



Submission

**Review of New Zealand
Health and Disability System**

May 2019

Nāu te rourou, nāku te rourou, ka ora ai te iwi

With your food basket and my food basket the people will thrive

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Executive summary

Aotearoa's health and disability system needs major change and strong leadership to deliver the necessary alterations to meet current and future challenges. The problems associated with our ageing population, growth in non-communicable disease, need for a system which is both fair and affordable, and requirements to meet our international obligations must be addressed.

Alzheimers NZ has been working in the New Zealand health and disability system for over thirty years and is well acquainted with both the nature of the problems and measures which can make a positive difference. We are grateful for the opportunity to take part in the Review of the Health and Disability System and offer recommendations for its improvement as follows:

1. Adoption of an appropriate public health approach to reduce demand on the system by keeping as many people as well as possible for as long as possible.
2. Reducing the demand for expensive secondary and tertiary services by shifting both the focus and resources to primary care and community/home support provision enabling a greater proportion of health issues to be addressed before they escalate into major problems.
3. Supporting health and wellness; reducing unnecessary duplication and stress by improving the links both within the health and disability system and with other services.
4. Delivering nationally consistent quality services at the appropriate level by adopting measures known to be effective in dealing with the growth in non-communicable disease.
5. Enabling measurement of the effectiveness of the health and disability system and better policy and planning by collection of appropriate data.
6. Making good use of existing community expertise and service provision by supporting the not-for-profit sector to deliver efficient and effective services.

Alzheimers NZ can point to an array of evidence, but our strongest comes from our own sector. Dementia provides a useful illustrative example as its relevance applies to much of the health and disability System.

Introduction

Thank you for the opportunity to engage with the Review of the New Zealand Health and Disability System. Alzheimers NZ agrees that review of the system is urgent. Our health and disability system faces a demographic time-bomb; spiralling issues around non-communicable disease; equity and efficiency concerns; and, the need to ensure New Zealand keeps meeting its international obligations. All these issues impact on areas for review as identified in the terms of reference.

Alzheimers NZ is well placed to comment as we have been engaged with health and disability system issues since our formation in 1986. Since that time, we have been representing people living with a significant non-communicable condition at a national level by raising awareness, providing information and resources, advocating for high quality services, and promoting research about prevention, treatment, cure and care.¹

Submission outline

This document is intended to assist the reviewers in wise decision-making to develop a health and disability system which is well planned and co-ordinated and capable of successfully meeting the challenges before our country.² It covers the following three areas:

1. The need for reform

This section examines the problem areas identified in the introduction: the demographic changes; the need for better approaches to non-communicable conditions; ensuring the health and disability system is fair and affordable; and, the need to meet New Zealand's international obligations.

¹ Alzheimers NZ also supports local Alzheimers NZ organisations throughout New Zealand, each of which is a member of Alzheimers NZ. Our local Alzheimers organisations provide support, education, information and related services directly to members of their communities who are affected by dementia. These services may include:

- Information and education to assist with understanding and living with a dementia diagnosis;
- Support for family, friends and whānau coping with the demands of caring; and
- Support groups and day programmes for people affected by dementia.

² It is also designed to be dementia-friendly, therefore we are using size 14 font.

2. Improving the health and disability system

Our suggestions on how improvements can be made to the health and disability system have been organised according to how they fit with the terms of reference. Alzheimers NZ is particularly concerned with the following issues:

- a. Keeping people well (*The role of the public health and prevention in supporting health and wellness*);
- b. Enabling early intervention (*The importance of primary health care as the foundation of a person-centred health and disability system*). We also address the need for community / home-based support;
- c. Improving links between agencies which support health (*Contribution of and the interaction between health and other social sector agencies in supporting health and wellbeing*);
- d. Appropriate levels of care (*The capacity of the health and disability system to deliver the appropriate level of care and ensure the care is safe and of high quality*); and,
- e. Being able to measure the effectiveness of the health and disability system (*The role of data and evidence in informing policy development, investment decisions, and provision of services*).

