BRAIN INJURY REHABILITATION UNIT

(Australian Council of Healthcare Standards Accredited)

LIVERPOOL HEALTH SERVICE

A Teaching Health Service of The University of NSW
Elizabeth Drive, Liverpool NSW 2170 AUSTRALIA

Enquiries 9828 5495
Facsimile 9828 5497 *Postal Address: Locked Bag 7103 LIVERPOOL BC NSW 1871*

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

30.7.04

Dear Sir/Madam

Re: INQUIRY INTO AGED CARE

The Brain Injury Rehabilitation Unit, Liverpool Health Service is pleased to have the opportunity to contribute the attached submission to the Inquiry into Aged Care. The submission responds to the third term of reference.

The submission has been prepared by staff from the Unit who have a wealth of experience working directly with people with high care needs after a brain injury and their families. It also draws on a relevant research project currently being undertaken by the Unit.

Residential aged care facilities are not an appropriate accommodation option for young people with brain injuries. When admissions occur it is because there is no other alternative. The number of young people living with a high level of disability after a brain injury is increasing yet we have not seen evidence of progress on the development of more appropriate supported accommodation options for this population.

We welcome the Senate's focus on this issue and hope that it will provide the impetus for creating a better future for young people with brain injuries in need for supported accommodation.

Yours faithfully

Dr Adeline Hodgkinson MBBS FAFRM
Director

On behalf of:
Marianne Bush, Barbara Strettles, Maggie McFadyen, Katherine Hopman,
Dr Grahame Simpson and Gaurav Tandon

SUBMISSION OF:

**BRAIN INJURY REHABILITATION UNIT (BIRU),
LIVERPOOL HOSPITAL, SYDNEY**

TO

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

"This is a place for dying, not a place for living" - The plight of young people with acquired brain injury in nursing homes

Prepared by:

Dr Adeline Hodgkinson	Director	
Marianne Bush	Senior Community Social Worker	
Barbara Strettles	Residential Services Manager	
Maggie McFadyen	Social Work Team Leader	
Katherine Hopman	Senior Community Occupational Therapist	
Dr Grahame Simpson	Research Officer	
Gaurav Tandon	Executive Officer	NSW Brain Injury Rehabilitation Program Directorate

Correspondance to:
Marianne Bush
Brain Injury Rehabilitation Unit
Liverpool Health Service
Locked Bag 7103
Liverpool BC 1871 NSW

Ph: 02 9828 5495
Fax: 02 9828 5497
E-mail: marianne.bush@swsahs.nsw.gov.au

1. AIM OF SUBMISSION

This submission responds to the third term of reference.

The submission addresses the failings of existing service support systems that have resulted in young people who have complex support needs as a result an acquired brain injury (ABI) being accommodated in high level residential aged care facilities.

These failings are summed up by the title of this submission, which is a direct quote from the wife of 32-year old man resident in a nursing home, who stated that "this is a place for dying, not a place for living".

2. KEY TERMS

Acquired brain injury can occur as the result of trauma (e.g. motor vehicle accidents), stroke, anoxia/hypoxia, infections, tumours and toxins.

The primary focus of the submission is on young people with ABI sustained as a result of trauma, typically motor vehicle accidents, that result in catastrophic injuries.

Young people are defined as people between the ages of 16-65 years. The majority of people with ABI that are the subject of this submission are aged between 18 and 50 years of age.

The Brain Injury Rehabilitation Unit (BIRU) at Liverpool Health Service has provided a continuum of care for the past 28 years. Services include acute inpatient rehabilitation; community outreach including medical review, case management, therapy and vocational re-entry; residential transitional living rehabilitation and residential respite.

3. INTRODUCTION

25 people with ABI have been discharged from the Liverpool BIRU to high-level residential aged care facilities in the period 1999-2003. This group included 15 males and 10 females. The average age of the group was 39.5 years with 5 members of the group under 30 years of age. The youngest person discharged to a high level residential care facility was 19 years.

The BIRU did not consider that high level residential aged care facilities were an appropriate accommodation option for any of these clients. In every case it has occurred because there was no other option.

The appropriateness of younger people with ABI residing in residential aged care facilities is a major and deepening concern for the Liverpool BIRU. The number of people living with a high level of disability after a brain injury is increasing and there is little evidence of progress on the development of age and disability appropriate supported accommodation options for this group other than current use of residential aged care services.

We are, therefore, pleased that the Senate Inquiry into Aged Care has included this issue as a specific term of reference and that we have an opportunity to respond.

