



**Alzheimer's  
Australia**  
Living with dementia

**Response to the Productivity Commission Draft  
Report: Caring for Older Australians**

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**Prepared by: Glenn Rees, CEO and Ellen Skladzien, Policy Manager  
with the consumer networks of Alzheimer's Australia**

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# Response to Productivity Commission Draft Report

## Overview

Alzheimer's Australia welcomes the Draft Report of the Productivity Commission which sets out a new vision for aged care, one of greater choice, flexibility and personal responsibility. Alzheimer's Australia has long advocated for many of these transformational reforms including separation of accommodation and care, increased priority for community care, empowerment of consumers and greater flexibility in service delivery.

Alzheimer's Australia agrees with the principles set out in the report to guide the reform of aged care (Productivity Commission, 2011, p91):

- Promote independence and wellness of older Australians and their continuing contribution to society
- Ensure that all older Australians needing care and support have access to person centred services that can change as their needs change
- Be consumer-directed, allowing older Australians to have choice and control over their lives
- Treat older Australians receiving care and support with dignity and respect
- Be easy to navigate- Australians need to know what care and support is available and how to access these services
- Assist informal carers to perform their caring role
- Be affordable for those requiring care and for society more generally
- Provide incentives to ensure the efficient use of resources devoted to caring for older Australians and broadly equitable contributions between generations.

Concerns about the report are more about the issues that require further discussion or are not addressed than the philosophy and principles that underpin the report. There is unease for example about:

- How quality and equity of care can be assured in the new system
- How the market will work and how possible market failures will be addressed (e.g. in respect of the homeless or rural areas).
- The absence of a mechanism to ensure both competitive and fair wages for nurses, personal carers and support staff and to ensure appropriate levels of staffing.
- The proposed approach to consumer co-contributions and income and asset testing and the implications that it may have for the social welfare system.
- How the needs based assessment approach will work and how present or future governments will manage it to control costs.
- The complexity of designing a funding model applicable across community and residential care
- LGBTI seniors being included under the category of culturally and linguistically diverse and not being recognised as a special needs group in the Aged Care Act.
- How the new system will address concerns about poor oral health and lack of access to good dental care in the aged care system.

Alzheimer's Australia will pursue these issues through the National Aged Care Alliance and expects that much of the detail will inevitably be part of the implementation process.

This submission will focus specifically on the aspects of the reform that directly relate to the care of individuals with dementia and their family carers. It has been drafted in consultation with the state and territory Alzheimer's organisations and the National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group.

The Commission seems to imply at points in the report (e.g. pages 42-43) that dementia is just another chronic disease. The reality is that dementia is core business of aged care. The majority of residents in aged care have dementia, it is the most disabling of all conditions among older people and is one of the main causes of institutionalisation. Already there are some 269,000 Australians who have dementia— a number that will grow and place greater demands on community services if family carers are to be able to care for the person with dementia longer at home (Access Economics, 2010). It is clear that individuals with dementia will benefit from many of the proposed recommendations, but it is a disappointment that the Commission did not explicitly address dementia in any of the 42 recommendations.

There is also a need to recognise, respect and value the range of social, cultural, religious and linguistic differences amongst client groups and how these groups access and receive services in the broader dementia and aged care sector. Our approach in this submission is to address areas of concern for diverse groups within the relevant sections of our report. This reflects our view that an understanding of diversity and equity needs to permeate the whole report with a goal of developing and delivering quality services that will meet the needs of an increasingly diverse ageing population.

Alzheimer's Australia has identified six priority areas that need attention in the final report:

- **The impact of dementia on aged care**

The reform of aged care needs to be underpinned by a comprehensive strategy to address dementia. This should not only embrace measures that underpin the quality of dementia care (training, dementia care research, the integrated suite of services through the National Dementia Support Program) but initiatives to improve timely diagnosis and to create safer hospitals and funding for cutting edge research into the cause and prevention of dementia.

- **The funding model**

The new funding model needs to recognise the higher costs involved in caring for people with dementia, and the need for innovative funding for individuals from diverse backgrounds who have difficulty accessing care. The behavioural supplement of the ACFI and Dementia EACH packages were important policy decisions which recognise the higher costs involved in caring for people with dementia. The funding model recommended in the final report must explicitly recognise the need for a dementia supplement as set out in the layered model in Attachment B to the draft report. The funding model must also support the principles of choice, and consumer directed care outlined by the Commission. Further action is needed on expanding choice of providers for respite and providing a trial of a cash option for both care and respite.

- **The interface of the mental health sector, disability and aged care**

The needs of individuals with severe behavioural symptoms and individuals with younger onset dementia will not be met until the structural barriers between the state-funded mental health system, the disability sector and the Commonwealth funded aged care systems are addressed. The aged care system should take funding responsibility for care for both of these groups as they require specialised aged care services which may not be available in the

mental health or disability sectors. Higher funding levels are needed for individuals with severe behavioural and psychological symptoms of dementia which are not recognised in the funding model proposed by the Commission.

- **Gateway**

People have different pathways of accessing services and therefore the Gateway must build on and network with existing services. For example, it is critical that those using the Gateway are not denied access to the integrated suite of services provided through the National Dementia Support Program that are block funded by the Commonwealth. These services include carer education and counselling, National Dementia Helpline, support groups, information services and Living with Memory Loss Programs. Moreover, these services also assist some older people to come to terms with the fact that they have dementia though memory loss and other programs. Over 10 years these services have been evaluated and found to be effective.

- **Respite Care**

Reform of respite care should be a priority in the first stage of reforms because it is a critical support for family carers who care for a person with dementia at home. Respite care needs to address the needs of the person with dementia for social activity and engagement. The lack of appropriate activities is one of the reasons that many carers do not use respite despite saying that they need it. The resources allocated for residential respite are not being fully utilised. Of all the service areas this one is where choice and flexibility hold the key to better carer support. For this reason, Alzheimer's Australia recommends extending 'approved service provider' to include family and friends and a trial of a full cashing out option.

- **Prevention**

There is a growing body of evidence that suggest a number of lifestyle and health factors may substantially reduce the risk of developing dementia. The reform agenda should include an emphasis on prevention and wellness and should ensure new lateral thinking in linking physical health to brain health and that older people are not left out of the preventative health agenda. Dementia should be included in preventative health campaigns for diseases that are linked to dementia and in the work of the newly established Australian National Preventive Health Agency.

Alzheimer's Australia understands the Commission's rationale for pushing ahead with reform quickly and the risk of losing the impetus. But Alzheimer's Australia believes that the risks inherent in a five year transition are too great and that it is an unrealistic goal. There is a need to take service providers, consumers, staff and professionals along with each stage of the reform processes.

These reforms will not only require changes in legislation and regulation but also a major cultural shift for aged care providers, workforce and consumers. A longer transition period would ensure true change in the philosophy of aged care provision in Australia and the adequate functioning of the proposed safety nets. Opportunities for true reform are infrequent, and the greatest risk to this reform process is inadequate transition and implementation arrangements.

