



OFFICE OF THE
PUBLIC ADVOCATE

Office of the Public Advocate submission to the Senate Inquiry into
Aged Care
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This submission is endorsed by the Acting Public Advocate, Dr David Sykes.

Executive Summary

The focus of this submission is in relation to three terms of reference of the inquiry: These are: the appropriateness of the placement of young people in aged residential services; the effectiveness of Home and Community Care (HACC) programs in meeting the current and future needs of older people and the effectiveness of transition arrangements between hospital acute care settings and aged residential facilities or the community.

This submission has highlighted the inappropriateness of placing young people in residential facilities designed to meet the needs of people over 65. Such facilities face significant difficulties in attempting to meet the psychological, social or rehabilitative needs of young people and it is an ineffective use of resources. More flexible approaches to meeting the needs of this group need to be developed. This submission also highlights the limited effectiveness of HACC programs because of chronic under funding and a fragmented service system. The consequence of this is that services often do not meet individual needs, thereby failing to prevent premature admission to an aged care residential facility. These services are also limited in their capacity to respond to the growing demand for community care. Finally, this submission highlights the growing pressures in the hospital system, which can sometimes lead to inappropriate or poorly planned discharge to the community or residential care facility in order to free up a hospital bed.

The case studies presented are drawn from the experience of this Office.

Introduction

This submission from the Public Advocate in Victoria to the Senate Inquiry into Aged Care will address the following Terms of Reference of the Inquiry:

- Term of reference (c). The appropriateness of young people with disabilities being accommodated in residential aged care facilities
- Term of Reference (d): The adequacy of Home and Community Care programs in meeting the current and projected needs of older people.
- Term of Reference (e): the effectiveness of current arrangements for the transition of older people from acute hospital settings to aged care settings or back to the community.

About the Public Advocate

The Public Advocate in Victoria is appointed by the Governor in Council pursuant to the *Guardianship and Administration Act 1986 (Vic)*. The Office of the Public Advocate (OPA) represents the interests of people with a disability, aiming to promote their rights and dignity and to strengthen their position in society. It is a statutory office, independent of government and government services, and can highlight situations in which people with disabilities are exploited, neglected or abused.

The Public Advocate delegates his authority to his staff, who may be advocates, investigators or guardians. The office also coordinates the Private Guardian Support Program, the Community Guardians Program, the Community Visitors Program and the Independent Third Person Program in Victoria. Further material on the role of the Office can be provided if required by consulting OPA's website: www.publicadvocate.vic.gov.au.

Term of reference (c): The appropriateness of young people with disabilities being accommodated in residential aged care facilities

The Public Advocate considers that accommodation and support services should be focused upon the needs, wishes, desires and aspirations of the individual with a disability. These services should be sufficiently flexible in the way they provide assistance to the person with the disability through the life span. Services should provide adequate training and support to their staff to ensure that the service is responding effectively to the needs of people with disabilities.

Whilst the main focus has been on young people in nursing homes, it is the experience of this Office that young people are placed in a variety of accommodation settings whose primary target group is older people. There is therefore a need to examine the whole issue of young people in aged care facilities rather than just nursing homes.

- According to the Young People in Nursing Homes National Project, there are more than 6000 young people living in aged care residential settings in Australia (Morkham 2004). The Public Advocate believes that young people with disabilities are inappropriately placed in nursing homes, reflecting the lack of choices for community accommodation for people with disabilities. This placement of young people (under 65) in residential aged care facilities is totally inappropriate for the following reasons:

- The dominance of a model of care in aged care residential facilities which is primarily focused upon the physical care needs of the residents can be at the cost of equally important social and personal needs. This can have a profound effect on the sense of self worth and identity of a young person. Where there is attention given to the social needs of residents in these facilities these are directed at the majority of residents aged over sixty five. The consequence of this can be significant isolation and alienation of the young person.
- It is recognized that the term ‘young people’ encompasses a broad age range below the age of sixty five. However, a common element is the fact that this group below the age of sixty five has a different range of social and emotional needs that can be difficult to address in aged care facilities for a number of reasons. The young person is often in the minority making it more difficult for the facility to respond to their needs. The facility may lack the expertise to respond adequately to the needs of younger residents. Indeed the primary reason for young people being in these facilities tends to have more to do with their physical care needs. The younger cohort is likely to have a significant representation of high level care needs. This group includes young people physically incapacitated through road and other trauma. There are a proportion of people with an Acquired Brain Injury (ABI) as a consequence of alcohol misuse and trauma. There are also people experiencing the degenerative effects of specific medical conditions such as Multiple Sclerosis (MS) and Huntington’s disease. The group is therefore likely to represent a broader and at times more complex range of care issues than older people who are more likely to have similar disabilities such as dementia and age related frailty. As a consequence this group of people represents particular challenges in devising accommodation options that can meet both their physical care and psycho-social needs. However, what is clear is that the placement of young people in aged care facilities can significantly limit their quality of life. Careful consideration needs to be given to developing appropriate alternatives based upon the needs of the individuals concerned.
- Social, and physical, environments are invariably set in accordance with the perceived needs of the main group of residents and often the staff is also trained to meet such interests. This can have the effect of disadvantaging the young person; disconnecting them from their former social and personal experience. This lack of relevant stimuli can have the effect of impeding a person’s recovery or assisting them come to terms with their new circumstances.

