

Chair  
Cabinet Social Wellbeing Committee

## **Initial engagement to support the development of a new Carers' Strategy Action Plan 2019 - 2023**

### **Proposal**

1. This paper seeks your approval to undertake initial engagement with carers to better understand their needs and priorities. Engagement will be via two channels:
  - an accessible online survey which will enable all carers to inform the development of the Carers' Strategy Action Plan.
  - face-to-face workshops with particular population groups. The four populations are Māori carers, Pacific carers, younger carers, and older carers.

### **Executive Summary**

2. Individuals, family and whānau carers are people who support wider family or friends with a disability, illness, or health condition who need additional help with their everyday living. In New Zealand, a carer is most likely to be a family member. These carers are more likely to be working age women who are caring for an older person. 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.
3. 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 informal carers. The Strategy outlines a vision and guiding principles which will be carried forward into the next Action Plan. The Strategy is a cross-government partnership with key agencies and the New Zealand Carers Alliance (a consortium of 45 not-for-profit organisations seeking progress for family carers).
4. The 2013 Census identified approximately 430,000 carers in New Zealand. This was about 10 per cent of the population, and reflected a 13 per cent increase from the 2001 Census. This may not, however, represent the true number of carers. Demand for carers is growing as a result of changing demographic trends, including an ageing population and the increasing prevalence of long-term conditions.
5. The current Action Plan 2014 - 2018 will expire at the end of this year and officials across a range of agencies, including the Accident Compensation Corporation (ACC) and the Ministries of Social Development (MSD), Health (MoH), Business, Innovation and Employment (MBIE), and Education (MoE) are working with the Carers Alliance to develop a new Action Plan. This presents an opportunity to think about how we can better support carers, given the importance of what they do and in response to future trends.
6. Carers are a diverse group, reflecting a variety of ages, genders, ethnicities and cultures. There is some information about key challenges and opportunities for carers from previous Action Plan consultations, research, and engagement with the Carers Alliance.

7. However, research in the New Zealand context is limited. Recognised issues for this sector include:
  - being able to take a break is important, but accessing flexible respite care services is still difficult for many
  - formal support systems are complex and can vary depending on region
  - people do not always see themselves as carers, and may not be aware of services and supports, and
  - a care role can have a wide range of impacts on individuals including, health, finances, employment, education, culture and more – but supports and/or services often do not focus on the needs of carers.
8. The limited New Zealand research means little is known about the needs of some groups of carers. To ensure that a new Action Plan is driven by the actions carers think are the most important, I propose:
  - releasing an online survey to all carers to follow up and expand on previous feedback, and
  - holding a small number of targeted workshops with Māori, Pacific, younger and older carers to understand their particular experiences of care and what they need to support their care role.

## **Background**

9. Carers are people who support family or friends with a disability, illness, or health condition who need additional help with their everyday living. These care arrangements are often described as ‘informal’, but can be highly structured and cover a spectrum of care needs. Care, in these contexts, can range from unpaid through to entering into employment-type arrangements with the care recipient.
10. In 2008 Hon Ruth Dyson launched the Strategy in response to a call to action by the Carers Alliance to improve supports for carers. Actions in previous Action Plans have been led by a range of agencies (MoH, MSD, MBIE, ACC and MoE). MSD has had a leadership role in the development of the Action Plan, while most initiatives have been led by MoH due to the strong linkages between carers and the health system. Other agencies have been involved in actions, such as supporting pathways to employment, protecting employee rights, providing information on the caring role (including health and safety), and providing opportunities for education, training and development.
11. The 2013 Census identified approximately 430,000 carers in New Zealand. This was about 10 per cent of the population, and reflected a 13 per cent increase from the 2001 Census. Of the people who identified as being a carer, 63 per cent were women. This pattern changes for carers over 65 years of age where men are more likely to be a carer than women. Infometrics estimated that the replacement value of support provided by carers in 2013 was within the range of \$7.3 billion to \$17.6 billion.<sup>1</sup>
12. Demand for carers is growing as a result of changing demographic trends, including:
  - the ageing population
  - the growing prevalence of long-term conditions
  - more older people being supported to live in their own homes

<sup>1</sup> Infometrics. (2014) The economic value and impacts of informal care in New Zealand.