3. How Alzheimers NZ and other not-for-profits can help improve New Zealand's health and disability system

The voluntary and community sectors provide important elements of New Zealand's health and disability system. This third section identifies the value of these services. Obviously, the ability to deliver such services is dependent on the existence of supportive settings conducive to this work.

The need for reform

1. Demographic change is a major challenge

Aotearoa is facing a major demographic challenge which necessitates wise decisions about the health and disability system. There are implications for the

entire system as current unmet need collides with rapid increases in demand due to the ageing population.

The ageing population is not a surprise and the implications of conditions associated with ageing are well known, as are the consequences of continued inaction on these problems. However, successive New Zealand governments have ignored these issues and the scale of the challenge. The result is spiralling impacts associated with rapidly growing numbers of people with dementia and other age associated conditions.

Almost 25% of the population will be 65+ by 2036. If nothing is done differently, care of older people will account for 50% of District Health Board (DHB) expenditure by 2025/26, an almost 20% increase since 2015/16.³ Around one third of all hospital admissions are currently for people over the age of 65.⁴ Obviously, a new approach is urgently needed so we can flatten the curve of accelerating demand and spend the available resources more wisely.

Dementia provides an excellent example of implications associated with the demographic challenge. It is both common and strongly correlated with age. It is estimated that around 70,000 people currently have dementia and the number is expected to increase rapidly. The estimated population with dementia grew by 29% between 2011 and 2016 and numbers are forecast to increase to 170,000 by 2050.⁵ These numbers do not include the inter-generational impact of dementia and the many family and friends significantly affected. Dementia is expensive with associated health and social care costs almost matching the combined costs of cancer, heart disease and stroke.⁶ The implications for the health and disability system of this growing demand are considerable.

³ Associate Minister of Health (2016) *Healthy Ageing Strategy* Ministry of Health. p.13.

⁴ Ministry of Health *Publicly funded hospital discharges – 1 July 2014 to 30 June 2015* (2017) www.health.govt.nz/publication/publicly-funded-hospital-discharges-1-july-2014-30-june-2015

⁵ Alzheimers NZ (research by Deloitte Access Economics) (2017) *Dementia Economic Impact Report* (DIER) Wellington: Alzheimers NZ. P.8.

⁶ Luengo-Fernandez, R., et.al, (2010). *Dementia 2010: The prevalence, economic cost and research funding of dementia compared with other major diseases*. A report produced by the Health Economics Research Centre, University of Oxford for the Alzheimer's Research Trust. Cambridge: Alzheimer's Research Trust.

2. Action is needed to address non-communicable disease

Non-communicable disease (NCD) and mental illness are growing concerns throughout the world. The World Health Organization (WHO) has commented that the “growing trend of population ageing has enormous ramifications for the prevention and management of NCDs.”⁷

In New Zealand, more people are living with disability, long-term physical and mental health conditions, and increasing multimorbidity. Some groups are affected more than others, such as Māori and Pacific peoples, and those living in high socioeconomic deprivation areas. Long-term conditions comprise 87.3 percent of all health loss in New Zealand, a five-percentage point increase since 1990.⁸

Some long-term conditions are virtually being ignored in our country. In the case of dementia, the *Lancet* is describing it as “the greatest global challenge for health and social care in the 21st century”,⁹ and the OECD identifies it as an urgent policy issue which is the “fastest growing major cause of disability globally”.¹⁰

However, New Zealand’s response to dementia has been so poor that even the United Nations is asking our Government about *steps taken to include people with dementia and other cognitive losses among its health priorities* in its review of our application of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).¹¹

3. Need for a fair and affordable health and disability system

Everyone agrees New Zealand needs an equitable, efficient, sustainable public health system which delivers quality services. We also all agree that effective

⁷ World Health Organization (2018) *Time to deliver: report of the WHO Independent High-level Commission on Noncommunicable Diseases* Geneva, p.7.

⁸ Ministry of Health (2018) *Health and Independence Report 2017: The Director-General of Health’s Annual Report on the State of Public Health*. Wellington: Ministry of Health, p. xii.

⁹ Livingston, G. *et.al.* (2017) “Dementia prevention, intervention, and care.” *The Lancet*. DOI: 10.1016/S0140-6736(17)31363-6 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31363-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6/fulltext)

¹⁰ OECD (2015) *Addressing dementia: The OECD response*, Paris, OECD Publishing, p. 19.