Ruth

Ruth is now 23 and a total quadriplegic as a consequence of road trauma. Despite her limited conversational capacity Ruth is able to indicate her awareness of her environment and those things that please/displease her. She shares a four bed ‘room’ with three ladies in their late 80s early 90s that have significant dementia and also require total personal care. Ruth has minimal privacy, has no space to put her posters of her favourite pop and sporting stars and has to accept the “majority” interests in watching a shared TV. Staff was unaware of her interest in music and thought it somewhat novel that she would want to listen to music via a personal CD player. Ruth now exhibits significant behavioural problems as a consequence of her frustration with her environment.

- Whilst the general standard of nursing homes is slowly increasing a significant proportion remain based on hospital ward models and afford little privacy to the residents. This issue can be significant for a young person who often moves into residential care aware of their surroundings and a memory of their former living circumstances. This lack of privacy also tends to exacerbate the social limitations placed on young people i.e. the playing of their own type of music, watching TV/Videos/DVDs etc.

Ray

Ray is now in his early 40's. He has an ABI as a consequence of alcohol misuse and road trauma. He is fully mobile and able to care for himself. He lacks insight into his moderate cognitive deficits and is susceptible to financial/emotional exploitation. He has no family. For the past six years he has lived in a non-pension SRS catering for frail aged and mildly demented older people. The facility has a good range of 'in house' programmes, which, essentially, are geared towards "sing a-longs" physiotherapy and history talks. Ray feels isolated by the majority age group who has no understanding of or connections to his more contemporary interests. He is often required to turn "his" music off. Ray has formed an attachment to a female resident of similar age, however, this is actively discouraged by both the facility management and the woman's parents on the basis that the couple are 'disabled'.

- Similarly, young people in aged related accommodation settings are often faced with the additional stress of their older counterparts dying. Not only can this have a significant depressive effect upon the young person, it also requires them to 'renegotiate' their relationships with new residents on an almost constant basis. This occurs in a context when the young person has often resolved to "survive", "beat the illness" and "make the best of what I have".

Chris

Chris is a 40 year old male with severe paraplegia requiring high-level physical care. He entered a large nursing home five years ago due to lack of alternative placement. The nursing home specializes in the frail aged in the last stages of their life. He has some understanding of his surroundings. Chris is the only resident who has been there for the full five years and carers estimate that the home's population has turned over three times during this period of time. Chris' mother is an active member of the 'residents' committee and has spent a considerable amount of time attempting to improve Chris' environment to reflect his age and cultural needs.

- The young person can also experience disadvantage if they reside in a Commonwealth funded facility, because it can adversely affect their capacity to access appropriate aids and equipment (such as a wheelchair) and necessary ongoing rehabilitation or attendant care services to enable them to access the community. As these are state-funded services, the residents of these facilities can be ineligible, having to pay for these services out of their own pocket.

Although there is no 'preferred' alternative model there is a clear need to consider more creative and flexible ways of responding to the needs of younger people with disabilities so that they are no longer inappropriately placed in residential aged care facilities.

Term of Reference (d): The adequacy of Home and Community Care programs in meeting the current and projected needs of older people.

- The Office of the Public Advocate recently produced a paper entitled: *Is community care a cost saving preventative measure or a genuine alternative to residential care?* (Kelsall 2004). In relation to Home and Community Care programs (HACC) the report noted that HACC is the main provider of community care services, and is chronically under funded, as are the other community care packages such as CACP, EACH or Linkages. Unmet need is high and the inflexibility of the service system means that individual needs are not met.
- The Public Advocate believes that community care needs to be funded in a more flexible way and provided in response to individual need on a case by case basis rather than as a package model that assumes that recipients can fit into pre-conceived and pre-determined packages.
- Despite stated Government policy which encourages the provision of community based care as a desired alternative to residential aged care, it was estimated by the Allen Consulting Group that residential aged care receives 1.01% of GDP compared to Community Care receiving only 0.18% (Allen Consulting Group (2002) cited in Kelsall 204:8). To meet the current and future needs of older people community care funding needs to be increased to meet the level of unmet need. More flexible approaches to community care are required, if we are to prevent the premature admission of people into aged care residential facilities.

