers' Strategy and Action Plan, and to appropriately acknowledge the valuable insight that carers and the caring community has given us through this consultation process.

> "The most important thing New Zealand must consider as it reviews this Action Plan is whether it is moving forward or backward. The answer must be determined by outcomes for carers — not by the volume of reports produced, the number of consultations held, or the number of stories collected." – Written submission

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7277POL | AUG 2026