

# Alzheimer's Australia NSW Submission Productivity Commission Inquiry into Caring for Older Australians

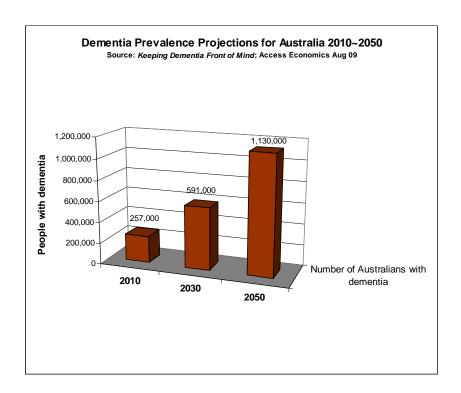
Thank you for the opportunity to respond to the Inquiry into caring for Older Australians in Australia. With the ageing of Australia's population and the numbers of people with dementia set to increase four-fold over the next 40 years, Alzheimer's Australia NSW has a particular interest in ensuring the viability of age care services into the future. In 2008 approximately 60% of people with dementia were living in the community and of those 37% were not receiving services. 40% of people with dementia were in residential care, making up approximately 55% of people in residential care. (Access Economics, 2009a)

## NSW consultations with consumers and other stakeholders

Alzheimer's Australia NSW has undertaken extensive community consultation to survey people living with dementia and their carers, as well as other stakeholders such as service providers, to gather their opinions, issues and suggestions with regard to aged care services in Australia. Alzheimer's Australia NSW has eight regional consumer committees around NSW and recently conducted a consultation with key stakeholders in the Tweed region. Those consulted spoke about a rigid system that made it "difficult to adjust the service to meet the needs of the client and the continual pressure to deliver services within a system where there were,"more clients and not enough funding".

# **Dementia**

The number of people in Australia with dementia continues to rise dramatically, with Access Economics predicting numbers to double to almost 600,000 by 2030 and rise again to almost 1 million by 2050. This number doesn't include family carers and others whose lives are also affected. The cost of replacing family carers with paid carers is estimated at \$5.5 billion per annum.



According to the Australian Bureau of Statistics, dementia is now the third leading cause of death in Australia after heart disease, stroke and lung cancer. By 2030 some experts predict dementia will be the leading cause of death.

Dementia is not a normal part of ageing. While it's more common to be diagnosed with dementia after the age of 65, it is important to remember that not just older people get dementia. Dementia can happen to anybody. People in their 40s and 50s are also diagnosed with dementia.

People may think that dementia is just about losing your memory, but the term is used to describe the symptoms of a large group of diseases that cause a progressive decline in a person's functioning. There are more than 100 different types of dementia, the most common being Alzheimer's disease, which in Australia accounts for around 50-70% of all types of dementia. Dementia not only affects memory, but also intellect, rationality, social skills and what would be considered normal emotional reactions.

Dementia impacts on all parts of both the health and aged care systems – including primary care, early intervention, acute care, medication management, community care, residential care and palliative care. It will shortly become the number one health condition affecting Australians and needs to be considered a priority area in future health and aged care reforms.

Aged care services must become more responsive to the growing numbers of people with dementia and their carers and dementia must be given priority in both the aged care and health reform agendas. Alzheimer's' Australia NSW

supports the Commission's view that any review of the aged care system cannot be made in isolation of the health and disability services systems and welcomes the discussion of reforms in both health and disability services. However all three systems are highly interdependent and many issues have been raised by both consumers and service providers that many of the problems in all three systems are related to the different funding mechanisms in each siloed service and transition and access issues when impeded the smooth transition of clients from one system to another.

Alzheimer's Australia NSW urges the Productivity Commission to consider the enormous impact dementia will have on the future delivery of aged care services and wishes the Commission to consider the following key recommendations.

# Key recommendations in summary

- 1. Increase community and residential aged care funding to meet future demand.
- 2. Create sustainable funding for aged care services, including consideration of alternative funding mechanisms to ensure the sustainable provision of aged care into the future.
- 3. Build a trained dementia care workforce to meet future demand.
- 4. Implement dementia quality care and quality of life standards as part of the accreditation process for dementia-specific residential care facilities and ensure that all standards are directly related to quality, person-centred care outcomes.

#### Recommendations in detail

# 1. Increase community and residential aged care funding to meet future demand

According the latest Intergenerational Report, the ageing of the population will lead to an increasing demand for community and residential aged care support services. The current system of rationed residential aged care places and community care packages do not adequately reflect the real cost of delivering care. In addition, the current planning ratios for calculating the numbers of places and packages have not kept pace with demographic changes and increasing numbers of people with dementia, particularly in those 85 years of age and older. Under the existing system there is not enough funding to meet current demand for dementia-specific residential and community aged care and, with a four-fold increase in the numbers of people with dementia by 2050, demand for dementia services will quickly outstrip supply. In addition, allocations are currently made on the basis of large planning regions, which can lead to vacancies in some areas and long waiting lists in others. Consumers and providers complain that people are often unable to access vacant packages in another region when the region they reside in has long waiting lists. There needs to be the more flexibility with

the ability to move packages across regional and State boundaries to meet need. There is also a need to create more social supports for people with dementia and their carers and more flexible respite options. The more carers can be supported in the community the less likely the person they are caring for will need to enter residential care prematurely.

