



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

Alzheimer's Australia Submission on the Draft Report of the Productivity Commission Inquiry into Disability Care and Support

Thank you for the opportunity to make a submission on the draft Inquiry Report. This submission has been prepared in conjunction with our National Consumer Advisory Committee.

In summary, Alzheimer's Australia recommends that

- Access to care should be based on need and not age. Individuals with younger onset dementia (ie under 65) should be able to access appropriate age appropriate dementia services through the aged care system or disability services according to their needs.
- The priority for younger people with dementia with or without a previous history of disability is improved access to assessment services. Without that some will continue to be denied access to services.
- The principles advanced in respect of consumer directed care and cashing out should be adopted consistently across the disability and aged care system as otherwise there will be new barriers in place to better relating the two systems in the longer term.
- The final Inquiry report should reflect the important role that organisations outside the disability sector - such as Alzheimer's Australia - currently play in the delivery of services to people with a disabling condition and carers. This discussion should make recommendations about their future roles.
- The disability sector receives support during implementation to access needed skills development around the impact of dementia.

General Comment on the Draft Report

We support the general thrust of the report and the potential of recommendations to improve support and care for people with a disability who are ageing and those who have younger onset dementia.

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Draft report on Disability Care and Support
February 2011

In particular we believe the Commission is right to:

1. Recognise that 'While there are many similarities between the conventional disability system and aged care, there are also many differences, such as in philosophy, employment goals, the duration of care and support, and the areas of greatest competence (such as management of dementia). These differences suggest there are grounds for two distinct systems.' (Page 14)
2. Support better co-operation between the different sectors while promoting consumer choice.
'While the two systems should not be integrated, they nevertheless have to interact efficiently and meet people's reasonable preferences.' (Page 3.18)
3. Propose an approach that ensures that 'people would be able to use the support system that best met their needs regardless of the funding source.' (Page 3.18)

Alzheimer's Australia particularly welcomes the recognition of the need to ensure, not only that people with a disability who pass the pension age should have the choice of which system they wish to be in, but that 'There would also be scope for people with a disability who are aged less than the pension age to use the services and features of the aged care system, with the costs being met by the NDIS until the person reached the pension age.' (Page 3.19)

4. Recognise the importance of early intervention for 'those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives.' (Page 13)

Such an approach would be very beneficial for people with younger onset dementia and support their carers in maintaining their long-term care role.

5. Support individualised approaches including consumer directed care and cash options as consumers will benefit from improved choice, particularly those from regional areas or diverse communities (Indigenous, CALD etc).
6. Emphasise the need for effective assessment of changing needs and protocols to facilitate assistance for individuals from the various sectors.
7. Recommend a substantial increase in funding.

Further comments follow about:

- Younger onset dementia;
- Assessment;
- Outcomes;
- Choice;
- The role of disease-specific peak organisations; and

- Implementation.

Younger onset dementia

A key concern for Alzheimer's Australia is the vexed issue of obtaining and maintaining access to appropriate services for those affected by dementia before 65.

Currently there are approximately 16,000 individuals with younger onset dementia, including those with Alzheimer's disease or frontotemporal dementia or dementia resulting from cardiovascular conditions like stroke or neurological conditions like Parkinson's disease and Multiple Sclerosis.

In the current system, there is a significant risk of younger people with dementia being shifted between disability and aged care services without their needs being addressed. Younger people with memory concerns - or other cognitive change - and no history of other disability may experience difficulty in gaining access to assessment services, either because disability services are not equipped to assess cognitive impairment or because aged care services refuse assessment because they are not 'frail aged'. This exacerbates the existing disadvantage from any delays in obtaining a timely and accurate diagnosis of the cause of their functional change.

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 may be required to navigate a second unfamiliar system. Then they may experience acute problems in accessing services that are age appropriate. While the current aged care sector has more experience in supporting people with dementia, there remains a serious lack of age appropriate services available for those who may be otherwise well.

Assessment

Improving assessment processes has potentially the greatest benefit of all the changes proposed and merits particular attention in the planned pilot. Implementing this change well will benefit Australians with progressive conditions including dementia. We agree that assessment should be planned and ongoing rather than a phase of care.

