SUBMISSION TO SENATE INQUIRY INTO AGED CARE
July 2004

This submission is in response to the section of the above inquiry concerned with:

(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 and specific conditions are met under current funding arrangements;

1. Background information

HOPES is a small community based organisation committed to the establishment of appropriate supported accommodation and respite options for Tasmanians (under the age of 65) with acquired disabilities, and neurological conditions. For several years we have sought funds to develop a co-operative living model, as an alternative to aged care nursing home and other inappropriate accommodation options, for this group of people.

Currently 'younger people' in Tasmania, who need support for day-to-day living due to neurological disorders or acquired disabilities, have very few options (unless they fall under the Motor Accidents Insurance Board (MAIB) 'Future Care' legislation, or have adequate compensation).
Due to the inadequacy of current options, people with acquired disabilities are often kept in acute hospital beds for far longer than necessary, while a 'place' (generally inappropriate) is found for them. This not only restricts their rehabilitation, but also adds to the shortage of acute care hospital beds. Following assessment by the *Aged Care* Assessment Team, they are then placed in an aged care nursing home, if family members are unable to take on the responsibility of their care.

Tasmania has more than 150 people under the age of 65 in aged care nursing homes, some of whom have been there for many years, but some admitted recently (illustrating that the process is continuing). Over time these people become institutionalised and are accepting of their environment; family members feel the person is 'safe and cared for', and are loathe to complain about issues for fear of losing the little they have, and governments are prepared to turn a blind eye to the inappropriateness of this situation.

2. Appropriateness of young people with disabilities being accommodated in residential aged care facilities

Younger people placed in residential aged age facilities:

a) have little or no contact with their peer group, and can seldom access age appropriate social activities -
The younger resident may well be the only person under 70 or 75 years of age in the facility. Friends, and people in their age group, find it difficult and uncomfortable to visit such a place. Financially, the resident has little money left from their pension to visit others (requiring a taxi or maxi-taxi); and must fit outside visits around staffing requirements of the facility – meal times, showering, transfer to bed etc. Nursing home residents are reliant on the homes' transport, usually a mini bus, accompanying elderly residents on their outings. The alternative is to hire a maxi taxi (an expense, even with discount, which is often beyond the scope of the person on a disability pension – particularly at weekends or after 7.00 p.m., when double tariff is charged).

b) lose access to community rehabilitation, and funding for appropriate equipment (e.g. self-propelling or electric wheelchairs) -
The rehabilitation and equipment needs become the responsibility of the facility. However, funding is allocated on the basis of the needs of the frail aged. Physical therapy is minimal, and manual chairs supplied by the home are not custom built and often unsuitable for the younger resident. Electric and self-propelled chairs are not supplied by the home, and residents are often discouraged from purchasing their own (with costs ranging from $4000 to $15000) in case they run into elderly residents, or damage doorways etc. Should a younger resident choose to purchase a wheelchair and/or access community rehabilitation, they are responsible for all costs involved – including seating assessment, transport to and from the other facilities, and therapists fees where relevant. This situation leads to increased dependence and reduced physical ability for the younger resident.

c) are separated from partners and/or children, and social networks -
When a person is placed in an aged care facility, there is no place for a partner or children. Sometimes this means a partner with a milder disability is left to fend for him or herself in isolation in the community; sometimes it means young children are separated from a parent, only able to visit in hospice like surroundings, with a large number of very elderly, frail residents. For someone already trying to come to terms with vastly reduced abilities, such separation can be soul destroying for all parties.

d) lose, or are unable to build on or maintain their initial level of independence (because everything is 'done' for them – to speed up staff obligations) -

Staffing levels and resources in aged care facilities mean that tasks which residents may be able to carry out, with time and support, are performed by staff on a communal basis (e.g. preparing meals, simple household chores). In every aspect of life the resident becomes the receiver of care, never a productive member of the community.
The situation for this group of people is exacerbated by the continually rising age and frailty of fellow residents – due to programs designed to keep the elderly in the community for as long as possible. Many of these elderly residents also suffer from dementia, and the younger person may have no one but busy staff members who can communicate with them.

e) continually lose (and grieve for) elderly residents they have befriended -
Friendships do occur between younger and older residents, but (with an anticipated stay of 2-4 years before death) the younger resident is left to regularly grieve the loss of a friend.

f) often face this change alone, with no preparation -
The person with a disability may well be placed in an aged care facility due to the death of their primary carer. In this situation, they face two traumatic situations at once – the loss of a beloved parent, and the totally foreign surrounds of a staffed facility for elderly residents.

g) are taking up places designed for the frail aged, resulting in elderly people being kept in hospital beds -
This is a continuing problem Australia wide. One Tasmanian hospital this week reported having 47 elderly patients in acute hospital beds because nursing home placements were not available.

Respite Options.

Aged care facilities are often the only respite option available for families caring for a younger adult with disabilities. This situation is not only inappropriate for all the reasons given above, but the respite bed is often situated in a locked dementia section of the facility. This is because most homes only have one respite bed, and they must be prepared for wandering, demented 'guests'.
To be totally surrounded by people with varying stages of dementia, and to be physically unable to move out of the locked unit, is incredibly stressful for a younger person used to family support in their own home.
As a result many families opt to forego respite, adding to their overall stress and potentially leading to an earlier need for full-time care for their family member.

3. Appropriate Accommodation Options.

It should be the right of every person to have some choice in where they live, and with whom. Although support needs may limit choice for some people, governments and communities should be obliged to ensure suitable options are available.

It is essential that state and commonwealth governments work together (along with local government) to plan and fund suitable alternatives. Although both commonwealth and states have recognised the need to address the issues of an ageing population and disability, their 'partnership' arrangements so far have only amounted to meetings, research suggestions, and short term projects with strict guidelines. The underlying problems, current situation, and long-term forecasts are well documented.

We need:

- true partnership arrangements for planning and funding;
- flexible trial accommodation projects in each state, with long term support built in to those which are successful;
- genuine input from people with disabilities and their families;
- a process for individualised funding for respite.

Some alternatives already submitted include:

- A co-operative housing model, including transitional accommodation to enable people to increase their skills and prepare for community living, while family members are still available to assist (see attached HOPES project).
- A younger person specific unit utilising existing nursing home infrastructure.
- Small group home or cluster unit development with off site support.
- Individual funding packages to enable families to access flexible respite options.

We urge the Commonwealth Government to take a leadership role here, to ensure our younger people with disabilities have the best possible lifestyle, and to avoid a major crisis when the current 'ageing carers' can no longer assist.

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