Re: Draft Carers' Strategy Action Plan

To: CAPsubmissions@msd.govt.nz
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Submitted by: Rare Disorders NZ
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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract. This submission is in regard to the Draft Carers' Strategy Action Plan.

Rare Disorders NZ

Rare Disorders New Zealand (RDNZ) is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300,000 New Zealanders with rare disorders and the people who care for them. We help those living with rare disorders to navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

Our vision is for New Zealand/Aotearoa to become a country where people and whānau living with a rare disorder experience best possible health and wellbeing. We seek to achieve this by enabling and empowering people with rare disorders to best benefit from services and therapies available in New Zealand, and by championing their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand

Submission

Thank you for the opportunity to provide feedback on the draft Carers' Strategy Action Plan. Rare Disorders New Zealand has engaged with other organisations whose work intersects with carers and largely our concerns and issues align, and many are already reflected in the discussion document.

The primary point of difference for Rare Disorders New Zealand is that **we ask that carers of people living with rare disorders are explicitly named and considered in the Carers' Strategy Action Plan**. The Ministry of Health's 2024 Aotearoa New Zealand Rare Disorders Strategy[i] acknowledges that "there are unique experiences that the rare disorders community face when accessing the health and social sector". The Rare Disorders Strategy sets out how the health system will work to improve outcomes for people and whānau living with rare disorders and requires that those involved in designing, commissioning or providing new policies or services routinely consider the needs of people with rare disorders. The Carers' Strategy Action Plan is an opportunity for the social sector to pick up on this directive and ensure that carers in the rare disorder community are considered, recognised and planned for.

An estimated 80% of rare disorders have a genetic cause[ii]. While many appear for the first time in a family, others recur across generations or affect multiple children. This means carers for someone living with a rare disorder may be living with a rare disorder themselves or supporting more than one family member with that disorder. Additionally, 70% of rare disorders begin in childhood, and 95% have no approved treatment[ii]. This means that family members of people living with rare disorders frequently become lifelong carers and face increasing anxiety and concern for how the person's care needs will be met when they can no longer care for them.

Our 2023 voice of rare disorders survey[iii] found that 69% of people living with a rare disorder required assistance from an informal carer, and for these people an average of 2.4 whānau/family members and/or friends were involved in their care and support during an average week. Access to services was difficult for the survey respondents. People did not feel informed at all around the rights related to the consequences of their rare disorder (79%), relevant social services that can help them (73%), financial help they could be entitled to (66%), cultural services e.g. interpreters, whānau care services (64%), nor relevant health specialists and services for the disease (54%). Unsurprisingly, 27% of primary carers for people living with a rare disorder often felt unhappy and depressed and 30% often felt that they could not overcome their problems.

We hear from carers of people living with a rare disorder that they often face additional administrative burden due to pursuing a diagnosis for the person they are caring for, advocating for best practice care in the absence of established care pathways, and struggling to get support from government agencies as they don't neatly fit into a tick box. Rare disorders frequently straddle both physical disability and chronic health conditions and don't fit well into either system.

Page 9 of the Carers' Strategy Action Plan discussion document states that "the action plan aims to… ensure supports and services are tailored to specific groups, for example young or older carers, Māori and Pacific carers, women carers, carers in rural areas, working aged carers, and carers who provide care for those with complex conditions such as dementia". Rare Disorders NZ requests that rare disorders feature in this list and are added to the example of complex conditions so it reads "…such as dementia or rare disorders". In addition to this, carers who themselves have a health condition and/or a disability need special consideration, as do carers who will be life-long carers.

Rare Disorders NZ supports a rolling Action Plan provided there are clear milestones tied to clear timeframes with accountability for named government agencies. This will need to be combined with regular, scheduled public and lived experience reviews and feedback as the rolling nature of the plan evolves and emerging needs and issues for carers are added to the plan.

Currently text within the discussion document indicates that the review of priority areas, actions and immediate deliverables will "ensure alignment with Ministerial and Government priorities and to make sure that we are moving towards an enabling future for carers." It is disappointing this does not include consideration of co-design and how public and lived experience priorities and views will be incorporated. We hope to see this in the final iteration.

