Mental Health Foundation
mauri tū, mauri ora
OF NEW ZEALAND

Submission on the Draft Carers' Strategy Action Plan

By the Mental Health Foundation of New Zealand

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Email to: CAPsubmissions@msd.govt.nz
Ministry of Social Development

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Tuia te rangi e tū nei
Tuia te papa e takoto nei
Tuia i te here tangata
Tihei mauri ora.

He hōnore, he korōria ki te atua ki te runga rawa
He whakaaro maha ki a rātou kua haere ki te wāhi ngaro
Rau rangatira mā, ānei ngā whakaaro me ngā kōrero nā Te Hauora Hinengaro.

Thank you for the opportunity to provide a submission on the Draft Carers' Strategy Action Plan.

The Mental Health Foundation of New Zealand (MHF) is an independent voice for better mental health, which works to promote everyday actions that lift mental wellbeing, provides tools that support people through tough times, and advocates for a better mental health system and society.

While the MHF does not explicitly represent the views of carers, we are concerned that carers experience significantly poorer wellbeing than the general population. Evidence shows that carers have much higher rates of depression and anxiety, and many are not seeking support for their own mental health needs. Carers also report very high levels of loneliness, lower life satisfaction, and poorer physical health compared to the general population. Carers aged under 35 years report particularly concerning outcomes, including the lowest levels of physical health and the highest levels of depression and anxiety.[i]

Although current data does not clearly specify the proportion of carers supporting people with mental health and/or addiction challenges, anecdotal evidence suggests that unpaid and informal carers play a significant role in supporting people experiencing mental distress in Aotearoa New Zealand (see Appendix One for quotes from whānau Māori caring for family members under the Mental Health (Compulsory Treatment and Assessment) Act).

Our submission offers insights from a mental health and wellbeing perspective and reflects on the limited system-level progress made to better support carers since publication of *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction* in 2018.

We thank Tricia Hendry for her expert contribution to this submission, and feedback from other carers of people experiencing mental health challenges. We have also consulted with Yellow Brick Road in the development of this submission.

Definition of carers

The proposed definition of carers does not explicitly mention young carers. While definitions vary (*Mahi Aroha – Carers' Strategy Action Plan 2019-2023* identified young carers as those aged 25 and under, while Carers NZ uses a broader under-35 definition), there is clear recognition across the sector that younger carers experience distinct impacts.

The most recent *State of Caring* survey (2022) reports that 4.6 percent of carers in Aotearoa New Zealand are classified as young carers;[1] and we agree with the statement in the draft Action Plan that this is likely an underestimation.[2] The survey was not population-representative, and young carers may be less likely to self-identify as 'carers' or be aware of/participate in carer-focused research.[3] While the cohort may be comparatively small, the available evidence indicates disproportionate negative wellbeing impacts: 46 percent of young carers reported

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[1] Out of a sample size of 1,648 carer respondents.
[2] An MSD infographic notes that nearly 1 in 10 carers are aged 15 to 24 years old (8 percent), which would translate to about 34,400 young people.
[3] We note the previous Carers' Strategy Action Plan states "Young carers may not want to draw attention to themselves, which makes determining the number of young carers difficult."

the lowest levels of general mental health of all carers, and they also experienced the highest rates of loneliness (84%).[ii] As such, **we recommend specifically acknowledging this underrepresented demographic, for example, by widening the references to 'children' to encompass 'young people' more broadly**. Additionally, we note 'parents' are not mentioned, and believe the definition would be more well-rounded if this group was also included.

Furthermore, many people may not identify as carers, even if they would be considered carers under this Action Plan. Many carers have indicated they are missing out or have missed out on supports that they should know about.[iii] We urge the Ministry of Social Development to promote the Plan and any associated resources developed under it widely and equitably, so that people recognise when they may be eligible for support and are aware of the services available to them.

