CHAPTER 5

FUNDING FOR RESIDENTS WITH SPECIAL NEEDS

Current funding arrangements do not appropriately support the provision of residential aged care services to older people presenting with special needs including dementia, residents with challenging behaviours and complex care needs. Funding arrangements support a standard service response to all needs with some special needs not being met, such as older people needing mental health care who experience access restrictions to generic residential aged care.[1]

5.1 Residents in aged care facilities with special needs, including those with dementia, mental illness and requiring palliative care, require additional services and support. The staff providing for their care also require skills to ensure that they have the ability to manage complex care needs. This chapter looks at the care needs of these groups, the findings of the Hogan Review[2] and current funding arrangements, including recent Commonwealth initiatives.

Funding arrangements

5.2 The Hogan Review provides a detailed examination of funding arrangements for residential aged care including special needs groups. The following is a brief overview.

5.3 The Commonwealth provides subsidies to providers of aged care. Fees are also paid by individuals. The Resident Classification Scale (RCS) provides the basis on which the subsidies are paid for each resident. The subsidy is calculated as follows:

- a basic subsidy determined by the resident's classification under the RCS; plus
- any primary supplements; less
- any reductions in subsidy resulting from the provision of extra services, adjusted subsidies for government (or formerly government) owned aged care homes or the receipt of a compensation payment; less
- any reduction resulting from income-testing of residents who entered residential care on or after 1 March 1998; plus
- other supplements, including the pensioner supplement, the viability supplement and the hardship supplement (which reduces charges for residents who would otherwise experience financial hardship).[3]

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1 *Submission* 180, p.8 (Victorian Government).

2 Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra, 2004.

3 Hogan Review, pp.201-08.

5.4 At the time of the Hogan Review, primary supplements were provided for:

- concessional and assisted residents: for those who are unable to afford to pay an accommodation bond or charge;
- respite: paid to offset the higher administration and care costs of respite care;
- charge exempt resident: for those who were in an aged care facility on 30 September 1997 and who move to another facility where they would otherwise be eligible to pay an accommodation charge;
- oxygen and enteral feeding: for those requiring on-going oxygen or enteral feeding;
- payroll tax; and
- transitional resident supplement.

The hardship supplement provides for residents who experience difficulty in paying for their care. It may be paid for specific classes of resident or for individuals who apply for a hardship determination.

5.5 The Department of Health and Ageing (DoHA) stated that a significant component of the current RCS focuses on the additional effort needed to assist people who have problems of cognition or who need additional care around the management of problem behaviours. Funding for people with dementia was estimated to be $2.3 billion in 2004-05.[4]

Hogan Review

5.6 In reporting on the arrangements for funding the care needs of special needs groups, the Hogan Review stated that it had received evidence that there were expectations that more complex care would be provided by aged care facilities. This included complex pain management, palliative care, wound management, dialysis and tracheotomy care. The Review also noted that providers questioned the adequacy of the subsidies payable for people with a range of specific care needs including dementia and stroke and people from diverse or disadvantaged backgrounds.[5] The Hogan Review examined the needs for those residents with dementia, those requiring palliative care, those in remote and rural areas, the elderly homeless and people from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse backgrounds.

5.7 The Review supported the approach for basic subsides to be determined on level of need for care, supplemented by additional payments for extraordinary care needs that add significantly to the cost of care. The Review recommended:

Recommendation 6 Funding supplements

4 *Submission* 191, p.38 (DoHA).

5 Hogan Review, p.212.

> The arrangements through which supplements are paid for the provision of oxygen and enteral feeding should be extended to other specific care needs or medical conditions.
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> These specific care needs could include:
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> (a) short-term medical needs, such as IV therapy, wound management, intensive pain management and tracheostomy;
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> (b) specific care needs, such as for dementia sufferers exhibiting challenging behaviours or for residents requiring palliative care; and
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> (c) care needs of people from diverse or disadvantaged backgrounds such as the homeless elderly and indigenous Australians.
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> The rate of payment of any new supplements should reflect the incremental increase in the cost of providing the appropriate treatment and/or level of care.[6]

Government response

5.8 As part of the 2004-05 Budget, the Commonwealth announced its response to the recommendations of the Hogan Review. These include new residential care supplements to be introduced in 2006 'to better target assistance to people with higher care needs by supporting the provision of care to people with dementia exhibiting challenging behaviours and people requiring complex palliative nursing care'. An additional $11.6 million over the next four years was provided to strengthen culturally appropriate aged care. It was noted that care needs of people from diverse or disadvantaged backgrounds are supported by a number of Australian Government programs.[7] The cost of the new supplement 'will be absorbed from within existing resources'.[8]

5.9 The Commonwealth also stated that it considered that 'extending supplements to other conditions or circumstances would add unnecessary complexity to the payment system and administration'.[9]

Other Commonwealth programs

5.10 The Commonwealth also supports a number of programs which target special needs, particularly people with dementia, including Home and Community Services, Community Aged Care Packages and Extended Aged Care at Home packages. A range of targeted dementia services include the Dementia Education and Support Program, the National Dementia Behaviour Advisory Service, the Early Stage

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6 Hogan Review, p.282.