¹¹ See [The Government’s response to the UN Committee on the Rights of Persons with Disabilities \(Word version\)\[DOCX, 205 KB\]](#), p.70.

health and disability services make a considerable difference to individual and collective wellbeing.

Aotearoa is dealing with the legacy of earlier policies which increased social and economic inequality.¹² This creates challenges for the health and disability system which are linked with other areas of life.

The current health and disability system focuses on secondary and tertiary care at the expense of services at the primary and community levels. In doing so, it creates an expensive top-heavy system which deals with problems when they become crises, rather than preventing the crises from occurring in the first place or dealing with them at a lower level. Supportive policies do exist, but these are not translated into service and/or resource provision at the appropriate place or level.

Again, dementia provides a good example. It drives a very significant proportion of demand for acute hospital care across all adult specialties. Some of this is too little too late, some of this is preventable resource use, and some of this is money poorly spent on treatments which may not be appropriate.

There does exist a *New Zealand Framework for Dementia Care* policy document which sets out an array of measures which should happen at the primary, community or homecare level, but these are mostly not happening. Community and homecare services for dementia do exist, but these are largely provided by NGOs without the capacity and scope to deal with the broad expanse of needs involved in this issue.

The current approach is not sustainable. For dementia alone, Government and other associated costs are spiralling. Alzheimers NZ's *Dementia Economic Impact Report* (DIER) estimates a 75% increase occurring between 2011 and 2016 (\$955 million in 2011 to \$1,676 million in 2016). These costs are projected to reach almost \$5 billion by 2050.¹³

¹² See Statistics NZ http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-progress-indicators/home/social/income-inequality.aspx

¹³ Alzheimers NZ (research by Deloitte Access Economics) (2017), p.11.

4. Meeting New Zealand's international obligations

Aotearoa does not exist in a vacuum. We have multiple international commitments which include Sustainable Development Goal (SDG) number 3 about healthy lives and the requirement to promote wellbeing for all at all ages,¹⁴ numerous human rights obligations,¹⁵ and requirements associated with being a signatory to the *WHO Action Plan on the Public Health Response to Dementia 2017- 2025*.¹⁶

Even if we restrict the examples to dementia, Aotearoa is currently breaching numerous human rights obligations. Three examples closely relate to *Article 25* of the *UN Convention on Rights of Persons with Disabilities* as follows:

- a. *Persons with disabilities have the right to ... early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among ... older persons;*¹⁷

However, it is estimated that only around 50% of people with dementia get a diagnosis, and there is little support following that diagnosis.¹⁸

- b. *Persons with disabilities have the right to ...health services as close as possible to people's own communities, including in rural areas;*¹⁹

However, service provision is uneven, as an Alzheimers NZ Advisory Group member discovered: "There is no regular respite where I live. Our

¹⁴United Nations, *Sustainable Development Goals* <https://www.un.org/sustainabledevelopment/health/>, accessed 10 April 2019.

¹⁵ *Article 25* of the United Nations' 1948 *Universal Declaration of Human Rights* states that "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services."

¹⁶ World Health Organization; (2017) *Global action plan on the public health response to dementia 2017–2025*. Geneva: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=4B5D93D723E4D08E620C24AF88FD3C97?sequence=1>, pp. 14-15.

¹⁷ United Nations, Department of economic and social affairs, (ND), *Convention on the rights of people with disabilities*, Article 25b, Health <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

¹⁸ Alzheimer's Disease International (2016) *World Alzheimer Report 2016 Improving healthcare for people living with dementia coverage, Quality and costs now and in the future*, Alzheimer's Disease International (ADI), London, p.6.

¹⁹ United Nations, Department of economic and social affairs, (ND), *Convention on the rights of people with disabilities*, Article 25c, Health <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

GP, social workers and nurse assessor all tell me that I MUST have 2 weeks of respite every 6 to 8 weeks. We were allocated 91 days of respite by the nurse assessor and I was told to look on *Eldernet*. There I found there was no regular respite service in our DHB. The allocation was misleading and disheartening – what is the point in having access to 91 days of respite when there are no services?”

