

In Confidence

Office of the Minister for Social Development

Chair, Cabinet Social Wellbeing Committee

## **Mahi Aroha: Carers' Strategy Action Plan 2019-2023**

### **Proposal**

1. This paper is seeking approval to release *Mahi Aroha: Carers' Strategy Action Plan 2019-2023 (Mahi Aroha)*.

### **Executive Summary**

2. The New Zealand Carers' Strategy was launched in 2008. The Strategy is supported by five-year action plans which address key priorities identified by carers and the Government. This paper outlines the development and focus areas of *Mahi Aroha: Carers' Strategy Action Plan 2019-2023*, the third action plan under the New Zealand Carers' Strategy, and seeks approval for its release.
3. *Mahi Aroha* was developed in partnership with agencies across government and the New Zealand Carers Alliance.
4. Carers throughout New Zealand were given the opportunity to share their views. Consultation identified emerging issues for carers. Carers highlighted an inability to save for retirement and older age. Several carers spoke about the incidence of violence in their lives, perpetrated by the person they were caring for. Many of these carers were either parents caring for disabled children, or spouses caring for a loved one living with dementia. These carers spoke about the shame, but also the complete lack of awareness and support for those living in their situation.
5. *Mahi Aroha* is underpinned by a wellbeing approach. Although it is for all carers, it has an additional focus on four target populations: Māori, Pacific, older and young carers.<sup>1</sup> This recognises the particular needs of these groups of carers.
6. *Mahi Aroha* contains 17 actions. It is organised under four focus areas based on what carers said was most important to them:

<sup>1</sup> For the purposes of *Mahi Aroha*, an older carer is a carer aged 65 and over, and a young carer is a carer under the age of 25.

- *recognising* carers and their contributions
  - *navigating* available supports and systems
  - *supporting* carer wellbeing and building skills
  - *balancing* paid work, study and other options.
7. The Carers' Strategy includes an ongoing programme of monitoring through an annual report on progress to the Social Wellbeing Committee against *Mahi Aroha's* objectives, with the first report due in November 2020.

## **Background**

8. The Carers' Strategy is a cross-government strategy for carers, recognising the valuable contribution they make to society. Carers support people with a disability, health condition, illness or injury who need additional assistance with their everyday living.<sup>2</sup> One in ten New Zealanders are in a care role, and this number is likely to increase as the population ages and people live longer in their communities. The care role falls inequitably across the population, with the majority of carers being women. Māori and Pacific communities are also disproportionately represented.
9. The Carers' Strategy is supported by five-year Action Plans, with the previous plan spanning 2014 - 2018. Officials have worked in partnership with the New Zealand Carers Alliance and a cross-agency working group to develop *Mahi Aroha*. During July and August 2019, carers throughout New Zealand shared their views on the *Mahi Aroha* discussion document through: face-to-face workshops (general workshops, hui or talanoa), an online survey, email or written submissions.
10. This consultation showed broad support for *Mahi Aroha*. Carers noted that for them, the significant issues have not changed since the development of the 2014 - 2018 Action Plan, and the work to progress these needs to continue. These include a need for increased support when things are not going well, assistance with the increasing financial pressures of caring, and a desire for greater choice and agency in how they access and make use of the supports and services available to them. This desire for greater flexibility was expressed strongly in relation to respite care and training and development opportunities, among others. These issues endure because of their complexity and reflect the challenges of joining up across different areas of service provision.
11. My officials have produced a Summary of Submissions report outlining and analysing the feedback received during consultation. This document will be publicly released to coincide with the launch of *Mahi Aroha*.

## ***Mahi Aroha* aims to value carers and the caring role**

12. Individual, family, whānau and aiga carers support people living with a disability, health condition, illness or injury who need additional help with their everyday living.

<sup>2</sup> For the purposes of the Carers' Strategy and *Mahi Aroha*, this definition of a carer excludes paid professional carers and foster carers.

Carers play a crucial role in enabling people to live and participate in their communities and reduce their need for support through the health and aged-care systems.

