



Ageism and Age-Discrimination

Thank you for the opportunity to inform the Independent Expert's report on ageism and age-discrimination.

Introduction: Alzheimers New Zealand and submission focus

Alzheimers NZ has a strong interest in ageism and age discrimination as we represent people living with dementia. We raise awareness of dementia, provide information and resources, advocate for high quality services, and promote research about prevention, treatment, cure, and care.

We work with local Alzheimers organisations who provide support, education, information, and related services directly to members of their communities.

Dementia associated ageism is the focus of this submission. New Zealand has a rapidly increasing number of people who either have dementia or are caring for someone who has dementia. The number one correlate of dementia is age, therefore discrimination against those living with dementia is a de facto form of ageism. Much of the problem could be remedied with an effective, well implemented dementia plan. Both of New Zealand's major political parties have committed to such a plan, but positive action around implementation is yet to occur.

Question 1: Dementia as an example of age discrimination

Aotearoa has a rapidly ageing population. In 2015, 20.3% of New Zealanders were aged 60 years or above. By 2030, estimates suggest that 27% of the population will be aged 60 years and above. Estimates also suggest that by 2034, just over a fifth of the total population will be aged 85 years and older.

At present, it is difficult to see how the existence of the ageing population is informing Government policy across the generations. New Zealand does have *He Oranga Kaumātua*, its *Better Later Life Strategy*.¹ However, there is no action plan as yet. New Zealand's recent Budget Policy Statement is silent on the ageing population even though this is one of the most significant

¹[Better Later Life - He Oranga Kaumātua 2019 to 2034](#) |

determinants of New Zealand's social and economic context. One impact of the shortage of positive action is more and more people are joining the rapidly expanding population of those affected by dementia who are struggling to access their human rights.²

Dementia is a major cause of disability and dependency among older adults. It has been estimated to account for 11.9% of the years lived with disability due to a noncommunicable disease and has a significant impact not only on individuals but also on family/whānau, communities and societies.³

Others have noticed the problem. The ageism may not be intentional. However, New Zealand's lack of implemented action around the ageing population generally, and dementia specifically has ageist results. The recent UN visiting Independent Expert described people with dementia in Aotearoa as among the "most ostracized and the vulnerable of the vulnerable".⁴

Question 2: Causes of ageism (using dementia as an example)

Ageism and its causes are difficult to assess without data. The Independent Expert commented on the need for human rights indicators that can serve to identify specific shortfalls in the exercise of rights by older persons. She commented that 'data ... should not only be disaggregated by age but also ensure that age cohorts reflect the heterogeneous nature of the older population – in particular Māori and Pasifika - to allow for a differentiation of older and very old persons, who have different needs and capacities'.⁵

There is a shortage of quantitative data around indicators for assessing human rights. However dementia organisations do know the concerns of the people they represent, and that people living with dementia are losing access to human rights because:

- ***Service availability is problematic*** - Services exist but there are gaps across the whole dementia journey; the system is difficult to navigate, community-based living well programmes are hard to access; families

² Alzheimers NZ (2021) [Submission to the Finance and Expenditure Select Committee on the Budget Policy Statement](#) 2021

³ [Improving Dementia Services in New Zealand - Dementia Action Plan 2020 to 2025 May 2020](#)

⁴ Kornfeld Matte, R (2020) [End of Mission Statement by the United Nations Independent Expert on the enjoyment of all human rights by older persons, Ms. Rosa Kornfeld Matte, on her visit to New Zealand](#)

⁵ [Ibid.](#)

are overwhelmed yet respite care is limited and inflexible; and palliative care services for people living with dementia are poorly developed.⁶

- **Services are inequitable** - There are few 'by and for Māori' services, and access to and availability of services is inequitable across urban-rural and District Health Board boundaries, speciality area, and population groups.
- **Quality is variable** – Services are often limited to medical solutions; over-use psychotropic drugs continues; and, services often fail to consider the need for meaningful connection, activity, and stimulation.
- **Stigma and discrimination are rife** - Stigma and discrimination create barriers to accessing services and support; decision-making authority is often denied to people living with dementia.
- **The literature regarding Māori and dementia is lacking** – Māori do have a high prevalence of health conditions, such as diabetes, cardiovascular disease, stroke, and a history of traumatic brain injuries, which are risk factors for the onset of dementia. Further, Māori experience differential access to determinants of health, access to health services, and quality of healthcare compared to others living in Aotearoa New Zealand, which also increases their risk.

However, the lack of literature results in Western biomedical views prevailing. There are few explanations or descriptions of the impact on whānau in the current literature. “Current protocols and tools used in the diagnosis of dementia have not included Māori in their development and validation, and are therefore culturally biased, inappropriate and lack accuracy for this population.”⁷

Question 5: Action plans to raise awareness, combat ageism and move toward a more age friendly and inclusive society

The dementia sector has drafted a Dementia Action Plan but the plan requires implementation.⁸ Both major political parties committed to the action plan in

⁶ See Smith, E., Lamb-Yorski, R., Thompson, A., & Grootveld, C. (2019). [This is our story: A qualitative research report on living with dementia](#). Wellington, New Zealand: Litmus

⁷ Dudley, M; Menzies, O; Elder, H; Nathan, L; Garrett,N; Wilson, D (2019) [Mate wareware: Understanding 'dementia' from a Māori perspective](#), NZ Medical Journal, Vol 132 No 1503.

⁸ [Improving Dementia Services in New Zealand - Dementia Action Plan 2020 to 2025 May 2020](#)

their election manifestos in 2020, but actual implementation and funding is yet to occur.

The plan focuses on four major areas designed to assist with people being able to better access their human rights:

1. ***Keeping people well in the first place by reducing the incidence of dementia*** - Research suggests that proactive evidence-based interventions focused on modifiable risk factors could reduce the population risk of developing dementia by between 10% and 20% and/or slow progression.⁹
2. ***Supporting people living with dementia and their family/whānau care partners/supporters to live as well as possible*** - The focus here is on access to a timely, accurate diagnosis as well as to the right support and assistance. This will improve quality of life, reduce the impact on the health system and reduce the costs caused by higher levels of care and emergency care.
3. ***Building accepting and understanding communities*** – Reducing/ ending stigma and improving awareness, improving understanding, and removing barriers to inclusion will help people access the help and support they need. These measures will also help reduce isolation.
4. ***Strengthening leadership and capability across the sector*** - The dementia sector is complex and fragmented. Making the changes needed to implement the Plan requires leadership from government and a strong focus on capability across the sector.

Conclusion

Aotearoa is a signatory to the *WHO Global Action Plan on the Public Health Response to Dementia 2017-2025* which aims to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries.¹⁰ The Plan requires signatories to take action to improve the rights of people living with dementia, and thus

⁹See Gill Livingston, *et.al.* (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, *Lancet* 2020; 396: 413–46 Published Online July 30, 2020 [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6).

¹⁰ WHO (2017) [Global Action Plan on the Public Health Response to Dementia 2017-2025](#)

reduce ageism. We hope significant progress occurs soon and that we are able to describe a more positive situation around ageism, dementia and human rights the next time we report.