



## **Submission to the Senate Community Affairs References Committee Inquiry into Aged Care**

**July 2004**

The Benevolent Society welcomes the opportunity to make a submission to the Inquiry into Aged Care. The focus of this submission will be on 'the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements' (Inquiry Terms of Reference c)) and 'the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly' (Inquiry Terms of Reference d)). For clarity, this submission will primarily examine these terms of reference separately, however some common themes are apparent.

The Benevolent Society acknowledges the increasing amount of Government financial support to residential care and community care providers. However, residents with special needs in aged care facilities, and elderly people who are potential or current clients of HACC programs, have unmet needs under current funding arrangements. This is due to a variety of reasons, and various programs face unique issues. However, two primary issues have emerged:

1. The amount of funding allocated to programs is inadequate to service the needs of all clients/ potential clients. This will intensify in the future.
2. The way funding is allocated is inadequate to deal with the complex care needs of many clients or to satisfactorily support innovative programs that do not fit established criteria for funded programs.

These issues will be examined below in the context of the specific aspects of the terms of reference to be addressed.

### **Background on The Benevolent Society**

The Benevolent Society is Australia's first non profit organisation. Since 1813 we have worked to meet key social challenges head-on. Our mission is to anticipate changing social needs and drive innovative, effective responses in high need communities. We are a 'whole of life' charity with four key program areas – ageing, women's health, children and families, and social leadership.

Our Centre on Ageing provides a number of residential and community based aged care services throughout the Greater Sydney region. We have been operating residential aged care facilities for 40 years, and community programs for over 15 years.

The Benevolent Society currently operates six residential aged care facilities in the Sydney metropolitan area. Five are low care facilities, including one that is a secure facility for people with dementia. The sixth is Eric Callaway House (ECH), in Sydney's eastern suburbs, which is a purpose-built secure nursing home providing specialised care for people with dementia and disturbed behaviour.

We also provide a number of community based aged care programs, including seven currently funded under Home and Community Care (HACC). These programs include Home Assistance services in Northern, Central and Eastern Sydney; Northern Beaches Food Services (a meals-on-wheels service); Eastern Suburbs Options Program; Greenwood Cottage Day Centre; Flexible Respite for people with disabilities; and Homeshare NSW. A detailed diagram showing the range of programs provided by our Centre on Ageing is provided in Attachment A.

### **The extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements**

The Benevolent Society believes that current funding arrangements are inadequate to meet the needs of residents with special needs. This view is informed by our experience operating residential aged care facilities for both mainstream and specific needs clients. The demand on mainstream residential facilities to cope with residents with special needs is of growing concern, and will no doubt be exacerbated by expected demographic changes in the future. Specific aspects of these pressures are examined below.

We are also concerned with the adequacy of current funding arrangements in meeting the needs of residents who have dementia and disturbed behaviour, based on our experience of running a specialised service for this client group.

#### **Caring for clients with dementia and disturbed behaviour**

Eric Callaway House (ECH), a nursing home in Sydney's eastern suburbs, has 43 places, is a secure building, and provides specialised care for people with dementia and disturbed behaviour. It currently has 22 residents in Resident Classification Scale (RCS) Category 1, 22 in Category 2, and one respite place.

These figures are well above the NSW average for high care facilities, but ECH operates at a significant loss (-\$178,418 for 2003/04). The Board of The Benevolent Society has continued to support the operation of ECH because it is providing such a valuable service, but it cannot do so indefinitely.

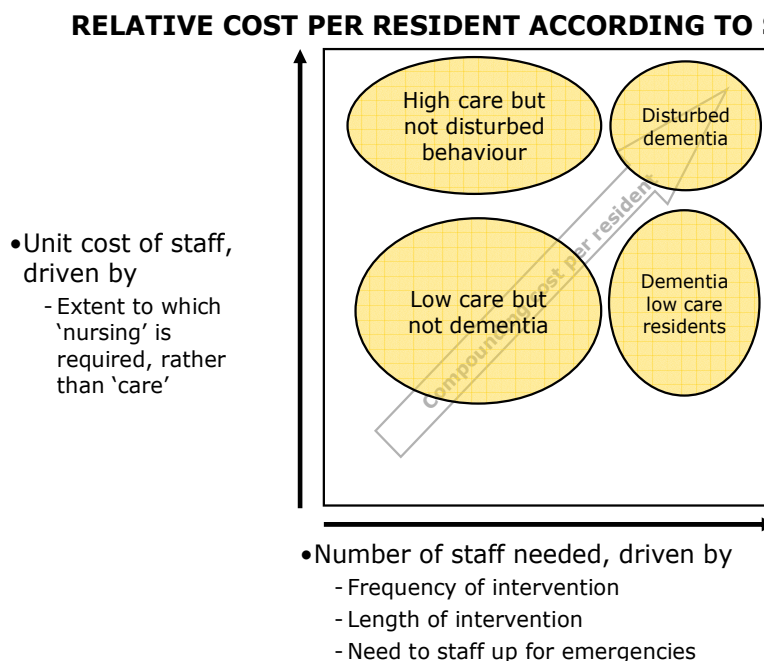
It is the only high care facility in Sydney's eastern suburbs that is willing to provide care for people with advanced dementia who not only need a secure facility but who may be agitated and aggressive. It receives so many enquiries from people all over NSW seeking such a facility that we estimate we could fill it four times over.

