Brain injury
ASSOCIATION of TASMANIA

Visit: Sport & Recreation House
Selfs Point Rd CORNELIAN BAY TAS 7008
Write: PO Box 702 MOONAH TAS 7009
Phone: (03) 6278 7299
Fax: (03) 6228 0855
Email: enquiries@biat.org.au
Website: **www.biat.org.au**

30July 2004

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Re: Senate Community Affairs References Committee Inquiry into Aged Care

Please find following a submission from the Brain Injury Association of Tasmania (BIAT) on (c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extend to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements – of the Terms of Reference to the above.

Background Information

The Brain Injury Association of Tasmania Inc (BIAT) works to promote issues related to Acquired Brain Injury (ABI), raise awareness of brain injury and reduce the incidence. Our aim is to improve the quality of life for people with ABI in Tasmania.

BIAT promotes community awareness and understanding of ABI, in terms of both prevention and the impact of acquired brain injury on the lives of individuals, families and the broader community, through training, resources and educational programs.

BIAT lobbies to address systemic issues that impact on people with ABI. BIAT can refer clients to a wide range of service providers and to other relevant groups. BIAT also provides an information services that is available to any member of the community.

The Brain Injury Association of Tasmania is a non-government, state-wide organisation that has a range of members. The Association receives funding from the Motor Accident Insurance Board Injury Prevention and Management Foundation Charities Committee and the Department of Health and Human Services.

BIAT is a member of the National body, Brain Injury Australia, which is a peak organisation addressing systemic issues for people with ABI at a State and Federal level.

Young People in Nursing Homes

In Tasmania, there are two groups of people with acquired brain injures, whose issues are either inadequately addressed or ignored:- those currently living in aged care facilities and those living inappropriately with family members (who are under considerable stress to keep them out of aged care facilities). Little has been done, apart from acknowledging there is a problem, to address the issues.

Tasmania currently has 155 people, under the age of 65, in aged care nursing homes. These people have lost access to community rehabilitation, appropriate equipment and age appropriate social networks. In addition to 'taking up' places designed for the frail aged (resulting in elderly people being kept in hospital beds) they often lose their initial level of independence, report to be lonely and isolated (the lack of age appropriate activities, food and diet, and the 'serene and quiet' atmospheres of the nursing home environment are cited as key characteristics contributing to one's sense of loneliness and isolation), have few opportunities to participate in community life, have limited choice with regard to daily living and have limited space and privacy.

There is an unknown number, in Tasmania, of people with acquired brain injury being cared for in the community by ageing parents. Living at home with the family creates tensions (often resulting in family breakdown), encourages dependence and can only last as long as the primary carer is able to maintain that role. Apart from the stress on family relationships, it is inappropriate for adults in their 30s and 40s to be living at home with parents.

The needs of these people are **not** met under current funding arrangements. For these people there are no future long-term accommodation options, there are no transitional options for people to prepare for life in the community and there is very little appropriate respite (often a bed in a locked dementia unit of an aged care nursing home). Funding for appropriate community based accommodation options, with transitional programs (while families are still able to assist) and flexible, appropriate respite is needed as a matter of urgency.

Currently there are only two options, in Tasmania, for non-compensable people with acquired brain injuries who are unable to live independently. If family members cannot support them, the "Aged Care" Assessment Team assesses their needs for placement in an aged care nursing home.

The lack of appropriate accommodation specifically designed to meet the social, emotional, physical, and recreational needs of people with acquired brain injury (ABI) has resulted in it being commonplace for this particular group of people to be placed in nursing homes regardless of age (CDHAC, 1997; Cameron, Pirozzo, & Tooth, 2001; Stringer, 1999).

From the perspective of 'service providers', Cameron et al. (2001) considered the appropriateness of nursing homes for people with moderate to severe ABI under the age of 65 years. Their findings highlight that the least favoured type of accommodation for people with ABI is aged care facilities. Cameron et al emphasized that the nursing home setting is not an appropriate placement option for people below the age of 65 with ABI. The Commonwealth Department of Health and Aged Care (CDHAC) acknowledges that the nursing home environment, rarely, if ever, enhances the quality of life of young residents and should only be considered as a last resort (CDHAC, 1997).

Most residents in nursing homes are elderly and have reached the final years of their lives whereas it is often the case that people with moderate to severe ABI have many years to live. A major

concern is the psychological and social implications of repetitive grief and loss where the death of a roommate often results in another elderly person in the final years of his/her life replacing the person who died. (Cameron, 2001; Nolan, 2000; Stringer, 1999; CDHAC, 1997).