7 The Hon Julie Bishop, Minister for Ageing, *Investing in Australia's Aged Care: More Places, Better Care*, May 2004, p.22.

8 *Budget Measures 2004-05*, Budget Paper No.2, p.190.

9 *Australian Government's Response to the Review of Pricing Arrangements in Residential Aged Care*, p.2.

Dementia Support and Respite Project, Carer Education and Workforce Training, and Psychogeriatric Care Units.[10]

5.11 In January 2005, Australian Health Ministers jointly agreed to the development of a National Framework for Action on Dementia. The Framework will 'provide an opportunity to co-ordinate a strategic, collaborative and cost-effective response to dementia across Australia'. Consultations with peak bodies, families and carers are to take place to develop 'a shared national vision for action on dementia'. A national forum will be held in July 2005. The consultations will lead to the development of a draft National Framework to be considered by Australian Health Ministers in November 2005.[11]

5.12 The Commonwealth has also made dementia a National Health Priority with a $320.6 million package over five years targeting better prevention, treatment and care. In February 2005, funding of $52.2 million over four years for the first component of the package was announced for additional research, improved care and early intervention programs. In the 2005-06 Budget funding of $225.1 million over four years was provided for 2 000 new dementia-specific Extended Aged Care at Home places. Funding of $25 million over four years was also provided for dementia training for up to 9 000 residential aged care workers and 7 000 people in the community who come into contact with people with dementia, such as police, emergency services and transport staff.[12]

5.13 DoHA noted that, in relation to mental health, the National Mental Health Plan 'calls for improved cooperation between the mental health and aged care sectors to ensure that Australians experiencing a mental disorder receive the best possible care. The delivery of mental health services, however, is constitutionally the responsibility of individual State and Territory Governments'.[13]

5.14 The Commonwealth's Ethnic Aged Care Framework seeks to improve partnerships between aged care providers, culturally and linguistically diverse communities and the Department of Health and Ageing and ensure that the special needs of older people from culturally and linguistically diverse backgrounds are identified and addressed. The Commonwealth also funds the Partners in Culturally Appropriate Care initiative under the Framework. This provides funding to organisations in each State and Territory which help to link culturally diverse communities with aged care providers to develop more culturally sensitive services and provides cross-cultural training for staff of residential age care services.

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10 *Submission* 191, p.12 (DoHA).

11 DoHA, *National Framework for Action on Dementia Consultation Paper*, http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-dementia-nfad.htm

12 DoHA, *Ageing Factsheet 1 – Helping Australians with dementia, and their carers – making dementia a National Health Priority*, 10 May 2005.

13 *Submission* 191, p.39 (DoHA).

Responses to current funding arrangements

5.15 The difficulties of providing residential aged care for people with special needs are well documented.

5.16 The provision of services for the very large, and growing, number of people with dementia has been a significant problem. There was evidence that it was difficult to place people with dementia in aged care facilities which provide adequate levels of care. Witnesses pointed to the lack of dementia-specific funding and the failure of the RCS to adequately capture behavioural problems as the causes of the lack of places for those with dementia.[14] The Office of the Public Advocate Qld stated:

> [The RCS] is seen as not adequately recognising the support needs of people who have behavioural challenges, especially people with dementia and psychiatric illnesses. Although many of these people do not have high levels of personal or nursing care, the intensity in nature of their needs means that they require more personalised attention because of the impact of their behaviour on themselves and other residents.[15]

5.17 The Australian Society for Geriatric Medicine stated that current funding arrangements are 'extraordinarily documentation intensive but fail to generate a useful care plan' and fails to adequately recognise the resources required for management of behaviours in intermediate stage dementia care and leads providers to pick and choose patients who are easier and better reimbursed.[16] They also result in a financial disincentive for the provision of restorative care and rehabilitation and fail to provide any incentive to provide medical treatment on site rather than transfer residents with new medical problems to state funded hospitals. The Society concluded that:

> Appropriate and expert behavioural management, rehabilitation, illness and injury prevention, and on site acute and sub-acute medical care would all be cost effective to the Australian community, and preferred by most residents and their families. Current remuneration of specialized medical services and organization of public hospital aged care services does not support the provision of this care within the Residential setting.[17]

5.18 The Benevolent Society argued that 'facilities for people with dementia and disturbed behaviour are structurally under funded and their operation is dependent on the commitment of organisations to carry heavy financial losses. This is not sustainable in the long term.'[18]

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14 *Submissions* 193, p.14 (Queensland Government); 196, p.8 (Aged Care Qld); 200, p.7 (Tasmanian Government).

15 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

16 *Submission* 80, p.3 (Australian Society for Geriatric Medicine; see also *Submission* 92, p.3 (Southern Cross Care).

17 *Submission* 80, pp.3-4 (Australian Society for Geriatric Medicine).

18 *Submission* 187, p.3 (Benevolent Society); see also *Submission* 196, p.8 (Aged Care Qld Inc).