At the same time the Government must respond to consumer demands for quick action to improve the aged care system. Alzheimer's Australia would advocate for the development of a mid-level community care package, a budget-holding option for new community care packages and increased numbers of packages as a first step in the reform process to smooth the transition to a seamless system between community and residential care, increasing access to flexible respite and strengthening assessment and information.

# Actions

## The impact of dementia on aged care

1. The Commission should recommend action to build on the Dementia Initiative including:
  - Taking action to improve the time to diagnosis for people with dementia
  - Making hospitals safer places for people with dementia
  - Increasing funding for NDSP in line with the prevalence of dementia and recurrent funding for Service Access Liaison Officers who work in partnership with diverse communities to improve access to services
  - Increasing funding for research into the cause, prevention and care of dementia including funding for research that focuses on the needs of individuals from diverse backgrounds who have dementia
  - Support for activities which improve the quality of dementia care in Australia including knowledge translation, workforce training for aged care and hospital workforce and research into care for individuals with dementia.
  - Ensuring that culturally appropriate assessment tools are accepted on the PBS.

## Funding model

2. A funding model needs to be developed that recognises the extra cost of dementia care and guards against market failures by:
  - Introducing a layered funding model that includes a dementia supplement across all layers of care. The details of this supplement should be further developed in consultation with consumers, providers and experts such as the Psycho-geriatric Care Expert Reference Group and should include funding for individuals with mild to moderate behavioural symptoms and the costs of engaging and training qualified staff to care for these individuals.
  - Recognise the importance of flexibility and choice for aged care services by:
    - Extending the 'approved providers' for respite to include family, friends and others.
    - Providing a budget-holding option for all new care packages as a transition to the new system of choice through the Gateway.
    - Acknowledging that the principle of extending 'approved providers' may have wider applicability in personal care, transport, and meal services.
    - Conducting a trial of a cash option for both care and respite which could be modelled on the Commission's proposals for the disability sector.

## **The interface of the mental health sector, disability and aged care**

3. The barriers in access to services for individuals with severe behavioural and psychological symptoms of dementia and those with younger onset should be removed. This should include:
  - The aged care program should take responsibility for older people with severe behavioural problems and a tendering process should be introduced both to ensure delivery of psycho-geriatric services in all areas and collaboration between those in the mental health and aged care systems.
  - Access to care should be based on need and not age. Individuals with younger onset dementia should be able to access appropriate aged care services unless their needs are better served by disability services.

## **Gateway**

4. The Gateway should have a networked approach with multiple entry points to accessing aged care. Individuals who need access to low-level services such as specialised support and counselling should be able to access them through the Gateway or by directly contacting NGO's like Alzheimer's Australia. The Gateway should be a source of information about social and clinical outcomes of care services to enable informed consumer choice.

## **Respite Care**

5. Reform of respite care is critical to stage 1 of the reform process and should include:
  - Integrating respite into the new aged care model as a key component of care and support for both the carer and the care recipient. Entitlement to respite should be based not only on the assessment of a carer's need for a break but also of the need of the care recipient for social engagement and access to meaningful and culturally appropriate activities.
  - Ensuring flexibility and choice through consumer directed care models of respite including through the option of entitlements which could be used to employ a wider range of providers including friends and family and a trial of a cash option.
  - Expanded supply of specialised dementia respite for individuals with behavioural symptoms of dementia.

## **Prevention**

6. The approach proposed by the Commission to to prevention and wellness should link physical and brain health by:
  - Support for preventative health campaigns that tap into existing knowledge about ageing and prevention such as Alzheimer's Australia's Mind Your Mind ® public education program and adapting these programs to meet the needs of diverse groups;
  - Inclusion of dementia in existing preventative health campaigns for diseases that share similar risk factors to dementia; and,
  - A specific recommendation that healthy physical and brain ageing, including dementia risk reduction be included on the agenda for the newly established Australian National Preventive Health Agency.

## **Implementation**

7. In order to ensure a smooth transition the implementation of aged care reform should:

- Occur over a longer time frame of ten years.
- Increase access to community care packages (including through the introduction of a mid level community care package), expanded respite care and strengthened assessment and information in the first stage of the reform.
- Include consultations with consumers, service providers and other stakeholders such as the National Aged Care Alliance should be consulted throughout the implementation and should be included on the Aged Care Reform Taskforce. The consultation and the Taskforce should be inclusive of the diversity of the community, sector and consumer base.
- The implementation process should include collection of a strong evidence base and review points to assess the effectiveness of the implementation.
- The Australian Institute of Health and Welfare should be charged with the task of performing the role of a national 'clearinghouse' for aged care data.



# 1. Dementia

**Concern:** The reform of aged care needs to be underpinned by a comprehensive strategy to address dementia and improve the quality of dementia care.

**Evidence:** The Commission acknowledges that the majority of individuals in residential aged care have dementia and that the numbers of people with dementia will be increasing rapidly over the next 30 years resulting in an increased demand for specialised services and care (Productivity Commission, 2011, p 42-43). Strategies to address the challenge of providing quality care to an increasing number of individuals who have dementia were not discussed and no recommendations on dementia were made. This is a major gap in the report.

Dementia has been shown to be a significant predictor of entry to residential care even after controlling for functional impairment (Banaszak-Holl et al., 2004). It is estimated that 55% of individuals in residential aged care have dementia (over 100,000 residents in 2011) (Access Economics, 2009a); the AIHW estimates that 83% of high care residents have dementia (AIHW, 2007). In 2008, 80,000 full time residential aged care staff were needed to provide care for people with dementia (Alzheimer's Australia, 2009). Dementia can no longer be considered an issue effecting a small population of older adults in aged care.

Dementia should be centre stage in reforming aged care because:

- Dementia is the largest cause of disability burden in older people (Access Economics, 2009b).
- There are currently over 269,000 people with dementia and the numbers are projected to increase almost a million by 2050 (Access Economics, 2010).
- In 2009 there were over 35,000 people with dementia who do not speak English at home and this is projected to increase to 120,000 by 2050 (Access Economics, 2009b).
- In 2011 it is estimated that there could be up to 13,000 Indigenous Australians with dementia and that this may increase to 17,000 by 2018 (Access Economics, 2009a)
- In 2008, over \$5 billion was spent on health and residential care for people with dementia and dementia will become the third largest area of health expenditure by 2030 and the largest by 2060. (Access Economics, 2009).
- Dementia was the third leading cause of death in Australia in 2008 (ABS, 2010).

The Dementia Initiative - Making Dementia a National Health Priority was announced in the 2005 Budget with an additional \$320 million funding over five years and has received bipartisan support. This funding has been used to support high care community packages, expanded training initiatives, funding for dementia care research through the three Dementia Collaborative Research Centres, quality of care initiatives and funding of the National Dementia Support Program administered by Alzheimer's Australia. The recently published evaluation of the Initiative has shown it to be effective (LAMA Consortium, 2009).

