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SUBMISSION TO NATIONAL COMMISSION OF AUDIT

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ALZHEIMER'S AUSTRALIA

EXECUTIVE SUMMARY

Introduction

Alzheimer's Australia welcomes the opportunity to provide a submission to the National Commission of Audit. As the peak organisation representing the more than 320,000 Australians with dementia and the family carers who support them, our submission will focus on the health and aged care system.

Australia is experiencing a demographic shift with a rapid increase in the number of older Australians. The population aged 65 years and over is projected to increase from 3.2 million at 30 June 2012 to between 5.7 million and 5.8 million in 2031, and to between 9 million and 11.1 million in 2061.[1] As a result of population ageing, we are also facing a rapid increase in the number of people who have dementia. Currently there are more than 320,000 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050[2]. The increasing number of older Australians and those who have chronic illness such as dementia will have a major impact on both the health and aged care systems.

Alzheimer's Australia welcomes the bipartisan support for the 2012 Aged Care Reforms which set a framework for a world class aged care system that will be responsive to the increasing demands of the ageing population and have the potential to transform the way aged care is delivered in Australia at a relatively low cost. The reform package represents less than a 1% increase in total projected funding to the aged care sector over the next five years. Further consideration will need to be given to how the money originally allocated to the workforce supplement is targeted but it is imperative that this funding is directed towards improving the quality of the aged care system. Furthermore, any consideration of increasing user charges within the aged care program must be done in the context of funding strategies to improve quality of care.

Building on the aged care reforms

There are a number of cost-neutral approaches that could be undertaken to further extend the impact of the aged care reforms. It is imperative that steps are taken within health policy to implement dementia as a National Health Priority. Within aged care the two main policy goals of Alzheimer's Australia are to expand community care and improve the quality of residential care. In our view there are steps that can be taken to work towards these goals within the current funding envelope.

i. There is a need for coordinated action on primary and acute care to ensure better care for people with dementia and more efficient use of health care spending. This action needs to be supported by an agreement by Health Ministers to a new National Framework for Action on Dementia and an advisory mechanism to ensure coordinated advice to the Minister for Social Services and the Minister for Health on issues relating to dementia. This will lead to a more effective approach to implementing the funding in the Tackling Dementia package which relates to primary and acute care, as well as ensuring a coordinated and focused approach to

[1] ABS (2013). 3222.0 Population Projections, Australia (2012) to 2101

[2] AIHW (2012). Dementia in Australia

improving care across the health and aged care systems. There is also a need to promote a wider understanding of dementia risk reduction among Australians.

ii. Within the aged care sector, there is a need to ensure that the reforms are leading to better access to care and support for consumers. There is some uncertainty as to whether the number of community care packages, or the mix of levels of packages and residential care places, will meet consumer demands. It is imperative that the Government establish a benchmark for timely access to community and residential care and that the current ratios are reviewed and readjusted appropriately based on performance against this benchmark. It is vital that the new system is responsive and flexible to ensure consumers have access to the care they need where and when they need it.

iii. There is also a need to consider how to create services that are more responsive to the needs of consumers. For example, respite is a critical support for carers and people with dementia but often appropriate respite is difficult to access. For this reason, Alzheimer's Australia is advocating for a cost-neutral trial of "cashing-out" for respite which would explore both the benefits and risks of this approach.

iv. Further consideration must also be given to the care and support of people with behavioural and psychological symptoms of dementia (BPSD). There is evidence to suggest that antipsychotic medications are being used as a first line approach to care against clinical guidelines with the risk of death. Furthermore, the dementia and behaviour supplements in residential aged care should be linked to requirements for providers to be able to document their ability to provide care to people who have high care needs.

Alzheimer's Australia urges the Commission to be cautious that the search for savings does not undermine important reforms that are underway or lead to the delivery of poor quality services to vulnerable populations. Investment in health promotion, early intervention and community services and supports within both the health and aged care sector can lead to a significant reduction in health care costs and improved quality of life for older Australians.

2012 AGED CARE REFORMS

Alzheimer's Australia welcomes the bipartisan support for the 2012 Aged Care Reforms. The 2012 Aged Care Reforms set the framework for a world class aged care system which will be flexible and responsive to the increasing demands of an ageing population. These reforms represent a fundamental shift in the philosophy of care and support for older people in Australia. They provide a framework for developing a high quality system of care and support that provides consumers with greater choice and flexibility and represents a landmark change in how providers will work with consumers in identifying the best use of services to support them to meet their individual goals.