5.19 Witnesses welcomed the new funding supplement. The Queensland Government stated that the new funding supplement was 'an acknowledgement that the current RCS does not adequately address the needs of this growing subset of residents'. The Government went on to comment that the proposed three level model of basic funding with supplement for special needs clients 'should encourage providers to take these clients'.[19]

5.20 However, some witnesses argued that the additional funding may not be adequate to meet the care needs of people suffering from dementia and that careful development of the supplement will be required. ANHECA for example, commented that residential aged care is experiencing substantial growth in the number of cases of dementia amongst residents in high and low care. It is estimated that approximately 60 per cent of residents in residential care suffer mild to severe dementia. However, ANHECA stated that 'there has been no work undertaken to consider the real cost of providing residential services to those with dementia or with behavioural or other difficulties'.

5.21 ANHECA recommended that prior to the implementation of the dementia and palliative care supplement in July 2006, a substantial review needs to occur regarding the actual cost of providing such services. ANHECA commented that while the top subsidy payable to a level 1 resident in residential care is $118 per day, the average payment for an acute sector palliative care service can be as high as $430 per day:

> There is great difficulty reconciling these two quite separate figures. It is essential therefore, for government to look at the true cost of providing an effective palliative care program and an effective dementia program and to incorporate that cost provision within any revised residential care subsidy framework.[20]

5.22 COTA National Seniors argued that for the new measures to be effect, they need to include incentives for providers to offer quality dementia care including an improved mix of capital/recurrent funding, appropriate training for staff caring for people with dementia and support for innovation in care for people with dementia.[21]

5.23 The Tasmanian Government and other witnesses stated that the new supplements appear to be funded from existing funds and may therefore divert resources from meeting other needs. The Tasmanian Government also suggested that the use of supplements needs to be reconsidered in conjunction with the overall design of a more appropriate funding model.[22] ACS Australia stated:

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19 Submission 193, p.14 (Queensland Government).

20 *Submission* 74, p.12 (ANHECA).

21 *Submission* 174, p.13 (COTA National Seniors).

22 *Submissions* 200, p.7 (Tasmanian Government); 150, p.17 (VAHEC); 166, p.11 (CHA); 173, p.6 (ACS Australia); 196, p.8 (Aged Care Qld).

> Currently the proposal is to meet those very high needs by the redistribution of the existing pool of resources, and that is a source of some concern to us and our members, that if you do that then there are necessarily going to be people who are currently receiving services or who would have received such services into the future who will miss out. In other words, it could be seen as a form of rationing residential aged care as well as a form of targeting residential aged care.[23]

5.24 Concern was also voiced at the delay in introducing the proposed new funding model as this will mean that difficulties in funding places for the elderly with special needs will continue for some time.[24].

Areas of unmet need

Specialised facilities for dementia

5.25 There was debate in the evidence as to the need for dementia specific facilities. Some witnesses commented that dementia is not a 'special needs' any more, and should be incorporated into mainstream care.[25] Other witnesses stated that it was extremely difficult to care for both the frail elderly and those with dementia in the same facility:

> The situation for many dementia residents in Australia currently, certainly in Tasmania, is that they are in integrated models so that someone like me, who manages 74 beds and another 22 transition beds, is trying to manage people with wandering and sometimes gross behavioural disorders in with residents who are cognitively capable. That is totally unfair to both those with dementia and those without dementia.[26]

5.26 Victorian Association of Health and Extended Care (VAHEC) stated that only 5 per cent of high care and 6 per cent of low care beds are dementia specific with the majority of dementia residents being placed in mainstream residential services. The Association stated that 'whilst the majority of these services cater extremely well for residents with dementia, it is obvious their needs can be better responded to and met in dementia specific facilities'.[27]

5.27 It was argued that the lack of purpose built facilities for people with dementia may result in a number of problems:

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23 *Committee Hansard* 26.4.05, p.2 (ACS Australia).

24 *Submissions* 193, p.15 (Queensland Government); 57, p.11 (UnitingCare).

25 See for example, *Submission* 89, p.4 (Nurses Board of WA).

26 *Committee Hansard* 28.4.05, p.22 (Mary Ogilvy Homes Society)

27 *Submission* 150, p.17 (VAHEC).

- any facility can be labelled dementia specific whether it is purpose designed for dementia or not. This makes choosing the correct facility very difficult for carers and service providers;
- organisations wishing to build dementia specific facilities are unable to easily access best practice guidelines for their design or functional management;
- the length of stay of older adults in the acute hospital setting increases because of lack of facilities and creates the repeated transfer of residents between non purpose built faculties and increases safety risks for the individual residents, other residents and staff; and
- purpose built faculties have no policy or funding incentives to be utilised for older people with the greatest need for that specialised environment. Therefore in practise they appear to be utilised for residents that solve facility management problems rather than the strategic needs of the older people with dementia.[28]

5.28 The Mary Ogilvy Homes Society commented that while the Commonwealth has provided a funding component for dementia care, this is only recurrent funding: 'the majority of the industry would agree that it needs to be carried out in what is known as a segregated model, and that requires a capital funding stream to build buildings that are architecturally appropriate for residents with dementia'.[29]

5.29 Witnesses also identified a number of other difficulties in meeting the needs of residents with dementia. These included:

- people with dementia and co-existing psychiatric illnesses or intellectual disability require additional support and specialised management which is not always available;
- a need for further education and training especially in managing challenging behaviours, however, training budgets which could adequately meet the needs of staff;
- people with dementia who are physically fit often have difficulty finding appropriate placement. Many facilities are not equipped to manage people who are stronger and more agile;
- residential facilities have great difficulty in accessing specialist advice for residents with dementia and very complex needs and residents are sent to emergency departments unnecessarily;
- the need for alternative placement options where facilities cannot manage people; and

28 *Submission* 46, pp.1-2 (Dr R McKay, Ms R McDonald).