The Commission should recognise the strategic importance of the Dementia Initiative to ensure high quality dementia care and the important work of the initiative should be built on in the reform of aged care.

From a consumer perspective we agree with the independent evaluation of the Initiative that it has been effective and lifted the profile of dementia in key areas:

**Workforce training.** A critical component of the Initiative to date has been on workforce training, including through the National Dementia Support Program, Dementia Care Essentials and the Dementia Training Study Centres. Research suggests that training programs like these can result in increased knowledge about dementia, decreased use of restraints, and better outcomes for staff (Kuske et al., 2009). Individuals providing care to people with dementia should continue to receive training through these programs. This will be of increased importance for staff in the new Gateway and assessment teams.

**Support for people living with dementia.** Another integral part of the Dementia Initiative is the National Dementia Support Program. This Program provides information, support and counselling services to over 120,000 individuals with dementia and their families. Evaluations of the National Dementia Support Program (and its predecessor programs) have shown it to be cost effective to reduce stress for both the person with dementia and their carer (LAMA, 2009). The NDSP funding agreement for 2010-2013 did not increase funding for core services to reflect the increasing numbers of people with dementia. Over this period the projected increase in number of people with dementia will be 14% (Access Economics 2009b). This program should continue to receive block funding and funding should be linked to the projected growth in numbers of people with dementia so that the demand for services can be met.

Alzheimer's Australia, through the National Dementia Support Program has undertaken a partnership approach to ensure that our information, and service delivery is appropriate for culturally and linguistically diverse and Indigenous communities. We have developed national networks of consumers and service providers from these special groups who provide advice to Alzheimer's Australia on our services and who are dedicated to increasing awareness of dementia in CALD and Indigenous communities. Most states and territories also have Service Access Liaison Officers to promote partnerships between Alzheimer's Australia and those target groups at a disadvantage in accessing mainstream dementia care and support services. These programs need to receive recurrent funding to continue to improve access to services for those from diverse backgrounds.

**Dementia Research.** The Dementia Initiative has provided funding to dementia research through the three Dementia Collaborative Research Centres and dementia research grants, which have increased research capacity, promoted collaboration, attracted young researchers into the field of dementia care and positioned dementia researchers to apply for National Health and Medical Research Council grants and other major grants.

Despite the important work of the Initiative the level of funding for dementia research in Australia continues to be low, for both biomedical and psychosocial research, compared to other chronic diseases in terms of prevalence, cost to the healthcare system and disability burden. The average annual research funding for chronic illness in Australia from 2002-2007 was \$130 million for cancer research, \$90 million for research on cardiovascular disease, \$40 million for research on diabetes. Dementia receives only \$12.8 million (Alzheimer's Australia, 2008).

There is also a need for research which addresses the care for individuals from diverse backgrounds as this has been an area which has received inadequate funding and capacity building. For example, a review of 551 Australian articles on dementia published in journals and books between 2005 and 2007 found only four articles specifically related to persons from CALD backgrounds (Low et al., 2009).

**Quality dementia care.** The Dementia Behavioural Management Service (DBMAS) provides clinical advice and support to carers and to community and residential service providers on the management of Behavioural and Psychological Symptoms of Dementia (BPSD). The services combine expertise in dementia care and the translation of knowledge to service providers in both the management of individual cases and through training and seminars. In those states where the services are contracted to Alzheimer's Australia they form an important part of a suite of integrated services alongside those provided under the National Dementia Support Program.

**Community Care.** As part of the Dementia Initiative, the Government has provided Extended Aged Care at Home Dementia packages which are designed for individuals who require a high level of care and have psychological and behavioural symptoms of dementia but wish to stay in the community.

The strategic importance of the Dementia Initiative should be recognised both in promoting quality dementia care and the potential for improving the interface between aged care and the health system. The important work of the Initiative should be built on in the aged care reform through:

**Knowledge translation.** Dementia care will be of the highest quality when it is informed by research into best practice. Unfortunately, the uptake of evidence at the level of medical and biomedical research can take up to 17 years to be carried through in medical practice, care and policy (Balas & Borren, 2000). Alzheimer's Australia has established the National Quality Dementia Care Initiative to improve the quality of dementia care through addressing the gaps between what is known from research about best practice dementia care, and what is currently done. This is to be achieved through better collaboration between dementia care researchers, consumers and service providers, as well as funding innovative projects that address these evidence practice gaps. The Commonwealth should provide support for activities which promote the uptake of research to improve the quality of dementia care in Australia.

**Improving health outcomes.** The priority in addressing the health care needs of individuals with dementia is to provide an accurate and timely diagnosis. A recent literature review has found that "In general, GPs do not identify dementia early, do not complete a full assessment as described in the guidelines, and fail to provide the full range of recommended management options to their patients" (Williams, Byrne & Pond 2008, p1). Timely diagnosis enables people with dementia to get access to support and health services that may reduce complications and provide relief of some symptoms, as well as giving them time to plan for the future. (Alzheimer's Australia, 2007).

As the Commission noted (p 285), the development and use of culturally appropriate assessment tools, such as the Kimberly Indigenous Cognitive Assessment (KICA), and the Rowland Universal Dementia Assessment Scale (RUDAS) is important in improving diagnosis and care for diverse groups. Culturally appropriate assessment tools should be included as an option for assessment in qualifying for PBS access to dementia medications.

Hospitals are not safe places for people with dementia. Individuals with dementia have longer stays compared to individuals who do not have dementia and have the same medical concerns (Alzheimer's Society, 2009). In acute care individuals may not be identified as having dementia and therefore do not receive appropriate care (Maslow & Mezey, 2008). In some cases this may lead to an extended length of stay and a preventable admission to a residential facility. Unrecognised dementia is a major risk factor for delirium in older people hospitalised for common medical and surgical conditions. Delirium superimposed on dementia greatly lengthens length of stay (and cost) (Saravay et al, 2004). Preventive

interventions for delirium need to be predicated upon much better recognition of dementia in general medical and surgical patients (at or before the point of admission).

Even if diagnosed, the diagnosis and its implications may not be set out clearly in their hospital notes and staff may be unaware or unwilling to provide the additional attention required. Better outcomes for people with dementia in acute care, as well as less burden on hospital staff, can be achieved through cognitive assessment, awareness of cognitive impairment, and appropriate staff training.

The UK National Audit Office estimates that in the UK each hospital could save an average of £6 million a year by correctly identifying dementia patients, providing more appropriate and timely care, thus reducing length of stay and improving health outcomes (Royal College of Psychiatrists Centre for Quality Improvement, 2010). Although this has not been estimated in Australia, it is likely that there would be similar savings.