13. In 2008 Hon Ruth Dyson (then Minister for Social Development and Employment) launched the New Zealand Carers' Strategy (the Strategy) and an initial five-year supporting Action Plan aimed at better supporting carers. The Strategy is a cross-government partnership with key agencies and the New Zealand Carers Alliance.<sup>3</sup>
14. The Strategy's vision is that Aotearoa New Zealand is a society that values carers. This will be achieved when carers have choices and opportunities to participate in family life, social activities, employment and education; and when carers' voices are heard in decision-making that affects them. Since 2008, there have been two Action Plans, which have contributed to achieving the vision of the Strategy.
15. According to the 2013 Census, there are approximately 430,000 carers in New Zealand. This is 10 percent of the population and is a 13 percent increase compared to the 2001 Census. Of the people who identified as being a carer, 63 percent were women, mostly aged between 40 and 60 years. Nearly half of all carers are over 50 years old. We are aware that this data does not necessarily represent the full number and ethnic breakdown of carers in New Zealand.
16. Carers are of significant social and economic value to New Zealand society. They enable those who require care to live and participate in their communities, allowing greater independence, autonomy, quality of life and social inclusion. In 2014, Infometrics calculated a mid-range estimate of the labour replacement value of the work done by family, whānau and aiga carers of \$10.8 billion per annum.<sup>4</sup>

### ***Mahi Aroha* has been developed in partnership**

17. Officials from the Ministry of Social Development (MSD), together with officials from agencies across government, (including the Ministry of Health, Ministry of Education, Accident Compensation Corporation, Te Puni Kōkiri and Oranga Tamariki—Ministry for Children) worked with the Carers Alliance to develop *Mahi Aroha*. The content has drawn on:

<sup>3</sup> A consortium of 45 not-for-profit organisations seeking progress for family carers.

<sup>4</sup> Infometrics (2014) *The economic value and impacts of informal care in New Zealand*. In 2019 the value of this support is likely to be greater due to inflation and the possible increase in the number of carers.

- information about challenges and opportunities for carers from previous Action Plan consultations
- existing international and domestic carer-focused research
- priority areas for the Carers Alliance
- engagement with carers, including targeted engagement with Māori, Pacific, young and older carers carried out in October 2018 (SWC-18-MIN-0120 refers), and during July and August 2019 (SWC-19-MIN-0057 refers).

### **Carers' voices have informed the development of *Mahi Aroha***

18. In May 2019, Cabinet approved the release of the *Mahi Aroha* Discussion Document for consultation (SWC-19-MIN-0057 refers). The consultation process ran during July and August 2019 and provided carers throughout New Zealand with the opportunity to share their opinions on *Mahi Aroha* through face-to-face workshops, an online survey, and written submissions. Engagement was promoted through government agency networks and stakeholders, including the Carers Alliance.
19. In partnership with the Carers Alliance, MSD held 17 face-to-face workshops across New Zealand. These workshops were mainly focused on hearing the voices of carers themselves, but in some instances, were also attended by representatives of provider and advocacy organisations. Eight workshops were open sessions, four were hui, four were talanoa, and one was targeted specifically at ethnic communities. A variety of sessions were offered in order to help carers feel welcome, safe, and encouraged to share their views and experiences.
20. In total, 242 people attended the workshops, while 603 people responded to the online survey. Twenty-four written submissions were also received. Thirteen of these responses were from individual submitters, and nine from organisations.
21. The Action Plan is called *Mahi Aroha*. The name *Mahi Aroha* was tested with various groups before consultation began. These groups included the Ministry of Social Development's Māori Leaders Forum, the Māori Reference Group, and the Pacific Reference Group.

### **Consultation showed broad support for *Mahi Aroha***

22. Carers indicated that the significant issues have not changed since the development of the last Action Plan, and that the work to address these areas needs to continue. Carers expressed broad support for the content of *Mahi Aroha*.
23. Carers stated that the absence of respite options, the lack of support when things are not going well, and an inadequate degree of carer agency and flexibility in how they access and make use of the supports and services available to them is taking a significant toll on their wellbeing.

*“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.”*

*“Burn out. It’s such a big issue, but no one talks about us. All of us have had breakdowns, many of us have checked ourselves in to get help, to get a break away. But no-one ever talks about us, does anything about it. What we do helps the government so much and means they don’t have to do it. But we get treated like nothing.”*

24. During consultation, carers confirmed that they want their work to be recognised and valued. Recognition from service providers, employers and communities will contribute to carers receiving better access support and other opportunities.