- advances in medicine meaning younger people with high support needs are living longer in the community.
13. In addition to these trends, our family structures are changing and our population is becoming more ethnically diverse.
  14. Research about carers in the New Zealand context is limited. Recognised issues for this sector include:
    - being able to take a break is important, but accessing flexible respite care services is still difficult for many
    - support systems are complex and can vary depending on region
    - people do not always see themselves as carers, and may not be aware of services and supports, and
    - a care role can have a wide range of impacts on individuals including, health, finances, employment, education, culture and more – but supports and/or services often do not focus on the needs of carers.
  15. During engagement with carers on previous Action Plans they have continued to raise these issues, and work will be undertaken to consider these issues in the development of the new Action Plan. However, it is also important to better understand the less known issues and care experiences for specific carer population groups, including Māori, Pacific, younger and older carers. In addition to releasing an online survey to seek these views and perspectives from all carers, I propose initial targeted engagement with these four carer groups to inform development of a new Action Plan.
  16. The engagement I am proposing will assist how actions over the next five years are designed. My officials therefore need to work closely with the Ministry for Women, Te Puni Kōkiri, the Ministry for Youth, Ministry for Pacific Peoples, the Office for Seniors, Office for Disability Issues, and the Office of Ethnic Communities.

### **Sector expectations**

17. The current Action Plan 2014 - 2018 is on track to complete the remaining actions before it expires at the end of this year.
18. The Carers Alliance has voiced its concern about the low level of ambition of previous Action Plans to support the Strategy. The level of investment in the new Action Plan is likely to be reflected in the sector's support for it.
19. Earlier this year the Carers Alliance confirmed its top priority areas to be considered in the new Action Plan. These are:
  - a fair, consistent and accessible respite system, so people are able to take a break from their caring role
  - flexible funding options so families are empowered to choose their own support
  - changes to MoH and District Health Board (DHBs) Funded Family Care (FFC) policies
  - accessible continence support and services.
20. The \$80,000 per annum appropriation from Vote Social Development for the Strategy (for provision of information) means most actions are resourced from the relevant agency baselines and coverage of activity has been limited across the carer population groups. This includes small-impact initiatives such as developing resource material and coordination services.

*There is a lot of interest internationally in ways to better support carers and sustain care roles to reduce pressure on health and social care systems*

21. My expectation for the new Action Plan is that it is bold and aligned to the needs of carers. Achieving this will require cross-government effort.
22. There is growing global interest in better supporting carers due to similar societal trends of ageing populations, increasing long-term conditions, and pressure on health and social care systems. International research in countries such as the United Kingdom (UK) and Australia shows that carers can be supported by promoting a better work-life balance through more choice and flexibility. Examples include care leave; training, scholarships, information and counselling; and providing care allowances, cash benefits, vouchers and tax incentives. In 2014 the UK established legislation to protect carer rights and Australia has recently announced an annual \$600 payment for carers to help meet additional costs associated with care.

### **The strategic direction of a new Action Plan**

23. The development of a new Action Plan is supported by a wellbeing approach with a focus on actions intended to make a material change to the lives of carers and their families.
24. The approach takes into account Treasury's Living Standards Wellbeing Framework and the Whānau Rangatiratanga Framework. The Whānau Rangatiratanga Framework incorporates tikanga Māori principles, has been used in the annual Family and Whānau Status Reports, and as a tool to evaluate MSD's E Tū Whānau programme. It will ensure a Te Ao Māori perspective is embedded within the new Action Plan.
25. While carers are clear they value the caring role, they face challenges and experience other impacts as a result. When compared to people who do not hold the same caring responsibilities, carers may face poorer mental and physical health, loss of social connections, and negative impacts on financial circumstances and paid employment. This is particularly relevant for women, who are more likely to be carers, as the care role can have significant impacts on their health, employment, and ability to save for retirement. Carers' wellbeing is also important to the future of the care recipient.<sup>2</sup>