## **Action:**

- 1. The Commission should recommend action to build on the Dementia Initiative including:**
  - **Taking action to improve the time to diagnosis for people with dementia**
  - **Making hospitals safer places for people with dementia**
  - **Increasing funding for NDSP in line with the prevalence of dementia and recurrent funding for Service Access Liaison Officers who work in partnership with diverse communities to improve access to services.**
  - **Increasing funding for research into the cause, prevention and care of dementia including funding for research that focuses on the needs of individuals from diverse backgrounds who have dementia.**
  - **Support for activities which improve the quality of dementia care in Australia including knowledge translation, workforce training for aged care and hospital workforce, and research into care for individuals with dementia.**
  - **Ensuring that culturally appropriate assessment tools are accepted on the PBS.**

## 2. Funding model

**Concern:** Alzheimer's Australia has two concerns about the funding models in the draft report. Firstly, the Commission discusses a number of possible funding models, including a layered model with a dementia supplement, but makes no specific recommendations about how to provide for the higher costs associated with quality dementia care. Secondly, if we are to move to a system of greater choice and consumer empowerment the Commission must provide more flexibility and options for services, beyond 'approved providers'.

### Evidence:

#### Funding for Dementia

The Productivity Commission contracted Applied Aged Care Solutions (AACS) to provide an independent report on a new care and assessment model and has asked for further comment on the proposed approach. AACS has recommended a layered funding model which would provide basic support and care with supplements based on care needs including a two level dementia/mental health subsidy (Productivity Commission, 2011, Appendix B). The model would provide a single funding stream with three components:

- A base subsidy which would be determined based on low to high IADL/ADL needs (4 levels)
- Layered supplements covering specialist areas (including dementia, mental health, palliative care and nursing) with two levels of funding for each supplement.
- Care support needs (eg. Home modifications, transport, rural remote)

Individuals with dementia who have mild to moderate psychological and behavioural symptoms often find it difficult to access aged care. In many cases this is due to providers not receiving adequate funding to provide specialised care. As the Hogan Review (2004) noted "A resident who is mobile, wanders, has dementia and challenging behaviours (not once but many times a day) may well require constant supervision, continuous staff intervention, redirection and intervention to prevent risks of falls, episodes of aggression and increased anxiety levels. The resident is also likely to resist care and hence require considerable time and effort from staff to meet care needs."

The layered funding model proposed by the AACS includes a dementia subsidy across three levels of care regardless of where the care is provided. This is a step forward compared to the current model in which dementia/behavioural supplements for community care are only available for individuals requiring high-care through EACH-D packages. Alzheimer's Australia supports a layered funding model but further consideration must be given to how to accurately assess the additional costs of care associated with dementia. The Hogan Review (2004) argued that it is difficult to quantify the additional cost of dementia care is because of the progressive nature of the condition and the interaction of dementia with the management of other chronic health conditions. A two-level dementia supplement may not capture the full cost of care, especially for those with more behavioural concerns. The current Aged Care Funding Instrument has a three level behaviour supplement. A third level of the dementia supplement should be considered which could provide for the costs of care for individuals with dementia who require higher level of care due to their symptoms or the interaction between their symptoms and care for other medical conditions..

The dementia/mental health supplement should cover not only the extra costs associated with day to day care of individuals with dementia (e.g. time spent with the person) but also the

costs of providing high quality dementia care which includes employing and training staff with special skill sets, and the higher staff ratios required to care for those with behavioural needs.

The details of the supplement for mental health/dementia should be developed in consultation with the Psychogeriatric Care Expert Reference Group, consumers and providers who specialise in the care of individuals with behavioural and psychological symptoms of dementia.

### **A Flexible Entitlement System**

The Commission indicates that it aims to provide greater choice and consumer direction. This is achieved by giving individuals the ability to choose an 'approved provider' based on the entitlement that has been assessed at the Gateway. But the recommendations in the report stop short of providing real choice and empowerment.

In the Commission's recent inquiry into Disability Care and Support (2011), they recommend giving individuals with disabilities more choice including the option of employing family members or friends. "The Commission proposes a 'consumer choice' model, in which people with a disability (or their guardians) would:... have the choice (subject to some conditions — see below) to cash out their support package and manage it at the detailed level, allocating it to specific supports they assemble themselves (so-called 'self-directed funding'). Under self-directed funding, people could employ the support workers they want (and when), and choose to trade off some services against another." (p. 25)

It is unclear why older Australians should not have access to a similar model of 'consumer choice' with the same protections and accountability recommended in the disability report. As the Commission indicates in the disability report there is good evidence of the benefits of a system of greater choice: "There is widespread and compelling evidence that it leads to good outcomes (in life satisfaction, confidence in their care, feelings of control, health, employment, a variety of other wellbeing dimensions, and potentially all at lower cost)."

In the case of people with Younger Onset Dementia (YOD) who may be covered by the disability system until they turn 65, it seems odd that in the early stages of their disease they would have the option of cashing out their entitlement and employing friends and family if they wished, but once they reached the age of 65 they would be constrained to services they were assessed as needing, and providers which had been 'approved'.

Although access to choice and flexibility will be important for all aged care services, the area it is most critical is in respite, and for individuals from diverse backgrounds.

Needs for respite, whether emergency or planned, vary so widely in both the type of service, when it is needed, where it is provided and what type of care the recipient requires. The current system for respite is not meeting these demands, as can be seen from the difference in reported need for respite and uptake of services (Alzheimer's Australia, 2009). The reforms recommended by the Commission may improve access by costing and funding care more appropriately. It is unclear, however, how the market will respond and whether there will be adequate incentives to provide quality, specialised dementia respite care and whether the diverse needs for respite can be met.

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.

This may be particularly beneficial to the many diverse Australians. In 2009, some 97,000 (39%) of people with dementia live outside the capital cities and approximately 35,000 (14%) of people with dementia do not speak English at home. In 2050, 449,000 individuals with dementia will live outside capital cities and over 100,000 people with dementia will not speak English at home (Access Economics, 2009a).

The Commission acknowledges that there are concerns about access for these groups: “There is a risk that a more market responsive system will not deliver services to particular groups who require more costly services unless these are adequately funded.” (Productivity Commission, 2011, p 272). Expanding Consumer Directed Care would empower individuals to make decisions about their own care and enable them to purchase culturally and linguistically appropriate care through their community. In other countries that provide cash benefits the majority of these benefits are used to hire family members, neighbours, or acquaintances to provide services (WHO, 2003). For individuals from culturally diverse or Indigenous backgrounds this would mean being cared for by someone who speaks their language and understands their culture.

The Productivity Commission has indicated that one of the key components of providing services to individuals from special groups is to ensure that the new funding model takes into consideration the costs associated with providing culturally appropriate care, or care in a regional/remote area. It is imperative that this cost is not passed on to consumers through higher co-contributions that could result in an even lower use of services and support by already disadvantaged individuals. Providing expanded access to service provision beyond ‘approved providers’ may be one way of mitigating this cost.

In addition to respite, in the longer term, the principle of expanding ‘approved service providers’ might be applicable to other services, including personal care, transport and food services. These options should be considered after an evaluation of the success of the expansion of providers within respite.

