

**FIGHT ALZHEIMER'S
PROTECT AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

**Response to the COAG Consultation
Regulation Impact Statement**

National Disability Insurance Scheme

Alzheimer's Australia

Introduction

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. There are over 321,600 people living with dementia in Australia now, and this number is expected to increase by one third in less than ten years. Dementia is the third leading cause of death in Australia and more than 1.2 million people care for someone with dementia.

Recent statistics reveal that dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the fourth leading cause of disability burden overall.¹ However, a statistical focus on the prevalence of dementia in the over 65s creates an impression that dementia is 'an older person's disease' or a disease connected with ageing.

This is simply not the case. Dementia is not a normal part of ageing. It can affect people as young as 30, and there are approximately 24,400 people in Australia with younger onset dementia (that is, a diagnosis of dementia under the age of 65). The needs of this segment of the population are largely unmet, with many 'falling through the cracks' because they do not fit neatly into the aged care system or the disability sector. People with younger onset dementia are also under-represented in statistical data about disability in Australia, despite the fact that they require many of the same services as other people who are under the age of 65 and have a disability (e.g. accommodation support, community support, respite, advocacy, information, and referral services).

Similarly, it is important to note that the specific circumstances of a younger person with dementia vary greatly according to whether the dementia is disability related (e.g. Down syndrome); develops in a person who is aged 35 to 50, or develops in an older person likely to need ongoing care after 65 years of age.

Alzheimer's Australia is therefore pleased to have the opportunity to respond to the COAG Regulation Impact Statement (RIS) regarding the National Disability Insurance Scheme (NDIS), specifically as it relates to the tens of thousands of Australians with younger onset dementia. Our response is structured according to general principles to which the NDIS should adhere as well as comments on the specific options outlined in the RIS regarding the levels and governance of consumer choice and control.

General Principles

Alzheimer's Australia has been consistent in our message that access to care should be based on need and not age. As such, individuals with younger onset dementia must have equitable access to appropriate dementia services, regardless of whether it is through the disability sector or the aged care system.

Alzheimer's Australia supports the general principles of the NDIS as they have been outlined in the RIS, given that they focus on:

- Supporting the independence and social and economic participation of people with a disability;
- Providing reasonable and necessary supports, including early intervention supports;

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*; Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and prevalence 2009-2050*. Report for Alzheimer's Australia.

- Enabling people to exercise choice and control; and
- Promoting the provision of high quality and innovative supports.

These principles are crucial in supporting people with younger onset dementia (who do not develop the disease as part of an associated disability), whose needs may differ from other demographic segments because the dementia appears at an earlier stage in their life when they are likely to be more physically and socially active. Not only can the symptoms associated with dementia be more difficult to accept and manage in a younger person but when someone is diagnosed they are typically in full time employment; actively raising a young family; financially responsible for a family; and otherwise healthy.

With these broader principles in mind, Alzheimer's Australia has a number of priorities that should be considered in the management and implementation of individual support packages (ISPs), regardless of the option selected.

1. Early interventions are particularly important for people with younger onset dementia, since dementia causes sometimes rapid change and degeneration in cognitive mental actions. This makes planning ahead a vital early intervention strategy for ensuring people with younger onset dementia are actively involved in decisions about their life.
2. Diagnosis pathways must be more fully developed across all disability, health and ageing segments.
3. Service planning for people with younger onset dementia is under-developed. At present, people with younger onset dementia have limited choice in either the services they receive or the service provider that delivers them. Although organisations like Alzheimer's Australia can – and do – educate providers about the specific needs of people with younger onset dementia (as well as providing direct services to people affected by dementia), an ISP must be able to accommodate a range of services appropriate to someone with a primary or secondary diagnosis of dementia.
4. The principles advanced in respect of consumer directed care including “cashing out” should be adopted consistently across both the disability and aged care systems to prevent the creation of service barriers or discontinuity of service.
5. The transition from the NDIS to the aged care system must be considered in more detail. People with younger onset dementia receiving ISPs under the NDIS face a shift to a more rationed, tiered model of community care under the Aged Care Act 1997 (the shift of the latter system to consumer-directed care principles are admirable but nonetheless are ‘retro-fitted’ to existing residential aged care and community care programs). This creates a real danger that services obtained under the NDIS will no longer be available to an individual who has turned 65. Similarly, there is a danger that the quality of support for someone diagnosed with dementia before the age of 65 will be significantly different from the supports received by someone diagnosed at the age of 65 or over.
6. The NDIS should recognise and accommodate the important role that organisations outside of the disability sector - such as Alzheimer's Australia – already play in the delivery of services to people with a disabling condition as well as their carers.