29 *Committee Hansard* 28.4.05, p.22 (Mary Ogilvy Homes Society).

- lack of a thorough profile of people on admission, due either to the inappropriateness of the assessment tool or the desperation to place people.[30]

5.30 The ANF Victoria Branch noted that the Ageing in Place initiative was intended to address the needs of aged care residents with dementia but it argued that it had not been successful in giving high care dementia residents access to appropriate nursing and health care. Low care facilities or hostels do not have access to adequate nursing care as these facilities are only required to employ registered nurses on a 'casual' or 'call in basis'. The ANF argued that care in such facilities is not always and concluded that 'such lack of access to skilled nursing care by high care residents is untenable'.[31]

Mental health support

> There are special needs associated with people with mental illness or psychiatric disability, and a body of provocative literature has emerged over the last couple of decades showing that mental illness is commonly undetected and often poorly managed in residential settings. Some actually put the figure as high as 90 per cent or more of those in nursing home care or aged care facilities fulfil criteria for one or more psychiatric disorders in an environment that often presents significant difficulties for assessment and treatment.[32]

5.31 Many witnesses pointed to the need for specialised care for those elderly with mental health problems. Witnesses noted that more people who are ageing have a mental illness, particularly depression, and moving into aged care facilities. The Mental Health Co-ordinating Council (MHCC) indicated to the Committee that its research had found that the ageing process tended to exacerbate the symptoms of mental illness. This was due to the experience of multiple losses and increased physical problems associated with ageing. Many older people with long standing mental illness also experienced isolation and illness as they had become estranged from family and friends and withdrawn from society.[33]

5.32 UnitingCare indicated that as a result of people with mental illness accessing the aged care system there was an increasing need for crisis, acute and specialist psychiatric care. While Baptistcare stated that the needs of the mentally ill are very different to people who have dementia.[34]

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30 *Submission* 13, p.6 (Inner West 5 Home and Community Care Forum); see also *Submissions* 38, p.1 (Ms I Stanley); 2, p.1 (Shoalhaven Community Options Program); 203, p.11 (NSW Aged Care Alliance).

31 *Submission* 66, p.3 (ANF (Victoria Branch)).

32 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

33 *Submission* 75, p.1 (MHCC).

34 *Committee Hansard* 23.2.05, p.31 (Baptistcare); *Submission* 74, p.11 (ANHECA).

5.33 Staff in residential aged care facilities find it difficult to care for those with severe mental illness. The Office of the Public Advocate Qld commented that 'many of the staff in aged care facilities are not knowledgeable about even normal ageing and are not really able to understand some of the psychological symptoms and behavioural problems experienced by residents and, because of that, seldom seek appropriate mental health intervention once a problem is recognised'.[35]

5.34 MCHH concurred with the Public Advocate and identified an urgent need for increased training of staff in aged care facilities in both the care of people with mental illness and dementia:

> The needs of these residents are not currently being met to an adequate degree. This can cause deterioration in mental state and cognitive functioning with consequential decline in safety and quality of life. Additionally, when residents with these conditions are not cared for in an optimum manner, the resulting disturbances impact negatively on staff and other residents. This increases distress for residents and staff and contributes to the ongoing staff shortage.[36]

5.35 Dr R McKay also commented on the need for training:

> Training is very definitely an issue. You see some facilities where it is done very well and others where it is not. In the community in general the level of training seems to be declining, not improving…Whereas 10 years ago you could access people in the community with training, now it is extremely hard. That exacerbates the problem. You actually can have people going in to provide respite who actually may make the situation worse rather than better. This is not across the board. I have to emphasise that there are still some very good community services as well. But the training makes a huge difference.[37]

5.36 ANF Australia stated the key to providing appropriate care is the education of staff who work in the acute sector and in the residential sector and the community sector. Education for mental illness 'has been neglected a little because of the focus on dementia because of the large numbers that we are going to be looking at of people with dementia. It is a real problem'.[38]

5.37 The need for additional services and funding was highlighted in evidence. The ANF Victoria Branch stated that additional funding (around $50 per resident per day) for patients with mental illness is provided by the Victorian Government to ensure that appropriate care is provided. The ANF stated that elderly Victorians with mental illness were well service by access to public nursing homes but 'these homes would

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35 *Committee Hansard* 18.3.05, p. (Office of the Public Advocate Qld).

36 *Submission* 75, p.2 (MHCC); see also *Submission* 196, p.8 (Aged Care Qld).

37 *Committee Hansard* 11.3.05, p.66 (Dr R McKay).