In the shorter-term there needs to be a consideration of how to ensure choice for care needs. Once operational, the Gateway will provide individuals with the choice between various ‘approved providers’. The reality is that it may be five to ten years before this system is operational. As part of the transition to the new system, the government should provide consumers with the option of ‘budget holding’ for any new care packages. This would enable consumers to use the funds from their care package to access the most appropriate services to meet their needs and would begin the process of freeing up the supply of community care services.

Finally, there should be a trial of a full cash option for both care and respite. Older individuals would benefit just as much from choice as individuals with disabilities. It is unclear why the Commission is treating the cash option so differently for the older Australians. If the Commission is to be true to the guiding principles it describes “consumer-directed, allowing older Australians to have choice and control over their lives”, then any approach other than providing a cash option is a compromise.

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## **Action:**

- 2. A funding model needs to be developed that recognises the extra cost of dementia care and provides consumer-directed care:**
  - **Introducing a layered funding model that includes a dementia supplement across all layers of care. The details of this supplement should be further developed in consultation with consumers, providers and experts such as the Psycho-geriatric Care Expert Reference Group and should include funding for individuals with mild to moderate behavioural symptoms and the costs of engaging and training qualified staff to care for these individuals.**
  - **Recognise the importance of flexibility and choice for aged care services by:**
    - 1. Extending the 'approved providers' for respite to include family, friends and others.**
    - 2. Providing a budget-holding option for all new care packages as a transition to the new system of choice through the Gateway.**
    - 3. Acknowledging that the principle of extending 'approved providers' may have wider applicability in personal care, transport, and meal services.**
    - 4. Conducting a trial of a cash option for both care and respite which could be modelled on the Commission's proposals for the disability sector.**



### 3. Interface between aged care, disability and mental health

**Concern:** The needs of individuals with severe behavioural symptoms, and those with younger onset dementia will not be met until the structural barriers between the state-funded mental health and disability systems and the Commonwealth funded aged care systems are addressed and adequate funding is provided for the additional cost of caring for individuals with severe behavioural symptoms.

#### **Evidence:**

Individuals with younger onset dementia and those with severe behavioural and psychological symptoms of dementia (BPSD) often find difficulty in getting access to appropriate services. They find themselves bounced between various systems due to a lack of clear guidelines about who is responsible for their care. The reform of the aged care system needs to address the barriers that both of these groups face.

#### **Individuals with severe BPSD**

Care for individuals with **severe** BPSD and/or co-morbid psychiatric disorders is challenging and requires coordination of aged care and mental health services. The National Health and Hospital Reform Committee (2009) identified access to psycho-geriatric care as an area that needs reform. "As a matter of some urgency, governments must collaborate to develop a strategy for ensuring that older Australians, including those residing in aged care facilities, have adequate access to specialty mental health and dementia care services."

It is estimated that approximately 10% of individuals with dementia have severe BPSD, which equates to approximately 26,000 individuals in 2011. These individuals have complex care needs that can not always be addressed within a typical aged care setting. Instead, specialised psycho-geriatric care high dependency units which are designed to meet both the mental health and aged care needs of this group is the preferred approach (Psycho-geriatric Care Expert Reference Group, 2010).

Individuals with severe BPSD often face problems with access this type of care that addresses both their aged care and mental health needs because of structural barriers between the state-funded mental health system and the Commonwealth funded aged care systems (Department of Health and Ageing, 2008). These barriers and lack of adequate funding have led to a shortage of specialist psycho-geriatric facilities. As the Psycho-geriatric Care Expert Reference Group (2010) notes "there will be much higher numbers of older people with mental illnesses in years to come that will require management in generic settings".

Some states provide specialised care through aged care facilities that are funded through the Aged Care Act and are topped up with funding from the state government to provide high levels of mental health support (Department of Health and Ageing, 2008). This system may work well in some states, but in others there is a clear lack of collaboration and a gap in services. As a result, there is a need to clearly identify who is responsible for the care of older individuals with mental health needs. One option would be to introduce a tendering process for local psycho-geriatric services. This would allow for the collaboration that works well in some states to continue and would remove the gaps in services occur in other areas.

Individuals with severe BPSD require a higher level of care provided by highly trained staff and as a result their care is much more costly. The Aged Care Funding Instrument (ACFI) provides a behavioural supplement but this supplement does not cover the true costs of

providing care for those with severe behavioural concerns. The Commission acknowledges that individuals with behavioural issues may require higher levels of assistance and that the ACFI may not provide sufficient funding for these services. They suggest that funding concerns will be addressed through the benchmarking of pricing of care and support services (Productivity Commission, 2011 p 291-292). The new funding system must include a supplement which covers not only the additional costs of care for individuals with moderate behavioural concerns, but also those with severe behaviours including aggression, and the cost of training and supporting the staff that care for these individuals.

### **Individuals with Younger Onset Dementia**

In 2011 there are approximately 16,000 individuals who have younger onset dementia. There is a significant risk of younger people with dementia being shifted between disability and aged care services. When disability services are no longer able to meet a younger person's needs due to the progression of dementia, the person and their family carers are required to navigate a second unfamiliar system. The challenge is to develop a smooth and seamless service. In their inquiry into disabilities, the Productivity Commission states "People with disabilities should receive services from providers best skilled to meet their needs however so funded. So for example, a person with a severe long term disability such as multiple sclerosis may be best served by specialist disability service providers to the end of life. On the other hand, people who acquire early onset disabilities normally associated with ageing such as severe dementia might be best served by providers skilled in the support of older Australians."

Access to services should be based on care needs and not age. Age limits for access to aged care services for those with dementia should be removed. For those with a disability who develop dementia ongoing support from their existing service to avoid disruption might be the preferable course with those services drawing on the dementia expertise of the aged care service providers as appropriate.

### **Action:**

- 3. The barriers in access to services for individuals with severe behavioural and psychological symptoms of dementia and those with younger onset should be removed. This should include:**
  - The aged care program should take responsibility for older people with severe behavioural problems and a tendering process should be introduced both to ensure delivery of psycho-geriatric services in all areas and collaboration between those in the mental health and aged care systems.**
  - Access to care should be based on need and not age. Individuals with younger onset dementia should be able to access appropriate aged care services unless their needs are better served by disability services.**

## 4. Gateway system

**Concern:** The proposed new Seniors Gateway should build on existing services and be designed to ensure easy, flexible access to information and services. It should network with existing access points to aged care and with specialised support services of NGOs like Alzheimer's Australia. It should recognise that there are many different pathways that people take to gain access to services they require.

### **Evidence:**

The Productivity Commission has responded to consumers concerns about streamlining access to information and assessment (Productivity Commission, 2011 p239-243). The Commission proposes a Gateway that would be the access point for all government subsidised aged care and support services and would include:

- Information on healthy ageing, age appropriate housing, social inclusion
- Information on availability, quality and cost of care services and how to access the services
- Assessments of the needs of older people to determine entitlement to care
- Assessment of financial capacity to make co-contributions
- Initial care coordination services

The gateway would deliver services via a regional structure.