### *A populations approach*

26. While the Action Plan is intended to support all carers, some groups:
  - are reluctant to ask for help for a number of reasons (including traditional/cultural family values, stigma, and bullying for younger carers)
  - have difficulty accessing appropriate services and supports
  - may not identify themselves as being a carer, because caring may be seen as part of natural family responsibilities and they may therefore not attempt to access any formal services or supports.
27. This may mean people are not accessing services or supports to help them and this could be having avoidable negative impacts on their lives. This could be particularly pertinent for different communities, such as Māori and Pacific carers whose perspectives of, and approach to, caring for immediate family and wider whānau members is a strong feature

<sup>2</sup> These issues have been identified from ongoing consultation with the sector and findings from the New Zealand and international research including Goodhead, A. & McDonald, J. (2007) Informal Caregivers Literature Review: A report prepared for the National Health Committee. Health Services Research Centre, Victoria University of Wellington.

of the Māori and Pacific culture. Caring is also mostly undertaken by women. A Māori woman is more likely to be a carer than a woman in any other population group.

28. Due to the high percentage of carers across all population groups that are women, effort will be focused on developing an Action Plan that reflects this and considers options to better support women in their care role and improve their wellbeing.
29. There are also information gaps on the impact of care roles for young people, including their future trajectory of educational achievement, employment, and participation in society. In addition, as the population ages, there are increasing challenges facing older carers such as social isolation, the rising number of spouses experiencing long-term conditions, including dementia and Alzheimer's, and carers themselves who may have disabilities or need care.
30. Therefore I propose to include an additional focus on Māori, Pacific, younger and older carers. Initial targeted engagement presents an opportunity to engage with these groups in local communities to better understand their experiences and what they need to better support their care role.
31. Due to the increasing ethnic diversity in New Zealand and amongst carers, officials will also be connecting with the Office of Ethnic Communities to ensure that diverse carer population groups can contribute to the development of the new Action Plan including through the online survey engagement, and wider public consultation next year on the proposed options for a new Action Plan.
32. It is also important to better understand how the recognised priorities emphasised from engagement with carers over previous Action Plans impact on specific carer population groups. This is to ensure specific care experiences and unique needs of this group can be considered in the development of a new Action Plan to improve their wellbeing.

## **Engagement**

33. To assist the development process, I propose to undertake two phases of engagement with carers:

### *First phase: two streams of initial engagement*

- releasing an online survey through multiple channels to all carers to contribute to the development of a new Action Plan.

My officials are working with the Office for Disability Issues, Office for Seniors, and using translation services to ensure the survey is accessible to all carers.

- conducting workshops with Māori, Pacific, younger and older carers. These face-to-face engagements are focused on gathering information and testing existing knowledge of recognised issues for these carers and their families.

### *Second phase: Public consultation – early next year*

- engagement with carers on the draft Action Plan will occur through a public consultation process in early 2019. This will include re-connecting with those carers who were part of the initial targeted engagement activity in October.