38 *Committee Hansard* 11.2.05, p.40 (ANF).

not be able to continue to provide Psychiatric nursing care if they were reliant on Federal funding'.[39]

5.38 It was argued that the Commonwealth's failure to provide supplementary funding for mentally ill residents, undermined the provision of appropriate care. In addition there is also limited access to psycho-geriatric services or behavioural management support services.[40] For example, the NSW Aged Care Alliance noted that there was only one psychogeriatric unit in NSW.[41] In Queensland the Office of the Public Advocate noted that there was a problem with the provision of non-acute residential aged care places in Queensland for people with a psychiatric disability: 'it lags behind most other states, as does acute aged geriatric area spending as well as mental health spending more broadly. The lack of specific psychogeriatric services has been cited by the Royal Australian and New Zealand College of Psychiatrists by their faculty of psychiatry of old age.'[42]

5.39 Dr McKay also commented that the design of facilities for those with mental illness was important. With properly designed facilities for people who have mental illness or cognitive impairment the demands on staff are reduced, agitation is reduced and increases the safety for staff and residents.[43]

Homeless people

> The homeless elderly are certainly living in our community and they are doing it very tough. They deserve respect and they deserve to be treated with dignity. This is a critical time to ensure policy and funding decisions ensure homeless older people are not forgotten and indeed they, and those who care for them, should receive the assistance they need to ensure the highest quality of life.[44]

5.40 The elderly homeless are a small group but who, as the Hogan Review observed, are one of the most difficult groups to place in residential care.[45] In relation to funding of their aged care, the Hogan Review noted that 'while the elderly homeless attract a concessional resident supplement, they generally have no ability to pay an accommodation bond, compounding the problem of access to mainstream services'. The Hogan Review commented that given the funding problems of providing care for the elderly homeless, there are very substantial grounds for providing for the special needs of the most deprived of the elderly homeless. The Review's recommendation included extension of the funding supplement to disadvantaged groups, including the

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39 *Submission* 66, p.3 (ANF Victorian Branch).

40 *Submission* 196, p.8 (Aged Care Qld).

41 *Submission* 203, p.11 (NSW Aged Care Alliance).

42 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

43 *Committee Hansard* 11.3.05, p.66 (Dr R McKay).

44 *Committee Hansard* 11.2.05, p.4 (CHA).

45 Hogan Review, p.194.

elderly homeless, and targeted capital assistance to assist those services experiencing exceptional circumstances.[46]

5.41 The Commonwealth's response to the Hogan Review did not include extension of the funding supplement to the homeless and noted that the care needs of people from diverse or disadvantaged backgrounds are supported by a number of Commonwealth programs.[47]

5.42 As with evidence to the Hogan Review, witnesses pointed to the special needs of the elderly homeless and the difficulties they face accessing care. The elderly homeless are predominantly male and access services at a younger age than others. Generally homeless people or those at risk of homelessness have poor diets, have multiple health problems, multiple cognitive problems, are often alcohol dependent and are subject to social isolation.

5.43 The homeless lifestyle hastens the ageing process with premature ageing found in people in their 40s who have been homeless for a number of years. As a result they may require the intensive services appropriate to older people, such as HACC, CACP and residential aged care. The Brotherhood of St Laurence stated that they are often excluded from these services as they do not meet the age criterion and conventional models do not suit this group.[48]

5.44 When residential aged care is required, homeless people often find it difficult, if not impossible, to access services. CHA stated that currently, all providers who cater for this group are religious and/or charitable organisations.[49] St Bartholomew's noted that the small number of service providers that are willing to care for this group appeared to be dwindling. Mainstream services 'actively discriminate against this client group' and are reluctant to accept the elderly homeless because of their challenging behaviours.[50] For example, many homeless people have learnt coping behaviours which are not suitable in a normal community setting and so extra resources are often required to assist and retrain these people in acceptable behaviours. Homeless people often have poor interpersonal skills and are suspicious of people they don't know, including service providers, and it takes a great deal of time, which is not funded, to build up a relationship of trust. Other areas where homeless people require a different and intensive level of support include personal care, leisure activities, overcoming alcohol and/or drug dependency and medical and

46 Hogan Review, pp.xviii, xxi, 196.

47 The Hon Julie Bishop, Minister for Ageing, *Investing in Australia's Aged Care: More Places, Better Care*, May 2004, p.22.

48 *Submission* 52, p.5 (BSL).

49 *Committee Hansard* 11.2.05, p.4 (CHA); 23.2.05 p.24 (St Bartholomew's House).

50 *Submission* 54, p.2 (St Bartholomew's House).

dental issues.[51] In addition, without the appropriate resources, the wellbeing of other residents and the occupational health and safety of staff are at risk.

5.45 VAHEC stated that the RCS, even when maximised, does not reflect the level of care required by people who have been homeless and stated that 'the intensive care and one-on-one support required by these people cannot be provided by organisations within the current funding structure'.[52] St Bartholomew's noted that the Commonwealth had not implemented the Hogan Review's recommendation in relation to residential care. Witnesses recommended that the Aged Care Act be amended to include homeless people as a special needs group so that they can become eligible for Commonwealth funded aged care services.[53] The Brotherhood of St Laurence stated:

> I would not see it as an extra stream of funding. I think it is more about tapping into the funding but creating a special needs group within the Aged Care Act. I think Professor Hogan recommended that homeless people be taken into account with special needs funding. I think the Commonwealth's response was more or less that they saw that as a state government responsibility and that it was already being well catered for. We would strongly argue that it is not being catered for at all and that there is a need for a funding stream for homeless people.[54]