- c. *Persons with disabilities have the right to ... care of the same quality ..., including on the basis of free and informed consent;*²⁰

However, older people who experience dementia related conditions are sometimes “placed” in secure rest homes or residential facilities even when they do not want to be there. These individuals live in locked facilities and are prevented from leaving. Even if they are compliant and do not object, they have their liberty and personal choices curtailed.²¹

The *WHO Action Plan on the Public Health Response to Dementia 2017-2025* requirements are not onerous. However, despite New Zealand’s endorsement of the plan, our country is not meeting the standards expected. We have no action plan with funding and activities attached; no dementia awareness raising campaign; public funding contributes only 30-50% of training programmes for carers and reaches only a small proportion of those needing assistance; respite care is available but is inconsistent and of variable quality; there are no agreed indicators or measures monitored nationally; and, funding for dementia research remains inadequate by comparison with other research areas.

Specific issues: Areas for reform

Alzheimers NZ’s specific advice on how improvements can be made to the health and disability system has been organised according to how it fits with

²⁰ United Nations, Department of economic and social affairs, (ND), *Convention on the rights of people with disabilities*, Article 25, Health <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>.

²¹ See Fisher, M and Anderson-Bidois, J (eds.), *This is not my home A collection of perspectives on the provision of aged residential care without consent*, 2018, Auckland, Human Rights Commission.

the Review's terms of reference. We have identified five areas which will help create significant improvements to the shortcomings identified above, and these relate to the following terms of reference:

1. *The role of the public health and prevention in supporting health and wellness;*
2. *The importance of primary health care as the foundation of a person-centred Health and Disability System;*
3. *Contribution of and the interaction between health and other social sector agencies in supporting health and wellbeing;*
4. *The capacity of the Health and Disability System to deliver the appropriate level of care and ensure the care is safe and of high quality; and,*
5. *The role of data and evidence in informing policy development, investment decisions, and provision of services.*

1. Reduce demand on the system by keeping people well

It is well known that *public health and prevention in supporting health and wellness* can result in considerable improvements to community wellbeing. The current Coalition Government's recognition of community wellbeing and the significance of wellbeing economics draws upon years of clearly documented research closely aligned to effective public health.²² We note that the Ministry of Health identifies social and economic factors as the main determinant of health and wellbeing,²³ and that the recent Welfare Expert Advisory Group report recommends:

Increasing ... overall income support to levels adequate for meaningful participation in the community... (which reflects different family circumstances, for example, ...disabilities and regional area) ... (rec. 26);

Improv[ing] the health and wellbeing of people with health conditions and disabilities, along with carers of people with health conditions and disabilities who interact with the welfare system by... implementing

²² See work by Richard Layard; Amartya Sen; and, Richard G. Wilkinson and Kate Pickett, for example.

²³ Ministry of Health (2018) *Health and Independence Report 2017: The Director-General of Health's Annual Report on the State of Public Health*. Wellington: Ministry of Health, p. 13.

strategies to prevent work-limiting health conditions and disabilities (rec 40); and,

Includ[ing] in the scope of the New Zealand Health and Disability System Review the relationship between the health and disability system and the accident compensation scheme and how the relationship between these and the welfare system could be changed to improve outcomes for people with health conditions and disabilities and carers (Rec 41).²⁴

There are various approaches to keeping people well which can be utilised to reduce demands on the system such as life course models, socio-ecological models, the Pasifika Fonofale approach, and the indigenous Te Whare Tapa Wha mode of analysis. Their common element is an emphasis on underlying conditions which help support health (determinants of health) including: social gradients; housing availability and quality; neighbourhood characteristics; education; employment and working conditions; healthy environments; spirituality (e.g. Te Whare Tapa Wha), and culture (e.g. Fonofale).

Examples of how the determinants of health operate abound. In our own sector, there are solid reasons for ensuring communities support health by being both age and dementia friendly. Cities and towns which exclude disabled people encourage people with dementia to withdraw into the relative safety and comfort of their own homes. Isolation follows, generating further cognitive decline.