Regardless of their circumstances, all younger people with dementia will directly benefit from routine access to regular and ongoing assessment - and as needed, referral and case management - which is:

- Universally available regardless of location, age and co morbidities;
- Planned and proactive, minimising the current crises like inappropriate hospital admissions, that may occur when needed support is unavailable;
- Responsive to consumer needs as circumstances change and their condition progresses;
- Recognising the ability of many to self manage for a time, as well as their eventual progressive loss of capacity and function and the increasing role of family carers;
- Providing consumers with a smoother pathway to the most appropriate care by harnessing the range of quality support available across all sectors;

- Working with existing assessment arrangements like the Aged Care Assessment Program to provide better and harmonised pathways;
- Able to minimise inappropriate referral to services which do not meet needs;
- Supportive of the role and well being of carers, providing both early referral to information and advice and more targeted assistance as the care burden increases ;
- Promoting a skilled and effective workforce which understands dementia regardless of the sector;
- Using the existing expertise of both disability support organisations and condition specific organisations like Alzheimer's Australia to the advantage of both people with dementia and family carers.

Outcomes

An important outcome of the recommended approach will be equity in outcomes. People with a disability who are affected by dementia and those with younger onset dementia should not be disadvantaged in accessing services to meet their needs by:

- Their underlying condition, complex co-morbidities and changed behaviours as their dementia progresses;
- Their location – while the delivery mechanisms may be different, consumers should receive quality assessment and services regardless of the location and the distance from the nearest regional centre or capital city;
- Their cultural diversity – whether from Indigenous, CALD or GLBTI communities;
- Their source of support – the same quantum and quality of care should be available regardless of the sector that provides the support;
- Delays in timely and accurate diagnosis; and
- The rarity of their condition.

The proposed comprehensive and ongoing program monitoring and evaluation will be crucial in judging outcomes for consumers. Consumers should be involved in these processes in a meaningful way from the initial pilot.

Choice

As the Commission will be aware Alzheimer's Australia has been a strong advocate of consumer directed care and has supported a trial including 'cashing out' in its response to the draft report of the Productivity Commission Inquiry into *Caring for Older Australians*.

There is a real need for the flexibility that this approach provides in responding to the very different needs of younger people with dementia whether with or without a previous history of disability. Such support will promote creativity and innovation in the development of community and residential services for people with younger onset dementia who are rarely able to get appropriate support from currently funded service agencies.

We are delighted with the approach taken in the Report on this issue.

'People would have much more choice in the NDIS. Based on their needs assessment and their individualised support package, they would be able to:

- choose their own service providers
- ask a disability support organisation (an intermediary) to assemble the best package on their behalf
- cash out their funding allocation and direct the funding to areas of need they think are most important. There would have to be some controls over the latter to ensure probity and good outcomes. People would need support to adopt this option and, given overseas experience, it would take some time for many to use it.' (Page 2)

It will be an unfortunate consequence of the reforms of the disability and aged care systems if the important principles espoused by the Commission are not adopted consistently across the disability and aged care systems

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

Role of disease-specific peak organisations

These organisations do not appear to be considered within the draft report.

Organisations such as Alzheimer's Australia have developed considerable expertise in providing quality services including information, education, counselling and support. Our member organisations are skilled in working with people with dementia and the people who support them – both family carers and service providers.

The reach of our services is substantial. In 2009-10, the major program – the National Dementia Support Program – funded a range of services including:

- Over 32,000 contacts with the National Dementia Helpline;
- Some 64,000 contacts at the Dementia Memory and Community Centres;
- More than 8,000 contacts for early intervention and counselling; and
- Nearly 17,000 contacts in the information, awareness and education area.

These Nationally funded services are complemented at the local level by initiatives funded by State Government under HACC, and through other sources.

Many consumers may wish to continue to use our services and may be disadvantaged if this precludes them from using the new system as appropriate. The draft report would be improved by clarifying the role of disease-specific peak organisations including access to their services.

Implementation

As people with a disability age and many develop dementia - most before 65 - it will be important for the disability sector including the proposed agency to have sufficient expertise to meet these emerging needs. People affected by younger onset dementia will be best supported if their services are delivered by those who understand the impact of their condition.

While dementia education is becoming part of best practice for those who support people with Down syndrome, dementia education has not been a recommended part of disability education. Alzheimer's Australia is willing to partner the wider disability sector to build the necessary skills base.

As a consumer organisation, our focus is on achieving the best outcomes for individuals within a viable service sector. This will emerge from a 'joined up' system which operates in a seamless manner. Any 'transitions' between sectors as people age will need to be carefully managed in the consumer's best interest so that resulting burden and service gaps are minimised and best outcomes can be achieved.

Please contact Anne Eayrs, National Special Groups, if you require further information.

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