The Options

The four options outlined in the RIS range from preservation of the status quo to a high level of deregulation. Alzheimer's Australia acknowledges that legislative changes are required regardless of the option chosen, and that all existing state and territory regulatory arrangements will continue under the NDIS.

✘ Option 1: Choice limited to government funded providers

The option to limit participants' choice of providers of disability and dementia supports outlined in their ISP to providers directly funded by government in accordance with safeguard and quality standards is not supported by Alzheimer's Australia. Not only does this option fail to achieve an increase in consumer choice and control but it overlooks the value of certain elements of service delivery being provided by what are currently termed 'informal' supports – that is, people who are often best placed to know how to manage particular elements of the care of someone with dementia.

✘ Option 2: Choice from providers that meet regulatory standards

In this option, ISPs would be funded by the NDIS and the needs outlined in an ISP would be converted to funds that are under the control of the individual. People who are unable to manage their ISP (or who choose not to), would have their plan managed by an administering agency.

Alzheimer's Australia recognises that this option increases consumer choice and control as well as creating a service market in which innovation and quality can be more readily stimulated. However, even minimal regulations based on risk would not easily accommodate the inclusion of 'informal' service/care givers who may be best placed to support the needs of someone with dementia and for whom even minor regulation would be a barrier to service delivery.

It should also be noted that block funding will continue to play an important role in this and the following option. People with younger onset dementia (or those who develop dementia as part of another disability) have disease-specific support needs, and organisations such as Alzheimer's Australia have developed considerable expertise in providing quality services that span information, education, counselling and direct support. We also anticipate that the provision of disease-specific education and training to other service providers will be vital and a key role that organisations like Alzheimer's Australia could fulfil with some block-funded support.

✔ Option 3: Choice limited only in higher risk circumstances

This option increases the choice of service providers to include those who do not meet minimum quality assurance and service standards (except for critical supports) and is the option most strongly supported by Alzheimer's Australia.

Not only does it allow consumer choice and control in its truest sense but it avoids de-incentivising new, small or specialised service providers from entering or remaining in the market. It also allows for more flexibility in the selection of lower-level service relationships while protecting consumers with higher care needs through regulatory assessment. Important issues need to be addressed in the development of these arrangements to ensure those providing care are properly remunerated and protected by OHS arrangements.

Of the three sub-options, option iii, that is a combination of industry self-regulation, minimum regulation and higher regulation for participants with significant cognitive impairment, is preferred. This method allows for people with dementia to tailor their ISP according to their care needs and the risks associated with particular supports. It also empowers consumers (and their carers) to undertake their own 'due diligence' for their providers.

Again, under this scenario, Alzheimer's Australia repeats the message that some block funding should be accessible to specialist organisations and for organisations operating in remote and isolated areas (to ensure appropriate access).

× Option 4: No limit to choice

This option (no regulation apart from generic regulation frameworks) has the potential to lead to poor outcomes for people with dementia and is not supported by Alzheimer's Australia. Not only would there be no protection for consumers in the determination of prices that may be charged by providers but it would expose more vulnerable members of society to exploitative or unsafe arrangements.

Conclusion

Option 3iii most closely resembles the Productivity Commission's recommendations and provides the most flexibility for consumers managing their ISPs, while ensuring protections are in place for people with higher care needs. It represents the most responsive model of the NDIS for people with younger onset dementia or dementias that develop as a result of another disability.

Alzheimer's Australia welcomes the reform of Australia's disability sector and is pleased to have had the opportunity to outline our views on the COAG Regulation Impact Statement. We are happy to have any of our comments reflected in the RIS made public after COAG's consideration.

I am would be happy to meet to discuss any of the points raised in this paper, and I can be contacted on: **P:** (02) 6254 4233; **E:** glenn.rees@alzheimers.org.au, or via my assistant, Mrs Terri Richardson, at **E:** terri.richardson@alzheimers.org.au.

Yours sincerely



Glenn Rees
CEO
Alzheimer's Australia
1 February 2013