Members of our Advisory Group tell us they get told to ‘pack up their lives’, are treated like ‘third persons’ and get considered as ‘no longer any good’ for their jobs/community roles. People lose confidence, jobs/roles and social status. The nation loses out as people withdraw and dramatically reduce their contribution to wider society.²⁵

²⁴ Welfare Expert Advisory Group (2019) *Whakamana Tāngata: Restoring dignity to social security in New Zealand*, Welfare Expert Advisory Group, Wellington.

²⁵ Alzheimers NZ (2018) *Submission to the Government Inquiry into Mental Health and Addiction* <http://www.alzheimers.org.nz/getattachment/Our-voice/Policy-documents-and-submissions/Alzheimers-NZ-Mental-Health-Review-Submission.pdf/>

Age/dementia friendliness as part of a public health approach makes New Zealand more inclusive, assists older people, those who care, those with disabilities, those with young children, and those with dementia to live better lives. This knowledge is well known overseas, is advocated for by the WHO,²⁶ and is acknowledged in the *Healthy Ageing Strategy*.²⁷ Adopting such a public health approach makes sense as the associated positive impacts on both physical and mental health reduce pressure on the health and disability system.

At a more specific level, public health measures such as vaccination, fluoridation, tobacco control, anti-stigma and discrimination campaigns and warmer drier homes have all been shown to improve health. Their success and the success of other varieties of health promotion and risk reduction can have a significant positive impact even in the case of a progressive illness such as dementia which shares most of the risk factors associated with other non-communicable diseases.

Evidence compiled by Livingston *et.al.* for the *Lancet Commission on Dementia, Prevention, Intervention and Care* shows effective risk reduction measures have the potential to delay or prevent around 35% of dementia cases.²⁸ Childhood education below age 12; active treatment of mid-life hypertension; increased physical activity; social engagement; reduced smoking; management of hearing loss, as well as management of late-life depression, diabetes and obesity, can all help to reduce levels of dementia. Effective health promotion and risk reduction across the life span is likely to have measurable positive benefits.

²⁶World Health Organization; (2017) *Global action plan on the public health response to dementia 2017–2025*. Geneva: <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=4B5D93D723E4D08E620C24AF88FD3C97?sequence=1>, pp. 14-15.

²⁷ Associate Minister of Health (2016) *Healthy Ageing Strategy* Wellington: Ministry of Health. <http://www.health.govt.nz/publication/healthy-ageing-strategy>.

²⁸ See Livingston, G., *et.al.* (2017) "Dementia prevention, intervention, and care." *The Lancet*. DOI: 10.1016/S0140-6736(17)31363-6 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)31363-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31363-6/fulltext) accessed 10 October 2017. p. 6.

2. Shift focus and resources to primary care and community/home support and reduce demand for secondary and tertiary services

Alzheimers NZ agrees that primary health care should be the foundation of Aotearoa's health and disability system and that community and home support services are equally important. Shifting both the focus and resources to these areas makes sense.

Delivered well, both primary and community/ home services can mean most needs are met before they escalate into more serious conditions. Both are cheaper than secondary and tertiary care and both can dramatically reduce demands on more specialist services. For many of the non-communicable conditions, re-orienting the current top-heavy approach towards primary and community support could make a significant difference to the wellbeing of individuals, family/whānau, and the wider community. This would need to be in both urban and rural areas, as access to services can be a major challenge for those living beyond urban boundaries.

Once again, our own sector provides some useful examples. We have already identified that only around 50% of people with dementia even have a diagnosis. Early intervention could make a significant difference, and for those over 65, could be part of the super gold card holders' current free health visit. These could easily be extended to include cognitive impairment and hearing tests.²⁹

People should not have the difficulties they currently report in Alzheimers NZ's recent research. For example:

Nobody offers help, you've got to go and find it and ask for it. You have to go to your doctor and some doctors don't want to give it [information on services] either, which to me is quite strange. (Person with dementia).³⁰

Increasing the role of primary care services and community/home support will help people affected by dementia to live better, help keep them at home for

²⁹ Addressing hearing loss can reduce dementia prevalence by up to 8%.

