

To: The Secretary community.affairs.sen@aph.gov.au
Senate Community Affairs References Committee

Senate Inquiry into Aged Care

Submission re: young people in nursing homes

In this submission I focus on the Term of Reference that relates directly to the young people in nursing homes:

“ (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 of specific conditions are met under current funding arrangements;”

The issue is important to me because I consider the current support and accommodation arrangements are unsatisfactory for young people.

Many young people with an Acquired Brain Injury (ABI) have no option but to live in nursing homes. These young people desperately need an appropriate environment and resources to achieve their potential and engage in life. Their needs are not met in an environment designed for the frail elderly. Often as a result of surrounds that are inappropriate to a young person, they suffer escalating social isolation.

The ones who suffer most are those with non-compensable injuries as they have inadequate funding support. Funding battles between the Federal and State governments in relation to people with disabilities and people in nursing homes remain unresolved and young people continue to suffer without adequate funding support to provide them with assistance and opportunities which could be considered basic human rights.

These young people do not suddenly give up on life because they become disabled. Inside they have the personality, hopes and desires they had pre-injury. Their life ambitions are still ahead of them. Can you imagine how frustrating it would be if you were trapped day after day in the company of people with dementia, when instead you could be interacting with people your own age and having opportunities to share recovery programs and engage in life?

Consider a young person in a nursing home's reality:

- An aged care facility is designed to accommodate the needs of the elderly for a few years prior to their death. Such facilities rarely consider the younger persons changing needs and different stages in their young lives. Many young people will ultimately endure **decades** in such accommodation.
- A young person may have to witness the deaths of hundreds of the co-sharers of their “home” in their lifetimes. This is not normal for a young person.
- Young visitors are discouraged by the sounds and smells of aged care facilities. As a result the young person needing nursing home levels of care receives fewer and fewer visitors as time passes and they lose the opportunity to grow socially with their peers. A nursing home has a very different feel and message to a home in the community.
- Young people require opportunities for choice and decision making that would not be of concern to elderly people with dementia. They want to choose their clothes their music, cool décor, do shopping etc and have interaction with people with a common interest, e.g. their own age group. Providing these opportunities takes time and special attention beyond what aged care facilities can economically cater to.

- These young people suffer sensory deprivation. Young people do not want to spend excessive time in bed, typical of the routine for elderly in nursing care. They are desperate to get out into the environment and experience the elements, plan ahead for new excursions etc. By contrast, many elderly at end of life are just happy to be kept warm and fed.
- The young people want opportunities to engage with life and people in the community as would be typical of young life. Instead it is day after day with just carers and the elderly.
- It is easy in such environments for young people to become depressed. This requires special attention. They should have the stimulus to give them plenty of laughs, as have their peers.

These young people should not be prisoners to the sights and sounds of old age. They need their own environment and their own special care; a place to live and call home.

I believe there should be funding for equipment and funding for community access to young people with ABI in nursing homes.

I believe there should be appropriate funds allocated to proactively consider models for supported care for young people with ABI so that they can live in an environment which will stimulate them and optimise their recovery and provide a place which they can reasonably call "home".

I believe that opportunities for programs, such as the Slow to Recover Program for young people with ABI, should be expanded for young people requiring nursing home levels of care to maximise their chances for improvement and recovery, particularly in restoring their facility to communicate. This should be continued for ten years or more as many recover late.

Thank-you for your time

Janine Hellard