



Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Alzheimer's Australia Submission to the Productivity Commission Inquiry into Disability Care and Support

Thank you for the opportunity to make a submission in this important area. This submission has been prepared in conjunction with our National Consumer Advisory Committee.

Dementia is not a normal part of ageing and should be seen by all sectors as a disability in its own right. While Centrelink recognises people with dementia aged under 65 as being potentially eligible for the Disability Support Pension, the inconsistent way in which dementia is treated in other sectors may make life much harder for both the person with dementia and their family carers.

Currently people with a pre-existing disability – other than dementia - who develop dementia as they age, find it difficult to get the assistance that they need from either the disability or aged care sectors. At the same time, COAG has passed service responsibility for people diagnosed with dementia before 65 to the disability sector.

This COAG decision raises two policy issues. First where is the funding to come from to care for younger people with dementia and how, in respect of an emerging disadvantaged group, can National action be assured through eight State and Territory Governments.

Second, which sector is best equipped to care for people with younger onset dementia? The disability system has limited experience with this target group.

The aged care system already has the skills to care for people with dementia of all ages and in practice, it is to these services that people with younger onset dementia have turned. This does not mean that current service provision does not need to be tailored better to the social support needs of younger people. The means need to be found to ensure that existing skills are engaged for both younger and older clients, regardless of their living arrangements and age.

The Dementia Epidemic will have an impact on the way in which care is provided within disability services in the future. Regardless of the age at which a diagnosis of dementia is made, those affected should be able to benefit from quality care delivered by well trained service providers who can meet their needs. This should be independent of the potential source of the funding, whether disability, aged care or otherwise. Any future disability arrangement should include as a central tenet that need and appropriate assessment of that need are integral to the support provided. Transitions between care types regardless of the Government funding sources should depend on change in need, not be based base on age alone.

This submission addresses the following areas:

- Dementia;
- 'Age related' disability;
- The impact of dementia on people with another disability as they age;
- The impact of providing care for people with younger onset dementia on the disability sector subsequent to the recent COAG decision;
- The recommended characteristics of the new system.

Dementia

Alzheimer's Australia is the National peak body for people with dementia, their families and carers and provides leadership in policy and services. Our State and Territory member organisations provide information and education, support and advocacy services.

Dementia is the term used to describe the symptoms of a large group of conditions that result in a progressive decline in cognition. These include decline in memory, reasoning, communication skills and the capacity to carry out activities of daily living.

Dementia does not discriminate. It can affect anyone in society irrespective of age, gender, education, ethnicity and pre-existing health condition or disability.

Dementia is not a natural part of ageing, but it is more common as people age. Dementia may affect people under 65 including people in their 20s or 30s. While 25 per cent of people aged 85 or older have dementia, 3 out of 4 do not.

As the Australian population ages, the number of people with dementia will increase from 257,000 in 2010 to 565,000 in 2030 and around 1 million in 2050.

The impact of this growth needs to be taken into account in any future planning of disability and other care services, particularly in respect of people with a disability who may develop dementia and those who develop younger onset dementia. Further information about dementia is included at Attachment A.

'Age related' disability

The current approach to disability funding and programs provides assistance only to those under 65 when they first seek assistance, while those over 65 are generally

supported through the aged care sector. While the impact of disability is unique to every individual, it is difficult to see how the needs and circumstances of someone for example, diagnosed at 64 with Multiple Sclerosis or Parkinson's differ from those of someone diagnosed at 66. The services and expertise available should not depend on the individual's age at diagnosis.

As the definitions in the Productivity Commission Issues Paper indicate, the notion of disability is complex. In Australia, the definitions used in collecting population data differ markedly from those used in determining access to subsidised services. For example, people with impairment due to dementia are counted into ABS disability estimates but this group have been excluded historically from access to disability services, finding their support from within the aged care sector.

The AIHW (at <http://www.aihw.gov.au/disability/index.cfm>) notes the World Health Organisation definition and goes on to say:

Disability has long been regarded as a social issue, requiring social responses. A person with disability may need assistance - formal and/or informal - to fully participate in society. That assistance can be provided by families, unpaid carers, and/or formal services.

Services of relevance to people with a disability address needs corresponding to impairments or may seek to improve aspects of the physical or social environment in order to remove barriers and increase participation.