³⁰ Alzheimers NZ (Research by Smith, E., et.al.) (2019). *This is our story: A qualitative research report on living with dementia*. Wellington, New Zealand: Litmus.p.8.

longer, and help the health system to be more sustainable across the generations.

Around two-thirds of people with dementia live at home. They and their care partners rely on community and home-based services which are currently underfunded, inadequate, variable in quality, and often not known to exist.

Many people living with dementia are unaware they can increase the level of services as the dementia progresses (such as respite care or home support). They also do not know the process to increase services.³¹

Simply providing quality information, which is up-to-date easily accessible, culturally appropriate, consistent and regularly reviewed helps people understand dementia and learn how to live with it. Small things can make a big difference.

Providing for 12 months' post-diagnosis support to equip people with dementia, their families and care partners with tools, connections, resources and plans to allow them to live as well as possible with dementia could also be beneficial. The Scottish 5 Pillars Model of Post-Diagnostic Support takes this approach and has been evaluated with positive results.³²

The evidence around shifting the focus to primary care and community support for dementia are well known. However, despite the knowledge and the growing demands for services, little has been done, and no additional investment has been directed at community services for people with dementia for more than 10 years. The only increase in assistance in the dementia sector has been subsidies to residential care.

3. Foster health and wellbeing and reduce unnecessary duplication and stress by improving the interaction between health and other social sector agencies

Good links between agencies which support health are vital. In our own sector, relationships with other social agencies can either promote health or

³¹Alzheimers NZ (Research by Smith, E., et.al.) (2019). *This is our story: A qualitative research report on living with dementia*. Wellington, New Zealand: Litmus.p.60.

³² Alzheimer's Society UK (2016) *Dementia Advisors: a cost-effective approach to the delivery of integrated care*, Alzheimer's Society, London; Clarke, C et.al. (2013) *Healthbridge. An evaluation of peer support networks and dementia advisors in the implementation of the national dementia strategy*, Department of Health UK.

compound illness. Currently, too many people affected by dementia needlessly struggle losing their health, roles, incomes, relationships, friends, homes, mana, and independence amongst other facets of human dignity. Poor connections between services compound the problems.

People struggle with retelling stories multiple times, finding out what assistance is available or where to go to access it. Just finding their way through the available assistance can be problematic. Some services are not fit for purpose; others are staffed by individuals with either inadequate training or experience.

Many of these issues are closely associated with a health and disability system grappling with the growth in non-communicable disease and the associated lack of political will, commitment, capacity, and action; lack of policies and plans; insufficient technical and operational capacity; difficulties in priority setting; the impact of economic, commercial, and market factors; and, lack of accountability.³³

The dementia sector provides a graphic example. A *New Zealand Framework for Dementia Care* (2013) exists. Yet little action has been taken to implement the *Framework*. The *Framework* approach even specifically provides for greater efficiency, effectiveness and better interaction between health and other social sector agencies via the provision of navigation services. These are designed to provide the first point of contact for the person with a dementia diagnosis, and their family/whānau. Such services give advice, encourage self-management, explain pathways, co-ordinate referrals, and help people find their way through the health and social support system. The roles supplement rather than replace what already exists and overseas evaluations of these functions show positive outcomes for people with dementia and their care partners.³⁴

³³ World Health Organization (2018) *Time to deliver: Report of the WHO Independent High-level Commission on Noncommunicable Diseases* Geneva, p.7.p.12.

³⁴ Alzheimer's Society UK (2016) *Dementia Advisors: a cost-effective approach to the delivery of integrated care*; Clarke, C et.al. (2013) *Healthbridge. An evaluation of peer support networks and dementia advisors in the implementation of the national dementia strategy*, Department of Health UK.

Six years after the publication of the *New Zealand Framework for Dementia Care*, people with dementia and their care partners are still trying to find and connect with much needed services. The stress and lack of support takes a toll. InterRAI data shows that 55% of family or friends caring for a person living with dementia report feeling overwhelmed by the person's support needs, and that 44% of primary carers report feeling distressed or angry because of the demands of caring for their loved one.³⁵ Large numbers of family/whānau dementia care partners have clinically significant depression or anxiety, placing extra stress on New Zealand's already overwhelmed mental health services. Respite care is frequently difficult to access and/or is of insufficient quality which becomes a source of even more stress for both those who care and for the care recipient. Heightened stress, of course, is correlated with increased likelihood of abuse of either or both of the parties.

