SUBMISSION

TO: SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

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Introduction

The Hunter Brain Injury Service would like to make a submission to the Senate Community Affairs References Committee Inquiry Into Aged Care in relation to the following terms of reference:

> *(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 or specific conditions are met under current funding arrangements*
>
> *(d) the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly*

Background Information

The NSW Brain Injury Rehabilitation Program's (BIRP) target group is people of working age that have sustained a Traumatic Brain Injury, with the primary focus being those people who have sustained an injury as a result of a Motor Vehicle Accident. Each BIRP unit is able to extend its services to Non-traumatic Brain Injury cases where resources are available. The BIRP should be viewed as a specialist extension of general neuro-rehabilitation services. The establishment of the BIRP was based on the premise that people who have sustained a moderate to severe Traumatic Brain Injury require specialist rehabilitation care in dedicated units, whilst rehabilitation of less severe Traumatic Brain Injury could be provided through general neuro-rehabilitation services.

The BIRP was established to:

- Develop and maintain a network of services based on a supra area/regional model
- Research and evaluate services and outcomes for people with TBI
- Establish a clinical services network promoting seamless care and improving access to services for people with TBI
- Develop improved treatment coordination resulting in best practice care for patients receiving brain injury rehabilitation

Role of Hunter BIS

The Hunter Brain Injury Service (BIS) forms part of the network of units that constitute the NSW BIRP. It covers the geographical areas of the Hunter Valley and Central Coast. The BIS includes a Transitional Living Program, Outpatient service and Community Outreach team. The Transitional Living Unit is a residential therapy program that has accommodation for up to five people and operates weekdays with clients spending weekends at home. The Outpatient

Service allows clients living at home to attend for therapy appointments during the week. The Outreach Service works with people who are more geographically distant and still need help with issues related to their brain injury, or who are living in the community and have rehabilitation goals that do not require regular attendance at the unit. All streams of the service provide assessment, therapy intervention and case management to clients working on rehabilitation goals as well as consultation, education and support to local health and community services. The Brain Injury Service does not offer long term support to clients with brain injury with service continuation contingent upon the client having rehabilitation goals.

For the financial year 2003-2004 93 new referrals were accepted across the 3 streams, with a further 38 one-off consultations. Clients ranged from people coming straight from acute hospital following a traumatic or acquired brain injury to others for whom it had been some years since they sustained their injury. Of these referrals 15 young people have been identified as requiring age-appropriate supported accommodation in the immediate or short-term future.

The nature of moderate to severe brain injury in the younger age group means that this population will require ongoing supports to varying degrees until they meet the criteria for aged care services. These clients often have cognitive and behavioural sequelae that can best be managed in a supported & structured environment. Common difficulties include poor initiation, inability to mange finances, inability to undertake household tasks, visual deficits, impulsivity, poor insight, poor planning, memory deficits, non-compliance with medication, sexual disinhibition, depression, anxiety, aggression, physical limitations and alcohol and other drug problems. Some of the 15 young people identified above have a "hidden" disability that may not be immediately obvious. There appears to be poor planning in terms of the long term community care requirements of this client group, and little understanding of the nature of brain injury.

Trends Relating to Young People with Traumatic or Acquired Brain Injury and Nursing Home Facilities

1. <u>Increasing trend for young people with brain injuries who require nursing home or hostel level care to be referred for assessment of their ability to live independently in the community.</u>

During the period June 2003-2004 four (4) high needs people have been assessed. Of these two were in residential aged care facilities (hostel level), one was living in the home of his parents and the other came from acute hospital. The issues that have become obvious are:

i. There is reluctance by ACAT to assess these people for nursing home or hostel facilities. **The Brain Injury Service would support this due to the inappropriateness of**

accommodating younger people with brain injury with the aged.

ii. There has been reluctance on the part of the Department of Department of Aging Disability and Home Care to accept people with brain injuries for community group homes.

iii. There is an absence in the Hunter and Central Coast regions of any brain injury specific supported accommodation for younger people with brain injury. **It is the view of this service that such facilities are necessary in order to accommodate the specific cognitive, physical and psychosocial issues which present in the younger age group and to provide specific structural and behavioural programs in a consistent and cohesive manner.**

In the twelve months period cited above the remaining eleven (11) people were identified who are living independently in the community, either alone with services, or at home with a carer, but who are at risk of this arrangement breaking down. This is specifically within the group of people who are still receiving rehabilitation.

2. <u>People living in the community</u>

Due to the lack of suitable supported accommodation for people with brain injury, younger people are being accommodated inappropriately in Department of Housing accommodation, private rental, caravan parks or at home with a carer.

i. **It is difficult to obtain adequate services for high needs clients and to ensure that these are maintained at an adequate level.**

ii. **Consumers often find the cost of community services unsustainable.**

iii. **In addition, it has been our experience that services are often withdrawn due to the cognitive and behavioural issues associated with some of these clients because of OH&S risks to workers.**

3. Ageing Carers

The Brain injury Service is also aware of a number of clients where their primary carer/s are ageing and are no longer able to meet the care needs of their loved ones. Carers and consumers are aware that secure long term accommodation options are unavailable or unattractive.

This has resulted in mental health issues for both the carer and the client.