Impairment leading to disability results from a range of disease processes or as a result of accident or consequence of birth. Disability is not theoretically an age-related concept as people at any age may experience disadvantage and exclusion as a result of the interaction between their impairment and environment.

Historically, Government funded programs reflected the notion that people under 16 remained primarily the responsibility of their parents, people 65 or over were assisted solely within the aged care sector and those in between, ie 16-64, were of employable age and were eligible, if needed, for disability services.

Setting this style of eligibility led to some unintended consequences. For example, as established in 1993, the Continence Aids Assistance Scheme assisted people of 'employable' age with profound disability who were unable to ever work, while employed people 65 or over did not qualify for support. More recently the age criterion has been dropped and the eligibility criteria for this program broadened, in part reflecting the articulation between education and employment support, moves to healthy ageing and the 'retirement' of the traditional view of an employment age.

Many conditions including some forms of cancer, Type II diabetes, hypertension Parkinson's and dementia are more common as people age. This does not mean that they are a normal part of ageing. A key task of specialists like geriatricians is to ascertain which symptoms in older people might be addressed by treating the

underlying disease condition. In this context, management and treatment of dementia will remain difficult until research solves the existing mystery about the cause of Alzheimer's disease, the most common form of dementia.

People with another disability who develop dementia as they age

The numbers of people with a disability who develop dementia as they age will increase as dramatically, and in a similar way, to the general population. As people with a disability successfully age past 65, most will experience a similar risk of dementia to the general population. This means that around 11% of those aged 70 or older will develop dementia, affecting both their ability to continue to manage their own lives and the services that will be needed to support them.

The situation is exacerbated for people with Down syndrome, who because of the genetic basis of their impairment, are at significantly greater risk of developing Alzheimer's disease as they live into their 50s and 60s. Median life expectation for this group has increased from around 20 to 60 in the last 50 years with improvements in health care and other support. In recent years Alzheimer's Australia has developed both resources and training to support this part of the disability sector.

The impact of younger people with dementia on the disability sector

There are currently around 16,000 people with younger onset dementia who are aged under 65. Following decisions taken by COAG in 2008 responsibility for services for this group lies with the disability sector. Currently disability services are not adequately funded for this responsibility nor do they have expertise in dementia care. While dementia education is compulsory within the Certificate III in Aged Care, dementia is not a recommended elective for the equivalent Disability Services qualification.

To ensure seamless delivery of services, individuals who have not previously received support from disability services should receive age appropriate care services through the aged care system. Individuals with a disability who develop younger onset dementia should be provided care within the disability framework with access to other agencies as necessary for assistance in the provision of dementia care. As dementia progresses, any individual may need access to high level care packages or the kind of full time care currently provided within residential aged care.

Until recently, care for younger people with dementia has been provided and funded through the aged care system. Access to services has been problematic, in part because of the failure to provide appropriate social support and physical environments for this group within community and residential based services.

As a consequence of decisions taken by COAG, the needs of this group will now need to be addressed by the already stretched disability sector. Where such disability assessment and services do not exist there can be recourse to the aged

care sector but this means that people may be endlessly referred between the aged care and the disability systems.

Consumers have expressed three concerns with the current situation they find themselves in.

- First, how is the disability sector going to gain an understanding of the care and support needs of people living with dementia? Currently the disability sector has little experience of dementia and it will take time and resources to equip staff with the additional skills.
- Second, what resources are available to develop services appropriate for people with younger onset dementia? It is likely to be the case that accommodation and care services for those with intellectual and physical disabilities will not generally be appropriate for younger people with dementia.
- Thirdly, what requirement is there on individual States and Territories to embrace younger people with dementia within the COAG initiative? There is a significant risk of younger people with dementia being bounced 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, will the person and their family carers then have to navigate a second unfamiliar system? The progression of dementia in younger people can be quite rapid. How does the sector envisage developing a smooth and seamless service?

Many of the issues that younger people with dementia might expect to face in future could be resolved if the current separate sectors were articulated into a single access scheme that was designed to better meet individual needs. In this way the current expertise of the aged care system might be used to best effect to support all affected by dementia.