Key components of the reforms from the consumer perspective include:

- Expansion of community care from 64,800 in 2012 to 144,469 in 2022
- Inclusion of CDC approach in all new home care packages
- Supplements that acknowledge the additional costs of providing dementia care
- Expansion of respite services
- A new focus on quality including the development of transparent quality indicators
- Improved access to information and assessment through the Gateway

The reform package also includes for the first time in Australian health policy important funded initiatives to tackle dementia across the health care system over the next four years with:

- Initiatives to improve quality of dementia care in hospitals
- The expansion of the Dementia Behavioural Advisory Service (DMAS)
- Funding for programs to improve access to timely diagnosis
- A national program of dementia advisors to assist people with younger onset dementia in navigating the service sector and getting access to appropriate care and support.
- The world's first publicly funded dementia risk reduction program *Your Brian Matters*

Although the total value of the reform package is $3.7 billion, only approximately $580 million over five years is new money. The remaining component is made up of reallocation of funding through changes to the Aged Care Funding Instrument as well as a new regime of user contributions. The total additional funding is equivalent to less than a 1% increase in total projected funding to the aged care sector over the next five years. The reforms will transform the aged care sector, and provide the first steps for tackling dementia across both the health and aged care system with minimal additional tax-payer investment. Any cuts to the reform package would lead to significant detriment to both the aged care sector and the quality of life of older Australians.

Any proposal to increase user charges for aged care services should include consideration of how the additional revenue would be used to improve the quality of care services. Further detail around issues of quality care and strategies to improve quality can be found in the Alzheimer's Australia publication *Quality of Residential Care: A consumer perspective*[3]. There must also be safeguards to protect people who are not able to contribute more and to ensure that they receive equitable services. There are significant sensitivities around the inclusion of the family home in means testing arrangements that need to be considered if this is to be expanded beyond the current cap of $144,500.

There are common concerns across aged care providers, consumers and policy makers about workforce issues within aged care. The Government has suspended applications for the $1.2 billion workforce supplement, which was a key component of the Aged Care Reform Package, due to concerns about the design of the supplement and is considering how this funding will be utilised to support the aged care workforce. It is important that this funding is retained within the aged care system and used to support improvements in the quality of the aged care system. Given recent concerns around quality of aged care services, consideration should be given to including further expansion of the DBMAS and expansion of training and education programs, particularly around psychosocial approaches to managing behavioural and psychological symptoms.

In order for the reforms to progress smoothly, it is also important that there are sufficient administrative structures in place within the Department of Social Services to support the implementation of the aged care reforms. Successful implementation of the reforms will require significant administrative support and ongoing consultation with the aged care sector and consumer organisations.

BUILDING ON REFORM

There are a number of cost-neutral approaches that could be undertaken to further extend the impact of the aged care reforms. It is imperative that steps are taken within health policy to implement dementia as a National Health Priority Area. Within aged care the two main goals are to increase access to community care and improve the quality of residential care. In our view there are steps that can be taken to work towards these goals within the current funding envelope.

Health policy

Alzheimer's Australia welcomes the new administrative arrangements that bring responsibilities for aged care and disabilities under the Department for Social Services as it provides an opportunity to build coherent policy between the aged care and disability care systems. But there is a risk that aged care and dementia will become divorced from health policy.

[3] http://www.fightdementia.org.au/common/files/NAT/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

The 2012 Aged Care Reforms provide important funding to begin to tackle dementia across the health care system including through funding for a dementia risk reduction program, initiatives to improve primary care and acute care, and expansion of the DBMAS. This focus must not be lost with the administrative changes. It is important that a new National Action Framework on Dementia is agreed by Health Ministers to better plan and coordinate action to tackle dementia, and for an advisory mechanism to ensure coordinated advice to the Minister for Social Services and the Minister for Health on issues relating to dementia.

It is important, for example in developing preventive health policy, that action is coordinated on both physical and brain health. Recent research suggests that up to half the cases of Alzheimer's disease worldwide are potentially attributable to modifiable risk factors such as physical inactivity, midlife hypertension, midlife obesity, diabetes and cognitive inactivity.[4] The Australian Government was the first government globally to introduce public policy around dementia risk reduction and it is important that this initiative is built on at a local level and that links are made between dementia risk reduction and preventative health initiatives which are targeting heart disease, obesity and diabetes.

It is well established that access to early interventions and support for people with chronic diseases can reduce the overall cost to the health care system. People with dementia, however, face on average a 3-year delay between first noticing symptoms of dementia and getting a formal diagnosis.[5] It is imperative that access to timely diagnosis becomes a priority for Medicare Locales and that the funding provided through the Aged Care Reforms is carefully targeted.

Similarly, there is a need to ensure coordinated action to improve hospital care for people with dementia and to reduce unnecessary hospitalisations. As part of the 2012 Aged Care Reforms, there is $39 million to improve hospital care for people with dementia. This funding needs to be prioritised to ensure that it leads to better outcomes for consumers and more efficient health care provision. The average cost of care for a person with dementia in hospital is approximately 50% higher than for a person without dementia with the same reason for hospitalisation ($7,720 and $5,010 respectively)[6]. According to the AIHW, people with dementia face numerous hazards in hospitals, such as physical and cognitive decline and fall-related injuries. Recent research in NSW hospitals shows that the identification and reporting of dementia in hospital records is often poor. Dementia was not recorded as a diagnosis for almost half of the hospital stays for people with dementia in this study. [7]

Community Care

The central tenet of aged care is to enable older people to stay at home longer while recognising that for many entry into residential care will be necessary – often because the family carer even with support cannot continue to care, the older person has no family carer or the care needs of those with dementia are too great for the support network.