A consequence of this has been that some of this group have been receiving much needed additional respite to enable the parent/s to continue in the caring role.

However this additional respite has meant that local brain injury respite options have had to close their books and establish a waiting list, thus increasing the burden of care for those with more recent injuries.

4. Lack of Long-Term Case Management

The lack of long-term case management for young people with traumatic and acquired brain injury is a significant issue. There is a lack of ongoing oversight of the changing needs of clients, particularly in relation to re-assessment and/or co-ordination of services, and crisis intervention that can occur in a timely manner**.**

Our experience indicates that this contributes significantly to the breakdown of support services at a community and family level, as well as increasing the burden of care for (primarily) family.

SUMMARY

In summary, the experience of the Hunter Brain Injury Service is that residential aged care facilities are not the most appropriate form of supported accommodation for younger people with brain injury.

However, the current alternatives for younger people requiring this level of support are in many cases also unsuitable or inadequate. There are no brain injury-specific supported accommodation facilities in the Hunter or Central Coast regions. Where accommodation in the community is facilitated, it is often unsuitable in terms of the amount of community supports available and the cost of these services to consumers, as well as the ability of the support services to manage people with brain injury sequelae. This service is also aware of a

number of ageing parents for whom the burden of care is substantial and is affecting both the mental health of the carer and the person with the disability. Brain injury respite services are being increasingly called on to provide respite for this latter group, resulting in longer waiting times for more recent injuries. Long term case management, which may assist both carers and consumers to cope better, has not been readily available through the HACC services.

The younger brain injury population's projected needs extend in the vast majority of cases until they reach the age of 65 years. There appears to be poor planning in terms of the community care requirements of this client group, or recognition of the issues which are peculiar to people with a traumatic or acquired brain injury.

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Attached: Case Histories.

CLIENT	AGE	CURRENT STATUS
S Female	33	Moved from residential aged care facility to Dept of Housing. Complete breakdown of community support services. No family support available. Cognitive, physical, behavioural, psychosocial and AOD issues. Legal issues. Mental health issues. Requires significant structure to live safely in the community, currently inadequate. Extremely vulnerable.
G Female	43	Currently in residential aged care facility with potential to live independently **providing she has maximum supports**. No family support available. Cognitive, physical and psychological issues. Will require ongoing significant structure and community support for community re-entry to be successful.
M Female	43	Cognitive deficits requiring 24 hour support. Elderly and unwell parents > 70 years. Recently accommodated in group home for people with intellectual disabilities after lengthy wait in hospital rehabilitation facility. Trial at the Transitional Living Unit was unsuccessful.
R Male	33	Cognitive, physical, behavioural and psychological issues. Suicidal. Physical assaults of carer with AVO instituted by Police. Recently moved in Dept of Housing unit with community support. Still requires extensive ongoing involvement of carer. Unable to secure supported accommodation in group setting. At risk of supports breaking down. At risk of further criminal justice involvement. Mental health risks for both carer and consumer.
B Male	41	Cognitive, physical, behavioural and psychological issues. Aged carer (mother) > 70 years, father recently deceased. Living with carer, at risk of breaking down.
A Male	24	Physical, cognitive, behavioural issues. Psychological status unknown at this stage. Carer left after two weeks due to child protection and domestic violence issues related to aggression. Maximum attendant care support in place but also requires assistance of family and friends daily. At risk of breaking down. **Able to be maintained at present only because he has compensable status.**
A Female	41	Cognitive deficits requiring constant supervision, hypersexual, disinhibited and impulsive behaviour. Concerns about AOD use. Financial difficulties. Evicted from mobile home village due to behavioural issues. At time of writing no funding approved for supported accommodation. Child protection issues. Legal issues. Elderly parents unable to provide continuous support required.
L Female	37	Physical, psychological, cognitive, behavioural and AOD issues. Living independently in her own home. Behavioural issues have resulted in services being withdrawn, or client has “sacked” services. Legal/ criminal justice issues.
D	30	Paraplegia + brain injury. Cognitive deficits barrier to living

Male		independently. Behavioural issues. Application to Dept of Housing, will require significant community support. Cognitive deficits limit his ability to safely mange his paraplegia e.g. unable to catheterise, unable to transfer, self care is poor.
T Male	49	Cognitive, behavioural and psychological issues. Living in Dept of Housing with supports but same inadequate or hampered by consumer's cognitive deficits. Elderly parents > 80 and family members living nearby providing additional supports but at risk of breaking down due to carer burden.
A Male	57	Living independently. Cognitive deficits plus AOD issues. No community supports (refuses to pay), significant amounts of support required from relatives, at risk of breaking down. Gambling and financial issues.
C Male	18	Cognitive, physical, behavioural, psychological and AOD issues. Currently living between various family members with a view to obtaining Dept of Housing. Independent living not a viable safe option currently, at risk of homelessness.
B Male	34	Cognitive, behavioural and AOD issues. Currently living with parents, at risk of breaking down. Requires significant structure and supervision.
K	26	High needs living at home in rural area with parents. Access to repsite for parents limited. At risk of breaking down. Will not be able to live independently.
K	30	High needs (24 hour care) living at home with partner in a rural area. Would not be able to live independently.