The poor links and lack of support are self-defeating. Collectively the problems can result in earlier admission to residential care and an increase in the costs incurred, to individuals, the country and to people's wellbeing. Something as simple as improving the interaction between health and other social sector agencies can have significant positive results.

4. Deliver nationally consistent quality services at the appropriate level

Delivering the appropriate level of care and ensuring the care is consistent, safe and of high quality is a major challenge for our health and disability system. It is exacerbated by people's growing expectations. Given that the WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", then the demand for health is potentially infinite, with the smallest departure from the WHO definition being capable of being defined as an 'illness' potentially in need of 'treatment'. Already some are describing biological ageing itself as a

³⁵ InterRAI (2017) *Annual Report 2016/17* p.13. interRAI is a suite of over 20 clinical assessment instruments. In New Zealand, interRAI is the primary assessment instrument in aged residential care and home and community services for older people living in the community. interRAI stands for 'international Resident Assessment Instrument'.

'disease'.³⁶ Therefore, the review is tasked with difficult philosophical decisions about just what level of community health is desirable or practicably obtainable.

As with anything, health resources need to be considered alongside many other priorities. The demands associated with the ageing population mean a huge and growing part of the health and social service spend in this country will inevitably be spent on aged-associated costs which has implications for health and disability services in other areas.

More imagination, commitment to community wellbeing, and better planning is required to make the best and most equitable use of the resources New Zealand has. In the dementia space there are many well-founded cost-effective suggestions for improvement. As we have seen earlier, New Zealand is a signatory to the WHO *Global Action Plan on the Public Health Response to Dementia 2017-2025*. Our country could implement the actions required and have an action plan to fully implement the *New Zealand Framework for Dementia Care* (2013); we could have a national dementia awareness raising campaign in operation (the last one ran from 2014-2016); we could direct risk reduction and health promotion toward older adults to a greater degree than at present; we could develop agreed national indicators or measures, and we could devise wellbeing or quality of life measures for people with dementia.

The widespread knowledge of the facts about how dementia services could be improved mean it would make sense to redirect funding to nationally consistent home-based / community services for people with dementia.³⁷ It would also make sense to support the dementia-specific NGOs as they deal with the stresses of large caseloads which continually grow as workers are forced to take on more and more clients to meet the growing demand. Finally,

³⁶ Bulterijs, S., Hull, R. S., Björk, V. C., & Roy, A. G. (2015). It is time to classify biological aging as a disease. *Frontiers in genetics*, 6, 205. doi:10.3389/fgene.2015.00205.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4471741/>

³⁷Alzheimers NZ (2018) Changing the game for New Zealand's dementia community - Recommendations for Budget 2019 [http://www.alzheimers.org.nz/getattachment/Our-voice/Policy-documents-and-submissions/Alzheimers-NZ-Advice-for-Budget-2019-\(1\).pdf/](http://www.alzheimers.org.nz/getattachment/Our-voice/Policy-documents-and-submissions/Alzheimers-NZ-Advice-for-Budget-2019-(1).pdf/)

it would make sense to tackle the workforce capacity issues as opposed to continuance of the current inaction in this area.

In some places, just ensuring services exist would make a significant difference:

*Some DHBs and other regional funders are not investing in the respite services they should be, leading to inequalities across the country.*³⁸

Examination of the dementia sector is apposite. This lack of provision of nationally consistent quality services at the appropriate level in this easily-remedied sector is remarkable. It is even more remarkable given the 2017 Deloitte conclusion that ... *the magnitude of prevalence and costs of dementia make it one of the most significant public health burdens in New Zealand. As such, it needs to be one of the priorities for policy-makers.*³⁹

5. Collect appropriate data and evidence to inform policy development, investment decisions, and provision of services

What gets measured gets done. Data collection reflects priorities and enables planning. Improved data collection would assist with many of the problems faced by the health and disability system.