The current mix of aspirations, staged approach, and three priority areas combined with multiple actions some of which share a name, feels hard to track. Rare Disorders NZ would like to see the rolling action plan include a public dashboard of progress and next steps with clear milestones, timeframes and accountability, including a named lead agency. A public dashboard of progress will also be essential both to inform the community and build trust.

To be successful, the actions in the rolling plan will need sufficient resourcing and budget. There needs to be a clear plan for how emerging actions will be resourced appropriately and in in a timely fashion as they are added into the Action Plan.

Recommendations for the Draft Carers' Strategy Action Plan A3

Under the **Public awareness and outreach** or the **Services are accessible and easy to navigate** action, as an immediate deliverable we recommend that government agencies providing services to carers develop and deliver professional development around carers lived experience of navigating the support they offer and carers entitlements both internal to the agency and external. For instance, this could involve Work and Income case managers focusing on Supported Living Payment – Carer and the supplementary assistance carers may be entitled to like Child Disability Allowance, as well as learning more about other entitlements outside of Work and Income like Disability Support Services, and ensuring that where appropriate needs assessments have been carried out, and home support services for older people and others through Health NZ.

Under the **Services are accessible and easy to navigate** action, as immediate deliverables we recommend that:

- Government agencies are tasked with delivering guides (written and video) to explain carers entitlements and how to access them. Development of these guides should include advice from frontline staff and carers to ensure that common questions are adequately addressed. These guides do not need to be resource intensive and could be worked on in partnership with NGOs who frequently help carers navigate systems. For instance a carer focused video series like the one Rare Disorders NZ completed with the Ministry of Social Development for people with a rare disorder accessing support from Work and Income which can be viewed here: www.youtube.com/playlist?list=PLJ2MqH224kxVmNfroCsNNdW6qaFklQf2w
- Pathways and systems are designed such that a new diagnosis of a condition that is going to require ongoing care is accompanied by information on financial assistance available to carers and how to apply for it, for instance Child Disability Allowance and Needs Assessment, if applicable.

Under the **Services are accessible and easy to navigate** action, as a future state ambition we recommend that:

- A carer of someone with a chronic health condition receives equitable support to a carer of someone with a physical or intellectual disability (Health NZ funding for older people and others (including long term health conditions) vs Disability Support Services Funding).
- Entitlements for caring for someone with Disability Support Services funding for their disability and funding from Health NZ for their health condition is seamless from the carer/patient end. People are too often told that they need to talk to a different government agency as that part of their disorder is not covered by the same agency. Who pays for what funded service or equipment can be sorted out internally without the carer having to take on the administrative load.

- The administrative burden on caregivers is reduced and government agencies are able to share information such that there is not a constant need to repeatedly provide documentation and proof of disability or health condition and need for assistance. For instance, if someone has recently had Carer Support Subsidy renewed through their NASC, they should not then need to also reapply, provide documentation again and prove their entitlement to Child Disability Allowance from Work and Income.

Under the **Respite and taking a break from caring** action, we recommend that an immediate deliverable is to acknowledge that current respite availability is not meeting the needs of many carers and those they care for. It feels disingenuous to “promote the availability, diversity, flexibility and importance of respite and break options for carers, and what these mean for carers”, when for many there already is no availability both due to limited funding and limited options that meet needs.

We recommend that under the immediate deliverable “Establish a national picture and assess current levels of available respite services and break options”, a ‘Potential focus’ is added to include those with complex care needs for instance those who are all of the listed areas combined e.g. medically fragile, also experiencing mental health crisis, need behaviour support, are physically disabled and have a chronic health condition that needs monitoring and support.

Under the **Health and wellbeing** section we recommend that there is an action around access to mental health support for carers. We recommend that an immediate deliverable is that there is a specific funded pathway for carers as there is for other at-risk population groups.

