Alzheimer's Australia
Living with dementia

SUBMISSION TO SENATE FINANCE AND PUBLIC ADMINISTATION COMMITTEE INQUIRY INTO RESIDENTIAL AND COMMUNIY AGED CARE IN AUSTRALIA

WHAT IS ALZHEIMER'S AUSTRALIA?

Alzheimer's Australia is the national peak body for people living with dementia, their families and carers, and provides leadership in policy and services. Alzheimer's Australia manages a wide range of innovative national programs which provide information, support, counselling, training and education to people with dementia, their families and carers as well as to professionals working in the dementia field.

Alzheimer's Australia's eight State and Territory member organisations provide services and support for people with dementia and their families and carers.

Alzheimer's Australia recognises there are significant problems in the funding of residential care that may affect some providers' ability to provide high quality, flexible care. Shortfalls in the availability of capital funding inhibit the industry's ability to expand the provision of high care places where the current need seems to be the greatest. Inadequate indexation of subsidies, despite the Conditional Adjustment Payment, makes it difficult for facilities to provide the necessary skilled staffing hours.

The emphasis in this submission is on getting the balance of community care and residential care right. It is recognised that as more consumers choose community care rather than residential care, particularly residential low care, the main source of capital funding for residential care (i.e. bonds for low care) will diminish. This in turn will make it difficult for providers to construct the residential high care facilities that will be needed by people with dementia as their needs increase.

WHY IS DEMENTIA RELEVANT TO THIS INQUIRY?

It is estimated that some 227,000 Australians have dementia, with some 40% of these living in residential care (some 60% of total residents), and the other 60% living in the community. By 2030 there will be some 465,000 people with dementia. [1] The Australian Institute of Health and Welfare, in its publication *Dementia in Australia* (2007), estimates that whereas 1.9% of people between the ages 65-74 have dementia, and 8.4% of people aged 75-84 have dementia, some 22.4% of people aged 85+ have the condition.[2]

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[1] "Dementia Estimates and projections: Australian States and Territories", Access Economics, 2005,
[2] "Dementia in Australia". Australian Institute of Health and Welfare, 2007.

Data from the 2003 Survey of Disability, Ageing and Carers suggest that around 50% of residents in residential care facilities have dementia; 83% in high care.[3]

In 2002, it was estimated that around 18.4% of CACP recipients, 32.1% of EACH recipients and 5.4% of HACC clients had dementia.[4] Using these estimates with 2006-2007 client data suggests that some 9130 CACP recipients, 1475 EACHD recipients and 43,300HACC clients would have dementia. This is a total of 55,000 people when the 1344 people with dementia assisted by EACHD packages in this period are added in.

HOW DOES AGED CARE NEED TO BE IMPROVED FOR PEOPLE WITH DEMENTIA?

1. Improved Quality and Quantity of Care

There needs to be an increased priority in resource allocation to strengthen support services to family carers (who provide 70% of care[5]), to provide choice for older people who wish to stay at home as long as possible by increasing the quantity and quality of community care services, and sufficient funding to provide high quality residential care for those whose care needs have passed the point where they can be cared for in their own homes in the community.

One of the key aspects of quality has to be flexibility. Care needs vary considerably from person to person and for the same person over time. Funding that limits this flexibility by excessively constraining the purposes to which the funding maybe applied inhibits quality care. The more flexibility a funded care provider has in the type and level of care they can provide, the more likely it is that an individual's needs can be appropriately met.

2. Choice for consumers and their families

Consumer directed care (CDC) should be trialled in Australia as it offers the potential to provide choice for consumers, for consumers to receive more appropriate care in line with their needs and wishes, and enable a more efficient allocation of resources. CDC could provide choice in the form of cash, individualised budgets for the use of consumers held by approved providers or in participatory care where the consumer and provider agree the care to be delivered. CDC could be introduced most easily in Australian Government funded care packages and in respite care.

3. Recognition of the extra care needs of people with dementia

Dementia is a progressive condition where physical, mental, behavioural and social care needs change over time and affect more and more aspects of a person's functioning.

