Alzheimers New Zealand

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The Health and Disability Commissioner
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Tēnā koutou

Submission on the review of the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code)

Alzheimers NZ welcomes the opportunity to provide feedback to make sure the Act and the Code remain fit for purpose in promoting and protecting the rights of all New Zealanders accessing health and disability services.

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

The New Zealand population is ageing. With a rapidly ageing population, the number of people living with dementia mate wareware is also increasing at an unprecedented rate. Dementia mate wareware is one of the 21st century's health challenges. There is no cure, and none is currently on the horizon. Research suggests the number of people living with dementia mate wareware will increase by 240 per cent in 30 years. The number of people living with dementia mate wareware is increasing rapidly among Māori, Pacific Peoples, and Asian communities.

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 mate wareware. This is because dementia mate wareware is a major cause of disability and dependency influenced by symptoms, environments, discrimination, and inequality.

Alzheimers NZ's positions

Alzheimers NZ believes people living with dementia mate wareware have the same rights, privileges, and obligations as everyone else, including the fundamental right to participate in a society that recognises and provides for their needs. The Alzheimers NZ's Leadership and Advisory Group developed the Dementia Declaration that sets out what they need to live well.

Alzheimers NZ supports the Health and Disability Commissioner (HDC)'s recommendations from the Review that aim to meet the needs of all New Zealanders, particularly Māori and disabled people. We recognise that effective and timely resolution of complaints is essential and that the service models should be adapted to reflect modern expectations. In this submission, we present our comments and recommendations to support this review.

Better and equitable complaint resolutions

Alzheimers NZ believes that everyone using health services or disability services in New Zealand has rights outlined in the Code. On that basis, we support the HDC's suggestions for achieving better, simpler, and fairer complaint resolutions. These include:

- Broadening the principles for complaint resolution to focus on Mana (one’s dignity and authority) rather than a purely process-driven approach. This shift would help balance the interests managed by the HDC.
- Changing the language in the Code gender-inclusive to ensure it is accessible to all.
- Rewording the Code Right 1(3) to be inclusive of diverse groups, such as the Rainbow Communities, and to recognize the culture, language, and beliefs of various ethnicities, including Māori and Pacific cultures, while emphasizing important values like respect, leadership, family, and belonging.
- Clarifying complaint processes to support the rights of disabled individuals, encouraging early resolutions.
- Changing the Code to clearly define the role of whānau in the consumer-provider relationship, allowing whānau to participate appropriately, including making complaints on behalf of the consumer.

Recommendation

We recommend that if these changes are implemented, a public education campaign be launched to raise awareness of the new Act and Code. This campaign should use various channels and be available in relevant languages. It should include guidelines on the new complaint process and information about the support available to help disabled individuals when making complaints, ultimately aiming to improve services.

Making the Act and the Code effective for, and responsive to the needs of Māori

The number of people living with dementia mate wareware is rising rapidly, especially among ethnic communities, with Māori, Pasifika, and Asian populations being particularly affected. However, kaumatua living with mate wareware and their whānau face significant barriers in accessing services and share their experiences with the health services provided to them.

Alzheimers NZ acknowledges the importance of Te Tiriti o Waitangi and is committed to upholding its principles in all aspects of our mahi. We support the HDC’s recommendations and suggested actions aimed at making the Act and the Code more effective and responsive to the needs of Māori. We believe that Māori and disabled people from various ethnic backgrounds should have access to a safe and culturally appropriate process for making complaints or providing feedback. This ensures they receive the care and support they deserve.

Recommendations

We recommend that the HDC:

- Continue the engagement with Māori, hapū, and iwi organisations to ensure the Act and the Code meet the intention of the Review.
- Incorporate the Code with te reo Māori and other community languages, along with appropriate interpretations of principles and values, to help people understand and apply the Code effectively.

- Provide training for service providers to enhance cultural competence, improve advocacy services, and ensure that complaint processes are accessible for Māori and other population groups.

Making the Act and the Code effective for, and responsive to the needs of disabled people including people with dementia mate wareware

Dementia mate wareware affects memory, cognitive abilities, and behaviour. This is progressive which means that it gets worse over time. For most people, this condition affects their ability to understand and exercise their right as outlined in the Code, which leads to inability to express their needs.

Applying the HDC Code can be particularly challenging for people with dementia mate wareware because the processes are complicated and take a long time. People with dementia mate wareware find it difficult to understand the steps required to make a complaint or seek help, leading to confusion and frustration. The lengthy timelines for resolving issues can also further discourage them from pursuing their rights. These add unnecessary stress to their already challenging lives, making it even harder for them to exercise their rights and access the support they need.

<u>Recommendations</u>

Simplifying the complaint process will benefit disabled people including people with dementia mate wareware to exercise their rights under the Code. Our recommendations to the HDC to make the process to apply the Code easier, effective and responsive to the needs of disabled people include:

- Making healthcare facilities and services are accessible and inclusive for all disabled individuals such as wheelchair access, appropriate signage, and accommodating sensory needs.
- Training for health care staff on the needs and rights of disabled people, focusing on respectful communication and care practice.
- Engaging disabled people and work closely with organisations representing disabled people to identify barriers to access healthcare and develop strategies to address these issues.
- Providing accessible information about the Act and the Code in formats that are easy for disabled people, such as simple text, audio formats, and translations for non-English speakers.
- Establishing an independent advocacy services to help disabled people understand their rights and how to navigate the healthcare system.
- Encouraging disabled people to share feedback about their experiences and use this input to make improvements.