Under the **Financial wellbeing** action immediate deliverable to ‘develop a picture of available financial assistance for carers, focusing on levels of support and coverage and including analysis on any gaps and inconsistencies’**,** we recommend that this work includes financial support and entitlements for the person being cared for in situations where that person is reliant on the carer to manage and organise their day to day care and finances. We also recommend adding an immediate deliverable to investigate what is currently provided and what could be provided to support carers at times of transitions, including

- When a carer first takes on a caring role.
- When the person being cared for becomes an adult but continues to require a lot of support or complete support with finances and daily living.
- As discussed under the next action, planning for when a carer is no longer able to continue caring.

Under the **Carers' needs are considered early and fully** action, it is imperative that it is recognised in the future state section that for many carers, their care responsibilities will be for the remainder of their life. There may be no 'after caring' for many caring for their adult children, for instance. We recommend that immediate deliverables under this action include exploring availability of services and support to plan, prepare and transition for when the carer is no longer able to care for the person due to their age or own health or disability, and whether current options are suitable and what expansion of this may look like. This should include availability and funding mechanisms for residential care and supported independent living for those with complex care needs.

Under the **Monitoring and reporting** action, we recommend that the government agencies accountable and a title name for the lead from each agency are identified for each deliverable.

The remainder of this submission provides responses from our support group leads with lived experience of being a carer for a person with a rare disorder. Rare Disorders NZ would welcome engagement to further discuss this submission and the specific needs of carers for people living with rare disorders, why and how carers of people with rare disorders should be explicitly acknowledged in the Carers Action Plan, and the results of our 2025 Voice of Rare Disorders Survey, where a third of respondents were the primary carer for a person living with a rare disorder.

Discussion questions

1. 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 is a major step forward to addressing recognition and support for unpaid carers. Will there be a 'rolling' funding pool and 'rolling' resources to continue the Action Plan strategy? The responsibility for this appears to be allocated to NGO's who already struggle to acquire adequate funding and resources from the government so is this plan sustainable in future years?

2. 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?

Appropriate first steps yes, but again, which groups are accountable for these immediate deliverables, will they be adequately resourced, how and when will the outcomes be reviewed and/or renewed? Where is the co-design and consultation?

3. How can government work with communities to implement the Action Plan in the short, medium and long term?

Regular consultation with carer communities through co-design check-ins, regular reviews and updates and accountability, where is the overarching oversight and which group will be responsible for this?

4. Is there anything else that agencies should consider when implementing current actions to ensure what is delivered meets the needs of family, whānau, aiga and individual carers?

Great statement but it is lacking detail, which groups, who exactly will be providing governance and oversight, where is the funding and resourcing coming from, who carries out this work, will it be based on 'evidence' AND all this Data and Information has been collected and collated over past decades, how much money will be wasted on 'new' data gathering instead of building on data that has already been obtained?

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

Apply evidence based informed research from previous data and information sharing, consider consultation with 'lived experience' community, consult with all carer support groups to consider what has worked and what hasn't.

Additional comments

Carers should be recognised with their own Carer's Payment or Carers Allowance, not tacked onto a Supported Living Payment. MSD should recognise Carers as Carers. Tacking carers onto the Support Living Payment is disrespectful and feels like carers are an afterthought, not recognised for the huge role they provide. Carers should also be recognised for the support they provide when caring for multiple persons in their whanau. Review of Circumstances, SLP-Carer forms are routinely submitted by MSD staff into the incorrect review stream which causes anxiety and unnecessary monitoring from carers.

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[i] Ministry of Health. 2024. Te Rautaki o Aotearoa e Pā ana ki ngā Mate Mokorea - Aotearoa New Zealand Rare Disorders Strategy. Wellington: Ministry of Health.

[ii] **The landscape for rare diseases in 2024**
The Lancet Global Health,
The Lancet Global Health, Volume 12, Issue 3, e341

[iii] **Impact of living with a rare disorder in Aotearoa New Zealand**
https://raredisorders.org.nz/about-rare-disorders/2024-white-paper/