Framing and language

Many carers are propelled into the role, driven not by choice, but by a sense of duty, cultural expectation, or necessity. Nearly two-thirds of carers are employed outside of their caring role (63% in full-time or part-time work),[iv] and 32 percent of carers supporting more than one person had to give up paid employment to provide care.[v] Caring is therefore not a supplementary activity but, for many, a permanent and life-altering responsibility. The impact extends well beyond time commitment, affecting lifelong income security, career progression, education pathways, mental health, and social participation. **The Action Plan's framing should acknowledge the cumulative and long-term impact of being a carer, rather than positioning caring as a discrete or voluntary support function.**

Additionally, some of the language used to describe the deliverables is vague, such as "consider" and "explore". **We recommend using more direct and concrete language to confirm actions**, otherwise it will be difficult to assess progress and ensure accountability.

Te Tiriti o Waitangi

The Plan gives limited attention to the Crown's obligations to Māori carers and whānau Māori under Te Tiriti o Waitangi. Aside from a brief reference to potentially reflecting these obligations through the development of a government data and evidence strategy for carers, there is little detail on how Te Tiriti o Waitangi responsibilities will be upheld in practice. The action relating to cultural safety within existing services is minimal in scope and vague in its description. **We recommend the Plan more explicitly address the cultural appropriateness of services (whether existing or not), including how services are designed, delivered, and evaluated**. This should include meaningful partnership with Māori, support for Māori-led approaches to caring and wellbeing, and recognition of the collective role of whānau in care.

What do you think about the change to a 'rolling' Action Plan to improve outcomes for carers over the short- and long-term?

A rolling action plan could be a useful tool for responding quickly and flexibly to emerging needs, provided it is monitored consistently and robustly. However, its rolling nature increases the risk that actions and associated accountabilities maybe lost through new iterations of the Action Plan. To increase confidence of the sector that the Plan will culminate in tangible change, **we recommend each action clearly identify a lead agency, timeframe, investment stream, and measurable outcomes.**

We are concerned about the lack of corresponding investment information attached to the proposed actions and encourage the Ministry to make this information available as soon as is practicable.

Do you think the set of immediate deliverables are an appropriate first step towards achieving the Action Plan outcomes? How could we make these more effective for you?

Overall, while the MHF supports the aspirations of the Action Plan to achieve better outcomes for carers, we consider that the draft lacks a sufficient sense of urgency and focused action to realise these outcomes.

Many of the proposed actions focus on information gathering, mapping existing supports, and developing system-level processes, rather than delivering immediate improvements in support for carers. While these activities may be valuable, they risk making the plan overly government-focused, rather than centred on tangible improvements for carers themselves. As currently framed, several deliverables may have limited impact at the grassroots level. The Plan could benefit from a greater balance between efforts to improve the information base and actions that deliver practical support and benefits for carers.

The Plan also appears to assume that existing services are largely sufficient and that improving awareness or navigation will address gaps in support. However, feedback from carers we have engaged with, and their representative groups, suggests that in many areas, services are limited or do not exist at all. In these contexts, improving navigation alone will not resolve the underlying issue – service availability must first be strengthened before people can meaningfully access support.

The Plan would benefit from including deliverables to expand existing initiatives that are currently constrained by limited or unsustainable resourcing, particularly those already demonstrating positive outcomes for carers. Strengthening and scaling these initiatives could provide more immediate improvements in support for carers.

Recognition and appreciation

Public awareness and outreach: We support the proposal to launch a National Carers' Appreciation Day in 2026 as one mechanism to raise awareness of the value and contribution that carers make to our society. However, delivery must be meaningful and avoid becoming tokenistic or glossing over the difficult realities of life for carers. We have also heard that communications associated with this day should centre lived experience voices and stories, rather than relying solely on data.

Culturally safe and relevant services: Rather than only "considering" how cultural safety could be better integrated into the delivery and promotion of existing services, **we recommend developing practical guidance and resources to support service providers to embed cultural safety and competence into their work**.