Ageing with disabilities

> We know there are lots of adults with a disability who are now into their 50s and 60s, and parents who are in their 80s who have been caring for their loved one for over, in some cases, five decades. This is a very big cohort and I think that good collaboration between the states and the Commonwealth will be critical in terms of determining how this current unmet need will be addressed.[55]

5.46 NCOSS noted that at present 11 per cent (30 200) of those aged 45-64 and 4 per cent (13 000) of those aged 65 or over with severe or profound core activity restrictions report an early onset disability (i.e. acquired before age 18). It is anticipated that there will be an increasing number of people with an early onset or longstanding disability who are ageing. Between 2000 and 2006, the total number of people with a severe or profound core activity restriction is expected to increase by 11.6 per cent (137 600 people).[56]

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51 *Submissions* 54, p.3 (St Bartholomew's House); 150, p.16 (VAHEC).

52 *Submission* 150, p.16 (VAHEC); see also *Committee Hansard* 11.2.05, pp.4, 12 (CHA); *Submission* 200, p.7 (Tasmanian Government).

53 *Committee Hansard* 23.2.05, p.24 (St Bartholomew's House).

54 *Committee Hansard* 27.4.05, p.14 (BSL).

55 *Committee Hansard* 18.3.05, pp.4-5 (Office of the Public Advocate Qld).

56 *Submission* 204, p.12 (NCOSS).

5.47 Witnesses argued that people ageing with disabilities requires specific and considered responses from all levels of government to meet their needs. ACROD focussed on the need for improved linkages between service systems:

> Our view is that the response from governments to this development, this growing interface between ageing and disability, has been inadequate. Much of the policy effort at government level, it seems to me, in these human service areas where demand exceeds supply of services, goes into restricting entry, erecting barriers – setting restrictive eligibility criteria – rather than focusing on improving pathways and improving linkages between sectors. The result is an ineffective and inefficient interface between the two service systems.[57]

5.48 For example, it was stated that ACAT teams make assessments where they are largely unaware of the supports and services offered by the disability sector.[58] A further example was that of the provision of aids and equipment. ACROD noted that the responsibilities for the provision of aids and equipment are divided across government departments and between the Commonwealth and the States:

> …with the Continence Aids Assistance Scheme, the federal Department of Health and Ageing provides that for people in a rationed way; provides that for people who are under 65 or over 65 if they continue to work for eight hours a week or more, but when a person turns 65 and they have continence issues…They then become ineligible for that scheme and they have to then find an equivalent scheme funded by their state government.
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> That creates uncertainty and anxiety for them and I think is an inefficient and ineffective way of doing it. There has been enough research now that shows that, as a whole, the current schemes leave significant gaps, are inefficient and are fragmented.[59]

ACROD proposed that the states, Commonwealth and relevant non-government organisations could come together and develop a coordinated or centralised system which could ensure that there was equitable and available aids and equipment for people which, in the long term, would allow people to remain independent and so reduce the pressure on more formal services.[60]

5.49 In addition, it was argued that not only is funding not keeping pace with the increased demand for service, but also 'the funding formulae and administrative arrangements that govern the aged care and disability service systems seem to assume that a person is either disabled or aged, but cannot be both'. Like other witnesses, ACROD recommended that a person with a disability who is ageing should have

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57 *Committee Hansard* 11.2.05, pp.49-50 (ACROD).

58 *Committee Hansard* 11.2.05, p.54 (ACROD).

59 *Committee Hansard* 11.2.05, p.56 (ACROD).

60 *Committee Hansard* 11.2.05, p.56 (ACROD).

simultaneous access to both aged care and disability service systems and funding streams, according to their need. However, ACROD noted:

> …people who may have been long-term residents in state funded group homes – they may be people with an intellectual disability – and that is their home and has been their home for many years. When they age, because they are in a state administered and state funded group home, they are denied access to services that other people have access to; services such as community nursing, palliative care, dementia support and so on. This effectively denies them the right to age in place, which is a right that is increasingly expected by the general community.[61]

5.50 Baptistcare provided information on problems with service provision to a group of aged residents (some in their seventies) with disabilities in a residential facility in Perth. As it had to relocate the group from a facility which could no longer provide for their needs, it sought Community Aged Care Packages as a possible solution:

> We saw this as a possible solution that we might be able to work towards as we endeavour to relocate these people. We made an approach to the state government here, with whom we are working, and they in turn made an approach to the Commonwealth office here. We were not at the meeting, but the response that we were given was that there appears to be little scope in the Aged Care Act for the two bodies to work together to come up with a solution that may see something like that being a new initiative within an existing program. So that is an example we had towards the end of last year which I put to Minister Bishop as an opportunity that maybe her department could have a look at.[62]

Baptistcare concluded that 'there is an opportunity for Community Aged Care Packages to go out to people who are currently living either in the community or, perhaps, in a facility such as the one we have. That would address their immediate needs and let them remain where they are rather than relocate them'.[63]

5.51 The Greenacres Association commented that there were concerns about ageing people with a disability who have been living in the community and working in business enterprise. Greenacres stated that:

- there is an inability to secure the appropriate supports and services that they require to remain living a meaningful live in the community as they age;
- there is a lack of, and uncertainty about, service provision makes it difficult, if not impossible for these people and their supports to plan for the future; and

61 *Committee Hansard* 11.2.05, p.50 (ACROD).

