ABI Behaviour Consultancy

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Providing behaviour management support to people with acquired brain injury (ABI), their families, and people working with them.

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

Senate Inquiry into Aged Care

ABI Behaviour Consultancy Submission
28th July 2004

About the ABI Behaviour Consultancy
The ABI Behaviour Consultancy provides behaviour management support to people with acquired brain injury (ABI), their families and people working with them. Our staff are neuropsychologists and clinical psychologists with considerable experience in working with brain injury and behaviour.

The ABI Behaviour Consultancy is funded by the Victorian Department of Human Services DisAbility Services to provide statewide specialist *Behaviour Intervention Services* to adults with ABI.

Aged Care Issues for our service

There are many young people in aged care facilities

- A large proportion of clients seen by our service are inappropriately placed in aged care facilities. For example, 13% of client cases seen by the ABI Behaviour Consultancy are under 65 years of age and reside in nursing homes. Of concern, 69% of clients in nursing homes were judged as being "at risk" of losing their accommodation. In addition, 16% of clients aged below 65 years live in SRS or Hostel (low-level aged care) accommodation.
- We have had clients aged in their 20s, 30s, 40s and 50s living in nursing homes where the average age of other residents is approximately 70 years.
- There is little peer support for young people in these environments; individuals are isolated by age from the predominant resident group.
- In many regions of Victoria, aged care beds are the only option for people who have high-care needs. This is particularly the case if the person does not have access to compensation via TAC or WorkCover.

Inappropriate placements failing to address needs

- Care service revolves around personal care only.
- Many of our clients do not receive adequate physical care or rehabilitation therapy in aged care facilities, as these facilities are generally not set up to provide such services. Hostels and nursing homes are geared toward frail elderly persons and the emphasis is on increasing dependence, rather than promoting skill development or increasing independence.
- Because the environment is set up to manage the end of life, younger residents regularly see their co-residents die, and can find this highly distressing.
- There is often a marked lack of stimulation for younger individuals and they may lie alone in a room for hours unattended. We have seen clients deteriorate over time with loss of skill and function, development of severe contractures, social withdrawal, deterioration in mental state and emergence of behavioural problems.
- Social and recreational activities are typically not matched to their interests. For example, the situation often occurs where a young person's only social opportunities are to play bingo or sing "old time" songs with other residents old enough to be their grandparents. Not surprisingly, many younger residents reject these options, leading to increased withdrawal and isolation. There are few opportunities to participate in community life.
- Nursing home environments do not lend themselves to visits by the friends of younger people, increasing the effects of social isolation.
- The lack of appropriate supports in these environments can result in significant behavioural disturbance, including yelling and screaming, banging fists on the wall, biting, hitting and kicking staff, assaulting other residents. Behaviours can cause considerable disruption and distress to both staff, residents, and visitors to the facilities.

Education and training

- Nursing home staff not adequately trained to meet the needs of younger residents.
- Often aged care homes cannot afford the costs of comprehensive training for staff, which typically exceed $1000 per day for inservice workshops and backfill costs.
- These difficulties are compounded by high staff turnover rates, agency staff who are not familiar with routines or individual needs.
- It is not unusual for us to find cases where attending staff are not aware the person has a brain injury, the implications of this, and how to work positively with the resident.
- Our service is often called in when things hit crisis point. Ongoing education and training for staff could assist in assisting staff manage challenging situations more effectively, and respond proactively in early stages to avert crises.
- Staff may demonstrate negative attitudes to younger people with ABI, vocalising that "They do not belong here", "We are not equipped to deal with them", or "They are taking up an older person's bed".

Impact on families

- Family members often report high levels of frustration in tying to get their relative's care needs met. This can be the source of conflict between family members and facility staff.
- Family members may experience depression or anxiety associated with their relative's placement.
- If the family are not able to care for the individual at home, the decision to place the person can be devastating, marked by guilt and a sense of abandonment.

Recomendations

- ACCOMMODATION SUPPORT: **Development of more appropriate accommodation options.** A small number of ABI-specific small-scale group homes have opened in the Melbourne metropolitan regions in the past 2 years. Our service has been involved in the planning for these ABI Housing models. The establishment of these homes in the community has enabled people with both high-care and low care needs to move out of inappropriate placements including aged care facilities, supported residential services or hospitals into group homes supported by well-trained staff. We have seen successful transition of these individuals into the specific ABI houses. We recommend the development of additional housing options for younger people as alternatives to nursing home places. We recognise that this needs to occur under the auspice of the CSDA by the State Governments. We strongly recommend that the Federal & State Governments work cooperatively to develop a policy and funding strategy that can deliver realistic alternatives to aged care accommodation for younger people with high-care needs.

- ACCESS TO SERVICES: **Enable access to services based on need, rather than funding source.** Often there are restrictions to the services that can be accessed by those in aged care facilities. Community services such as case management, friendly visiting programs, and Home and Community Care often exclude persons who are in Commonwealth funded facilities (ie., funded by the Aged Care Branch of the Federal Department of Health and Aged Care). Having access to such services could make a real difference to individuals who are socially isolated, have limited access to money as the majority of their personal income is expended on accommodation and care.

- FLEXIBLE FUNDING: **Enable persons residing in aged care facilities to access flexible funding to better meet their needs**. We have seen cases where access to funding through such programs as Slow To Recover, Assisted Community Living Packages, and Statewide Flexible Funding has provided opportunities and significant gains for young people in aged care facilities.

- EDUCATION AND TRAINING PROGRAMS: **Ensure that aged care facilities and services have adequate funding resources for staff training and support**. Aged care facilities should have in place planned training and ongoing professional development programs that include fostering an awareness of the needs of young people with ABI and strengthening skills for working with this client group.

Please do not hesitate to contact the ABI Behaviour Consultancy if you have any questions.

Yours sincerely,

Suzanne Brown
Senior Clinician