[4] Barnes & Yaffe (2011). *The projected effect of risk factor reduction on Alzheimer's disease prevalence.*

[5] Alzheimer's Australia (2011) *Timely Diagnosis of Dementia: Can we do better?*

[6] AIHW (2013). *Dementia Care in Hospitals.*

[7] AIHW (2013). *Dementia Care in Hospitals.*

The two main policy goals of Alzheimer's Australia are to expand community care and improve the quality of residential care. In our view there are steps that can be taken to work towards these goals within the current funding envelope.

We share the concern about rationing of services highlighted by other stakeholders and the interest in entitlement. We agree that a more contestable marketplace will lead to greater choice and higher quality of care for older Australians. At the same time we are cautious about moving too quickly to an entitlement approach because we know that Government will need to control expenditure in some way such as increasing user charges, being prescriptive about services that are funded or raising the level of need required to be eligible for services. Such approaches are not guaranteed to produce greater equity as we have seen in universal approaches such as Medicare. Moreover the current allocation formula with all its weaknesses and distortions of the market has the advantage of certainty.

The preferred approach of Alzheimer's Australia is to be more pragmatic. We are pleased with the rapid expansion of community care over the next 10 years and believe that this is the first step towards creating a system that is more responsive to consumer demand. There will need to be a regular review of how well the allocations of community care and residential care are meeting demand. A benchmark should be set with regards to waiting times (e.g. 90% of people assessed as eligible for community care should have access to a package within 6 weeks). There needs to be a specific review of the mix of level 1–4 packages to ensure that there is sufficient support for people at all levels of care needs. The regular review should be used to readjust the formula as required to ensure that older Australians have timely access to the care they need where they want it delivered. Consideration should also be given to a higher level package to provide support for people with the highest care needs or to assist those who are living alone.

Respite

Respite care is a critical support for family carers and provides social engagement for people with dementia. But access to services is often difficult because respite services are not resourced to care for people with the behavioural and psychological symptoms of dementia and because the services are not available where and when they are needed. Family carers report that once the person with dementia develops behavioural symptoms or becomes incontinent many service providers refuse to continue to provide services.

The current system for respite is not meeting the needs of people with dementia and their carers, as can be seen from the difference in reported need for respite and uptake of services.[8] Given the range of needs and the difficulty in accessing appropriate services, extending the entitlement of respite beyond 'approved providers' to include family members (other than the primary carer), friends and others would be an important step in enabling individuals to get access to the care they need, when and where they want it.

International evidence suggests a number of benefits of programs that provide care recipients with cash which can be used to access services from a range of providers. These include a greater sense of choice and control, psychological benefits, assistance that better

[8] Alzheimer's Australia (2013), *Respite Review Policy Paper.*

fits needs delivered when and where it is required and greater satisfaction with care (see Arksey & Kemp, 2008 or Ottman, Allen & Feldman, 2009 for a review of international evidence on cash-for-service).

Alzheimer's Australia is advocating for a cost-neutral pilot of a cashing out respite program. This pilot would enable an accurate assessment of both the risks and benefits to this type of approach in the Australian context. It would be an important cost-neutral initiative that could lead to a more efficient approach to the provision of respite particularly for people with dementia.

Care and Support for People with Behavioural and Psychological Symptoms of Dementia (BPSD)

Consumers have serious concerns about the quality of care provided to individuals with severe BPSD. In addition, research has shown that about a quarter of people within aged care facilities are receiving antipsychotic medications, at significant cost to the PBS, and that only approximately 20% of these will receive any clinical benefit. The National Prescribing Service (an independent organisation which is funded by the Department of Health to promote quality use of medications) has noted:

> *"Analysis of PBS prescription data suggests a high level of inappropriate prescribing of antipsychotics in older people...there is a growing concern that antipsychotics and similar medicines are being overprescribed to people with dementia first line as a means of behaviour control."*

The Aged Care Reforms provide important initiatives to improve the care for people with BPSD including expansion of the DBMAS as well as the introduction of dementia and behaviour supplements that provide additional funding to cover the cost of providing quality care to this group of people. Access to this supplement is currently based on the patient's need (diagnosis and assessment of behavioural symptoms). If this supplement is to lead to better care and support then there is a need to link the supplement to requirements for the provider to document that they are able to provide quality care for individuals who are experiencing severe behaviour symptoms. In addition, there needs to be greater transparency around the use of psychotropic medications within aged care facilities.