62 *Committee Hansard* 23.2.05, pp.33-34 (Baptistcare).

63 *Committee Hansard* 23.2.05, p.34 (Baptistcare).

- services for ageing people with a disability must be sufficiently flexible to meet their diverse needs and must take account of changes in those needs as they further age.

5.52 The Greenacres Association noted that the people with disability they cared for had been supported for most, if not all their lives and 'would not cope without support (at least initially) in generic services, and the generic service participants were not keen to integrate with people with a disability'. Therefore effective transition programs and services are essential as a person with a disability reaches the age of retirement and eligibility for aged care services.[64] ACROD stated that transition from employment to retirement needed to be gradual so that the person had time to adapt to change. Initially the supported employee should receive a mix of non-employment activities and employment. ACROD stated that this requires movement from Commonwealth funded services to appropriate day activities funded by the States or Territories and aged care services funded by the Commonwealth: 'in theory bureaucratic and jurisdictional boundaries should not impede this, but, in practice, the boundaries are often barriers'.[65]

5.53 The Greenacres Association also stated that the Commonwealth's 'Assistance for Business Services' provides for access to a personal case manager to support those retiring from a business service. However, Greenacres commented that:

> In theory this sounds fantastic, but the reality is that that there are not services out there for these people to access. In the Wollongong area alone there was not a single appropriate service available until the NSW Department of Ageing Disability and Home Care funded the Retirement Options Program.[66]

5.54 Greenacres provided the Committee with details of its ageing service, Greenacres Retirement Options (GRO). This service provides a centre based day program for eligible individuals. The service offers a variety of activities both at the centre and in the community. Assistance for each activity is provided, the average being one GRO staff member to five retirees (or less). Priority is given to those individuals over the age of 55 that are retiring from a business service or have already retired and living with a family member. Retirees that live with a parent carer have the highest priority. Greenacres commented that this type of services is ground-breaking and the first of its kind in Australia.

5.55 The Department of Family and Community Affairs (FaCS) stated that the issue of people ageing with disabilities was a concern:

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64 *Submission* 32, p.4 (Greenacres Association) see also *Committee Hansard* 11.2.05 p.50 (ACROD).

65 *Submission* 26, p.3 (ACROD).

66 *Submission* 32, p.6 (Greenacres Association).

> Certainly the issue of people with lifelong disabilities who are ageing is a growing concern to us. It is in some ways a relatively new phenomenon. We are not accustomed to having large numbers of people with disabilities live to such an age, where they would be regarded in the traditional sense as potential aged care clients.[67]

The Department went on to note that 20 years ago there were only a handful of older people with down syndrome. Now there are over 1 000 people in Australia who are aged with down syndrome. The Department commented:

> We are clearly starting to face very real issues at that older age nexus. I admit that it is not something in the disability world that a great deal of attention has been paid to in the past. Increasingly we are doing that but I would still come back to my earlier point that it is really a case of the appropriate expertise and appropriate kinds of support, rather than trying to look at how a mix of services might go into the one service. I am happy to accept that there are needs for improvement in the services.[68]

5.56 The Department of Health and Ageing commented that it and FaCS 'have been working on, including through a small number of pilots under the aged care innovative pool, to test that issue of the increasing ageing needs being overlaid on disability needs'.[69] The Innovative Pool offered flexible aged care places to the States and Territories and other aged care providers, for time limited pilots to trial new models of service delivery at the disability services/aged care interface. Two specific categories for people with a disability were targeted, the first being for people with disabilities who are ageing. Six projects have been approved in this category for 2002-03 and a further three for 2003-04. These projects are all providing additional aged care services for people with disabilities who are ageing in disability supported accommodation settings.[70]

5.57 ACROD supported this development and stated:

> That is very good and I know that those pilots are subject to evaluation this year. I would hope that, subject to that evaluation, they not only continue but that the principle of combined funding and joint funding that is established by those pilots can be more broadly applied…It is a very promising development, because it involves cooperation between Commonwealth and state and sensibly involves shared funding. The clientele that are being provided with the service in those pilots have mixed needs and some of those needs derive from life-long disability and others derive from the fact that they are growing old. It makes sense, from a policy point of view, for both levels of government to be involved.[71]

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67 *Committee Hansard* 11.2.05, p.83 (FaCS).

68 *Committee Hansard* 11.2.05, p.84 (FaCS).

69 *Committee Hansard* 11.2.05, p.83 (DoHA).

70 *Submission* 191, p.37 (DoHA).

71 *Committee Hansard* 11.2.05, p.50 (ACROD).

