

Osborn Sloan & Associates Pty Ltd

Acquired Brain Injury Assessment & Community Rehabilitation

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

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SUBMISSION: SENATE INQUIRY INTO AGED CARE

This submission argues that residential aged care accommodation is an inappropriate setting for young people with acquired brain injury (ABI).

We outline five main reasons why young people cannot be adequately cared for in aged care settings and describe alternatives that are better for both the young people with ABI and the elderly residents. We illustrate the points made with a case study.

We write this submission from the perspective of a community-based service provider to people with severe acquired brain injury, many of whom have been initially assessed as requiring a nursing home level of care. Osborn Sloan and Associates personnel have specialist qualifications and extensive experience in neuropsychology and occupational therapy. We deliver a comprehensive range of diagnostic, rehabilitative and educational programs in the field of brain injury. Our goals are to assist people to achieve their optimal skills and encourage the social behaviours required to re-integrate, with support, into the life of their community. These goals necessarily include developing and sourcing appropriate accommodation for clients.

Our practice has been at the forefront of development of non-institutionalised rehabilitation for people with acquired brain injury and we were the recipient of the Australian Government Micro-Business Award in the 2004 Telstra Victorian Small Business Awards. As the attached case study illustrates, goals once considered unattainable can become a reality for people with even the most severe brain injuries. Individually-set and specifically-targetted interventions assist our clients to move from a restricted life, e.g. in a locked hospital ward or aged care facility, to an enriched life in a commonplace house in their local community.

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We list below some of the reasons why a young person with a brain injury should not be placed in an aged care residential facility for their rehabilitation.

Lack of access to appropriate rehabilitation

- Following a brain injury, people often experience a range of physical, cognitive, communication and behavioural impairments which occur in the context of many preserved skills and abilities.
- Those with the most severe injuries require slow stream rehabilitation, which emphasizes less intensive rehabilitation over a more extended time frame. Slow stream rehabilitation offers the best medium to long term outcomes for people with severe ABI, as their strengths are harnessed to allow them to achieve the highest levels of independence and self-control of behaviour. People have been shown to make improvements from brain injury for at least 5 and up to 10-20 years post injury.
- Slow stream rehabilitation cannot be offered in a hospital setting but can be successfully structured as an ongoing input integrated into the person's normal daily routine in a community environment. Unfortunately, for many severely brain injured clients a decision is made to transfer them to a nursing home setting before they have had the chance to demonstrate their potential for greater independence.
- Once in an aged care setting it is extremely difficult to work with people to promote skill development as the environment is geared towards providing care and staff are not trained to understand the particular issues and needs of the ABI client. Once placed in an aged care facility it is usually impossible to transfer them to less dependent settings and they may, unnecessarily, remain in nursing home care for the remainder to their lives.

Environment:

- Many people with a brain injury may have severe memory impairments where they become disorientated with their surroundings. As young people they may become confused by being surrounded with very frail, older people often in the end stages of their lives. Often many of our clients think they are 'sick' and in hospital and may be reluctant to leave their beds to participate in activities.
- The setting generally promotes dependence among this group and does not provide sufficient choice or a sense of control over their environment
- Routines are developed around the needs of elderly people and do not suit the young people of interest to this submission.

Friendships:

- Young people with a brain injury need a social support network around them. We encourage and support their young friends to be involved in their rehabilitation. Many friends of a young person with a brain injury report feeling fearful and uncomfortable and stop visiting their friends in an aged care settings.
- Establishing new, lasting friendships with other residents in nursing homes is not often feasible. Many residents at the nursing home are at the end stages of their lives and many are unable to communicate, and die after a short admission.

Challenging Behaviours:

- Many people who have experienced a brain injury have a reduced ability to self-monitor and control their behavioural responses. Challenging behaviours are common and are exacerbated by the confusion and disorientation they may experience in the unfamiliar and distressing surrounding of a nursing home.
- These people need specialist care from workers who are experienced in behaviour management techniques and have the time to address the various triggers to the behaviours (eg being rushed to complete a showering and dressing routine).
- Too often we see burn out for nursing staff as they are not trained in managing these particular behavioural problems.
- With inappropriate care, challenging behaviours typically escalate and often lead to the person with the brain injury being admitted to locked or psychiatric facilities.
- In contrast, we often see challenging behaviours diminish when the person is more individually managed in a more appropriate accommodation setting.
- Of particular concern is the issue of escalating challenging behaviour in young, physically-strong residents with ABI, and the risk that frail, elderly residents as well as staff are placed in.

