

Submission For Inquiry into Aged Care
Senate Community Affairs References Committee
Young People in Aged Care In Victoria Research

Summary

We are in the process of conducting some research which addresses part c) of the terms of reference. This study involves a survey of all nursing homes in Victoria to determine the number and the profile of residents under 65 years of age. At present, there is little current information about this population, which significantly inhibits service planning and development. This survey will collect non-identifying data about younger residents including demographic data, disability type and the level of care required. The survey also examines the social contact, community inclusion and the opportunities for occupation experienced by younger residents. This survey is the first in a series of studies, which will focus on young people with ABI residing in nursing homes. These studies will examine the impact of a residential environment on occupation, choice, control and community inclusion.

Researchers

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Background

With advances in medical technology over the past two decades more people survive extremely severe brain injuries which has resulted in a new group of young people with a complex array of physical and cognitive-behavioural disabilities (Papastrat, 1992). The fragmented ABI service system has failed to respond to the needs of this relatively new population of people with severe disabilities. There are approximately 107 people with ABI under 50 years of age living in aged care facilities (high care) in Victoria (Fyffe, McCubbery, & Honey, 2003). Young people are placed in nursing homes because alternatives do not exist that provide the physical care they require. In addition to young people who are currently living in nursing homes, there are many people with ABI who require nursing home level of care who are currently living with aging parents. This group of people are at risk of moving to aged care facilities when their parents are no longer able to care for them at home.

It has been recognised for many years that nursing homes are inappropriate, and the issue has gained media and community attention (Cameron, Pirozzo, & Tooth, 2001; Fyffe et al., 2003; Moylan, Dey, & McAlpine, 1995; O'Reilly & Pryor, 2002; Stringer, 1999). Young people in aged care facilities receive inadequate services because nursing homes are designed for people at the end stage of their lives and do not have the resources to assist young people to live full lives. Young people in nursing homes are amongst the most disadvantaged and vulnerable in our society with most of their disability pension taken on bed fees and their frequent exclusion from state funded services that provide adaptive equipment and facilitate community access (Fyffe et al., 2003; Stringer, 1999). The unattractiveness of nursing homes to younger visitors combined with limited support or funds to access the community further alienates this group from their peers. This often results in depression and exclusion from society. The combination of the physical environment, decreased personal finances and the limited staff resources in aged care facilities result in young people having very limited choice in both lifestyle decisions and everyday things such as what to eat, where to go and what to watch or listen to and who to spend time with (Attendant Care Coalition, 1999). This group of people are being denied their basic human rights, including the pursuit of meaningful activity, inclusion in the community and the opportunity to make a meaningful contribution to society. Many studies and reports have been completed by Government Departments and community organisations recommending the urgent development of alternative services, however progress has been slow (Attendant Care Coalition, 1999; Cameron et al., 2001; Fyffe et al., 2003; McNamara, 2001; Moylan et al., 1995; O'Reilly & Pryor, 2002; Pryor, Mott, & O'Reilly, 2002; Stringer, 1999). Young people continue to be admitted to nursing homes despite universal acknowledgment that it is inappropriate

Aims of the Study

- 1) To determine the exact number and the profile of people under 65 years living in aged care facilities (high care) in Victoria.
- 2) To measure the amount of social contact, level of community inclusion and frequency of

opportunities to engage in meaningful occupation (eg. leisure, self-care and productivity) experienced by people under 65 years residing in aged care facilities (high care).

Proposed Timeline

The survey will be sent in October 2004, preliminary data will be available by the end of 2004.

Data to be Collected

The survey will collect the following for each individual under 65 residing in an aged care facility in Victoria:

Demographic Data

- Sex
- First language
- Age
- Date of admission
- Residence prior to nursing home: own home, other nursing home, hospital, other
- Area of origin: town/suburb or post code
- Permanency of stay
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Care Needs

- Residential Classification Scale Level
- Complex care needs: ventilator dependent, pressure sores, challenging behaviour PEG tube fed, other
- Disability Type
- Additional services received

Participation

- Frequency of social contact with family
- Frequency of social contact with friends
- Frequency of going outside
- Frequency of community access
- Frequency of opportunities to engage in meaningful occupation

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