5.58 In regard to the provision of age related services to those ageing in supported accommodation, FaCS stated that it is government policy that Community Aged Care Packages are not available to people in subsidised residential care and that:

> The disability residential care services or the accommodation support services are very similar in principle at least to many other residential services. We would expect that the organisations running those services will be meeting the needs of the people that they are providing services for. It is difficult for me to think through why there would be a need for, or an expectation that – say for our colleagues in the Department of Health and Ageing but in health and aged care services generally – aged care services of any kind would be provided to somebody who is already in a residential care service and presumably having their residential care needs met.[72]

FaCS further commented that it was discussing the growing number of issues around people with disabilities living in residential care services who are developing conditions traditionally associated with ageing, such as Alzheimer's dementia, where there is again a growing recognition that those services do not necessarily have the expertise and the experience in handling those:

> As part of our current round of Commonwealth-state arrangements there are a couple of parts within that where we have agreed with the state governments that there are areas of expertise which are needed and that is something that we are discussing with our colleagues in Health and Ageing.
>
> I think it is going a bit far in that environment to suggest that there is a service model which should be provided. We certainly recognise there are areas where greater expertise is needed and state governments are working increasingly with Health and Ageing officers in the states to do that, but I do not think there is a situation at this stage where it is appropriate for two models of service or two accommodation support services to be provided to a person in the one residential setting. I agree with the need but I am not convinced there is a need for services from two agencies to go to that one person.[73]

Conclusion

5.59 The discussion in this chapter briefly canvasses a number of significant issues. Solutions to these issues must be found to ensure that adequate aged care is provided to all those in aged care facilities. The Committee considers that if the Commonwealth takes on the care of those in aged care, the Commonwealth is responsible for the total care of that person and the provision of all services. It must ensure that all matters pertaining to a person accommodated in an aged care facility are taken into account and the appropriate services are provided whether they arise from a condition related to ageing or a pre-existing condition such as a mental health problem or they arise from lifestyle such as homelessness.

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72 *Committee Hansard* 11.2.05, p.82 (FaCS).

73 *Committee Hansard* 11.3.05, pp.82-83 (FaCS).

5.60 In relation to the supplementary funding for dementia, while this is a welcome initiative, the Committee considers that it is not appropriate that these funds are drawn away from other programs. The costs of dementia and palliative care needs are increasing as are all costs in residential aged care. Funding the supplement should be provided in addition to that already provided. The Committee also considers that an appropriate review of the additional costs of providing care for those with dementia and those needing palliative care should be undertaken to ensure the funding supplement is sufficient to provide adequate care.

5.61 The Committee also notes that dementia is now a Commonwealth National Health Priority and that Australian Health Ministers have jointly agreed to the development of a National Framework for Action on Dementia. The Committee considers that this is a significant opportunity for ensuring that the increasing numbers of older Australians who are suffering from dementia receive adequate care and that they and their families are able to access a range of accommodation and care options.

Recommendation 29

5.62 That the supplementary funding for aged care for residents with dementia be provided for by additional funding and not funding from within the current budget.

Recommendation 30

5.63 The Committee recognises that the Australian Health Ministers have jointly agreed to the development of a National Framework for Action on Dementia and that the Commonwealth has recognised dementia's significance with a $320.6 million package of support over five years. The Committee recommends that all jurisdications work together with providers and consumers to expedite the finalisation and implementation of the Framework to assist all dementia sufferers.

Recommendation 31

5.64 That the Commonwealth undertake a review of the additional costs of providing care for those with dementia and those needing palliative care to ensure that the new funding supplement will be sufficient to provide adequate care.

5.65 Mental illness is a major health concern in the community. Evidence points to the exacerbation of mental illness with ageing. The elderly with mental health illness or psychiatric disability require additional and specialised care. They must have access to adequate accommodation and support options. In order for this to occur, the Committee considers that the funding supplement should be extended to services providing care for older people with mental illness. In addition, the Committee considers that a review of the provision of psychogeriatric services and the effectiveness of psychogeriatric care units needs to be undertaken.

5.66 The Committee also considers that there is a need to increase the training of the aged care workforce to ensure that mental illness in the elderly is recognised and that there is a skilled workforce to meet the needs of elderly people with mental illness.

Recommendation 32

5.67 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from mental illness.

Recommendation 33

5.68 That the Commonwealth investigate the provision of psychogeriatric services and the effectiveness of psychogeriatric care units.

Recommendation 34

5.69 That the Commonwealth provide targeted funding for the education of the aged care workforce caring for people with mental illness.

5.70 The Committee considers that while the elderly homeless are a small group, they require additional services to ensure that they receive appropriate aged care. The Committee is therefore disappointed that the Commonwealth has not provided a funding supplement for the elderly homeless. The Committee considers that the Commonwealth should reconsider this decision.

Recommendation 35

5.71 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from homelessness.

5.72 The number of people ageing with a disability is growing and they will need to access quality aged care services. While it is acknowledged that the Commonwealth is aware of this problem, the Committee is concerned that the barriers between the jurisdictions and within jurisdictions may impede the development and provision of services for those ageing with a disability.

5.73 Those working in the disability sector have built up the skills and resource base to assist those with disabilities. To these must now be added the skills and resources of the aged care sector. Without an understanding of both disability and ageing those ageing with a disability will not receive an optimum level of care.

5.74 The Committee considers a specific and focussed response is required.

Recommendation 36

5.75 That the Commonwealth respond to the growing needs of people ageing with disabilities by consulting with the States and Territories and stakeholders to identify ways to improve access by people ageing with a disability to appropriate aged care services including service provision in supported accommodation.