## **Alignment across key work streams**

34. The development of a new Action Plan is occurring alongside other key government work-streams and international obligations. These include:
  - development of the refreshed 2001 Positive Ageing Strategy

- work on Funded Family Care (FFC) and the MidCentral prototype of a transformed disability support system (commencing 1 October 2018), as well as the broader Health and Disability System Review
  - work on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the New Zealand Disability Strategy Action Plan.
35. I have agreed with the Minister of Health that respective agencies will work together to ensure coordination and sharing of information from engagements where appropriate.
  36. The recent consultation carried out to support the refreshed 2001 Positive Ageing Strategy has already provided valuable information on broader thematic issues concerning older carers and carers of older people.
  37. Other relevant work programmes include the Mental Health and Addiction Inquiry, the Youth Strategy, and the Welfare Expert Advisory Group (WEAG) work, looking at the interface between the welfare and other support systems. I have directed my officials to work alongside officials leading key work streams, as well as to provide information to the WEAG to ensure the current MSD benefit system that supports carers (such as the Supported Living Payment and Child Disability Allowance) is considered in any recommendations from its work.
  38. MSD will also ensure that the Strategy will make links with the development of the Child Wellbeing Strategy.

#### *Funded Family Care – led by the Ministry of Health*

39. FFC policies are of significant interest to the Carers Alliance. For many family carers the majority of the support they provide to family and friends is not paid. However, MoH, District Health Boards (DHB) and ACC have policies that allow for payment of family carers in specific circumstances.
40. Financial assistance to support and sustain a family member in their care role needs to be considered within the context of the Government's broader policies on family carers. MoH's policies about payments of family carers is an increasing issue for the disabled and caring sector. The Minister and Associate Minister of Health will report to Cabinet on options for change to FFC policy and legislation, including DHB policies around payments to carers, and the impact any potential changes to FFC will have on the wider population of family carers. MSD and MoH will continue to work together to collaborate and share information and to align engagement activity where possible.

#### *Flexible funding and individualised funding*

41. Disabled people and their families want greater control over the services and supports available to them. This is reflected in the trials currently underway as part of MoH's transformation of the disability support system to explore new ways of delivering these services and supports. Enabling Good Lives (EGL) demonstration sites are up and running in Waikato and Christchurch, with a prototype of the transformed disability support system commencing in MidCentral District Health Board region on 1 October 2018.
42. Recently the Carers Alliance commissioned a report on flexible funding titled: *Flexible Funding to Support Disabled People and Their Families: A review and analysis of New Zealand's flexible funding market*. This report proposed using structures such as EGL to accelerate the transformation of the disability support system through the release of individualised funding as personal budgets, as is being trialled, and to make urgent changes to how the current individualised funding system is hosted.



43. The Ministry of Health is currently investing over \$30 million per year in flexible respite budget to make it easier for 19,000 carers who support a person with a disability to take a break through an annual cash payment that enables families to buy respite services and supports that best meets their needs.

### Timeline for the new Action Plan

44. There are three key stages to developing the Action Plan:
- the release of an online survey and targeted engagement over September and October 2018
  - wider public consultation over the proposed new Action Plan in early 2019
  - intended announcement and launch of the new Action Plan in mid-2019.
45. The table below outlines the indicative timeline for progress:

Date	Activity
September / October 2018	<p>Releasing an online survey to all carers, and undertaking targeted engagement with specific carer groups (Māori, Pacific, younger, and older) to inform development of the Carers' Strategy Action Plan.</p> <p>This coincides with the Office for Disability Issues carrying out public consultation and initial engagement activity on a new action plan for the New Zealand Disability Strategy, and the Ministry of Health undertaking targeted engagement for Funded Family Care</p>
January / February 2019	Draft discussion document and proposed Carers' Strategy Action Plan for Cabinet consideration
February / March 2019	Wider public consultation on the proposed Carers' Strategy Action Plan
April / May 2019	Development of the final Carers' Strategy Action Plan for Cabinet approval
May – June 2019	Announcement and launch of the Carers' Strategy Action Plan

### Communication

46. My officials are working on a communications plan to ensure the public are engaged in this process and understand the linkages between the Carers' Strategy Action Plan and the other key work streams identified in this paper.
47. My office will provide suitable material for Ministers with related portfolio interests to use where necessary.