In particular, the content of this submission will draw upon a recent major initiative undertaken by the Liverpool BIRU in partnership with the NSW Motor Accidents Authority,

the Rehabilitation Studies Unit at University of Sydney and Price, Coopers and Lybrand researching the issue of young people with ABI in nursing homes within NSW.

4. SOURCES OF DATA FOR THE CURRENT SUBMISSION

The current submission draws on a broad range of data derived from two principal sources:

Extensive clinical experience of staff at the Liverpool BIRU
The BIRU has been in operation for 28 years. It services more than 100 patients with ABI through the inpatient rehabilitation component of the service each year. The BIRU Community Team staff currently provide services to 690 people with ABI resident in the community. This includes a small number resident in high-level residential aged care facility. The BIRU inpatient and community team, staff have had extensive experience in addressing the issues of complex high support needs among people with ABI.

Current Nursing Home Research Project
In 2004 the Liverpool BIRU obtained funding from the NSW Motor Accidents Authority to research the problem of the current lack of accommodation options for people with ABI who had high support needs.

The aims of the project were to:
- Document the existing care arrangements of people with high support needs after an ABI
- Identify the risk factors that increase the likelihood of a person with high support needs being admitted to a high level residential aged care facility
- Develop alternate service models that could meet the accommodation needs of young people requiring high levels of support after an ABI

Surveys were completed with people with high support needs discharged from the Liverpool BIRU inpatient unit to residential aged care facilities as well as other accommodation alternatives during the period 01/10/1999 - 30/09/2002.

54 people were identified as meeting the project criteria and 40 participated in the project. These included:
- 9 people with ABI who were initially discharged from the Liverpool BIRU to a high level residential aged care facility
- 31 people with ABI who were discharged to other options, typically the family home
- relatives of the person with ABI
- staff members involved in the discharge process or addressing the client's current accommodation needs

The full report is scheduled to be available by September 2004. The report will be of value to the Senate's Inquiry in the wealth of information it will provide about the appropriateness of residential aged care facilities from the point of view of the person with an ABI, their family and staff. In addition, the report will identify more appropriate approaches to meeting the accommodation needs of people with complex high support needs.

5. WHY YOUNG PEOPLE WITH BRAIN INJURIES ARE ADMITTED TO HIGH LEVEL RESIDENTIAL AGED CARE FACILITIES

Requesting admission for a young person with a brain injury to a high-level residential aged care facility is only taken as a last resort. The first choice would always be to return the person to their home and family, this invariably being the first choice of the person (when they can give their views) and their family.

When the person's discharge from inpatient rehabilitation is discussed with families, they are stunned and horrified to find that:

- there are no long term facilities that specifically cater for the needs of younger people with ABI
- the only long term residential option open to them is a high level residential aged care facility

The reason for this reaction is that most families still call these facilities "nursing homes" and many have memories of them as the place where an aged relative went to die, not where a young son or daughter goes to live.

In the face of this we see families muster their strengths; reorient their lives and attempt to take their relative home. An abhorrence of the alternative fuelled by their love for the person, the naturalness of a return home and hope for the person's improvement motivates them. The demands and complexity of undertaking such care at home is enormous. Frequently the person is ready to be discharged from inpatient rehabilitation well before the family is emotionally and practically ready to undertake the care. It takes time for families to adjust to the future, for home modifications to occur and for support services to be set up at home. This assistance is essential for families if caring for the person at home is to be a viable.

Returning home for the person with a high level of disability after an ABI is only possible to achieve when:

- **The person is able to fund their own care and accommodation requirements**

The only two sources for funding high support needs are through a compensation settlement or a large private income.

- Compensation schemes for injury including ABI across Australian states and territories vary widely in their target groups, eligibility criteria, and the level of support that will be provided.
- NSW has a fault-based scheme for road accidents, the primary cause of catastrophic injuries resulting in ABI with high support needs.
- In the current caseload, 66% of the Liverpool BIRU caseload are not eligible for compensation.
- There have been no instances in the BIRU's history where individuals with ABI or their families have had sufficient wealth to privately fund their own high-level support services.

5. WHY YOUNG PEOPLE WITH BRAIN INJURIES ARE ADMITTED TO HIGH LEVEL RESIDENTIAL AGED CARE FACILITIES (continued)

- **The family is able to provide the bulk of their relative's care and support needs**

Community support services do exist, however they are very limited when it is taken into account that the person requires care and/or supervision to be provided over the full 24-hour period.