The recommended characteristics of the new system

An optimal system for the delivery of care would provide services as needed, regardless of age. While the structure and design of such a system goes beyond the scope of this submission, Alzheimer's Australia takes the strong view that with respect to dementia, any new system should incorporate the following considerations:

- Accommodation, care and other support that is person centred and meets their changing needs regardless of their age, disability, culture and location.
- A single system of information, assessment and case management regardless of impairment or age. The recently announced aged care

arrangements may be a useful development which could be extended to encompass the wider range of care sectors.

- Consistent assessment of need regardless of age, impairment, setting or location.
- Service funding from the range of separate sources.
- Commitment from all spheres of government to help people with dementia to remain as active participants in their community as long as this is practicable and meets their wishes.
- An articulated system with seamless transitions as their needs and circumstances change, while at the same time offering optimal continuity and stability of care.
- Use of the best mix of mainstream services, aged care services, disability services or condition-specific services as appropriate.
- Consumer directed care across a range of models - including individual budget holding if desired - supported by optional brokerage and budget holding services.
- Understanding of the role of families and other informal carers and consideration of the support that they need to participate in care.
- Staff who are trained in supporting people with dementia or other cognitive impairment.

Conclusion

The implementation of the COAG decision will be long and complex and it is of concern that the short term consequences of the decision to hand responsibility for younger people with dementia to the disability sector have not been fully thought through. This needs to be considered in the Commission's consideration of the best long-term arrangements to support people with a disability.

An interim policy approach would be to waive the age limitation on access to aged care assessment and services for people of all ages as the disability system is not positioned to care for this group or funded with the considerable resources necessary to realise the decision taken by COAG.

Further information

We have attached the following documents for your information:

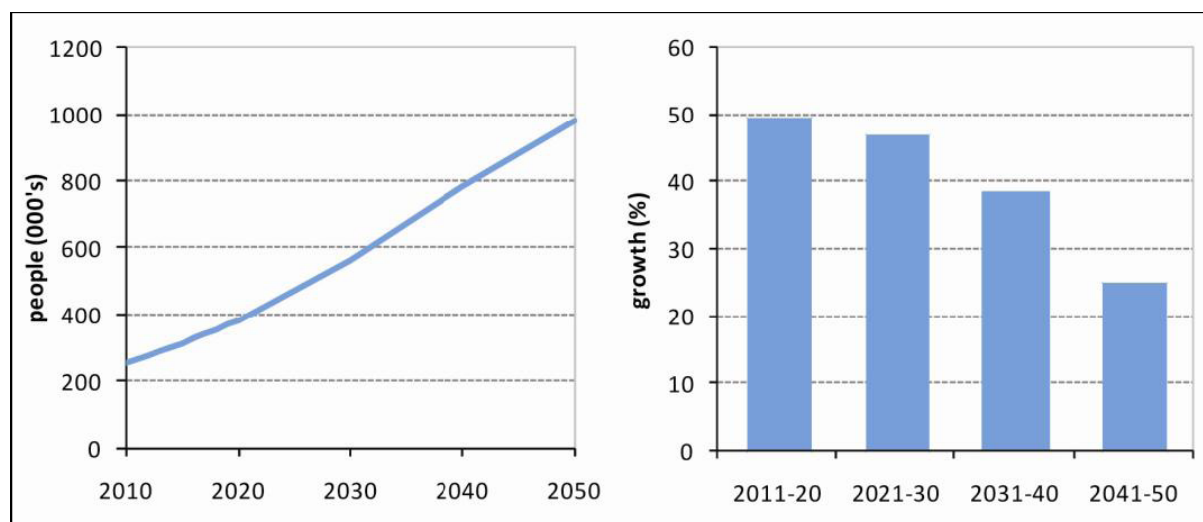
- *Down Syndrome and Alzheimer's Disease*, available on our website at <http://www.alzheimers.org.au/upload/DownSyndromeandAlzheimer'sDisease09.pdf>
- *Younger Onset Dementia – A Practical Guide*, available on our website at http://www.alzheimers.org.au/upload/QDC_YOD_feb09.pdf
- *Understanding Younger Onset Dementia*, available on our website at http://www.alzheimers.org.au/upload/QDC_YOD.pdf

- *In Our Own Words: Younger Onset Dementia*, available on our website at <http://www.alzheimers.org.au/upload/InOurOwnWords.pdf>
- The Communiqué from the *February 2009 Younger Onset Dementia Summit*, available on our website at <http://www.alzheimers.org.au/upload/YODCommunique2009.pdf>

Please contact me (telephone 02 6254 4233 or email glenn@alzheimers.org.au) if you require further information.