Facilities such as ECH care for residents who can be considered statistical "outliers", as their needs are so extreme they are unattractive to organisations

unwilling to invest the significant resources required in staffing and training to provide appropriate care. ECH has an excellent reputation for the high standard of care it provides, and it has very good relationships with the South East Sydney Area Health Service.

Current funding mechanisms for high care facilities do not take into account the significant amount of time that these “outlier” residents require. In other words, facilities for people with dementia and disturbed behaviour are structurally underfunded and their operation is dependent on the commitment of organisations to carry heavy financial losses. This is not sustainable in the long term.

The following diagram demonstrates some of the variables that we believe are not being taken into account in determining an appropriate way of providing adequate funding for facilities for people with dementia and disturbed behaviour:



We ask that there be recognition of the particular needs of facilities which are committed to providing care for people with dementia whose behaviour is too disturbed for mainstream high care facilities.

They are not a large group of people, but are significant. Estimates suggest around 50,000 people in Australia (nearly one third of people with dementia) currently exhibit significant behavioural and psychological symptoms of dementia.<sup>1</sup> The need for specialised accommodation for people with dementia who exhibit disturbed behaviour will increase as the overall numbers of people with dementia rise. A way forward may be the nomination of specialised

<sup>1</sup> *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*, Access Economics/ Alzheimer's Australia, Canberra, 2003, p. 93

facilities like ECH based on a specified population ratio, and funding them to provide the care needed by older people with such special needs.

### **Caring for clients with special needs**

It is not only in dementia specific residential settings that clients with special needs are accommodated. This is borne out by our experience in operating mainstream low-care residential facilities that accommodate residents with specific conditions or a mental illness. In these facilities, most residents are frail aged people with low care needs. However, we also accommodate some younger residents who have a specific condition, and some who are older but who have additional care needs due to a specific condition or mental illness, which is exacerbated by the ageing process.

### **Case study**

Huntington's Disease is a hereditary condition affecting the central nervous system. Residents with Huntington's Disease have care needs more complex than the majority of hostel residents. They are also likely to need residential care at a younger age than people without special needs, which extends their period of residence, and can also create tensions between them and other (older) residents. Acceptance can be difficult for both sides. Residents with special needs generally also require an increased level of care as the ageing process continues and interacts with their condition; this is intensified if the resident experiences the onset of dementia, in addition to their condition and the general effects of the ageing process. These needs can also translate into higher care costs to the provider, including:

- Increased levels of supervision
- Need for greater physical space for those with mobility problems such as those with Huntington's Disease, for the affected person's comfort and safety and for that of other residents
- Greater calorie needs often associated with lack of mobility control and with dementia.

We would like to emphasise the following from our experience operating residential facilities for people of a wide age range. Residential aged care facilities are also the residents' home, and this needs to be factored in when admitting a mix of residents of varying ages and care needs. It can be difficult for frail older people to accept the presence of younger people with complex needs who may also have behavioural issues, and vice versa.

We have two recommendations for moving forward:

- Fund separate residential facilities for younger people (under 70) with high care needs.
- Increase the level of support available to younger people with special needs in their own homes. This would need to be achieved by allocating increased funding to services, rather than reallocating funding that would otherwise be spent on supporting older people at home.

## **HACC programs' ability to meet the current and projected needs of the elderly**

The Benevolent Society operates a wide range of community based aged care programs, including a number funded under HACC. These programs are outlined in Attachment A. The Benevolent Society recognises the importance of providing support to older people to allow them to remain living independently in their own home for as long as possible. In recognition of this, we have been expanding our community programs over the past 15 years, and now provide support to over 1000 people in their own homes on a daily basis. While we recognise there will always be a need for residential aged care, it is generally predicted that the demand for home based services will increase at a greater rate over the next 40 years as the proportion of the population who are over 65 increases, and as more of these people will need some support in order to stay independent for as long as possible. It is also recognised that the demand for residential places is likely to outstrip supply, placing even greater emphasis on the role of community based care for older people.