The Brain Injury Association of Queensland Fact Sheet "Younger people with ABI in nursing homes" details the following reasons why aged care is not suitable for many younger people with an acquired brain injury:

"Social environment
There is a lack of peer interaction for younger residents who are in the minority and have nothing in common with other residents. Residents with ABI frequently seek staff contact in preference to other residents as they are closer in age, interests and can offer more meaningful interaction than some residents who are frail or have dementia. In general, aged care facilities primarily attempt to maintain a serene, quiet atmosphere for aged residents to live their remaining years. Social activities, entertainment, music, exercise and even diet understandable cater for the elderly.

Aged care building design for younger residents
In some facilities there is a lack of privacy and single rooms. Young residents with ABI may share rooms with people who are elderly and sometimes have dementia. Such living restrictions are likely to create feelings of depression, loneliness, frustration and boredom, thus compounding any existing problems of mood swings, behaviour and impulse control resulting from the brain injury.

As many people with ABI do not have a shortened life span their stay in supported care could be lengthy depending on the age of entry. Younger residents may experience significant loss, through death of many roommates when they reside in aged care facilities for a number of years.

Rehabilitation of younger residents in an aged care setting
Younger residents are usually more physically fit and stronger, requiring a very different level of stimulation and rehabilitation to frail aged residents. On average, younger residents with ABI require higher numbers of staff hours to meet their nursing and exercise needs than aged residents. Aged care staff are usually not trained in aspects of ABI. They frequently report problems in communication, managing challenging behaviours and managing the emotional needs or moods of younger people with ABI. Research has indicated that aged care staff believe that the social, cognitive and rehabilitation aspects of care were of greatest difficulty, and the areas in which the needs of this client group were being least catered for.

Meeting care needs
Aged care staff report the majority of needs as being met. However, there is a markedly different picture with regards to the rehabilitation, emotional, cognitive and social aspects of care. Staff often identify difficulties with providing supervision, communicating with, and managing the emotions and moods of residents with ABI, and dealing with their challenging behaviours such as disinhibition, verbal or physical aggression.

Adjustment issues for younger residents
For the resident, feelings of loss of independence and control, and post-placement depression are common in adjustment to the new environment and high levels of ongoing support and counselling are often needed. It is often the staff who work in aged care facilities who are faced with providing this complex and ongoing support, with a lack of resources, inadequate levels of training and skills in the area of ABI, and limited access to specialised rehabilitation and community services.

Family involvement
Often families wish to participate and be involved in all aspects of their relatives' care. Research has indicated limited family participation in the physical aspects of resident care, in contrast with more frequent leisure and social interaction. There are a number of possible reasons for this finding. Families may have chosen to hand the burden of care to professional staff but maintain social and leisure contact. Daily tasks of care are mostly completed in the morning and evening, at the times of day when visitors are either not available or not permitted to visit. Some families were

reported to have limited contact as a result of their own emotional distress. Sometimes young children and teenagers can be distressed by the aged care environment. It is also possible that aged care facilities do not encourage family participation in the physical aspects of client care, viewing this as predominantly the professional caregiver's role."

The Brain Injury Association of Tasmania is aware of a considerable amount of research conducted into the appropriateness of housing younger people with acquired brain injuries in aged care facilities; all have the same finding – Aged care facilities are inappropriate and inadequate for meeting the specific and complex needs of younger people with acquired brain injuries.

It is now time for both Commonwealth & State Governments to accept the responsibility and care of younger people with acquired brain injury and work co-operatively to address their needs. These people deserve to have access to appropriate accommodation and support when it is required.

The Brain Injury Association of Tasmania supports the National Young People in Nursing Homes Advocacy Alliance in its call for the following actions to be executed immediately:

1. The Commonwealth Government assume a leadership role in developing an administrative framework encompassing aged care, health, disability and housing, to resolve the issues of responsibility and the shortfall in resources at both Commonwealth and State/Territory levels.

2. The Commonwealth and the States/Territories agree to promote vastly improved coordination and cooperation across government sectors to ensure that young people accommodated in aged care settings have equity in access to disability services and supports and are provided with appropriate service pathways.

3. The Commonwealth and the States/Territories collaborate in the development of an agreed national policy framework that commits to systemic change to resolve this issue, incorporating targets for the relocation and diversion of young people from nursing home settings where required, and ensuring the avoidance of inappropriate placement in aged care facilities in the future.

4. All levels of government – Federal, State/Territory and Local – to work with the National Advocacy Alliance for Young People in Nursing Homes in the development of a sustainable service system that is responsive to the needs of young people with high and complex care needs and that allows individuals and their families to exercise their right to choice.