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Response to the National Disability Insurance Scheme Bill 2012

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.

Alzheimer's Australia is therefore pleased to have the opportunity to respond to the Senate Standing Committee's inquiry into the National Disability Insurance Scheme (NDIS) Bill 2012, specifically as it relates to the tens of thousands of Australians with younger onset dementia. Our response is structured according to three key themes we wish to explore and make recommendations on, that is the:

1. Eligibility of people with younger onset dementia;
2. Appropriateness of service models for people with younger onset dementia; and
3. Transition between the disability and aged care systems.

General Principles

Alzheimer's Australia supports the general objects and principles of the NDIS Bill 2012 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;
- 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, 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. The

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.

principles outlined in the NDIS Bill 2012 therefore align with the impetus of organisations like Alzheimer's Australia to concentrate on early intervention, empowerment of the individual with dementia and widespread supports for their carer(s).

1. Eligibility of people with Younger Onset Dementia

Chapter 3, subsection 24 outlines the eligibility requirements for the NDIS, stating that:

- (1) A person meets the disability requirements if:
- (a) the person has a disability that is attributable to one or more intellectual, cognitive, **neurological**, sensory or physical **impairments** or to one or more impairments attributable to a psychiatric condition; and
 - (b) **the impairment or impairments are, or are likely to be, permanent;** and
 - (c) **the impairment or impairments result in substantially reduced functional capacity** to undertake, or psychosocial functioning in undertaking, one or more of the following activities:
 - (i) **communication;**
 - (ii) **social interaction;**
 - (iii) **learning;**
 - (iv) **mobility;**
 - (v) **self-care;**
 - (vi) **self-management;** and
 - (d) **the impairment or impairments affect the person's capacity for social and economic participation;** and
 - (e) **the person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime.**

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person's support needs in relation to such an impairment or impairments may be likely to continue for the person's lifetime, despite the variation.

Alzheimer's Australia has identified those elements of the eligibility requirements that apply to people with younger onset dementia and these descriptors appear in the above excerpt in bold text. We therefore seek confirmation that people with younger onset dementia are included within the NDIS target group, as was recommended by the Productivity Commission.²

Recommendation 1: People with younger onset dementia are confirmed by the NDIS Implementation Agency as one of the NDIS target groups.

Clarification on this status will give the tens of thousands of Australians with younger onset dementia (as well as their families and carers) much needed reassurance that they can expect NDIS supports until the age of 65.

² Productivity Commission (2011), *Disability Care and Support*, vol. 1: p. 184; vol. 2: pp. 752-53.

This clarification should extend to the early intervention requirements listed at Chapter 3, subsection 25, and the ability of the NDIS Launch Transition Agency to prescribe or apply criteria to disability requirements and/or early intervention requirements (Chapter 3, subsection 27) should also be outlined in more detail.

It should be noted that 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. Appropriate service models for people with Younger Onset Dementia

Given the unique requirements of people with younger onset dementia, it is important that the service pathways encapsulated by the NDIS Bill 2012 are appropriate to their needs. Not only must diagnosis pathways be more fully developed in the primary care setting, but the transition from diagnosis to NDIS support must be subject to further analysis.

Service planning for people with younger onset dementia is similarly 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), the legislative direction given in the NDIS Bill 2012 needs to be broad enough to encompass these specialised needs.

Recommendation 2: The relevant NDIS Agency/Committee commissions work to be undertaken on the service models appropriate to people with younger onset dementia.

The dual focus of the NDIS Bill 2012 on balancing a person's goals and aspirations as well as the practical supports required to help them fulfil these goals will ensure that individual service plans will be comprehensive. However, the process for triggering the creation of a new/revised plan (Chapter 3, subsections 47-48) must also be simple, timely and responsive. The ability to easily instigate a new plan is imperative for people living with younger onset dementia, whose symptoms may progress rapidly.

Recommendation 3: Triggers for creating new or revised individual service plans must be responsive to the needs of people with younger onset dementia.

3. Transition between the NDIS and aged care systems

Alzheimer's Australia supports the notion that people diagnosed with younger onset dementia should continue to receive seamless and equitable care and support throughout their life, regardless of the stage of life at which they develop care needs.

However, Alzheimer's Australia has concerns that the NDIS Bill 2012 does not make any reference to the interface between, or transition between, the NDIS and the aged care

system. Not only is there a danger that people with younger onset dementia will continue to 'fall through the cracks' of both systems but there is a danger of lack of continuity from one system to the other.

The NDIS Bill 2012 is founded on the principle of self-directed, individualised funding, but people with younger onset dementia receiving services under this system 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.

Recommendation 4: The NDIS Bill 2012 should address the issue of the continuity/equity of individual service plans and budgets across the disability and aged care systems.

Conclusion

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 NDIS Bill 2012.

I am would be happy to meet to discuss any of the points raised in this paper, and should the Senate Standing Committee on Community Affairs wish us to participate in their hearings, 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



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