Occupational deprivation:

- As humans, we need to be occupied with meaningful activities. Despite severe physical or cognitive disabilities, every person can have goals, dreams and aspirations. Without purposeful activities many of our clients experience extreme boredom in the nursing home setting and are essentially cut off from the energy and diversity of the community at large.
- The activity programs in residential care facilities do not cater for the interests of young people

In our experience, aged care facilities are often seen as the “dumping ground” for clients with severe ABI. This view arises from the sad fact that more appropriate alternatives for their accommodation simply do not exist in the communities in which their family and friends live. This is a situation that requires urgent rectification.

What accommodation services would be appropriate for young people with a brain injury?

- Transitional living centres aimed towards supporting the person to develop their independent living skills prior to making decisions regarding long-term placement.
- Smaller group accommodation settings where the accommodation is developed around similar interests and abilities of the residents.
- Accommodation options which cater for the varied needs and wishes of this population with respect to geographical location, level of care and size of household.

- The opportunity to return to their familiar/home community where they can re-establish social connections and meaningful life roles.
- Slow stream pathways that account for the fact that the person with ABI may take years to rehabilitate, and may not show significant signs of improvement using short term assessment criteria. Sometimes this apparent lack of progress is inaccurately interpreted as indicating they will never respond to rehabilitation programs and are therefore placed in a nursing home.
- Trained staff to deliver care that is structured to meet their individual needs and to support and encourage participation in activities of interest with people of their own age.
- Environments which offer opportunities to access activities and integrate into the life of their community

I would be pleased to expand on these points should the inquiry require further clarification.

Yours Sincerely,
Susan Sloan

B. App. Sci. (OT), M. Sc. (Neuropsych.), MAPS, CCN, AAOT

Please find enclosed:

A case study which demonstrates the beneficial outcomes for a particular young person with ABI following her moving to appropriate accommodation

CASE EXAMPLE

The following case example is provided to illustrate the nature of our work.

In 1998 Maria was a 40 year old Architect when she suffered a massive cardiac arrest. Her breathing stopped for 9 minutes which deprived her brain of oxygen and resulted in severe injury.

The brain injury caused multiple and profound problems, particularly affecting memory, such that all new information slipped from Maria's mind within seconds. She was completely disoriented as to her situation and her behaviour was severely disturbed. She required assistance 24 hours of the day for all basic activities including dressing and toileting. Initial placement in an aged care facility was unsuccessful due to her behaviours and high care needs.

In 2000 Maria was admitted as an inpatient into a locked, neuropsychiatry ward. Whilst the hospital provided nursing and medical care, Osborn Sloan & Associates were engaged by Maria's father to provide Occupational Therapy, Neuropsychology and Case Management services. Maria self-funds her rehabilitation services, which supplement those available through the public sector.

Our role over the past four years has been to provide coordination and leadership of a multidisciplinary, slow stream, rehabilitation program. The program involves identifying immediate, medium and long term goals, developing a strategic approach and implementing a program to deliver these outcomes. This type of approach works to achieve incremental gains over an extended time frame and involved regular contact with Maria, family members and her care team. Training carers, including family, to effectively and efficiently support goal attainment was vital. Therapy input to identify meaningful activities and to develop broader social opportunities was provided. Reassessments and progress reports enabled the clinical input to be constantly reevaluated and fine-tuned.

Despite persistent severe memory problems, over the past four years, Maria has been helped to develop her independence in basic activities of daily living, participate in recreational activities and to use trained strategies to remain oriented to her environment. These improvements led to her no longer needing to be confined in a locked environment and future, community living options were canvassed. Whilst still assessed as needing nursing home level care this option was rejected by her parents as from past experience they knew it to be an inappropriate environment.

Unfortunately, many young people in Maria's situation are destined for institutionalised accommodation in nursing homes for the aged, living lives characterised by distress, boredom and loneliness. Staff of Osborn Sloan & Associates have however worked with Maria's father and the Department of Human Services to develop a long-term accommodation solution to provide Maria with appropriate care in a community setting, with the overall goal of maximising her quality of life.

Earlier this year Maria was discharged from the hospital and moved to a house close to her family, which is shared with another middle-aged woman who has had a stroke. Maria has a structured program of daily activity whereby she showers and dresses independently; she helps staff with cooking and other household activities. She participates in a full range of recreational activities including gym, sailing, music and computer activities.

As a result of this goal-directed, team approach Maria's life is now substantially happier and enriched by participation in a range of meaningful life roles. Whilst the transition from the hospital to the community has been a major milestone for Maria and her family, it does not signal an end to our services. The family has engaged us to continue our work with Maria and we expect to do so for many years to come. However, for the time being, her family visit frequently and feel reassured regarding her overall well being and future prospects.