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[3] Australian Institute of Health and Welfare, 2007, op cit.
[4] Australian Institute of Health and Welfare, 2007, op cit.
[5] "Disability, Ageing and Carers: Summary of findings." Australian Bureau of Statistics, 2004

Professor Brodaty and colleagues from the Prince of Wales Hospital in Sydney have set out seven different stages along the continuum of behavioural and psychological symptoms of dementia which should correspond to seen different types of service delivery. [6] These types of delivery range from a preventive approach at Tiers 1 and 2, primary care in the community at Tiers 3 and 4, management in nursing homes at Tier 5, management in psycho-geriatric units at Tier 6, and management in intensive specialist care units for the small numbers in Tier 7,.

This implies that there needs to be a range of services available for people with dementia, corresponding to the wide range of behavioural symptoms that occur as part of the condition

TERMS OF REFERENCE (a)

Whether current funding levels are sufficient to meet the expected quality service provision outcomes.

There needs to be a significant increase in funding for services aimed at helping older people continue living as independently as possible in their own homes in the community. This should be used to improve access to respite care both planned and emergency and both in home and residential settings, and additional community support services, particularly transport, personal care and day care.

To this end, Federal funding of community care services needs to be doubled over the next 5 years from the 2008-09 estimate of $2 billion (which is only 24% of the Commonwealth's aged care budget) to $4 billion.[7]

This increase should include an increase in the provision of CACPs, EACH and EACHD, increases in the average subsidy rate paid for these packages, and a real increase in HACC. Current COAG discussions may result in the Commonwealth taking responsibility for all HACC funding for aged people. This would enable an integrated approach to packaged care across CACPs, EACH and HACC.

Recommendation 1

There needs to be an increased priority in resource allocation to strengthen support services to family carers and frail aged people living in the community.

Recommendation 2

Commonwealth funding of community care services should be doubled over the next five years from $2 billion pa to $4 billion pa.

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[6] "Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery" Brodaty, H, Draper, B M. and Low, LF, Medical Journal of Australia, 178, 2003.

[7] "National Dementia Manifesto", Alzheimer's Australia National Consumers Committee, 2007

Recommendation 3

Sufficient resources need to be made available for a range of care services to enable people to have choice as to the type of care they wish to receive and the location of that care.

The extra care needs of people with dementia have already been recognised to some extent by the Federal Government in providing additional funding for EACH packages for people with dementia through the EACHD packages, in residential care through the Behaviour Supplement provided as part of the ACFI system of needs based funding, and in funding the National Dementia Support Program and Dementia Behaviour Management Advisory Services. These programs need to be continued and expanded if we are to keep pace with the increase in the number of people with dementia as more of Australia's population move into the older age groups.

The Access Economics analysis of the first 33,000 appraisals using the new ACFI system presents evidence that a person's care needs in the Behavioural Domain (which is largely about dementia behaviour) increase over time even when they are in care.[8] It is clear that the subsidy for dementia care in both residential and community care need to be increased as the length of life of people with dementia increases.

Given that the proportion of people with dementia among the frail aged will increase, it is crucial that all residential aged care facilities are "dementia friendly". This means that all residential aged care facilities should be funded to provide staff trained in dementia care, and there should be some way of monitoring this so that consumers can know which facilities manage dementia well. This will also involve increased capital funding to enable 'dementia friendly" facilities to be designed and constructed.

In addition there is a need for a number of dementia specific aged care facilities (or "wings "of larger facilities) to enable those people in Professor Brodaty's Tier 5 to receive adequate care. There is no data reporting on the provision of dementia specific places beyond 2003 when it was estimated some 6% of high care places and 5% of low care places were dementia specific.[9] Professor Brodaty estimates about 10% of people with dementia would require this form of care. At the very least there needs to be an assurance that dementia specific places will be maintained at around 5% of total places in the short term, with the need to increase this provision as the proportion of people with dementia in residential care increases. This assumes that mental health services and hospitals care for people in Tiers 6 and 7. While services for people with dementia and psychiatric problems remain inadequate, people with psychogeriatric disorders often receive inappropriate care.

Recommendation 4

The extra costs involved in helping people with dementia should continue to be recognised in Australian aged care programs.

