



15 March 2022

Health of Disabled People Strategy
Manatū Hauora - Ministry of Health
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Tēnā koutou

Submission on the development of the Health of Disabled People Strategy

Alzheimers NZ welcomes the opportunity to provide recommendations for the future Health of Disabled People Strategy (the Strategy) to improve health outcomes for disabled people, their families and whānau.

Alzheimers NZ represents people with dementia mate wareware and their care partners. We raise awareness of dementia mate wareware, provide information and resources, advocate for high quality services, and promote research about prevention, treatment, cure, and care. We support local community based Alzheimers and dementia mate wareware organisations throughout New Zealand. These organisations provide support, education, information, and related services directly to members of their communities who are affected by dementia mate wareware.

Dementia mate wareware and disability

Dementia mate wareware is a major issue for New Zealand. 70,000 New Zealanders were living with this health condition in 2020, and this number is expected to reach 170,000 by 2050 due to the growing ageing population.¹

The United Nations Convention on the Rights of Persons with Disabilities (the Convention) has the intent of protecting the rights and dignity of disabled people, including people with dementia mate wareware. This is because dementia mate wareware is a major cause of disability and dependency influenced by symptoms, environments, discrimination, and inequality.

Disability is a human rights issue because disabled people experience stigmatisation, discrimination, and inequalities. They are subject to multiple violations of their rights including their dignity, disrespect because of their disability, and they are often denied autonomy.

Alzheimers NZ is supportive of the development of the Strategy aiming to create the health system that is responsive to the needs of people with disability. We believe Aotearoa New Zealand should be a place where every person can fully participate in a society that recognises and provides for their needs.

The health and wellbeing

Disability is a global public health issue. Throughout the life course, disabled people face many barriers, causing worse health outcomes than people without disability. In the health care sector, such barriers may include lack of affordable options for access to care, physically inaccessible services, and limited availability to disability-confident service providers.

Alzheimers NZ is in the view that the Strategy must be guided by principles reflected in the Convention. These include respect for the individual autonomy and freedom to make decisions, non-discrimination, equality of opportunity and accessibility, gender equality, and respect for the continued dignity and value of disabled people as they grow older.

Alzheimers NZ recommends the Strategy apply person-centred care and life-course approaches, and include actions to address the social determinants of health. The Strategy should be relevant to and benefit all disabled people from birth to old age.

The Strategy should also outline prevention measures directed at improving the health and well-being of disabled people, reducing risks to health and promoting healthy lifestyles. As an example, prevention measures for people with dementia mate wareware could be guidance on good nutrition and the importance of physical exercise to attenuate cognitive decline.

Health care provision and system performance

Primary care is often the first contact for disabled people including people experiencing early signs of dementia mate wareware. It is important that primary care providers are trained to properly recognise early signs of dementia mate wareware so that they can diagnose people and refer to a specialist when it is appropriate. Alzheimers NZ recommends training for primary care providers on identifying, managing, and communicating with patients and their families about dementia mate wareware should be made available.

As disability cuts across all sectors and involves diverse factors, we recommend the Strategy apply a multisectoral and collaborative approach. This involves a range of organisations including government departments with portfolios such as health, disability services, finance, transport, and education, as well as non-government organisations, service providers, communities, disabled people themselves, their families and whānau.

Equally important, the Strategy needs to recognise the contribution of formal and informal carers who provide support of disabled people and their needs to fulfil their role. Care partners provide over one million hours of unpaid care every week¹ and about one million whānau carers are struggling, under pressure and do not feel valued.²

The Strategy should also include actions to strengthen data collection and support research on disability. Good quality data and research on disability are essential to provide the basis for policy and programs, resource allocation, and to better understand issues and solutions in providing health care for disabled people.

Responds to the needs and aspirations of tāngata whaikaha Māori

The Dementia Economic Impact Report 2020 (DEIR)¹ shows the numbers of people with dementia mate wareware are increasing at a faster rate among Māori, Pasifika, and Asian populations than those of European New Zealanders. The report confirms the situation causing significant equity issues in these communities.

Te Tiriti o Waitangi is a founding document that is fundamental to social and health policy in Aotearoa New Zealand. Alzheimers NZ recognises the significance of Te Tiriti o Waitangi and commits to meeting its responsibilities and ensuring the principles guide all aspects of our mahi.

Alzheimers NZ recommends the Strategy embed the role of Te Tiriti o Waitangi, Tikanga Māori and Māori concepts, and the needs and aspirations of tāngata whaikaha Māori. A strategy with culturally and linguistically competent care for tāngata whaikaha Māori shows that the health system recognises the diverse backgrounds and is influenced by multiple social, economic, and cultural factors, all of which should be included in a comprehensive care.

Conclusion

Equitable access to good health and services remains a challenge for many disabled people, particularly if their needs also intersect with other diverse lived experiences. Given multiple factors limit access to health care for disabled people, the health system needs to have actions and components to better consider disability and increase access to services. These actions include addressing social determinants, improving governance, and increasing levels of awareness, knowledge and data in health and related departments.

Since New Zealanders live longer, keeping older people healthy and independent involves more health services. Disabled people and older persons including people with dementia mate wareware are more likely to have more than one health condition and accessing health services could be expensive. Therefore, it is our challenge as a country to provide health care services that are fair and affordable.

Alzheimers NZ looks forward to the Health of Disabled People Strategy that acknowledges the diversity of health service users and put in place a fair and universal approach so that disabled people can enjoy their right to the highest attainable standard of health.

Ngā mihi nui

Catherine Hall
Chief Executive

¹ Ma'u E, Cullum S, Yates S, Te Ao B, Cheung G, Burholt V, Dudley M, Krishnamurthi R, Kerse N. Dementia Economic Impact Report 2020. Auckland, New Zealand: University of Auckland; 2021.

² The State of Caring in Aotearoa New Zealand. A report for Carers NZ and the Carers Alliance. August 202