*“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?’.”*

25. Carers also explained that some people in care roles do not see themselves as carers, making it difficult for the services available to reach these groups. Carers emphasised a need for timely, accessible, culturally safe and appropriate resources and learning.

### **Some emerging issues for carers were identified**

26. Carers spoke about the financial pressures they face as a result of their care roles. They described the transition from working to caring as being like a ‘cliff-face’ – going from income and stability, to inadequate financial support and instability.

27. The reduced income from not working came at a time when carers often faced increased costs. Many carers highlighted the multitude of medications and appointments necessary, the need to travel for regular appointments, and the necessary purchase of specialised equipment.

28. A majority of carers indicated that they have been caring for five years or more, and that these costs continue to increase for their families. For many, there is a real concern about how they will support themselves into retirement and older age. Many are facing the struggle of living in poverty.

*“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?”*

29. Some carers also spoke about experiencing violence from the people they are caring for.

*“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."*

### **The feedback has been summarised**

30. MSD officials have summarised the feedback and comments received during the consultation process. This information is completely anonymised. In order to show carers and other respondents that their views have been heard, I will release the Summary of Submissions report publicly, once Cabinet has approved *Mahi Aroha*. Once released, the Summary of Submissions will be posted on the MSD website, and will be sent out via the channels used to advertise the consultation and workshops.

### **Mahi Aroha focuses effort around four areas**

31. *Mahi Aroha* (attached as an Appendix) builds on the two previous Action Plans, and continues to contribute to the vision and direction of the original Carers' Strategy. It will work to improve the choices of parents and other carers, so they can better balance their paid work, their caring responsibilities, and other aspects of their lives.
32. The 17 actions of *Mahi Aroha* have been organised under the following four focus areas:
- **Recognising** – Recognising carers and the contribution that they make. New Zealand's carers are often not recognised for the important work that they do. This can make it hard for them because their role might not be acknowledged by health professionals, employers or teachers. It can mean they feel undervalued.
    - *Action 1.1:* Promote recognition by government, employers, and community of carers as a distinct group with specific needs and whose contributions are valued.
    - *Action 1.2:* Develop and implement a national campaign to raise awareness of carers and their contribution.
    - *Action 1.3:* Create a fund to research the needs of carers to support more tailored and informed responses. This will include research on young, older, Māori, Pacific carers; research on the barriers and impacts of balancing care and employment; and the incidence and impact of family violence for carers.
    - *Action 1.4:* Improve data about carers through opportunities to use existing data collection tools; and support the work to develop a tool to help identify young carers.
    - *Action 1.5:* Support the inclusion of young carers in policy development.

- **Navigating** – Supporting carers to access the assistance they are entitled to. It can be hard for carers to know where to go to find out about what support services are available.
  - *Action 2.1:* Identify and assess best practice options for supporting people and their carers with the management of continence.
  - *Action 2.2:* Strengthen navigation across all parts of the care and support system (including health, welfare, and ACC) to ensure carers are aware of, and supported to access, available assistance for themselves and those they care for. This includes improving information sharing through the National Health Information Platform (NHIP), and updating A Guide for Carers.
  - *Action 2.3:* Identify whānau, aiga, and family centred tools and initiatives that provide culturally safe and responsive approaches for Māori and Pacific carers and their whānau, aiga, and families.
  - *Action 2.4:* Improve the quality, accessibility and equity of services across New Zealand for carers to be able to take a break (including the Flexible Disability Respite Budgets - iChoose).
- **Supporting** – Caring for the carers by focusing on the supports available to them that can improve their health and wellbeing and help them manage the financial costs of caring.
  - *Action 3.1:* Identify and support young carers, their families, whānau and aiga to access the support they need.
  - *Action 3.2:* Help carers to be able to participate in social networks, have opportunities to keep up relationships, and enjoy interests outside of their caring role, with a specific focus on older carers.
  - *Action 3.3:* Enhance access to information, guidance and support of mental health and addictions, for carers and the services and organisations working with the families, whānau, and aiga of people who have a mental health and/or addiction issue.
  - *Action 3.4:* Change to health sector Funded Family Care policies and repeal of Part 4A of the New Zealand Public Health and Disability Act 2000.
  - *Action 3.5:* Review policy settings for financial supports for carers including consideration of: Attendant Care policy (ACC); Individualised Funding (MoH); the policy settings for Funded Family Care in the medium to long-term, to ensure a coherent set of financial supports for carers (MoH); Supported Living Payment - Carers (MSD).
  - *Action 3.6:* Consider a carer payment and/or other types of financial support for carer wellbeing.