There is a need to reduce the complexities of the current system that can be overwhelming and seem fragmented to those who are trying to navigate it. At the same time, it is important to recognise the diverse pathways that people follow through the aged care system, including how people come to the decision to seek access to formal services. A networked approach which allows for a multitude of entry points, with a common core of consistent assessment, would better meet the needs of consumers.

The Commission indicates that many programs that currently receive block funding from the Government would receive funding through the entitlement system and would therefore be accessed through the gateway. Exceptions will be made where "scale of economies, generic service need and community involvement indicates there is a need to do so" (Productivity Commission, 2011, p. LXI). It is unclear how the gateway would interact with NGO's like Alzheimer's Australia that provide information, early-interventions, counselling and support services.

In trying to simplify and streamline the system it is important that the Government does not create a monolith with added complexities for people who need access to low-level support services, or information and counselling. It may not be cost-effective or appropriate to require individuals to undergo formal assessment to access services that cost less than \$100 per week. This could create a barrier for those who would not identify as needing a formal assessment, and want access to early information and support.

For example, Alzheimer's Australia is able to provide support to people with dementia and their families through the National Dementia Support Program (NDSP) with a comprehensive suite of community based specialised services that have been developed in partnership with the Australian Government over nearly ten years. Every year this program provides over 120,000 Australians services through the National Dementia Helpline, information and awareness, counselling, education and training. Strengths of the program include its responsiveness to consumer needs, its integrated approach and its nationally consistent delivery, which is achieved by Alzheimer's Australia's federated members working closely with each other and at a state/territory level to maximise outcomes. The

evaluation of the Dementia Initiative found that the National Dementia Support Program was effective and cost effective (LAMA, 2009).

Requiring assessments through the Gateway for specialised support programs like the National Dementia Support Program, or other low-level services may reduce access to early-intervention services, support for carers in crisis and information.

Individuals often approach Alzheimer's Australia in the early stages of dementia and may contact the organisation before seeking formal assessment. Alzheimer's Australia runs a support program, *Living with Memory Loss*, for people with early stages of memory loss and their family carers. This 6-week program provides information and support and helps people who have recently been diagnosed come to terms with their diagnosis. The program has been found to be effective in reducing depression in the person with memory loss and reducing stress for the carer (Bird, Caldwell, Maller & Korton, 2005). For many individuals it is the first step towards accessing more formal support services. Early intervention programs for individuals with dementia and their carers, like *Living with Memory Loss* can lead to reduced placement in residential facilities and better outcomes for family carers (AIHW, 2009).

Carers who seek face to face counselling from Alzheimer's Australia often do so because they are experiencing stressful situations and want to address immediate 'crisis type' of concerns (AACCS, 2000). In an evaluation in 2000, over 80% of carers indicated that their burden level was improved after counselling, and a similar proportion felt better overall after the face to face support (AACCS, 2000). It is unlikely that Alzheimer's Australia would be able to provide these much needed immediate services if individuals needed an assessment before being able to access counselling.

Individuals will also be less likely to access services if they are required to pay a co-contribution. In a recent study of the use of carer support services in Europe, cost was one of the main reasons for not accessing needed supports or discontinuing use of these services (Lamura et al., 2008). If a user-charge was introduced in Australia, some individuals may choose to not access services until they hit a crisis point, which will result in worse outcomes for carers, people with dementia as well as the public health system. If organisations like Alzheimer's Australia continue to receive block funding, the Gateway could provide referrals to these organisations to encourage care recipients and carers to access specialised counselling and support. Alzheimer's Australia, could in turn, refer individuals to the Gateway when they need higher level care and support.

The proposed Gateway must also provide consumer-friendly information about the levels of care provided by different services and social and clinical outcomes of care services (e.g. Quality of life), in order to facilitate informed choices. Information on the quality of specialised services such as dementia care and psycho-geriatric care should also be available.

### **Action:**

- 4. The Gateway should have a networked approach with multiple entry points to accessing aged care. Individuals who need access to low-level services such as specialised support and counselling should be able to access them through the Gateway or by directly contacting NGO's like Alzheimer's Australia or through specialised advocacy bodies such as ethnic community groups. The Gateway should be a source of information about social and clinical outcomes of care services to enable informed consumer choice.**

## 5. Respite Care

**Concern:** Respite needs to be given a higher priority in the final report of the Productivity Commission given its importance to both carers and care recipients. Aged care reform presents an opportunity to address consumers concerns about respite. In the Draft report there were no specific recommendations on respite and it was unclear how respite fits in to the reform agenda.

**Evidence:** The Productivity Commission acknowledges the importance of respite for carers and some of the challenges that carers face in accessing respite, stating: “Informal carers and organisations that represent carers report that there are significant problems accessing assessments for respite care and the services themselves, for both planned and emergency respite.” (Productivity Commission, 2011 p 350-351). The PC suggests that the structural changes to the aged care system recommended in the report should give individuals more flexibility to access respite services that are better suited to their needs. It is unclear, however, how respite will be integrated into the new system of reforms. The PC has indicated that a carers assessment will include an assessment of need for planned respite, but it is unclear if respite will be funded as part of personal/health care or as a separate entity as part of ‘carer support’.

Both planned and emergency respite care are crucial components of support for carers and can enable individuals with dementia or other care recipients to continue to live at home for as long as possible. It also provides individuals with dementia opportunities for social engagement and participation in appropriate and meaningful activities. For example, Lucille (a member of Alzheimer’s Australia’s National Consumer Advisory Committee) said *“Respite made a huge difference. It gave me a chance to make more contact with my friends and my children, to participate in social activities. It gave me a tremendous amount of strength so that I could carry on. For the last 18 months my husband was in a wheel chair and couldn’t move. I kept him at home during that time and respite helped me to do that.”*

Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs. According to the ABS Survey of Disability, Ageing and Carers in 2003, for every three dementia carers who have used respite, there are two dementia carers who need respite but have not used it (ABS, 2003). The differences between need for and use of respite on the part of dementia carers and all carers are striking. Dementia carers are:

- About half as likely to say that they had no need and had not used respite;
- 50% more likely than other carers to need and have used respite; and
- More than 10 times more likely than other carers to say they need respite but had not used it. (Alzheimer’s Australia, 2009).