### Consultation

48. The Ministries of Social Development, Health, Education, Business, Innovation, and Employment, ACC and the Carers' Alliance are engaged in the development of a new Action Plan and have been consulted on this paper.
49. Other government agencies that have been consulted on this Cabinet paper include: the Treasury, Department of Corrections, Department of Internal Affairs (including Community and Voluntary Sector and Office of Ethnic Communities), Housing New Zealand

Corporation, Ministry for Pacific Peoples, Ministry for Women, Oranga Tamariki – Ministry for Children, Ministry for Culture and Heritage, Ministry of Justice, Ministry of Transport, New Zealand Transport Agency, Statistics New Zealand, Te Puni Kōkiri, New Zealand Police, Office for Disability Issues and Office for Seniors.

50. The Department of the Prime Minister and Cabinet and the Human Rights Commission have been informed.

### **Financial implications**

51. The costs associated with the consultation outlined in this paper will be covered by baseline funding.
52. Work is currently underway to develop the new Action Plan. Actions under this plan will likely require additional investment. This could be sourced through future budgets, and/or leveraging off existing revenue streams across government. My officials are working with agencies to explore potential activity across the five years of the Plan. Detailed proposals will be brought to Cabinet for consideration in early 2019.

### **Disability perspective**

53. A large number of carers look after people who have a disability. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities includes the contribution from carers about their rights to exercise choice over living arrangements and supporting the broader contribution carers make to help people to live and participate in their communities.
54. The proposal to undertake targeted engagement will include feedback and experiences from carers who look after disabled people, as well as carers who may have a disability themselves.
55. Officials are working closely with the Office for Disability Issues to share information and to ensure future actions from both the refreshed Disability Action Plan and the Carers' Strategy Action Plan consider the implications for the carer as well as the disabled person being cared for.
56. The online survey will be designed to enable disabled carers to participate and contribute their experiences to inform the design of the Action Plan.

### **Human rights and legislative implications**

57. There are no human rights or legislative implications arising from this paper.

### **Regulatory impact and compliance cost statement**

58. There are no regulatory or compliance cost implications arising from this paper.

### **Impact Analysis**

59. No Impact Analysis statement has been prepared for this paper. An Impact Statement will accompany the proposed Action Plan early next year.



## Gender Implications

60. While family carers are predominantly women and officials anticipate that engagement activity will be undertaken with mainly women providing care, views and perspectives from all carers will be considered in the new Action Plan.
61. Due to the high percentage of carers being women, it is important that the new Action Plan reflects this and considers options that support women in their care role and will make a material difference to their wellbeing.

## Publicity

62. My officials are working with the Carers Alliance to publicise the process. The communications plan to support this work is under development.

## Recommendations

I recommend that the Committee:

- 1 **note** that the Carers' Strategy Action Plan 2014 - 2018 will expire at the end of 2018 and a new Action Plan is being developed with partner agencies and the Carers Alliance.
- 2 **note** that carers play a crucial role to support people to live and participate in their communities and New Zealand's changing demographics means that there will be an increase in demand for carers to reduce the dependence on health and aged care systems.
- 3 **note** that a new Action Plan is supported by a wellbeing framework with goals to:
  - a. improve the wellbeing of carers and provide them with choice and options to support their role and have control over their lives;
  - b. assist the Government to respond to the current and future demographic trends and ensure the carer role is sustainable.
- 4 **note** that to develop a new Action Plan that makes a material difference for carers, it is important to better understand the care experience and needs of all carers.
- 5 **approve** the release of an online survey for carers, and for targeted engagement to be carried out with a focus on specific carer groups (Māori, Pacific, younger, and older carers).
- 6 **note** that targeted engagement on the new Action Plan will be coordinated appropriately with government consultation on the Funded Family Care work and a new Action Plan (2019 – 2022) for the New Zealand Disability Strategy.
- 7 **invite** the Minister for Social Development to report back in early 2019 on proposed options for a new Action Plan.

Authorised for lodgement.

Hon Carmel Sepuloni  
Minister for Social Development