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[8] "Testing the distribution of first 33,000 ACFI appraisals". Access Economics, 2008.
[9] "Review of Pricing Arrangements in Residential Aged Care: Full Report". Hogan, WP. 2004.

Recommendation 5

The provision of dementia specific residential care places should be maintained at between 5 - 10% of total places with the need to increase as the proportion of people with dementia in residential care increases.

TERMS OF REFERENCE (b)

How appropriate is the current indexation formula in recognising the actual cost of pricing age care services to meet the expected level and quality of such services.

The biggest anomaly as regards indexation is in community care. Community care has a very high proportion of its costs as labour costs, but the indexation of CACPS, EACH and HACC has been at a level. well below the increase in labour costs. The additional funding that flowed to residential care as a result of the Conditional Adjustment payment (CAP) did not flow to community care, despite its higher labour costs.

Figures contained in the Aged Care Industry Council submission to the CAP Review show that from 1996-7 to 2003-4, the Commonwealth's "COPO" indexation formula meant that the CACP subsidy increased by 21.6%.. During the same period, ordinary time earnings for full time adults increased by 47.3%.[10]

Indexation of community care subsidies clearly needs to be based on a labour component. The Conditional Adjustment Payment should be paid immediately to community care services. Continuation of CPI indexation simply means fewer services being provided as increases in wages costs eat into service provision hours.

Inadequate indexation of residential care subsidies also remains a problem, despite the Conditional Adjustment Payment. Indexing subsidies by the COPO formula when the industry has such high labour costs creates either financial difficulties for the provider, or reduced levels of care for the care recipient, or both

Recommendation 6

Community care places should receive the Conditional Adjustment Payment currently provided to residential care.

Recommendation 7

Indexation of subsidies for community care places needs to incorporate a much higher component for the costs of labour than at present.

[10] "Review of Conditional Adjustment Payment." Aged Care Industry Council, 2008.

The most difficult regional cost problem is the cost of delivering community care to remote areas, particularly remote indigenous communities. Diseconomies of scale. high cost of travel and the amount of time needed for care providers to help very small numbers of people all add significantly to the costs of providing care in remote communities. Although there are some increases in subsidy via the viability grants, which are based on regions, the CACP and EACH subsidy rates are inadequate for providing care to remote communities. Funding either needs to be provider based, as in HACC, regionally based, or else a more significant loading needs to be provided for community care services to remote areas.

The capital funding of residential care in rural areas also is difficult as bonds are not as readily obtainable as in the cities, and the lower property values mean that bonds on average will be smaller. The Government's accommodation supplement is insufficient to cover construction costs, particularly in high care.

Recommendation 8

Funding and subsidies for services in remote communities need to be increased.

TERMS OF REFERENCE (d)

Is there an inequity in user payments between different groups of aged care consumers, and, if so, how can the inequity be addressed?

Varying user payments do create difficulties in community care, leading to consumers being uncertain as to how much they are going to have to pay for different services.

The Commonwealth has guidelines for maximum user charges for CACPs and EACH which allow providers to charge different fees on a means tested basis. Because of the difficulties associated with means testing most providers charge only the minimum amount for CACPs and EACH.

In regard to HACC, there exists a national fees policy which, among other things, ensures that a person will not miss out on a HACC service because of inability to pay, and sets limits on the total level of fees for people receiving multiple services, but the policy allows each State and Territory to set its own fees. This has led to considerable variation across States.

In some states, each local government area has its own fees policy, while in one State services are able to set their own charges. The principles outlined in "The Way Forward" go some way to addressing this problem, which could be resolved if the Commonwealth had responsibility for the aged care part of HACC.

Alzheimer's Australia is not opposed to fees being charged for community care to those who can afford to pay, but there needs to be greater consistency in fee charging so that a person and their family know beforehand how much a particular service, or frequency of service, will cost them.

Fees for CACPs, EACH and HACC need to be brought into alignment as quickly as possible.

In respect of residential care bonds are a cause of inequity. This is because in areas where low care residential care is in excess demand and consumers have little choice in bed availability high bond charges may apply. It is also the case that while residents have a choice between periodic charges (similar to accommodation charges) and bonds in low care there is only the accommodation charge in high care.

