Senate Standing Committee on Community Affairs
Inquiry Into Aged Care

Submission by the Office of the Public Advocate - Queensland (July 2004)

Background

The Senate's Standing Committee on Community Affairs is holding an inquiry into aged care in Australia. The terms of reference for this inquiry include:

> *(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.*
>
> *(d) the adequacy of Home and Community Care Programs in meeting the current and projected needs of the elderly.*

The Office of the Public Advocate – Queensland

The Office of the Public Advocate was created under chapter 9 of the *Guardianship and Administration Act 2000* (Qld). Unlike other Australian states, the Queensland Public Advocate is charged with providing systemic advocacy for adults with a decision-making disability. This group includes people with a psychiatric disability, an intellectual disability, an acquired brain injury or some form of dementia. Under the Act, it is the function of the Public Advocate to:

- promote and protect the rights of adults with impaired capacity for a matter
- promote the protection of the adults from neglect, exploitation or abuse
- encourage the development of programs to help the adults to reach the greatest practicable degree of autonomy
- promote the provision of services and facilities for the adults
- monitor and review the delivery of services and facilities to the adults.

Part 1: Younger people in aged care facilities

The trends on younger people in aged care facilities

The number of younger people permanently residing in aged care facilities in Queensland, as reported by the Australian Institute of Health and Welfare[1], is as follows.

Year	Number of younger residents	Percentage of all residents
1998	1,137	(4.8%)
1999	1,167	(4.9%)
2000	1,204	(5.0%)
2001	1,223	(5.0%)
2002	1,264	(5.1%)
2003	1,273	(5.0%)

With the exception of the Northern Territory, Queensland consistently ranks as having the highest proportion among all states of nursing home residents under 65 years.

Additional information from the Commonwealth[2] reveals that 16% of younger Queensland residents are currently under 50 years old, an additional 45% are 50-59 years old, with the remaining 39% being 60-64 years old.

The Public Advocate's interest in younger people in aged care facilities

The interest of the Office in this issue relates to those adults with a decision-making disability who live in aged care facilities. That is, people with an acquired brain injury (30% of younger people in nursing homes), intellectual/psychiatric disabilities (20%) or neurological disabilities (22%)[3]. Consistent with the functions of the Office, our interest relates to the following:

- Are there sufficient, appropriate accommodation options for people to exercise some real choice about where and how they live, or are they forced into nursing homes by the lack of other alternatives?

- Do aged care facilities promote autonomy, development and protection from abuse, neglect and exploitation consistent with the General Principles of the *Guardianship and Administration Act 2000* (Qld)?

- What are the unique needs of younger people living in aged care facilities (including for housing, support, community participation, appropriate medical care etc.)?

- Are there better alternatives for younger people currently living in nursing homes?

- What commitments on the part of government (including shared responsibility across jurisdictions) and the community sector are necessary to provide for a better quality of life for these vulnerable people?

The Background

It is instructive to remind ourselves of the history of this issue. At one point in time, the nursing home option represented a collaborative response between two levels of government for younger people with disabilities, particularly younger people with an acquired brain injury who lived in a regional/remote part of the State. In the absence of other care alternatives, an agreement was created between the State and Commonwealth Governments to allow younger people to enter nursing homes, where they could receive the intensive medical care they required and still remain close to their own families and communities.

While, except in rare cases, the Office is not advocating that nursing homes are still the best option for these younger people, it would be a concern if current developments between the Commonwealth and the States over the issue of younger people in aged care were to signal a cost-shifting debate between two levels of government that had previously collaborated over the care arrangements for these vulnerable people.

Furthermore, while arguing that nursing homes are generally not an appropriate response to the needs of younger people with disabilities, the Office would not wish to be seen as criticising either the aged care sector or the many capable and sensitive aged care managers who are doing their best to care for this cohort, and are similarly concerned about their placement in nursing homes.

The Public Advocate's position on younger people in aged care facilities

Information on the presence, the entry processes, and the quality of life of young people in aged care facilities is received regularly by the Office from various sources including family members, current and former nursing home residents, and community-based service providers. Information is also received from community advocacy networks at the state and federal level.

Based on this information, the following represents the position of the Office.

1. As a general trend, aged care facilities have become all too regular placements for vulnerable younger people with both physical and cognitive disabilities. Although such facilities should be the last resort, after all other options have been exhausted, nursing home placement now happens all too quickly, apparently because of the lack of other alternatives. In most cases, the aged care option does not represent the freely made choice of the individuals concerned, or of their guardians, because of the lack of other alternatives.

