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

23 July 2004

Dear Mr Humphery

Headway Victoria is statewide information and advocacy service for people with acquired brain injury and their families. Since the establishment of the organisation more than twenty years ago we have been campaigning for appropriate care and support for the group of young people with high and complex care needs, who are often currently accommodated in Aged Care settings.

The Senate Inquiry into Aged Care provides an opportunity to again highlight the needs of this group, which are often overlooked in the planning and development of aged care services.

Headway Victoria wishes to particularly address the third term of reference of the inquiry. Younger people are often placed in nursing homes because there are no other options available that would more adequately meet their needs.

The appropriateness of young people with disabilities being accommodated in residential aged care facilities

As a matter of principle Headway Victoria does not believe aged care settings are an appropriate option for younger people with disabilities, however they are often the only available option. This is not intended as criticism of aged care which is effectively the safety net of a disability service system that fails to meet the needs of those with the most severe disabilities.

There is a range of reasons why aged care settings are not appropriate

- Staff do not have the requisite skills and knowledge in acquired brain injury
- Lack of rehabilitation orientation
- Lack of resources to purchase appropriate equipment to support the care needs of the individual
- Lack of resources to ensure the therapeutic input to ensure the maintenance of function let alone the rehabilitative potential of the individual is fostered
- Staffing levels often insufficient to maintain and foster independence.

Whilst there are mechanisms in place for complaints, it has been our experience in the advocacy service that consumers are reluctant to use them for a number of reasons. Firstly people do not want to jeopardise their current accommodation, as there are so few choices available. We have had at least two cases Secondly they have found them to be largely 'toothless tigers' with no capacity to ensure that problems are addressed in either a timely or adequate fashion.

The following case studies highlight these issues and are drawn from recent cases in our advocacy service

Case Study 1
A young man, Neil, suffered a severe hypoxic brain injury at 19 years of age and was accommodated in a nursing home for a number of years where his care needs were well looked after. This particular nursing home was highly committed to providing a quality response to the needs of young people.

A new facility opened closer to the home of his parents and they arranged for Neil to be transferred there so that they would be able to visit more frequently, and to make it possible for him to have more social contact with his friends. This facility was not well organised and over a number of months his health deteriorated markedly – due in particular to failure to, position him correctly or to adhere to an appropriate skin care regime. The nursing home was reluctant to use sufficient quantities of continence aids and he was often left wet and soiled for extended periods of time. He lost weight and his exercise and stretching programs were not followed. Despite giving notice of plans, he was never ready to go out at the pre-arranged times and so the anticipated increase in social outings was unable to occur. The family used the methods available to them to progress complaints but found this to be a time consuming process that resulted in many promises but no discernable improvements in care. They became completely disenchanted with the lack of 'clout' afforded to both the regulatory and complaints bodies as they watched their son deteriorate further and further.

Finally his skin broke down to such a point that hospitalisation was required, and three years later had still not repaired. As his health had deteriorated so badly the family were unable to find another nursing home place for him and he spent the last three years of his life in a palliative care facility, prior to his death at 27 earlier this year.

Case Study 2
Following a heart attack a 50 year-old man was admitted to a nursing home with severe hypoxic brain injury. Despite his partner's belief that he is capable of communication there has been no attempt to provide any speech therapy input other than swallow reflex testing. It was also her belief that he was often in pain. Staff at the nursing home did not support this view and t he DON of the nursing home had advised her that a person with his cognitive deficits would not be feeling pain (she has confused his inability to move his lower limbs with paraplegia). Seven years down the track he has been linked to Disability Services through Headway Victoria. Through this he has been able to access brokerage funds to purchase speech therapy ands is showing immediate progress in communication. He has indicated that he is in constant pain and a neurologist specialising in communication is coming to do an in-service with staff to educate them in techniques for identifying responses in people with non-verbal communication. It has also allowed for the purchase of a suitable wheelchair.
He has shown immediate response to the speech therapy and has now established a communication method. Physiotherapy input has focused on encouraging staff to position him correctly so as to minimise pain and facilitate the optimal arrangement for him. However staff are reluctant to comply with the positioning arrangements.

Despite these interventions staff appear to be persisting in their own belief that he is incapable of communication and in the mistaken belief that because he has no movement, he experiences no pain. This case highlights some of the training issues for people working with people with acquired brain injury and in particular non-verbal patients. These are the most vulnerable of people and it is often only those who know them extremely well who are able to recognise the signs of cognitive awareness and rehabilitation potential.
In this setting staff have resented the involvement of the advocacy service and the additional services being provided to the client. There appears to be a reluctance to see this as an opportunity to foster the well being of the client and there is a passive resistance to following the recommendations of the therapists. Unfortunately it is the only facility in the country town in which his family lives.