Community care is predicted to become increasingly important over the coming decades, and it is clear that current funding arrangements will be inadequate to deal with this need. In fact, they are insufficient to meet current demands. First, the overall amount of funding provided cannot meet the community's need. Second, because of narrow definitions of what constitutes a program eligible to be funded.

In our experience, the amount of funding currently provided specifically to HACC programs is insufficient to meet demand for the services, and this shortfall is expected to increase in the future. It is not only in the direct provision of services that demand is outstripping supply; many programs rely on being able to refer clients to other HACC agencies, for example Home Care, who face the same pressures. This can lead to "bottlenecks" where clients' progress through the referral system is stalled, preventing new clients from being accepted by the program.

Clients can also stall at many other points in the process because of the inability of HACC programs to service all their clients' needs. Many programs operate a 'two-tier' waiting list. Clients are first assessed for eligibility for the service, eliminating most inappropriate referrals. Those assessed as eligible are then listed as such until a place is available on the waiting list. Waiting lists are generally kept short, around 6 places, however those assessed as eligible but who are not on the waiting list can number into the hundreds. This has the side effect of disguising the true level of demand for services, and the amount of time clients wait before receiving a service. It can also affect efficiency, as many of those assessed as eligible never proceed to receiving services, meaning the time spent on their original assessment is redundant. As suggested below, revising referral processes and facilitating greater communication between agencies would help reduce wastage.

Pressure on HACC services and their ability to meet the needs of their elderly clients are exacerbated by the need to provide services to other client groups, such as younger people with a disability. The vast differences in the level of support needed by different clients must also be taken into account, as well as

the different levels of support programs are able to provide. For example, Home Assistance programs may support a frail older person in their home who only needs an hour or two of help per week with shopping or housework; other programs' clients may need hostel level support at home because of multiple needs, for example, dementia or disability in addition to the general effects of ageing. The vastly greater cost commitments involved in supporting high need clients must be taken into account when funding intensive services.

We have identified several possible ways forward for HACC funded programs:

- A vast injection of funds, sustained over the long term, is obviously preferred, although not likely to be feasible.
- In addition to an increase in funding to HACC agencies, we suggest that increasing the level of client contribution for services, where appropriate, could increase capacity to help a larger number of clients. If client contributions were appropriately means-tested, so as to include all those who have a need for services, charged at a level they are able to afford (even if that be nil), it would allow agencies to spread funding across a larger number of clients, while reserving the bulk of funding monies for those clients unable to financially contribute to their care. For this to occur, services would need to be able to retain surplus fees for use in further developing the service. Currently, surpluses must be returned to the NSW Department of Ageing, Disability and Home Care, creating little incentive for seeking higher client contributions. These measures would also help to offset some of the expected increase in funding shortfalls in the future.
- Revising referral processes to prevent or screen out inappropriate referrals and to eliminate overlapping referrals of one client to multiple services is also desirable. Greater communication between HACC agencies and programs is also needed to effect this change.
- Regular reviews of the needs of existing HACC clients should also be undertaken, to ensure that clients are receiving the level of care they need at the appropriate times. Greater communication between agencies would also help ensure the correct level of care is being provided for clients, and that agencies are not providing duplicate services to a client.

We would also like to emphasise the importance of innovation. For example, Homeshare NSW, a program of The Benevolent Society that currently receives HACC funding, matches an older person living in their own home with a younger person in need of accommodation. The younger person receives free rent in exchange for 10 hours per week of help around the older person's home. In many instances, the security provided to the older person by having someone around at night, as well as practical support around the home and companionship, can allow them to stay in their home without further provision of services for far longer than would otherwise be possible. In this way, Homeshare NSW also helps to build bridges between generations and thus strengthen social capital. Such 'win-win' programs, that are not financially intensive, should be further funded and new models for such services investigated.

## **Conclusion**

We acknowledge the Government's emphasis on the provision of services for the aged and the increased levels of funding arising from this. However, it is clear that the current funding arrangements are inadequate in meeting current demands on services, and cannot meet the predicted increase in the level of need in the future. Specialised residential facilities must be provided with greater levels of funding. Community services also need to be provided with more funding, and their efficiency optimised. Additionally, innovative responses to community need, especially those that are not financially intensive, must be investigated and adequately funded. In this way we will be able to meet the expected future increases in demand for aged care.

# Attachment A

## The Benevolent Society's Centre on Ageing programs

### CENTRE ON AGEING as at April 2004