The Code and the Act should align and be guided by principles reflected in the Convention

Disability is a global public health issue and people with disability often face many barriers that lead to poorer health outcomes. One of those barriers could be the limited access to complaint processes that are confident and accommodating for individuals with disabilities.

<u>Recommendation</u>

We recommend that the Code and the Act be developed to align with the principles reflected in the Convention on the Rights of Persons with Disabilities. These include respect for the individual’s rights, autonomy and their freedom to make decisions and give consent.

Support to make decisions

Alzheimers NZ believes that a supported decision-making process is important for people who are unable to make decisions due to their disabilities. We support the proposed changes to the Code aim to ensure disabled people including people with dementia mate wareware receive the necessary support to understand information and fully exercise their decision making abilities. This includes updating the language used in the Code to better reflect and respect the will and preferences of consumers.

Suggestion
While we strongly support supported decision-making, we suggest using 'a principled' as the foundation for this process. The principled approach recognises that when adults are unable to consent, decisions should be made based on supporters' best interpretation of what the person's will and preferences would be. This represents a shift from a binary approach where decision-making is made based on the person's best interests if a person cannot make a decision and communicate their will and preferences. Our position aligns with our submission to the Review of Adult Decision-Making Capacity Law Second Issues Paper.

A principled approach accommodates people with severe cognitive impairments such as people living with dementia mate wareware within the supported decision-making process. It also recognises the reality that supported decision-making will inevitably at times require another person making a decision on behalf of a person with a cognitive disability.

Consented research
We recognise that a human rights and ethical approach is crucial when it comes to consent for research. People who lack the capacity to make informed choices are particularly vulnerable to potential abuses of their rights and interests. Article 15 of the UN Convention on the Rights of People with Disabilities (UNCRPD) emphasises the right of people with disabilities to be protected from being subject to medical or scientific experimentation without their consent.

People with dementia mate wareware often want to participate in activities that affect their lives, including participating in research. It is crucial to obtain consent from people living with dementia mate wareware and that they participated in research projects.

Recommendation
Communications with the person with dementia mate wareware should be taken in place to confirm whether they understand and agree to participate. This helps validate any assumptions about their consent. At the same time, it is important to strike a balance between the rights to participate and the need to protect them. Safeguarding people with dementia mate wareware in research is vital, which is why maintaining high standards of research and monitoring by Ethics Committees is necessary.

Reporting mechanism
We acknowledge that the review suggests establishing a reporting mechanism to the Minister for Disabled People, in addition to current reporting to Minister of Health. While this initiative may improve service delivery, it could also create unnecessary complexity and confusion for service users who want to file complaints.

Recommendation:
We recommend creating clear communications and coordination process between the two ministers. This will ensure that both have the necessary support and guidance when addressing complaints, helping to simplify the process for individuals seeking assistance.

Improving the review process and clarifying decision-making guideline

Creating a right to appeal health and disability decisions will empower disabled people to challenge decisions made by health authorities when they believe those decisions are unfair or not in their best interest. An appeals process would also promote accountability within the healthcare system and ensuring that decisions are made transparently and justly.

Recommendation

While the HDC has made progress in improving the review process and guidelines for complaint resolution, we recommend that the HDC establish a transparent process and implement the Ombudsman's recommendations to create a more responsive healthcare environment. Transparency builds trust and accountability in the healthcare system, helping individuals understand the reasons behind decisions and empowering them to engage with the system and advocate for their rights and needs.

Other minor and technical amendments

Alzheimers NZ support suggestions for minor and technical amendments to the Act and the Code. These include:

- Conduct a review of the Act and the Code every 10 years, with the option of earlier reviews where necessary. While we acknowledge that such reviews can be time-consuming and resource-intensive, they are essential to ensure the Act and the Code remain relevant and effective.
- Withholding information while the investigation is ongoing is an important safeguard to maintain the integrity of the complaint process.
- Expanding the requirement for written consent for sedation equivalent to anaesthetic and for situations involving the potential risk of serious adverse effects will ensure consistent application of Rights 7(6)(c) and 7(6)(d).

Conclusion

In conclusion, the review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services will make our healthcare system remains responsive, accountable, and equitable. Given the increasing complexity of health and disability services, it is necessary to update the Act and the Code to align with modern standards of care and patient rights.

This review should ensure that every person, particularly marginalised communities such as Māori, has equitable access to quality care and support. By aligning the Act and Code with current best practices, we can create an environment that meets patients' needs and encourages them to take an active role in their healthcare decisions.

It is expected that the review will strengthen protection for people's rights and improve the processes to address complaints and concerns. By focusing on transparency, better decision-making, and following recommendations from oversight bodies, this review can help build a stronger health and disability system in New Zealand.

Ngā mihi

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