Services are accessible and easy to navigate: We note the action in the previous action plan *Mahi Aroha* to "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." Other than new information for whānau and family of someone being assessed and treated under the Mental Health Act (Te Pou, 2023), which is helpful but narrow in its application, we are unaware of other progress made on this action, and it is unclear whether the desired impact has been achieved, or if this work continues or needs expansion. The discussion document notes overall progress in implementing previous action plans, particularly for *Mahi Aroha* commitments, has been slow. **We therefore recommend this action be replicated in the proposed plan unless sufficient progress is documented.**

We support the action to "explore targeted approaches for improving service access and navigation for carers." However, as noted earlier, **we recommend strengthening the language beyond "exploring"**. We support the development of an accessible website or portal for service navigation and key information, which we hear is overdue. **We recommend drawing on the expertise of the Carers' Advisory Group and including young people in its development**.

Health and wellbeing

Respite and taking a break from caring: *He Ara Oranga* reported on the lack of support services for family and whānau to support their own wellbeing (pages 164-169). It reported that many feel isolated and experience anxiety or depression themselves, and they may support their family member at a high cost to their own mental and physical health. It found limited support and respite options are available and not all families can afford those that are, which can compound the harm of their situation.

He Ara Oranga suggested support for whānau should include information and advice, access to respite services, community support, peer support, and secondary and primary care options. The options available should reflect the diversity of families, including holistic family- and whānau-based services, as well as individual-based support. It recommended wellbeing supports provided to families and whānau needs to be reviewed by the Ministry of Health and other relevant agencies such as the Ministries of Education and Social Development and Te Puni Kōkiri and improvements made (Chapter 8, recommendation 25).

As a first step, we therefore support the action to "establish a national picture and assess current levels of available respite services and break options", and support mental health and addictions as a focus. **We recommend this assessment also review the affordability and accessibility of these options.** In line with *He Ara Oranga's* recommendation, **we also recommend this assessment be expanded, if not immediately then as a future priority setting, to review availability of**

community support, peer support, and primary and secondary care options for carers of people who have a mental health and/or addiction issue.

It would be useful to clarify what is meant in practice by a "national picture". Ideally, this information would be made available in an accessible, 'real-time' format for both service providers and carers. NGOs and local organisations are often well-placed to provide up-to-date information on available services, and government could play a coordinating role to ensure this information is consolidated, navigable, and well-promoted. However, we reiterate that this action will only be meaningful if it is accompanied by increased capacity and access to appropriate supports.

Carers' needs are considered early and fully: We heard feedback that needs assessments focus primarily on the person being cared for and yet are used to determine the respite supports or services allocated to carers. At present, the emphasis is solely on the person with care needs, yet different families require different levels of respite. If the person declines support, the carer is left without access to respite at all. This places carers in an unsustainable position and fails to recognise their needs, wellbeing, and role in ongoing care. **We recommend the establishment of separate needs assessments, with one assessment for the individual and what they require, and a distinct assessment for the carer(s).** This aligns with the *State of Caring* findings that 86 percent of respondents said that family, whānau and āiga carers should have their own targeted needs assessment. Respite hours should then be allocated to the carer, rather than to the person receiving care.

Financial security

Much of the elevated anxiety and depression experienced by carers is linked to the financial pressures associated with their role. Carers have strongly identified a need for more practical support, including greater financial assistance and improved access to financial resources. Many carers (59%) report struggling to pay their bills, and 15 percent have gone into debt due to caring. A lack of awareness of available services and supports can also increase financial strain, with some carers paying out of pocket to meet care-related costs. Over time, these pressures have significant long-term consequences: 20 percent of carers report being unable to save for retirement at all, 34 percent say their retirement plans have been negatively affected, and only 14 percent report no financial impact from caring.[vi]

While several of the proposed actions align conceptually with the finance-related recommendations from the *State of Caring* report, many focus primarily on mapping existing supports and gathering further information rather than implementing changes that improve carers' financial security. We recognise that the current Plan is intended to lay the groundwork for future improvements; however, **we encourage the inclusion of previously recommended actions that could deliver more immediate support for carers**. For example, the Plan could commit to delivering specific initiatives to support working-age carers to balance paid employment and caring responsibilities.