- **Balancing** – Supporting carers to balance work, study and other commitments with their caring role.
    - *Action 4.1:* Launch of Carers New Zealand CareWise initiative to ensure workplaces are carer friendly and that carers are supported to stay in or return to employment when caring ends.
    - *Action 4.2:* Support flexible study, training and education opportunities. Explore ways to credit skills and experience towards any training, qualifications and/or employment.
33. The actions in *Mahi Aroha* reflect consistent and long-term priorities for carers – improving respite, increasing financial support, and achieving greater recognition of carers. *Mahi Aroha* also incorporates the issues which emerged during the latest consultation process.

### ***Mahi Aroha* introduces an additional focus on target population groups**

34. Like the previous two Action Plans, *Mahi Aroha* is for all carers. However, caring is not the same for everyone. Therefore, *Mahi Aroha* includes a particular focus on four target population groups: Māori, Pacific, older, and young carers. A population focus means continuing to support all carers while recognising the diversity of our population and addressing the different supports carers may need.
35. The experience and impact of caring can reflect culture, age or gender. For instance, many carers, particularly those who come from Māori and Pacific backgrounds, do not identify as being carers. They are therefore less likely to access existing services and support available to them. More needs to be done to ensure these carers are able to access the support they are entitled to, and to ensure that services are culturally safe and appropriate.
36. There are also some carer groups who we simply do not know enough about. For example, there are information gaps about young people who have experience of providing care. This includes understanding how caring impacts young people's participation in education and employment. Additionally, as the population ages, there are increasing challenges facing older carers. These include social isolation and the increasing number of people suffering from dementia.
37. It is likely that future Action Plans will include other population groups, such as refugee and migrant populations.

### ***Mahi Aroha* aligns with this Government's focus on wellbeing...**

38. Our Government has expressed a desire for every New Zealander to have access to world-class education and healthcare, to live in a home that's healthy and in a community that is safe, and to realise their potential. The first priority in this wellbeing focus is to ensure that everyone who is able to, is either earning, learning, caring or volunteering. *Mahi Aroha* is part of the response to this priority.

39. *Mahi Aroha* uses a wellbeing approach. Focus areas and objectives incorporate the Treasury Living Standards wellbeing domains. These include cultural identity, social connections, knowledge and skills, and income.

**...as well as a range of ongoing key Government work-streams**

40. *Mahi Aroha* aligns with ongoing work by the Ministry of Health on the Funded Family Care policies and I Choose, which are priorities in *Mahi Aroha*. Other relevant work includes (but is not limited to):
- The overhaul of the welfare system, informed by the report of the Welfare Expert Advisory Group.
  - Better Later Life Strategy (Office for Seniors)
  - Healthy Ageing Strategy (Ministry of Health)
  - New Zealand Disability Strategy (Office for Disability Issues)
  - Transforming Respite: Disability Support Services Respite Strategy (Ministry of Health)
  - He Korowai Oranga (Ministry of Health)
  - 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing (Ministry of Health)
  - Health and Disability System Review
  - Disability Support System Transformation (Ministry of Health)
  - The Government response to the Mental Health and Addictions Inquiry

**Mechanisms are in place to monitor progress in implementation of *Mahi Aroha***

41. The Carers' Strategy includes an ongoing programme of monitoring through an annual report on progress against *Mahi Aroha*'s objectives. Under the last Action Plan the reports were provided to the Minister responsible (during that time the Minister for Seniors and then the Minister for Social Development). In order to ensure accountability MSD will continue to coordinate the annual cross-agency progress report.
42. As this is a cross-agency Action Plan, I seek your agreement to have the annual monitoring of progress reported to the Social Wellbeing Committee, with the first report being due November 2020.