The Productivity Commission has not addressed the key concerns of consumers in regards to respite with regards to access to appropriate care, flexibility and choice, or the importance of respite to the care recipient. Our consumers report endless examples of the difficulties that a lack of appropriate service can cause. For example:

***“the respite service had limited hours and my dad was only eligible to attend 3 days a week. This caused me great distress as it meant that 2 days he was at home for extended hours by himself. The other problem was that they were only open from 10am and closed at 3.30. The bus would drop him off (with no-one at home) and drive off and he would ‘high foot it down the road’ after they had gone around the corner. Many a day, he was picked up by the local police and held in the ‘lock up’ until one of us could come home.”*** Tara (QLD Member of Alzheimer’s Australia Consumer Dementia Research Network)

***“The best thing the service providers did for me was to arrange 48 hour respite care once a month. The carer spoke my parents’ language, and looked after mum and dad, so I was able to concentrate on my business. After moving interstate, the service providers changed and I was offered only a couple of hours of care per week and there were no bilingual respite carers available. I suppose I felt that it was my responsibility anyhow so if there weren’t other people- bad luck for me. If I had better respite care mum would have stayed at home with me for at least another year or two which we both wanted.”*** Danijela (TAS Member of Alzheimer’s Australia Consumer Dementia Research Network)

***“I often feel the need for respite. However, I am reluctant to send my husband to a service where he sits in front of a television all day. Respite facilities should offer a range of stimulating activities, particularly suited for men.”*** (Carer from WA)

***“I live in a regional area but the only respite I could get was for an hour at a time. I would need to go shopping and it was 100k drive to the shops. It was impossible to get the respite I needed”*** (Carer from regional NSW)

***“When I went to pick my mom up from respite I found that she wasn’t properly dressed and was tied to a chair. I didn’t use respite for a long time after that because I didn’t want my mom to suffer just so that I could have a break”*** (Carer from NSW)

Carers of people with dementia report difficulty in accessing services which meet both their needs and the needs of the person with dementia. Recent research conducted in Australia shows that one of the main barriers to accessing out of home respite care is a concern that the service use experience will be negative for the person are caring for (Phillipson, Jones, and Magee, 2010). Caregivers are less likely to utilise respite services provided in day centres if they perceive they are not attractive and beneficial to the care recipient with dementia, even if they themselves need a break (Phillipson and Jones, 2010a). Caregivers are concerned that the use of in-home services can lead to conflict with the care recipient, or a disruption to their care routines (Phillipson and Jones, 2011), and that the use of residential respite services may result in deterioration in the condition of the care recipient (Phillipson and Jones, 2010b). In fact, survey research with Australian caregivers demonstrated that beliefs that service use will result in negative outcomes for the care recipient are a stronger predictor of which carers will use out of home respite services than is their assessed need (e.g. burden or depression) (Phillipson, Jones and Magee, 2010). Assessment for respite need should not focus solely on the carer’s needs, as suggested by the PC, but should also consider the needs of the care recipient.

Family carers also report that once the person with dementia develops behavioural symptoms or becomes incontinent service providers refuse to continue to provide services. There is a need for respite care that meets the varying needs of individuals with dementia, including their need for social engagement. This requires staff that have dementia specific training, mentoring, and monitoring of care practices.

A second reason for not utilising respite is the lack of flexible services. Needs for respite, whether emergency or planned, vary so widely in both the type of service, when it is needed, where it is provided and what type of care the recipient requires. The current system for respite is not meeting these demands, as can be seen from the difference in reported need for respite and uptake of services (Alzheimer’s Australia, 2009). The reforms recommended by the Commission may improve access by costing and funding care more appropriately. It is unclear, however, how the market will respond and whether there will be adequate incentives to provide quality, specialised dementia respite care and whether the diverse needs for respite can be met.

It is also unclear how respite will fit into the new entitlement system. Currently respite is provided through National Carers for Respite Program, Home and Community Care and the Residential Respite Program. This system creates barriers to use through different program eligibility, funding, fees and requirements.

In order to improve access to services and support, the 'Seniors Gateway' should assess both the needs of the carer and care recipient for respite. Individuals should be provided with an entitlement to planned respite and a pool of emergency respite which can be accessed as needed. 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 which 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 fits needs delivered when and where it is required
- Assistance from individuals that the care recipient knows and trusts
- Greater satisfaction with care (see Arksey & Kemp, 2008 or Ottman, Allen & Feldman, 2009 for a review of international evidence on cash-for-service).

For example, there is evidence of good outcomes of a system which enables individuals to purchase care services from non-accredited providers (including family) from the US Cash and Counselling Demonstration project. Individuals seeking care services were randomised to either a group that received a cash budget to purchase services or to traditional agency services. Most individuals in the cash group chose to get care from friends or relatives. Individuals in the cash for services group had greater satisfaction with performance of the carer, and the relationship with the carer than individuals receiving traditional services. They also had greater reductions in unmet needs for help with household activities and transportation. The cash system was shown to be at least as safe as agency directed care in terms of adverse events and individuals receiving this care had similar health outcomes as those receiving traditional care from accredited providers. There was also no evidence of abuse, with fewer instances of theft by caregivers in the group receiving care from cash (Foster et al., 2003).

The Commission will need to explore options for implementing such a system. One model could require that individuals, including family members other than the primary carer, could apply to be an 'approved respite carer', similar to the 'registered carer' system in the child care sector. They could be required to meet standards such as having a first aid certificate or a police check. A second option would be a budget holding system in which service providers would be hired to administer the funds and negotiate arrangements and contracts with the provider chosen by the care recipient (including friends and family). Regardless the specific model adopted, it is clear that there is a need for a more flexible system of both planned and emergency respite.

The Commission should also trial a cash-out option for respite, similar to what is suggested in their report on the disability sector, to enable greater choice in accessing services.

## **Action:**

5. **Reform of respite care is critical to stage 1 of the reform process and should include:**
  - **Integrating respite into the new aged care model as a key component of care and support for both the carer and the care recipient. Entitlement to respite should be based not only on the assessment of a carer's need for a break but also of the need of the care recipient for social engagement and access to meaningful and culturally appropriate activities.**
  - **Ensuring flexibility and choice through consumer directed care models of respite including through the option of entitlements which could be used to employ a wider range of 'approved providers' including friends and family, and conducting a trial of a cash option for respite entitlement.**
  - **Expanded supply of specialised dementia respite for individuals with behavioural symptoms of dementia**



## 6. Prevention

**Concern:** The Productivity Commission says that the aged care system should aim to promote independence and wellness of older Australians but does not go far enough in recommending action on preventative health.

**Evidence:** The Commission makes a single specific recommendation with regards to prevention which is to include information on healthy ageing and social inclusion within the proposed gateway.

The Commission acknowledges the potential benefits and cost effectiveness of preventative health and wellness programs but raises concerns about the evidence base for some of these initiatives: “Given the claims about the potential cost-effectiveness of prevention and early intervention measures, there is a need to know more about the effectiveness of different interventions in preventing or reducing the likelihood of particular outcomes” (Productivity Commission 2011, p 439) The Commission suggests that research with a focus on prevention and early intervention for older people could be conducted within the new National Health Promotion and Prevention Agency.