Case Study 3
A young aboriginal man suffered a hypoxic injury due to attempted hanging whilst in police custody. His injuries have resulted in short term memory loss and significant disorientation. The only facility available within his rural setting that provides the level of supervision he requires is a locked dementia facility. He has been there for five years and has slipped back significantly since due to the lack of stimulation. He is increasingly reluctant to speak and care for himself.

For the last two years he was unable to access either case management or recreational supports as the regional DHS office policy specifically excluded people living in nursing homes from access to state funded disability programs. His parents, pensioners, are currently paying from their extremely limited funds to get a carer to take him swimming for half an hour per week. He also attends an indigenous activity program for two hours a week. Currently a small amount of brokerage funds has been made available to purchase some short-term case management to attempt to secure additional support dollars. This has not been successful.

DHS has no plans to assist him with more appropriate accommodation. With a normal life expectancy he probably has another thirty to forty years living in a locked facility with disoriented and demented older people.

If this is the only available place that can accommodate him then we as a community should surely be prepared to support his quality of life in a far more comprehensive way than is currently the case. Attached to this submission is a letter from his mother that outlines the difficulties in finding a suitable place for him

Case Study 4
A young man entered a nursing home following a traumatic brain injury. At the point of entering the facility he was able to manage his own transfers from bed to wheelchair and wheelchair to toilet with assistance. However staff found this to be too time intensive and were concerned about back injuries. They insisted on the use of a hoist even though the man was in an active rehabilitation mode and being able to do his own transfers was a requirement of him being able to move out of the facility. Over time, through lack of regular reinforcement his ability to manage his transfers declined.
The lack of priority given to the rehabilitation goals of the individual is the key issue here. Nursing staff can often consider therapeutic input as the role of therapists however the rehabilitation potential of the individual is best supported by a coordinated approach across the disciplines.

What we believe needs to happen

A recent study commissioned by the State Government in Victoria[1] identified three key reasons for younger people entering the nursing home system:

- Care needs require a level of nursing care not available in any other setting
- As a transition between acute/sub-acute care and the community where slow stream rehabilitation can occur
- There are no places available at a lower level of care

Recent data indicates that the numbers of younger people entering nursing homes continues to increase despite the development of new accommodation options. This is symptomatic of the crisis in disability services where there are almost 2000 people considered to be of urgent or high need for accommodation in Victoria alone[2].

Whilst Headway Victoria does not believe aged care settings are the appropriate place for younger people, we also recognise as said earlier, that in the absence of any appropriate options, and due to the failure of the Commonwealth and States to come to a solution in the CSTDA, they are often the only choice available. We therefore believe it is incumbent upon the aged care sector to ensure that younger people receive a quality of care that supports their potential for rehabilitation in a setting that is sensitive and responsive to their needs.

This will require attention to the funding models and a greater degree of liaison and cooperation across both Federal Departments and between the Commonwealth and States. We call on the Commonwealth Departments of Health & Ageing and Family & Community Services to take leadership in developing a resolution to this matter by bringing together the relevant parties (including families and younger people themselves) and working toward the development of a strategic response.

The specific remedies we believe are required are:

1. Development of a long-term strategy to prevent admission of younger people into nursing homes
2. Development of a long-term strategy to move the existing cohort into accommodation and support options that meet their needs and support their potential to be active members of their communities
3. Development of an assessment tool and funding model that is responsive in a holistic sense to the needs of younger people with high and complex care needs
4. Ensure that younger people in nursing homes have access to regular health assessments and rehabilitation oriented therapy services
5. Ensure that in accordance with the Aged Carte Standards, there is sufficient resources to access equipment and aids that support an optimal level of functioning for younger people
6. Ensure that the rights of younger people in nursing homes are vigorously pursued, as the numerous systemic barriers to appropriate support and care for this group leave them extremely vulnerable.

Conclusion

As a member of the Young People in Nursing Homes Consortium, Headway Victoria has welcomed recent initiatives by the Department of Health and Ageing through its Innovative Pool, and a range of other developments that have taken place at a state level to create options for young people with high and complex care needs. We encourage the formation of a Taskforce involving both Commonwealth

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[1] Fyffe, McCubbery & Honey (2003) *Young People With ABI Less Than 65 Years Requiring Nursing Home Level Of Care*, Disability Services Division, Department of Human Services

[2] 3000 Families waiting for Disability places, The Age 27/4/04

Departments and relevant state counterparts to work in collaboration in the development and implementation of a ten year plan to ensure that younger people with high and complex care needs are offered opportunities to maximise their health and well-being in settings that are responsive to their expressed needs and wishes.

Yours sincerely

Merrilee Cox
Executive Officer