David

David is a 68 year old man who has had a long term psychiatric disability associated with his experiences in Poland during WW2. He also has serious heart disease, is on the waiting list for surgery and requires medication twice each day. He has been in a psychiatric hospital but his psychiatric condition is now stable. David can become angry and aggressive and needs a CACP package to support him. Discharge planning indicates a need for an Aged Psychiatry case manager, RDNS (community nursing) to monitor his medication, meals on wheels, home help, assistance with shopping and some personal care. David is adamant that he is not going into residential care as "this is a free country". However RDNS and aged psychiatry refuse services as they regard him as an occupational health and safety risk to their workers. Other community services say that he is unreliable and erratic and is frequently not home when they attend and sometimes tells them to go away. Only the meals on wheels services, run by volunteers is successful. After an "unsuccessful" trial at home, David is considered to be too much at risk without sufficient community support and monitoring of medication and he is placed in low level residential care. David is deeply unhappy.

Term of Reference (e): the effectiveness of current arrangements for the transition of older people from acute hospital settings to aged care settings or back to the community.

The Public Advocate is concerned about a range of issues in this area:

- In rural and regional areas a number of interrelated problems mean that transition arrangements are largely ineffective:

- A lack of extended and interim care beds in nursing homes or hostels or funding for same to hospitals, unlike the availability of such transitional services in metropolitan regions.
 - Some regional areas have no nursing home or hostel or only one. This means that a choice of accommodation facilities is non-existent. In some areas people are sometimes placed two hours away by car from their relatives including sometimes being “geographically divorced” from their frail spouses.
 - Some large regional areas have NO specialist medical residential services such as psycho-geriatric or acute care units.
 - In rural and regional areas there is a shortage of specialist medical staff to treat older people, such as psycho-geriatricians, geriatricians and neuro-psychologists.
- Hospitals only allow the next of kin or guardians a very short time and a limited range of choices regarding listing and placement of people with ACAS assessment for residential aged care. These policies are punitive with the hospital giving little or no regard to such factors as: the ability of the next of kin or guardian to be able to visit appropriate facilities and nominate ones that provide appropriate levels of care, are conveniently located and meet the older person’s social and/or cultural needs. If suitable listings or placements are not found within the hospital’s nominated timeframe, the hospital can discharge the non-competent person against their wishes or that of their next of kin or guardian. It is questionable whether these policies are legal, but their legality has not been tested as far as the Public Advocate is aware.
 - The difficulty of finding appropriate placement post hospital for people with high and complex needs especially psychiatric problems as well as acquired brain injury.
 - A lack of adequate case management in the system to ensure that appropriate planning and provision of service occurs.

Hospitals repeatedly fail their duty of care to patients in the discharge process through inadequate planning.

- The limited number of community packages, long waiting lists, and the absence of packages which offer a greater level of support.

Helen

Helen is 82 years old and has been in an acute ward of a general hospital in country Victoria since having a hip operation three months ago. She has been assessed by ACAS as requiring low level residential care. Due to her mild/moderate dementia and lack of mobility it is unsafe for her to return home. Helen, however, is adamant that she will return home and so a guardian is appointed to make decisions about her accommodation.

The guardian determines that Helen should go into residential care and she is placed on waiting lists. Within two weeks of the appointment of the guardian, the hospital has discharged Helen to her home "to wait for residential placement", stating that she no longer requires acute care and is blocking a bed for someone who needs treatment. When the guardian rings the hospital, she is told that the only other acceptable alternative would be to place Helen 150kms from her home town and family contacts.

Conclusions

Term of reference (c): There is a need to resource and develop more flexible accommodation and support arrangements for young people with high physical care needs.

Term of Reference (d): The current range of community care packages needs to be extended to offer greater levels of care to a greater number of people in the community.

Term of reference (e): The acute hospital sector needs to take greater responsibility for ensuring that patients' health and welfare are maximised through effective discharge planning processes.

References

Kelsall, Cassia (2004). *Is community care a cost saving preventative measure or a genuine alternative to residential care?* Office of the Public Advocate, Melbourne.
www.publicadvocate.vic.gov.au/publications/systemicadvocacy/

Morkham, Bronwyn (2004). 'Young people in nursing homes', *Parity* v.17, no.4, Insert.