To illustrate this, when a person with ABI who has complex high-care needs is discharged from the BIRU, clinical experience of the unit staff has found that, with much negotiation, the following support services may be obtained for the family:

- a maximum of 14 hours of Home Care per week to assist with personal care
- access to a day programme once a week that provides transport to and from the programme (8 hours per week)
- flexible respite care (6 hours per week)

This means that, if they are fortunate, families may be able to obtain 28 hours a week of support. There are 168 hours in a week and the other 140 hours need to be filled by families.

Services that do offer higher level of support are largely inaccessible. For example:

- People with ABI needing in excess of 14 hours of service from Home Care each week are placed on the waiting list for the High Care Needs Pool. Some clients have been on this waiting list for years. The BIRU has never succeeded in a client being offered a service from this scheme.
- The Attendant Care Scheme does target people with very high physical care needs but is rarely accessible by people with an ABI due to their level of cognitive disability and inability to direct their care.

- **When family support is not available**

When families are not in a position to provide the 140 hours of care and supervision per week and the person is non-compensable, the only alternative is to look for a supported accommodation option offering a high level of care.

The only option is admission to a high-level residential aged care facility because of the:

- Poverty of services in NSW that specifically target the long-term supported accommodation needs of young people with an ABI who have high care needs
- Dearth of supported accommodation services for people with other disabilities for which people with an ABI would potentially meet admission criteria; or be prioritised for admission, in the rare event that a vacancy arises.
- Accommodation support services that are willing to accept young people with an ABI who has high support needs are unable to access recurrent funding at the level required to meet their needs.

Aged Care Assessment Teams (ACATs) are reluctant to extend approval for young people with a brain injury to enter residential aged care facilities. They are however aware of the lack of alternatives and will, as a last resort, give approval when a person's high care needs cannot be met by any other means.

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE

- **A misfit amongst the aged**

Elderly people and young people with an ABI can both find themselves in need of high levels of support. This does not mean that the needs of both groups can be appropriately met in the same facility. There are inherent tensions in any congregate living situation where the needs of the group compete with the needs of the individual.

Residential aged care facilities target the health and care needs of the aged. While they may well, within the limits of the service, try to offer an age and disability appropriate service to the young person, even with best efforts the person's presence remains a misfit. At worst the person's presence can give rise to serious issues around duty of care.

By the time an elderly person moves into a high level facility they are reaching the end of their lives. Stays are commonly weeks or months in length. The whole orientation of the facility is geared towards meeting the needs of the aged residents by providing increasing levels of care as their health deteriorates and abilities are lost. The focus of providing care appropriate to the aged is integral to the training of staff, the programme of activities and even the décor.

When young people with an ABI are admitted to high level residential aged care facilities, it is because they need care and supervision provided over a 24-hour period. This can be due to their high physical care needs alone. It can also occur due to the severity of cognitive difficulty alone or, more commonly, a combination of physical and cognitive factors.

In contrast to the aged, many young people with an ABI continue to improve slowly over time with spontaneous improvements as well as in response to appropriate therapy and stimulation. Others may make few gains but have the potential to maintain their abilities. Stays can be measured in decades. This means that we have young people attempting to continue their rehabilitation and live a life with meaning in a milieu that is oriented to assisting older people maintain their abilities, manage their deteriorating health and end their life with dignity.

6.1 What the person with an ABI and their families say

The appropriateness of accommodating young people in high level residential aged care facilities has been chillingly summed up by two young male residents from the research project who, when asked what the "not so good things" were about their accommodation.

Comment from young people with an ABI:

"it's like looking death in the face……they come in and I watch them go downhill and die" (male with ABI, aged 40 years)

"I don't like my daughters coming here to visit me, so I see them when I am at my mums" (male with ABI, aged 34 years)

More commonly, the person with an ABI in a high level residential aged care facility has cognitive and communication problems and is not able to clearly articulate their views. For some, their distress or frustration with their circumstances becomes manifested in challenging behaviours such as screaming, swearing, throwing objects and hitting out. The person becomes labelled "difficult" and can become feared by other residents, visitors and sometimes the staff.

The view that high level residential aged care facilities are not "places for living" is echoed by the relatives. In response to the question concerning what were the "not so good things" about their relatives' accommodation, relatives made a number of poignant comments.