Alzheimer's Australia NSW calls on the Australian Government to

- increase the availability of dementia specific community high care packages (Dementia EACH-D packages) and dementia-specific high care residential care places to meet future demand.
- recognize and respond to the need for more residential and day centre facilities designed specifically for acute dementia patients.
- target services to regions with the highest proportions of ageing populations and the highest dementia prevalence rates and allowing flexibility to shift packages according to areas of demand.
- provide programs that create social supports and interventions for older people who may have become isolated in their communities, particularly carers and people with dementia living alone.
- create more flexible packages that meet the individual needs of each client.
- boost the availability and access to short term respite with overnight respite facilities attached to day centre programs.
- ensure the cost and availability of community transport is factored into the delivery of aged care services.
- include capital works funding and the costs related to facility hire in any service delivery costs. Capital funding must be addressed to adequately reflect the real cost of delivering residential care and ensure a provider can continue to meet aged care standards for continued accreditation.

# 2. Create sustainable funding for aged care services, including consideration of alternative funding mechanisms to ensure the provision of sustainable provision of aged care into the future.

A recent Grant Thornton Report argued that the aged care sector is already under stress with up to 40% of providers currently struggling. For example, the recent collective decision by some providers not to tender for beds brought the sustainability of the sector into question. Catholic Health Australia claims there is no real relationship between aged care subsidies and the real cost of care and the quality outcomes required. The Aged Care Association Australia (ACAA) maintains that a defined and costed benchmark of care is required and that the benchmark must reflect the real cost of providing a quality aged care service in different regions around Australia and allow for the flexible delivery of aged care services responsive to the needs of the individual consumer.

Numbers of residential facility beds needed by 2050 requires immediate and ongoing support for the residential care industry. The current Commonwealth Government \$56.5 million zero interest loan scheme for aged care providers for the construction of new facilities needs to be continued and funding increased to promote a larger scale capital building program to keep pace with future demand.

Access Economics predicts that it will become increasingly important for people with the capacity to pay to do so, allowing the government to continue to provide a safety net for those without financial means to cover dementia care costs. Accordingly consideration should be given to creating a form of Healthy Ageing Savings Account (HASA) or similar mechanism to fund aged care. This account should be considered in addition to current Medicare levies and superannuation arrangements.

## 3. Build a trained dementia aged care workforce to meet future demand.

Access Economics warns that associated with the increase in the number of people with dementia will be a rapid rise in demand for care services and workers to meet care needs. There is a projected shortage of 153,000 paid and unpaid carers for people with dementia in 2029 relative to 2008. The April 2009 report by Access Economics for Alzheimer's Australia, 'Making Choices: Future dementia care projections, problems and preferences' concluded that the projected substantial and growing deficit in the dementia care workforce on the basis of current trends is a "matter requiring urgent planning responses". Aged care reform needs to urgently address the need to attract and appropriately train a dementia care workforce to ensure quality dementia care.

Alzheimer's Australia NSW calls on the Australian Government to

- ensure the training and supply of dementia specialists such as dementia trained nurses, psycho-geriatricians and aged care workers, particularly in rural and remote regions.
- investigate incentives for attracting and retaining aged care workers, including initiatives to attract culturally appropriate staff.
- ensure dementia education and training is a mandatory part of aged care training and tied to accreditation standards for care providers.
- ensure minimum qualifications for different levels of care workers, including dementia specific qualifications for supervisors and managers.
- include training and succession planning for staff into funding for services.
- explore amending migration qualifications to encourage professionals carers from overseas to join formal carer workforce
- 4. Implement dementia quality care and quality of life standards as part of the accreditation process for dementia-specific residential care facilities.

Alzheimer's Australia is concerned that although person centered care is often declared in principle it is rarely implemented on the ground. Provision should be made in any aged care reform to address this issue and look for ways to ensure that implementing person centered care practices is tied to funding. Access Economics estimates that up to 50% of people living in residential care facilities have a diagnosis of dementia; however current aged care standards do not include quality care or quality of life measures related specifically to dementia care. Alzheimer's Australia NSW supports the recommendation of the National Health and Hospitals Inquiry that aged and community care providers are required to meet standards for quality of care and quality of life measures related to the care of dementia patients.

Alzheimer's Australia NSW calls on the Australian Government to

- develop clear criteria around the provision of best practice dementia care in residential care facilities. Expanding the scope of Aged Care Standards & Accreditation Agency to establish dementia care standards across residential and community care (HACC and EACH-D packages) that would include establishing measureable standards for dementia quality care and quality of life.
- ensure those quality standards and outcomes are readily available to consumers when making choices regarding residential care.
- implement mandatory staff ratios for dementia specific high care facilities.
- allocate specific places in every health region for the accommodation and care of those people with dementia with behavioural issues.

#### References

Access Economics, *Making Choices: Future Projections, Problems and Preferences.* 2009(a) Alzheimer's Australia.

Access Economics, *Projections of dementia prevalence and incidence in NSW: 2009-2050.* 2009(b) Alzheimer's Australia NSW.