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Secretariat

United Nations Human Rights Office of the High Commissioner

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Alzheimers NZ welcomes the opportunity to provide input for the report of the Independent Expert on the enjoyment of all human rights by older persons on legal capacity and informed consent of older persons.

This submission focuses on older people and people with dementia and is based on issues where immediate change can occur to ensure the availability of adequate and quality health care for them.

Introduction

Alzheimers New Zealand was established in 1986 and is a lead organisation at a national level representing people with dementia and their care partners. Our work is shaped by the Dementia Declaration and advice from the Alzheimers NZ Advisory Group. Our role includes raising awareness of dementia, providing information and resources, advocating for high quality services, providing practical tools to support a dementia friendly New Zealand, and promoting research. We support local Alzheimers NZ community-based organisations throughout New Zealand. These organisations provide support, education, information, and related services directly to members of their communities who are affected by dementia. We also work in partnership with other organisations, including New Zealand Carers' Alliance, Health Coalition Aotearoa, Federation of Primary Health, and New Zealand Coalition to End Loneliness. We are also a member of the Alzheimer's Disease International.

Dementia

Dementia is an umbrella term for a collection of symptoms that are caused by disorders affecting the brain and impact on memory, thinking, behaviour and emotion. Ninety percent of people living with dementia are over 65 with Alzheimer's disease being the most common form. The risk of dementia increases with age and this health condition impacts more women than men, about 30 percent higher.

Dementia is one of the 21st century's health challenges. The World Health Organization recognises dementia as a [public health priority](#). There is no cure, and none is currently on the horizon. Dementia is a progressive condition that causes a change in cognitive ability over time. It is a major cause of disability and dependency among older adults and interfering with a person's ability to look after themselves.

In New Zealand, 70,000 people living with dementia in 2020 and due to the growing ageing population, this number is expected to reach [170,000 by 2050](#). The increase will be more

significant among Māori, Pacific Peoples and Asian communities who experience both earlier onset and greater prevalence than other ethnicities.

National legislation that addresses issues of decision-making autonomy and legal capacity.

There are laws in New Zealand, such as the Protection of Personal and Property Rights Act 1989, that recognise and support decision making autonomy. However, there are barriers in the legislation that prevent some populations such as people with dementia, older people, and people with disabilities from participating in society. The current laws relating to legal capacity also do not take into account Māori perspectives and the multicultural nature of New Zealand.

Alzheimers NZ made a submission in response to the NZ Government's review of the decision-making law review in 2023. While supporting the review, we also provided recommendations to ensure people with dementia are supported when making decisions about their lives. We recommended that the updated law should include the Māori concepts relevant to adult decision-making, better terminology to determine health conditions of disabled people, and provide guidelines for better decision-making arrangement mechanisms.

These recommendations aligned with the [Dementia Mate Wareware Action Plan 2020-2025](#) which was developed by the NZ dementia sector to improve the quality of life of people with dementia. The Action Plan was also developed to ensure people with dementia are valued and respected and are able to exercise and enjoy their human rights.

Challenges faced by people with dementia to the exercise of their legal capacity and its impact

Dementia is a significant human rights issue. Dementia affects cognitive function that limits people with this health condition from expressing themselves, making their needs are often ignored or overlooked. People with dementia face stigma and discrimination, which creates even more barriers to accessing support according to their unique needs and exercising their human rights.

The [United Nations Convention on the Rights of Persons with Disabilities](#) has the intent of protecting the rights and dignity of disabled people, including people with dementia because dementia is a major cause of discrimination and inequality. The Convention acknowledges disabled people have legal capacity regardless of their impairments.

Alzheimers NZ does not believe that current health services for people with dementia and older people in New Zealand are adequate. Services are fragmented, inconsistent and inequitable. Years of underfunding has created a gap in the health system causing too many people with dementia are unable to get the support they need. Furthermore, people with dementia and their care partners need to navigate through the myriad of processes when accessing services due to inconsistency and disintegration of health services.

Alzheimers and dementia organisations are the primary source of service in the community across New Zealand. However, because of the increasing demand due to the increasing number of people with dementia, accessing post-diagnostic support from these services is challenging. As many as 30,000 people with dementia in New Zealand cannot get support from community-

based dementia services. Access to services is even more inequitable for Māori, Pacific People, and Asian communities, and those in rural areas.

Access to support plays a critical role in the health equity and the human rights of people with dementia. Without support, people with dementia are likely to experience a faster decline of their cognitive function. Unless action is taken to address disparities in accessing healthcare and support, human rights issues faced by people with dementia will continue to grow.

Data and access to information

The New Zealand Government collects national data on health conditions, but it does not collect data on dementia. Current estimates data on dementia are obtained by Alzheimers NZ. The lack of a formal national data on dementia impacts on our understanding of how dementia impacts on the social and economic welfare of people affected by this health condition in New Zealand, the supply and demand of appropriate services, and people's ability to access human rights. These include creating barriers to seek the voices representing people with dementia themselves, access information of benefit for them, and control over their own lives and alternative choices.

Conclusion

Dementia is a major cause of disability and dependency among older adults. It is a progressive condition that causes a change in cognitive ability over time. It ultimately will interfere with their ability to look after and expressing themselves, making their needs are often ignored or overlooked. They also face stigma and discrimination which creates even more barriers to accessing health care and the support they need.

We are concerned that despite being one of the [leading causes of health loss](#) in New Zealand, dementia has not been made a public health priority. We recommend that the New Zealand Government implement the [WHO's Global action plan on the public health response to dementia 2017 – 2025](#) recommendations to protect the rights of people with dementia to access health care and achieve equitable health outcomes for people with dementia in New Zealand.

Alzheimers NZ also recommends the New Zealand Government to fully fund and implement the Dementia Mate Wareware Action Plan to improve access to dementia services and contribute to achieving equitable health outcomes for people with dementia particularly among Māori and Pacific communities.

Your sincerely,



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Chief Executive Officer