Comments from relatives:

"they don't do life planning here, it's all about dying"

"this is a place for dying, not a place for living"
(wife of a 32 year-old person with ABI)

"I don't like visiting him in the nursing home"
(father of a 41 year-old person with ABI)

"his friends don't like visiting him there".
(wife of a 59 year-old person with ABI)

6.2 Experience of the Liverpool BIRU staff

In the experience of the BIRU, high-level residential aged care facilities are well aware of their limitations in meeting the needs of younger people with an ABI. They do consider the needs of the young person and reach out, within their limits, to attempt to meet the person's needs. There are however insurmountable obstacles to face that mean that they fall far short of being appropriate. Limitations include:

- **The physical structure, staffing and nature of the environment**

The physical structure of high level residential aged care facilities in itself presents a major barrier to meeting the rehabilitation and social needs of young people with an ABI.

- High level residential aged care facilities are generally large institutions with a "hospital feel" about them
- Bedrooms and bathrooms are mostly shared
- Dining and indoor and outdoor leisure areas are shared with many others
- Resident's personal space is frequently limited to a bed, a very small wardrobe, a small sidetable (enough to fit a few photos) and maybe a chair
- Even the very small personal space does not belong to them and they may have to relocate rooms to better suit the needs of others in the facility
- Residents receive regular intrusions from other residents who may wander into their room, creating difficulties in protecting their few possessions from loss

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.2 Experience of the Liverpool BIRU staff (continued)

- **The physical structure, staffing and nature of the environment (continued)**

The nature of the environment also disadvantages people with ABI in terms of exposure to activities that may facilitate further recovery of function. In particular the environment:

- Disconnects residents from normal domestic routines such as shopping, planning what to have for dinner, preparing meals, cleaning and washing, all of which are planned and provided for them without their involvement
- These routines offer a myriad of opportunities to exercise and stimulate rehabilitation therapy as well as well as allow participation in, and add a purpose to, life.

People with ABI become more dependent or disabled, because a nursing home environment cannot not be individually structured to compensate for their cognitive, physical and behavioural impairments. In particular:

- People with ABI can often achieve more independence if their environment is individually structured to meet their needs. For example a person may be able to manage certain personal care and domestic tasks if visual cues are positioned appropriately in the environment. Leaving their toothpaste and brush near the hand basin may prompt an individual to remember to clean their teeth. Seeing the washing up on the kitchen bench can prompt a person to remember to wash up
- In a large congregate living environment it is not possible to use the environment to compensate for the person's memory problems in a manner that enables them to use the abilities that they have retained.
- Implementing rehabilitation routines can also be time consuming and high level residential aged care facilities have very limited 1:1 staffing available for working on rehabilitation activities. It takes more time, for example, to keep prompting and refocusing a person to put on each item of clothing, and do up each button, than to do the buttons up for them. It takes more time to assist someone to practice walking than it does to push them in a wheelchair.

Family visits are encouraged but families often struggle with finding meaningful ways to contribute to the person's life within the facility.

- Family members may want to assist with care and therapy routines but doing so may clash with the goals of the institution and staff. Their participation may disrupt established routines in the facility, place additional pressures on staff time and raise issues of Occupational Health and Safety.
- Some family members are successful in finding a place for themselves yet remain cautious of their role as their relative is "owned" by the facility.

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.2 Experience of the Liverpool BIRU staff (continued)

- **Meeting social and recreational needs**

A major social limitation within residential aged care facilities is the lack of age and gender appropriate individually tailored activities available for young people.

- Most facilities employ diversional or recreational therapists, who design a program of group activities for residents.
- There is extremely limited opportunity to provide 1:1 recreational activities to suit individual resident's interests, or to assist a person to be able to participate in a group activity.
- The majority of aged residents are female and the majority of young residents with an ABI are male.
- The group activity programmes are unable to meet both the interests of an 85 year old grandmother and a 35 year old single man
- As a result, the clients themselves, family and staff report that the person with an ABI does not join in the activities available.
- Ultimately they are labelled as bored, unwilling to participate or disruptive rather than appreciating that they cannot participate without assistance or may not be interested in what is on offer.

Some families try to ameliorate the situation by taking their relative out for regular social leave. This contributes greatly to maintaining the person's connection with their family and friends and enhancing their well-being. Social leave is limited to 63 days a year which, in some situations, is too short.

In summary, how does a young person with an ABI live a life in this environment?
How can they, for example:

- Personalise their space so it reflects their personality and interests?
- Pursue their personal interests such as playing rock music or watching action videos late at night?
- Maintain important social ties such as being able to invite their friends over to socialise and just "hang out"; pursue an intimate relationship with their wife or husband; have their young children come to play with them and have visitors feel comfortable?

