



Feedback on the draft Carers' Strategy Action Plan

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1. Key points and recommendations

IHC fully supports the findings of *The Economic Contribution and Sacrifices of Unpaid Family, Whānau and Aiga Carers in New Zealand* (Heyes & Grimmond, 2022), and further recommends that the Ministry of Social Development (MSD):

1. Strengthen the immediate deliverables for Recognition and Appreciation by creating more awareness about who is a carer and expanding the consideration of cultural safety to explicitly include intersectional caregiving factors.
2. Amend the immediate deliverables for Health and Wellbeing to include increasing the availability of respite and break options for carers.
3. Amend the immediate deliverables for Financial Security to include increasing financial assistance available to carers.

Our Chief Executive's (CE) Advisory Group is made up of people with intellectual disability. Cutting across the three priority areas of the Draft Action Plan, they said it would help for their carers: "to be recognised, treated well and listened to".

2. About IHC

IHC advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is largest provider of services to people with intellectual disabilities and their families in Aotearoa New Zealand. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in workplaces and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide specialist services such as behaviour support and training.

IHC advocates for the rights of all people in Aotearoa New Zealand with an intellectual disability an estimated population of 47,000.

3. Recognition and Appreciation

IHC recommends the MSD strengthen the immediate deliverables for Recognition and Appreciation by creating more awareness about who is a carer and expanding the consideration of cultural safety to explicitly include intersectional caregiving factors.

Many carers do not identify themselves using the word 'carer', therefore may not say they are a carer in the Census, seek out financial or other support, or understand their entitlements. The words 'brother', 'whānau', 'partner' etc, can obscure the additional loading that can occur in relationships that include those with disability, health condition, illness, or injury. Targeted awareness campaigns, including within government departments, could support greater recognition and awareness.

Carers sit at the intersection of unpaid work and a multitude of other factors. As identified by Heyes and Grimmond (2022, p. 12), "caring is not something that happens in isolation. Caring is just one part of unpaid carers' lives, and they often face other challenges which influence and are influenced by their caring responsibilities."

Of the 500,000 unpaid or informal carers identified in the Census 2023, over 40,000 are likely to be young carers, aged 15 to 25 years old (Donnan et al., 2023). The Census is likely to undercount the carer population for a number of reasons (Heyes & Grimmond, 2022), including that it captures carers > 15 years old, and young carers can begin their roles as young as three years old (Donnan et al., 2023).

Overall, carers are:

- Much more likely to be women
- More likely to be or sole parents or unpartnered
- More likely to be Māori and Pacific Peoples, particularly if they are young
- More likely live in high deprivation areas, particularly if they are young (Donnan et al., 2023; Heyes & Grimmond, 2022).

Our sector partners furthermore include that carers have often experienced trauma, which also needs to be considered.

4. Health and Wellbeing

The availability of respite and break options is woefully inadequate, largely due to insufficient Carer Support payments. For example, full-time unpaid carers (providing more than four hours of care per day) may qualify for Carer Support, a subsidy intended to enable carers to take breaks (“respite”) from caring responsibilities.

Currently, Carer Support for people with disabilities is set at \$80 per day, approximately \$3.33 per hour, while Pay Equity rates for support workers range from \$23.50 to \$28.35 per hour. This imbalance should be rectified, or, at a minimum, Carer Support must be indexed to inflation and the rising costs of relief care so that carers can realistically afford to secure a break.

Our sector partners describe the oxygen mask effect. On a plane, you are told: “put your own oxygen mask on first before helping others.” It means you need to look after yourself first, so you are able to help someone else. Carers need to have adequate supports available to maintain their own wellbeing, so they can keep providing for those with disability, health condition, illness, or injury.

We echo the CE Advisory Group when they ask for, “back up for Carer’s for respite/holidays,” and call on the MSD to amend the immediate deliverables for Health and Wellbeing to include increasing the availability of respite and break options for carers.

5. Financial Security

We know that 67.3% of people with intellectual disability aged 0-14 have at least one parent in the household not in full-time work as at 2023 Census (Beltran-Castillon & McLeod, 2026). This illustrates the increased financial sacrifice that carers make.

IHC has called for the Supported Living Payment to be tripled and supports Heyes and Grimmond (2022) as they ask for the payment to be available to anyone with caring responsibilities, including partners, at rates corresponding to the cost of providing the same care in a funded setting.

6. Conclusion

The current draft Carers’ Strategy Action Plan is characterised by exploratory language, for example “consider”, “develop a picture”, “map out,” instead of firm commitments and concrete action. We urge MSD to strengthen the plan by including

measurable outcomes, such as those outlined in this submission. The plan should have real impacts that can be identified through regular evaluation cycles.

Thank you for the opportunity to submit feedback on the draft Carers' Strategy Action Plan. We wish you well with this important work.

7. References

Beltran-Castillon, L., & McLeod, K. (2026). *From data to dignity 2026: Health and Wellbeing indicators for New Zealanders with intellectual disability*.
<https://www.ihc.org.nz/publications/from-data-to-dignity-2026>

Donnan, L., Gaffney, J., & Bruce, T. (2023). Voices from the margins: Aotearoa/New Zealand young carers reflect on their experiences. *International Journal of Environmental Research and Public Health*. 3;20(15),
doi:10.3390/ijerph20156511.

Heyes, R., & Grimmond, D. (2022). *The economic contribution and sacrifices of unpaid family, whānau and aiga carers in New Zealand for Alzheimers NZ, Carers NZ, the Carers Alliance, IHC and the Ministry of Social Development*.
<https://carers.net.nz/wp-content/uploads/2022/12/Infometrics-Economic-Contribution-of-Caregiving-November-2022-FINAL.pdf>