2. In general, aged care facilities do not serve the needs of vulnerable younger people with disabilities well. (In fact, some are beginning to challenge the use of nursing homes for all age cohorts.) Aged care facilities do not provide the intensive support required to meet people's unique needs, they do not promote practices that allow people to pursue their own autonomy and development, they do not encourage the formation and maintenance of freely-chosen relationships with people of one's own age, and they provide limited safeguards from abuse and neglect. It is acknowledged that reform efforts have been underway in the aged care sector for some time. However, while these reforms may realise some benefits for older residents, they are yet to significantly improve the quality of life or care for younger people with disabilities in nursing homes.

3. It should also be recognised that life within the congregate living environment of a nursing home is institutionalising. In nursing homes, people lose their capacity for choice over the most basic life decisions, they are grouped together with others with whom they have not chosen to live, they are socially isolated from the wider community, and they have virtually every aspect of their lives controlled by others. The impact of this can be especially devastating for a younger person.

4. The ongoing presence of younger people in aged care facilities is indicative of the failure of Commonwealth and State Governments to collaborate with respect to the care of this group of vulnerable people. In many respects, younger people in nursing homes have fallen between the gaps in government. Aged care is a federal responsibility, funded by the Commonwealth. Accommodation for people with a disability is a state responsibility, funded by State Governments.

5. This problem is also symptomatic of a flawed human service response – a response based on the assumption that a person's only needs are for nursing care and for a roof over their head. It is also based on the assumption that nursing home care is better than the alternative – homelessness. This response ignores the complexity of a person's real needs: the need for a sense of home, for appropriate and holistic support, for real (non-paid) relationships with people of their own choosing, for protection against abuse and neglect, for opportunities to participate in the community and to achieve their life aspirations. Furthermore, the threat of homelessness is a poor benchmark against which to assess the success of any service response.

6. Once in a nursing home, it is unlikely that younger people will exit. There are significant barriers to the realisation of other alternatives for their housing and support. For example, they are typically ineligible for an individual disability support package or other disability service, given that they are already receive "care" and "housing".

7. The Office recognises that a diversity of opinions exist about the most appropriate alternatives to nursing home care for this cohort. There is some debate about whether other forms of congregate care should be used, such as special purpose nursing homes or cluster housing for younger people with a disability. The apparent cost-saving feature of congregate models of care may appeal to government, particularly if residents need intensive medical care. Congregate care models also represent a familiar and well-worn path in human services, particularly for people who challenge the capacity of the service system to respond to their unique needs in other ways.

   Despite this, serious questions should be asked before resorting to congregate models of care. Given the long history of institutional abuse and neglect, it needs to be recognised that these service types may not represent the free choices of the individuals (given that other alternatives often do not exist), may not provide for their development and autonomy, and may in fact expose them to a greater risk of abuse, neglect and exploitation.

Recommendations

In light of the above, This Office recommends the following actions.

1. As a first step, action should be taken to divert additional younger people with disabilities from entering aged care facilities. The Commonwealth, in partnership with the states, should also identify who are the 6073 permanent younger residents of nursing homes (1273 of whom are in Queensland), and where they currently live throughout the State?

2. The Bilateral Agreement of the Commonwealth State and Territory Disability Agreement (CSTDA) with Queensland has paved the way for a better approach, by highlighting the need to strengthen cross government linkages with respect to younger people (under 50 years) who have been inappropriately placed in aged care facilities. It is important that tangible outcomes be achieved through this Bilateral Agreement. Targets should be established – and met – for the relocation and diversion of young people from nursing homes where it is found that this is required. A variety of funding mechanisms could be agreed to by both levels of government to achieve this outcome.

3. The Bilateral Agreement targets only younger people under 50 years old. As indicated above, over 80% of younger people in Queensland aged care facilities are from 50-64 years. Thus any initiatives undertaken within the context of this Commonwealth-State agreement will fail to reach the majority of younger people in aged care. It is recommended that both the Commonwealth and the States expand the parameters of their work to encompass people over 50 years.

4. Another option worthy of serious consideration is the conditional transfer of funding (and hence, responsibility) for younger nursing home residents to the States. Such a transfer could be achieved under the auspice of the CSTDA, and would provide the incentive and imperative for the States to develop alternative models of care for younger people with disabilities. The transfer of this funding would be conditional on clearly articulated and agreed outcomes.

5. The resolution of the Commonwealth-State funding/responsibility issue would then pave the way for the states to develop and implement alternative and innovative models of care for this cohort of vulnerable people. Such an endeavour should be broad-based and consultative, should focus on innovative service responses, and should be informed by experience both in Australia and elsewhere. It should not be driven by the simple imperative to cut costs through creating alternative forms of congregate care.

6. It is known understood that significant outcomes were realised through a four-year Western Australian initiative, which saw almost 100 people with Multiple Sclerosis move from nursing homes to smaller community-based accommodation. This initiative and others like it may represent alternative models of care for younger people with disabilities who currently live in aged care facilities.