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.3 Accessing community based resources and activities

In addition to the problems with the physical structure, staffing and nature of the environment of an residential aged care facility, and the problems encountered in seeking to meet the social and recreational needs of young people with ABI resident in such facilities, there are a broader set of problems encountered in seeking to access a range of other support services by virtue of their living circumstances.

Living in a residential aged care facility excludes residents from accessing services and resources available to people with similar abilities, but who live in the community. For example:

- **Not eligible for Programme of Aids for Domestic Purpose (PADP)**

Residents are not eligible to apply for specialty equipment through the PADP scheme. An item such as a motorised wheelchair can significantly improve a physically impaired resident's quality of life by allowing them to get themselves around in their environment.

Few people can afford to purchase this item themselves. Without this piece of equipment a person cannot freely take themselves out to enjoy the sunshine of the courtyard. They are often left in their room and only provided with the opportunity for change when a staff member has time to "move" them to another area and when the chair they use is not being used by another.

- **Not eligible for Community-based respite and recreation services**

Residents of residential aged care facilities are in the main excluded from participating in many community based recreation programmes for people with disabilities as they target supporting people living in the community. Being able to access such programmes could offer an opportunity to socialise with peers and participate in everyday community life.

There has been some recent development of community-based recreational programmes which can be accessed by young people with disabilities in residential aged care facilities. This is an improvement, but there are still issues with availability of transport, frequency and cost of social opportunities.

- An activity once a week is better than none but there is still much time left in the week to fill
- Transport also remains a barrier to accessing any community programme as the facility is rarely able to provide transport for a resident to attend a programme on a regular basis
- Residential care fees leave little money in surplus to provide for regular taxi transport, even at the subsidised rate or to pay for modest costs associated with outings such as entry fees or lunch

- **Carer Payment and Carer Allowance**

Some family members try to improve their family member's life in a facility by visiting daily. This is often for many hours each day and they significantly assist with individualising their relative's life within the facility and augmenting care and therapy routines. They remain however ineligible for Centrelink Carer Payment or Carer Allowance benefits that they would be eligible for if they provided the same level of care at home.

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.4. Duty of care issues – managing the challenging behaviours of some young people with an ABI in high-level residential care facilities

Meeting the needs of aged people as well as younger people with brain injuries in the one facility is not appropriate and can raise serious duty of care issues.

The Liverpool BIRU has had numerous experiences of young people with an ABI presenting with challenging behaviours within residential aged care facilities. This refers to behaviours which may cause harm to the person or to others and which challenges the ability of staff to provide care. Challenging behaviours reported by nursing home staff have included:

- Screaming
- Verbal abuse
- Hitting out, hitting or injuring themselves
- Throwing objects
- Physical abuse
- Exhibitionism
- Refusal to cooperate and refusal to eat

These behaviours stem from the person's cognitive disability and are often in response to their environment. For example a short attention span, impulsivity and low frustration tolerance are not uncommon issues for people with severe ABI. The problems become further complicated if the person has communication difficulties which mean that they may have trouble expressing themselves, understanding what is being said to them or comprehending what is happening in their environment. This can exacerbate the person's level of anxiety and stress and which may be expressed as challenging behaviours.

The ideal management approach to challenging behaviours after ABI should conform with the principle of using the least intrusive intervention.
In terms of people with ABI, this means

- Behavioural management strategies
- Structuring the environment to minimise the possibility of behavioural outbursts
- Implemented by appropriately trained staff
- Sedating medication should only be used conservatively and should generally not be the front-line treatment strategy

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.4. Duty of care issues – managing the challenging behaviours of some young people with an ABI in high-level residential care facilities (continued)

In the experience of the BIRU, high level residential aged care facilities do not offer the environmental structure needed to compensate for the person's cognitive disability. Further more, staffing is often not adequate to being able to effectively implement behaviour management programmes.

Residential aged care facilities are not set up to manage people with ABI who have challenging behaviours. As a result, BIRU staff have observed:

- Medication used as the front-line management option
- Medication used as the only management option
- People with ABI regressing in their functioning. For example a man in his 40's who could remain continent when toileted regularly had to resume wearing continence pads as staff were not able to consistently implement a toileting programme.
- Escalation of challenging behaviours to the point where the person's behaviour put the physical safety of other residents at risk

In the worst case scenario the facility's ability to meet their duty of care to the person, the safety of the other residents, relatives, visitors and staff is severely compromised creating a high level of chronic distress for all concerned.