Recommendation 9

User fees for CACPs, EACH and HACC need to be brought into alignment as quickly as possible.

TERMS OF REFERENCE (e)

Is the current planning ratio between community, high- and low-care places appropriate?

Need for increase in community care ratio

The current planning ratios are strongly weighted in favour of residential care. Alzheimer's Australia believes there should be a significant increase in the planning ratio for CACPs, EACH and EACHD to enable frail aged people a real choice between residential care and community care. The current planning ratios of 44/1000 age 70+ high residential care, 44/1000 70+ low residential care, and 25 /1000 70+ community care (including CACPs EACH and EACHD) result in only 22% of places being for community care.

It is proposed that the community care provision ratio be brought up to 30/1000 70+ over 5 years in order to help correct this balance. This would entail around 11,000 additional community care places by the end of that period.

It is recognised that this increase in community care provision will impact on demand for residential care, particularly low care. The change will need to be managed in a way which enables low care residential facilities to adapt to changing consumer demand.

Recommendation 10

The provision ratio for community care places should be increased from 25/1000 70+ to 30/1000 70+ over the next 5 years

Need to bridge gap in subsidies between CACPs and EACH

At the same time an attempt should be made to bridge the large subsidy gap between CACPs and EACH. The CACP subsidy is currently $34.75 per person per day, the EACH subsidy is $116.16 per person per day, and the EACHD subsidy is $128.11 per person per day.

The huge difference between the CACP subsidy and the EACH subsidy makes it very difficult to provide continuity of care for people as their care needs increase. Service providers need to have a combination of all three subsidies which they can then pool, in order to cater for the gradual increasing care needs, particularly of people with dementia.

Concept of "community care places"

A better way may be to abolish the distinction between CACPs, and EACH in the allocation of places, with "community care places" being allocated instead. Because of the current disparity between the planning ratios for CACPs and EACH (84% to 16%), a subsidy level for community care places would need to be struck at a somewhat higher level than the average to enable genuine continuity of care.

It is suggested that a subsidy rate for community care places of $59 per person per day would enable the equivalent of 70% CACPs and 30% EACH.

Because of the very small numbers and highly specialised nature it is not proposed to include EACHD in this arrangement.

Recommendation 11

The gap in subsidy levels between CACPs and EACH needs to be bridged, possibly by introducing the concept of "community care places".

TERM OF REFERENCE (f)

What is the impact of current and future residential places allocation and funding on the number and provision of community care places?

Ultimately the relative numbers of residential care and community care places should be determined by consumer choice. Consideration should be given to enable consumers to choose between residential and community care at the point where they are assessed by an Aged Care Assessment Team as eligible for Government subsidy.

This could be achieved by separating the care and accommodation components of residential care developing a system of assessing care needs that covered community care needs as well as residential care needs (which the ACFI currently does). This assessment would then determine the level of individual subsidy a person was entitled to, and the person would be free to choose to receive that subsidised care at home or in residential care.

The highly structured nature of the planning ratios and the high level of occupancy of most forms of care make it difficult to assess consumer preferences for care. A system which was flexible enough to enable consumers to make a choice about the location of care would enable a much better fit between services and consumer needs and wishes.

Such an arrangement would mean allocating "aged care places" rather than residential care or community care places. Organisations would be favoured in this allocation that were able to offer a wide range of community and residential care and thereby enable a high level of choice for consumers. Such an arrangement would also enable consumers to move in and out of different forms of care as their needs required, while being able to be case managed by the same provider.

Such an arrangement would also lend itself to trials of consumer directed care, where consumers who so wished could take control of their own care management and planning. Consumer directed care has been shown overseas to have significant advantages in terms of helping people maintain their social functioning and independence while living in the community.[11]

Recommendation 12

Consideration should be given to enabling consumers to have a choice as the type and location of care they wish to receive at the point where they are assessed as eligible for Government subsidy

Recommendation 13

Care and accommodation components of the residential care subsidy should be separated so as to facilitate consumer choice as the location where they wish to receive care,

Recommendation 14

Consumer directed care should be trialled in Australia

[11] "Consumer-Directed Care: A Way to Empower Consumers?" Tilly, J. and Rees, G. Alzheimer's Australia Paper 11 2007.