



Committee Secretary  
Senate Community Affairs References Committee  
PO Box 6100  
Parliament House  
Canberra ACT 2600

## **Inquiry into Planning Options and Services for People Ageing with a Disability**

Thank you for the opportunity to make a submission to this Inquiry.

As the Australian population ages, the number of people with dementia will increase from 257,000 in 2010 to 592,000 in 2030 and over 1.1 million in 2050. These need to be taken into account in any future planning of disability and aged care services in respect of people with a disability who develop dementia and those who develop younger onset dementia (sometimes in their 30s).

### **People with a disability who develop dementia**

The numbers of people with other causes of 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.

### **Younger people with dementia**

There are currently around 16,000 people with younger onset dementia who are aged under 65.

Care for this group 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 situation they now 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?

### **Age eligibility**

The current approach to disability funding and programs provides assistance to those under 65 when they first seek assistance. 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.

### **Conclusion**

In recent correspondence, the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, indicated that:

'a key reform goal across most disability service systems in Australia is to move away from primary reliance on specialist disability service systems, towards establishing greater connections and pathways between a broader range of human services for people with disability and their families.'

The decision raised by COAG raises two policy issues. First where is the funding to come from for care of 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 the 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. But current provision does need to be tailored to the social support needs of younger people.

The means needs to be found to ensure that their skills are engaged for both younger and older clients, regardless of their living arrangements and age.

All people with a disability as they age are best supported by:

- Accommodation, care and other support that is person centred and meets their changing needs regardless of their age, disability, culture and location;
- Commitment from all spheres of government to support them to remain as active participants in their community as long as this is practicable and meets their wishes;
- Seamless transitions as their needs and circumstances change;
- Consumer directed services supported by optional brokerage and budget holding services;
- Staff who are trained in supporting people with dementia and other cognitive impairment.

The implementation of the COAG decision will be long and complex and it is of concern that the consequences of the decision to hand responsibility for younger people with dementia to the disability sector have not been fully thought through.

An alternative policy approach for consideration by the Committee would be to wave the age limitation on access to aged care assessment and services for people of all ages with dementia 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.

The decision taken by COAG may have achieved the impossible by making access to services even more difficult for people with younger onset dementia.

### **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](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](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](mailto:glenn@alzheimers.org.au)) if you require further information.

There are no sections in this Submission which are confidential and we agree to the submission being published in its entirety.

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24 May 2010