Facility A seeking help:

" he ran away because he didn't like the elderly"

and

" hit an old lady because she hit him, hit an elderly man because he was hitting other residents and hit the door because he was frustrated (not allowed any more social leave)"

Facility B seeking an alternative accommodation placement:

" his behaviour has escalated to the point of strongly compromising the other 80 residents care and quality of living. We have had constant complaints from families and visitors. Residents and staff fear for their safety."

The behaviour complained of included constant shouting, swearing, verbal abuse, constant demands for attention and for cigarettes, spitting, urinating on the floor, hitting, kicking and throwing objects.

6. WHY ARE RESIDENTIAL AGED CARE FACILITIES INAPPROPRIATE (cont)

6.4. Duty of care issues – managing the challenging behaviours of some young people with an ABI in high-level residential care facilities (continued)

In the case of facility B, assistance was offered with designing and implementing a behaviour management plan oversighted by staff from the BIRU. The programme was not able to be instituted because, even with education, the facility could not provide sufficient and consistent staffing to implement the programme. The facility sought the person's admission to a psychiatric hospital, however, this was refused as the person's problems stemmed from his brain injury and not a mental illness. Instead, pressure was inappropriately placed on the family to take the young man home.

In response to this type of scenario the BIRU has found it increasingly difficult to find a high level residential aged care facility willing to admit younger people with an ABI, even with ACAT approval for admission.

7. BARRIERS AND INACTION IN CREATING AN ALTERNATIVE FUTURE

The current failure of services to provide suitable long-term accommodation services for some of the most vulnerable members of our community is an issue that needs to be addressed with urgency.

- No services in NSW that specifically target the long term supported accommodation needs of young people with an ABI needing high-level care
- No evidence of progress in creating more appropriate options that will halt the need to consider high level residential aged care facilities as an accommodation option for this population
- No evidence of the creation of pathways that will relocate individuals currently inappropriately accommodated within them.

The reasons for this lack of progress stem from a lack of action and commitment among government at both the state and Commonwealth levels. In particular:

- **Lack of action within NSW Department of Ageing Disability and Home Care**

In Feb 2004 the NSW Department of Ageing Disability and Home Care (DADHC) released a draft discussion document titled Future Directions 2004. It identified the need to work with the Australian Government and other agencies to develop support options to meet the needs of people with high and complex medical support needs including young people with a disability who reside in high level residential aged care facilities. However it proposes no strategy to advance the issue.

7. BARRIERS AND INACTION IN CREATING AN ALTERNATIVE FUTURE (cont)

- **Failure of coordination and cooperation between the Commonwealth and state governments to act to address the issue**

In 2003/4 the Commonwealth Department of Health and Ageing offered funding through the Aged Care Innovative Pool to address the needs of young people with disabilities who are currently inappropriately placed in residential aged care facilities. Commonwealth funds would have supported flexible care places for the individuals while they transitioned to more appropriate care. Ongoing funding would, however, be the responsibility of the State. To our knowledge, no submissions came from NSW to take up this opportunity.

8. FINAL

The people with ABI and their relatives are sick and tired of:

- the lack of political will that has allowed this unacceptable situation to continue for more than a quarter of a century
- the endless destructive cycles of blame-shifting, cost-shifting and responsibility shifting exhibited by the Commowealth and State governments that has led to a paralysis in resolving this complex yet urgent human rights issue

There are young people with an ABI currently inappropriately accommodated in residential aged care facilities; some of whom seriously compromise the care of aged residents within the facility.

Families who have undertaken the care of their relative at home are looking for alternatives, especially for when they are no longer able to continue to provide the care.

The number of people living with a high level of disability after a brain injury is increasing.

Until suitable alternatives are created, applications for admission to residential aged care facilities will continue to need to be made.

Within this context,
The Liverpool BIRU welcomes the Commonwealth's focus on the issue of the appropriateness of accommodating young people with disabilities in residential aged care facilities.

The BIRU is pleased to have the opportunity to respond to this issue reflecting the needs of young people with a high level of disability following an acquired brain injury.

We hope that the Senate Inquiry will provide the impetus to identify, at a policy level, that ABI is a specific disability with unique needs and to move forward, so that a better future is created for young people with high care needs after a brain injury in need of supported accommodation.

We would welcome an invitation to speak to the Inquiry Committee about the unpublished findings from the study, or to expand on, or clarify any other aspect of this submission.