**Launching the Action Plan**

43. I intend to launch *Mahi Aroha* on 5 December 2019.
44. I request that Cabinet authorise me to make minor editorial and design changes to the *Mahi Aroha* as required prior to the launch and public release.

## Consultation on this Cabinet Paper

45. MSD has worked in partnership with the Carers Alliance to ensure *Mahi Aroha* reflects the things that matter most to carers. *Mahi Aroha* also includes actions on four priorities for the Carers Alliance.
46. Consultation has been undertaken with The Accident Compensation Corporation, Corrections, Department of the Prime Minister and Cabinet, Kāinga Ora, Ministry of Business, Innovation and Employment, Ministry of Culture and Heritage, Ministry of Education, Ministry of Health, Ministry of Justice, Ministry of Transport, Ministry of Foreign Affairs and Trade, Ministry for Pacific Peoples, Ministry for Women, Ministry for Youth Development, New Zealand Transport Agency, Office for Disability Issues, Office for Seniors, Oranga Tamariki—Ministry for Children, Police, Social Investment Agency, Statistics New Zealand, Te Puni Kōkiri, Tertiary Education Commission (TEC), and The Treasury.

## Financial Implications

47. s 9(2)(f)(iv)

[Redacted]

48. s 9(2)(f)(iv)

[Redacted]

## Legislative Implications

49. There are no direct legislative implications in this paper, though legislative change may be required to progress some actions.

## Impact Analysis

50. A Regulatory Impact Analysis Statement is not required.

## Human Rights

51. *Mahi Aroha* is consistent with the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993.

## Gender Implications

52. Caring is a heavily gendered role in New Zealand. Sixty-three percent of our family carers are women, and unpaid carers are twice as likely to be female. Women who are in caring roles devote an average of 30 hours per week to caregiving, on top of any paid work and other family commitments.
53. Our consultation process reflected the disproportionate number of women in caring roles, with 86% of survey respondents, and 78% of workshop attendees being women.

While *Mahi Aroha* is for all carers, it recognises the gender imbalance, and considers options that support women in their care role. Action 17 has a specific focus on supporting carers back into the employment and training. In addition, actions that specifically address the needs of the four target populations – Māori, Pacific, young and older carers – are also expected to benefit women within these population groups.

### **Disability Perspective**

54. Many carers are supporting a disabled person or have a disability themselves. Consultation on *Mahi Aroha* included feedback and views from carers who look after disabled people, as well as carers living with a disability. Supporting the wellbeing and sustainability of people in a care role could in turn enhance the ability of disabled people to live well and independently and reduce cases of abuse against disabled people in the care context.
55. *Mahi Aroha* complements the New Zealand Disability Strategy 2016. MSD will continue to work with the Office for Disability Issues to share information and ensure that actions from both *Mahi Aroha* as well as the refreshed Disability Action Plan 2019-2023 align.
56. *Mahi Aroha* also aligns with the United Nations Convention on the Rights of Persons with Disabilities (Articles 19 and 23 specifically).

### **Publicity**

57. I will host a launch event for *Mahi Aroha* on December 5, 2019.
58. MSD, in partnership with the Carers Alliance, will use their communications channels, including their key stakeholder relationships, their website, and social media to promote the launch and raise awareness of *Mahi Aroha*. MSD will manage stakeholder and media enquiries in co-ordination with my office.

### **Proactive Release**

59. I intend to proactively release this Cabinet paper as soon as possible in accordance with proactive release guidelines.

## Recommendations

60. The Minister for Social Development recommends that the Committee:

1. **note** that consultation on *Mahi Aroha* has been completed and indicated broad support for the Plan.
2. **agree** to the release of *Mahi Aroha: Carers' Strategy Action Plan 2019-2023*.

**Agree/Disagree**

3. **authorise** the Minister for Social Development to make minor editorial, design and formatting changes to *Mahi Aroha* as required prior to public release.
4. **agree** to launch *Mahi Aroha* on December 5 2019.

**Agree/Disagree**

5. s 9(2)(f)(iv)



6. **agree** that the next annual monitoring of progress report to the Social Wellbeing Committee will be due in November 2020.

**Agree/Disagree**

Authorised for lodgement

Hon Carmel Sepuloni

Minister for Social Development