Alzheimer’s Australia supports the need for greater research into the efficacy of preventative interventions. At the same time the Government should make use of the research evidence that is currently available on prevention. There is a growing body of evidence that suggests a number of lifestyle and health factors may substantially reduce the risk of developing dementia. These risk factors overlap with those for other chronic illness, particularly cardiovascular disease (Alzheimer’s Australia, 2010). The evidence base is being further developed by the Dementia Collaborative Research Centre on Prevention, in which Alzheimer’s Australia Vic is a partner.

Unfortunately only 50% of Australians believe that it is possible to reduce the risk of developing Alzheimer’s disease and other forms of dementia. But even among those who are aware there is something they can do to reduce risk, approximately 60% of Australians are not aware of the potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries (StollzNow, 2010).

Individuals who are culturally and linguistically diverse and Indigenous population groups often have even lower levels of awareness of dementia and negative cultural attitudes towards dementia. First generation Italian, Greek and Chinese Australians are significantly less likely to identify symptoms of dementia compared to third generation Australians. In addition, when asked about the cause of dementia, recent immigrants were more likely to suggest that old age, stress, or personality was the cause of dementia, while third generation Australians were more likely to identify dementia as a brain disease (DCRC, 2010). Further work must be done to increase awareness and information about dementia in these groups.

Alzheimer’s Australia has developed and successfully implemented the first stage of the Mind Your Mind® public education program which provides information on ways to reduce risk for dementia. This public education program needs to be extended to culturally and linguistically diverse and Indigenous populations, as well as to a broader geographic audience across Australia. The program aims to increase awareness of dementia risk reduction and an investment in this approach may contribute to reducing the numbers of those with dementia.

Providing information on prevention in the proposed Gateway will be limiting as most older Australians will not access the Gateway until they are seeking care services, and information about preventative health should be provided to individuals of all ages. Information about the effects of a healthy lifestyle on brain health should also be included in existing government public health campaigns that address behaviours and diseases that are linked to dementia such as cardiovascular disease, diabetes, obesity and smoking. The Government should include these links in the work of the new Australian National Preventive Health Agency.

**Action:**

- 6. The approach proposed by the Commission to prevention and wellness should link physical and brain health by:**
  - **Support for preventative health campaigns that tap into existing knowledge about ageing and dementia risk reduction such as Alzheimer's Australia's Mind Your Mind<sup>®</sup> public education program and adapting these programs to meet the needs of diverse groups.**
  - **Inclusion of dementia in existing preventative health campaigns for diseases that share similar risk factors to dementia.**
  - **A specific recommendation that healthy ageing and dementia risk reduction be included on the agenda for the newly established Australian National Preventive Health Agency.**

## 7. Implementation

**Concern:** The Government must take a considered and gradual approach to the implementation of the proposed aged care reform in order to ensure a seamless transition that protects consumers.

**Evidence:** The Commission has recommended a gradual implementation of reform over a period of five years followed by a review of the implementation process. The Commission recommends that the Government should:

- Announce a timetable for changes
- Consult with providers, consumers, carers, and government on issues arising from the implementation
- Embed feedback processes and enable fine-tuning of the new system
- Grandfather current users of care services and relevant financial arrangements of providers
- Sequence reforms carefully to facilitate adjustment
- Establish an Aged Care Implementation Taskforce to oversee the implementation

Given the complexity of the current system the Government should consider recommending a longer time scale for implementation, ensure ongoing consultation throughout the implementation, and refine the reforms based on these consultations and an evidence base.

The suggested reforms represent a major shift in how aged care is provided in Australia, and to ensure a smooth transition the reforms should occur over a ten year period. At the same time, in order to ensure continued support for the reform process, it will be important for consumers to see the positive effects of reform of aged care quickly.

One of the areas of reform that is of greatest interest to consumers is greater choice and availability of community care. Action on community care should be a priority for the first stage of the reforms. The Productivity Commission has recommended an increase of both residential care places and packages by 10-20% during the second stage of reforms (p 460). The increases in supply of community aged care should not be delayed until the second stage of reforms as suggested by the PC, or occur at the same level as residential aged care. The first stage of reforms should include an introduction of a mid-level community care package, an increase in the number of community care packages above the baseline set by the 70+ ratio and an option of budget-holding for any new community care packages in order to meet consumer demand for care at home. The initial stage should also include expansion of respite services and trial of a program to expand providers to include funding for respite care from non-accredited members of the community. It will also be important to begin the process of strengthening existing assessment information in laying the foundations for the Gateway.

Extending the period of implementation would enable providers to plan adequately for changed financial arrangements and incentives and for consumers to plan for the financial implications of the new co-contributions for aged care. It would also allow for the set up of the new financial vehicles, such as the Australian Pensioners Bond and would provide the Government with adequate time to identify and address any unexpected issues that arise from implementation. In order to ensure good outcomes for consumers there needs to be ongoing consultation throughout the reform process. It is imperative that these consultations are not tokenistic but are used to inform the implementation process and to refine the new system. As such, the proposed Aged Care Reform Taskforce, which will be charged with implementing the reforms, should comprise not only senior bureaucrats as proposed, but also individuals who have most at stake in a successful reform process- consumers and service providers.

As the rationing of the system is lifted it will be important to ensure that adequate safety nets have been included in the reforms. The Government should have an ongoing assessment of whether

individuals who are financial disadvantaged and those who require specialised care are able to access appropriate and affordable services.

The implementation of the reforms should be guided by a strong evidence base. Data should be collected on the time to access care, clinical and social outcomes for care recipients and carers and quality of care. This data should be used to ensure quality and timely access to care and also to identify the ways in which the co-contribution system affects consumer choice and access to care services.

The Commission has recommended that the proposed Australian Aged Care Regulation Commission should perform the role of a national 'clearinghouse' for aged care data (Recommendation 13.1). If this recommendation is implemented it would result in a duplication of infrastructure and expertise that is already available through the Australian Institute of Health and Welfare (AIHW) and would result in additional expense. It also raises questions about transparency, as the same organisation that is charged with regulation of aged care would also be reporting on outcomes and data. The AIHW is an independent statutory authority which has well established data expertise and has significant familiarity with the relevant datasets, including linking them together to look at pathways, and they produce a series of publications on aging and aged care each year. It is clear that AIHW would be best placed to be the new 'clearinghouse' for data in aged care.

### **Action:**

#### **7. In order to ensure a smooth transition the implementation of aged care reform should:**

- **Occur over a longer time frame of ten years.**
- **Increase access to community care packages (including through the introduction of a mid level community care package), budget-holding for new packages, expanded respite care and strengthened assessment and information in the first stage of the reform.**
- **Include consultations with consumers, service providers and other stakeholders such as the National Aged Care Alliance should be consulted throughout the implementation and should be included on the Aged Care Reform Taskforce. The consultation and the Taskforce should be inclusive of the diversity of the community, sector and consumer base.**
- **The implementation process should include collection of a strong evidence base and review points to assess the effectiveness of the implementation.**
- **The Australian Institute of Health and Welfare should be charged with the task of performing the role of a national 'clearinghouse' for aged care data.**

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