Once again, dementia provides a good example. It is a major feature of the health demands associated with our ageing population; it is one of the array of non-communicable diseases increasing in significance; it provides a major challenge to Aotearoa's ability to maintain a health and disability system which is both fair and affordable, and is a clear example of how New Zealand fails to live up to its international obligations.

Dealing with all these issues would be made significantly easier in the presence of better data collection, meaningful indicators and increased research. The Ministry of Health does not gather much-needed statistical data to inform evidence-based policy. The Ministry of Health does collect data on diabetes, cancer, arthritis, obesity, stroke. Some data is available from interRAI assessments but much more is needed to learn about dementia.

³⁸ Alzheimers NZ and IHC in association with Carers Alliance (research by Synergia) (2019) *Respite in New Zealand: We must do better*, Synergia, Wellington.

³⁹ Alzheimers NZ (research by Deloitte Access Economics) (2017) p. 14.

The most comprehensive national data New Zealand has about dementia comes from research work commissioned by Alzheimers NZ and carried out by Deloitte. Even then, the work is based on extrapolations from Alzheimer's Disease International's Australasian estimated prevalence data.

The data around Māori populations is particularly lacking, which of course results in policy vacuums and therefore undermines the ability of Aotearoa's indigenous people to exercise their equal right to health. Those who conducted Alzheimers NZ's research made a plea first in 2008 and repeated in 2011 and 2016 for data to accurately model Māori and Pasifika prevalence rates.⁴⁰ Their eleven-year-old plea remains unheard. They could only conclude:

While there is evidence that the incidence of dementia may be higher for Māori and Pacific peoples in New Zealand, due to a higher prevalence of cardiovascular risk factors, no data [our emphasis] were available to enable modelling of the extent of this difference.⁴¹

Alzheimers NZ can help improve the health and disability system

Making good use of existing community expertise and service provision by supporting the not-for-profit sector to deliver efficient and effective services makes sense. Government and not-for-profit organisations working together can make significant improvements to Aotearoa's health and disability system. Not-for-profit organisations bring in money, solutions, community knowledge; access to communities of people who live with dementia and other conditions; access to service providers, service users, volunteers, research and information. They also have specialist skills and are therefore not interchangeable with more generic organisations. The best solutions are found when government and not for profits work well together. Funding and the legislative context remain significant issues for non-profit organisations and

⁴⁰ There is now also a growing issue around other populations as peoples of Asian descent grow in number and begin to outnumber Māori in older age groups.

⁴¹ Alzheimers NZ (research by Deloitte Access Economics) (2017) p. 22.

have important implications for their capability, capacity and ability to innovate.

Alzheimers NZ is but one example of a not-for-profit able to assist. The services we provide are some of the least expensive, flexible, quickest and easiest to implement in the health system.

Conclusion

Aotearoa's health and disability system needs major change and strong leadership to deliver the necessary changes to meet current and future challenges. The problems associated with our ageing population, growth in non-communicable disease, need for a system which is both fair and affordable, and requirements to meet our international obligations must be addressed. Alzheimers NZ has been working in the New Zealand health and disability system for over thirty years and is well acquainted with both the nature of the problems and measures which we know can make a positive difference. We are grateful for the opportunity to take part in the Review of the Health and Disability System and offer recommendations for its improvement in the section below.

Recommendations

Significant changes are needed to New Zealand's health and disability system if it is to both meet the needs of the population and meet the challenges associated with the problems identified above. The following measures will help:

1. Adoption of an appropriate public health approach to reduce demand on the health and disability system by keeping as many people as well as possible for as long as possible.
2. Reducing the demand for expensive secondary and tertiary services by shifting both the focus and resources to primary care and community/home support provision enabling a greater proportion of health issues to be dealt with before they escalate into major problems.

3. Supporting health and wellness; reducing unnecessary duplication and stress by improving the links both within the health system and with other services.
4. Delivering nationally consistent quality services at the appropriate level by adopting measures known to be effective in dealing with the growth in non-communicable disease.
5. Enabling measurement of the effectiveness of the health and disability system and better policy and planning by collection of appropriate data.
6. Making good use of existing community expertise and service provision by supporting the not-for-profits sector to deliver efficient and effective services.