Some of the proposed actions would also benefit from further clarification. Regarding the proposal to "develop a picture of available financial assistance", **we recommend more clearly outlining how this information will be used and who it is intended to support.** Similarly, **the action to "map out potential pathways" for carers is vague and we recommend clarifying what is meant through examples.** Most employers currently offer limited structured support for carers. Existing initiatives that promote carer-friendly workplaces, such as CareWise, may provide a useful starting point, and the Plan could consider supporting organisations such as Carers NZ to further expand this work.

Data and information

Monitoring and reporting: We are pleased to see the proposal to develop a monitoring and reporting framework including the identification of core indicators to measure the success of the rolling Action Plan. Clear reporting processes and accountability mechanisms will enable the sector and public to track progress over time. **We recommend that reporting be made publicly available and include regular updates to the responsible Minister(s) and annual reporting to Cabinet or another appropriate body.**

Improved data collection: In addition to the proposed actions, **we recommend identifying priority areas for future research to better understand carers' needs and experiences.** Partnering with academic and community-based researchers could support the development of robust and independent evidence to inform future policy and service design.

We also encourage stronger coordination between government agencies in the delivery and ongoing refinement of the Action Plan and research priorities – greater collaboration across agencies, researchers, and community organisations could help ensure that insights from research are translated into practical initiatives that support carers' wellbeing.

Many of these actions are intended to form the basis for future actions. What should we consider as we review and form future actions?

The Mental Health Bill is seeking to embed supported decision-making processes and roles in relation to compulsory mental health assessment and treatment and is due to come into force in 2027. The MHF has expressed concerns to Parliament about how the new supported decision-making regime established by the Bill will be brought to life successfully. At the heart of this is the need for adequate training and guidance for the workforce to ensure decision-making supports are always effective and available to people under the Mental Health (Compulsory Treatment and Assessment) Act and their carers who may assume legislated roles such as a nominated person. **We recommend the provision of information and support for whānau, family and carers in relation to supported decision-making under the Mental Health Act be a future priority for the Action Plan.**

Conclusion

Thank you for considering our submission and recommendations to strengthen the Draft Carers' Strategy Action Plan. We are available to provide further information and advice as required.

Mauri tū, mauri ora,

Shaun Robinson
Chief Executive

Appendix One

The MHF's November 2022 focus group[4] with whānau Māori who have supported family members under the Mental Health (Compulsory Treatment and Assessment) Act talked about the need for more support for whānau in the mental health and addictions system:

We haven't had any support really. Ah well, looks like we have to look after this boy for the rest of our lives. (Whānau participant)

I feel a bit isolated. (Whānau participant)

Even though our son is the one on the meds, what about us? We are not feeling good. I am feeling my own physicality suffer, just from worry or stress. It is about the health and wellbeing for everyone, for the whānau and whaiora. (Whānau participant)

One of the things I say to staff is, you have to deal with this for a few hours a week, whānau have to live with it 24/7... As time has gone on my worry has lessened, but it is still there. It is something I think that people who work in the system don't understand because for whānau it is something we live with every day. (Whānau participant)

It is all about support networks. But we don't know any. (Whānau participant)

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[4] MHF internal report (2023) available on request.

References

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[i] Synergia. (2022). *The State of Caring in Aotearoa: A report for Carers NZ and the Carers Alliance*. https://carers.net.nz/wp-content/uploads/2022/07/State-of-Caring-Report-Aug2022.pdf

[ii] Ibid.

[iii] Ibid.

[iv] Ministry of Social Development. (n.d.). *Who are carers?* https://www.msd.govt.nz/documents/what-we-can-do/community/carers/who-are-carers.pdf

[v] Carers New Zealand, & New Zealand Carers Alliance. (2023). *Who are New Zealand's family, whānau, and āiga carers?* https://carers.net.nz/wp-content/uploads/2024/10/Carers-Infographic-Dec-23.pdf

[vi] Synergia. (2022). *The State of Caring in Aotearoa: A report for Carers NZ and the Carers Alliance*. https://carers.net.nz/wp-content/uploads/2022/07/State-of-Caring-Report-Aug2022.pdf