7. In considering alternatives to nursing home care, the Commonwealth and states should jointly develop a holistic assessment framework for understanding people's real needs, and for identifying genuine alternatives to life in an aged care facility. Such a framework would be guided by factors such as:

    - Who is the person? What aspirations do they have for their life?
    - What important relationships does this person have in their life?
    - What would a real "sense of home" look like for this person?
    - What are their unique needs for personal support and/or medical care?
    - What are their own choices for where, how, and with whom they live?
    - What would genuine personal development and community participation look like for this person?

Part 2: Community care programs for elderly citizens

The Public Advocate's interest in community care programs for elderly citizens

In speaking to this issue the Office is particularly concerned for the best interests of older adults who experience some form of dementia which impact on their decision-making capacity.

The Access Economics Report 'The Dementia Epidemic: Economic Impact and Positive Solutions for Australia' (2003) provides a rigorous analysis of the anticipated financial costs to the community through the rapid increase in dementia. It also provides a strong argument for more positive public awareness of dementia. The Report argues that the community should be encouraged to view this condition with more optimism and hope, and that the predicted increase can be seen as an opportunity for some innovative and progressive developments in the way Australia cares for its older citizens.

> *In Australia there were over 162,000 people with dementia in 2002 including 6,600 under 65 with 'younger onset' dementia…reaching the 500,000 mark around 2040…In Australia dementia already costs $6.6 billion…In 2002 over 5,000 Australians died from dementia while thousands of others experienced its disabling and distressing symptoms…*[4]

Historically dementia, and Alzheimer's disease in particular, has provoked fear in the minds of many people. This response may have as much to do with the community's negative perceptions of the aged care system as with the fear of losing cognitive functioning and autonomy. Nevertheless the anticipated loss of control over one's life is a source of deep angst.

Additional financial and human costs accompany the alienation associated with the loss of personal control, relationships, valued roles and lifestyle that typically occurs on entry into residential care.

It is recognised that older Australians want to continue living at home for as long as possible. This is particularly important for people with dementia where familiar environments and routines help to maintain competence in daily living.

Recent advances in the treatment of dementia offer hope that the productive and meaningful years of life can be extended. The location for the most effective delivery of these interventions is increasingly being recognised as the person's home, unless there is a clear indication of its unsuitability.

Older people report that staying in their own home helps to keep them more independent while most people living in residential care settings admit to not viewing their current living situation as 'home'.[5] It is recognised, that while there has been an attempt to provide a home-like setting, this has become a "genteel façade behind which institutional patterns, not domestic ones, persist".[6]

The Public Advocate's position on community care programs for elderly citizens

The Office supports the position that government has taken over two decades to encourage older people to live at home through the provision of formal community care programs to supplement the informal support provided by families.

The question is, however, is community care working?

While much has been done to enhance home and community services in recent years reports received by this Office indicate that a significant shortfall exists

Clearly for a number of people who can manage on just a few hours of support each week, current arrangements have meant that they have been able to remain at home. Some may say that older people are being helped to remain at home but are experiencing an impoverished lifestyle. There are concerns about excessive complexity, lack of flexibility and the threats to self-direction even within the person's own domain.

There are many others who would have preferred to remain at home, but they have not had that option. This is because a sufficient level of support could not be provided within the limits of a Community Aged Care Package, or through another Home and Community Care program.

Furthermore this Office accepts the views received from service providers and families across the State that the community care system is not meeting the needs of those who require it. There are reported deficiencies in regard to availability and flexibility resulting in services being less relevant to peoples' needs than they might otherwise be.

The Office accepts the evidence that there are inadequate levels of service provision; fragmentation, difficulties with access, an uneven distribution and an overly complex pattern of programs, regulations and administration.[7]

The Office reiterates the importance of early intervention strategies integrated with the provision of an expanded and better resourced comprehensive home and community support services as an indicator of areas for wise investment for the future

Recommendations:

The Office submits the following recommendations:

1. The Commonwealth should respond appropriately to the demonstrated need to significantly increase funding for community care for older Australians.

2. Increased funding should not only address the spread but the intensity of support so that individuals are receiving the level of support that they require.

3. Steps should be taken to simplify and enhance the effectiveness of the community care system in Australia over the next three years.

The Office suggests that, if we develop positive approaches now, Australia can demonstrate leadership in providing quality responses to its older citizens, with world-class models of care and prevention.

For further information

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Endnotes

[1] *Residential Aged Care in Australia* series, Australian Institute of Health and Welfare

[2] unpublished data, sourced from the Commonwealth Department of Health and Ageing, obtained by the *Young People in Nursing Homes National Project*, January 2004

[3] MS Society of Victoria, 2004.

[4] Access Economics 2003

[5] Hammer, R. (1999), the lived experience of being at home. Journal of Gerontological Nursing. November 25(11).

[6] Willcock D, Peace S, and Kellaher L, (1987) Private lives in public places: Tavistock publication

[7] Community Care Coalition April 2004