Glenn Rees
Chief Executive Officer
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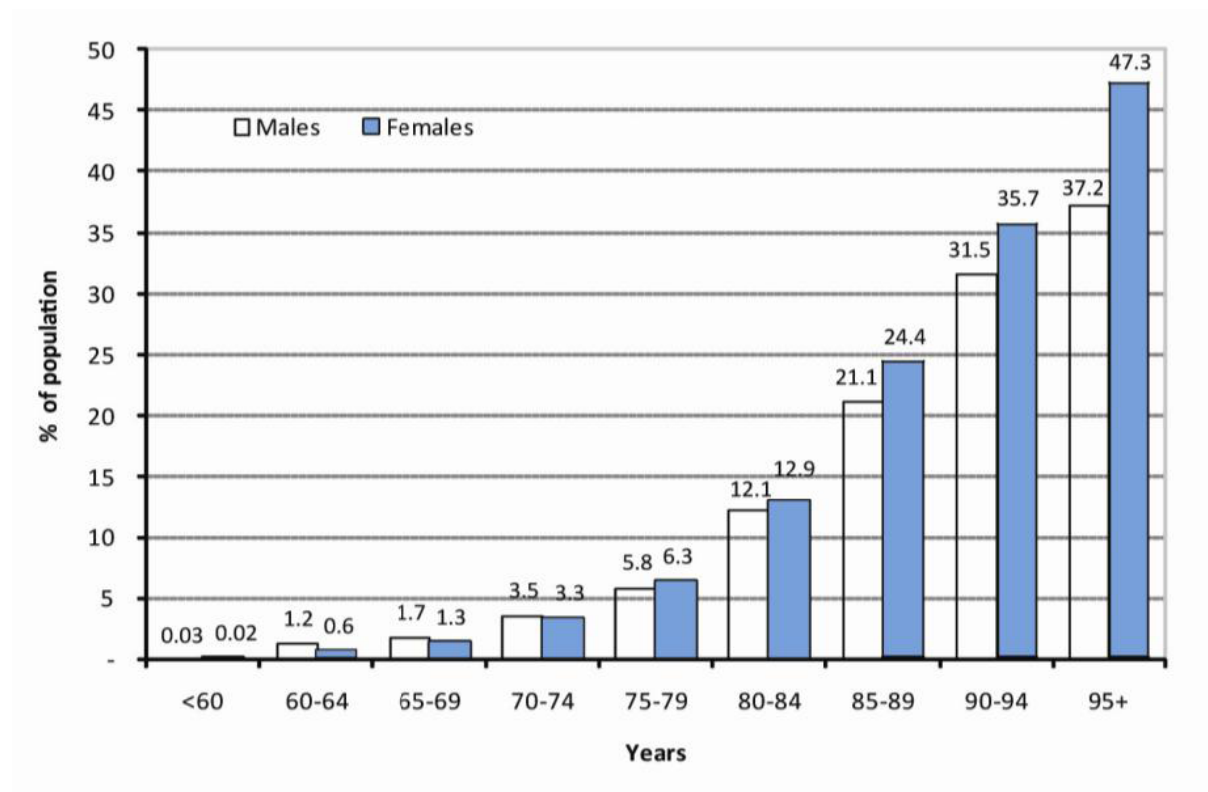
Growth in number of Australians with dementia



Source: Access Economics, *Caring places: planning for aged care and dementia 2010-2050*, Volume 1.

- There are currently around 250,000 people with dementia in Australia.
- By 2050 this will increase to around 1,000,000.
- There are around 1 million family carers of people with dementia.
- It is estimated that there will be more than 75,000 new cases of dementia this year.
- By 2060 spending on dementia is set to outstrip any other health condition.

Risk of dementia by age



Source: Access Economics, *Caring places: planning for aged care and dementia 2010-2050*, Volume 1.

- Dementia is the third largest underlying cause of death.
- Dementia is the leading cause of disability in Australians over 65 years.
- In 2008, about one in eight or 20,000 people died with dementia.
- By 2020 there will be around 75,000 baby boomers with dementia.