

Brain Injury Australia (BIA)

'I just want a life'

Submission to the Senate Community Affairs
References Committee

*'Inquiry into the Funding and Operations of the
Commonwealth State/Territory Disability Agreement'*

August 2006

1. Introduction

Brain Injury Australia (BIA) is the national peak acquired brain injury organization representing, through its State member organizations¹ and network relationships, the interests and needs of people with acquired brain injury (ABI), their families and carers. A major component of BIA's role is:

- advocacy for government program allocations and policies that reflect the needs and priorities of people with acquired brain injury and their families, and
- the provision of effective and timely input into policy, legislation and program development through active contact with Federal Government ministers, parliamentary representatives, Federal Government departments and agencies, and national disability organizations.

The Senate Inquiry into the Commonwealth/State/Territory Disability Agreement (CSTDA) provides an unique opportunity for individuals with disabilities, their families and friends, peak bodies, service providers and the community to:

- reflect upon the intent and impact of the CSTDA, and
- comment on strategic priorities and future directions for policy and program development relating to the needs and aspirations of individuals with a disability.

In reading this submission it is important to have an understanding of what is meant by the all-inclusive term 'acquired brain injury', coupled with an awareness of the multiplicity and complexity of the impact this can have on the lives of individuals and those closest to them. A definition and impact information have been included to assist this understanding.

In addition, the submission cites some significant statistical data about the prevalence, needs and unmet needs of individuals with an ABI. However, it is the inclusion of the lived experiences of individuals with an ABI that highlights the current lack of a whole-of-life, whole-of-government strategy to support the fundamental rights and needs of individuals with an ABI as members of our community.

2. Inquiry into the CSTDA

The terms of reference for the Senate Inquiry are:

- a. an examination of the intent and effect of the three CSTDAs to date;
- b. the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
- c. an examination of the ageing/disability interface with respect to health, aged care and other services, including problems of jurisdictional overlap and inefficiency, and
- d. an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

The current CSTDA identifies five priority policy areas:

- strengthen access to generic services for people with disabilities;
- strengthen across government linkages;
- strengthen individuals, families and carers;
- improve long term strategies to respond to and manage demand for specialist disability services, and
- improve accountability, performance reporting and quality.

BIA's submission primarily focuses on assessing the effectiveness of the current CSTDA, particularly in terms of the high level of unmet needs for individuals with an ABI.

¹ Please refer to Appendix 1 for a list of BIA member organizations across Australia

3. Understanding acquired brain injury

The following information is included for the purpose of understanding the scope and complexity of ABI and its impact on the lives of individuals. It provides a context for meaningful discussion about the needs and unmet needs of individuals with an ABI and their families.

What is Acquired Brain Injury?

Acquired brain injury is injury to the brain which results in deterioration in cognitive, physical, emotional and/or independent functioning. Acquired brain injury can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, and degenerative neurological diseases of stroke. These impairments to cognitive abilities, emotional wellbeing and/or physical functioning may be either temporary or permanent and cause partial or total disability and psychological and social upheaval.

The onset of an acquired brain injury can occur at any age as the later data analysis will demonstrate.

What is the impact of an acquired brain injury?

An acquired brain injury is potentially one the most devastating disabilities, with a huge range of effects due to the complexity of the brain. The number and severity of problems resulting from a brain injury will differ from person to person because each individual's brain injury varies in the extent and location of damage. The long term effects of brain injury are difficult to predict and can range from mild to profound. The extent of some of these changes may only become apparent over time.

The impact of an acquired brain injury for the person and their life may be visible, seemingly 'invisible' at first glance, subtle, medicalised, confusing, misunderstood and highly complex.

A widely perceived myth is that a brain injury is simply a type of intellectual disability. People with an acquired brain injury usually retain their intellectual abilities but may have difficulty controlling, coordinating and/or communicating their thoughts and actions. It is common for many people with an ABI to experience one or more of the following:

- increased fatigue (mental and physical);
- increased time required to process information, plan and solve problems;
- physical co-ordination difficulties and temporary or long term loss of mobility in specific limbs or parts of the body which may lead to difficulties with balance;
- communication difficulties including speech impairment and/or partial or full loss of literacy skills;
- visual impairment, for example, loss of peripheral vision;
- onset of epilepsy due to scar tissue on the brain;
- memory problems, most commonly short term memory loss with problems, for example, in remembering people's names, appointments, messages or details;
- poor concentration;
- a loss of insight in some cases, which may result in difficulty seeing and accepting changes in thinking and behaviour;
- difficulty in controlling emotions, for example, crying or laughing at inappropriate times or rapid mood changes;
- difficulty in controlling behaviour, for example, low frustration levels and increased irritability. In more severe situations this may lead to a person becoming homeless or inappropriately entering the criminal justice system;
- difficulty judging how to behave in social situations including, for example, interpreting and responding to social cues, shifting between topics of conversation, regulating the volume and tone of voice;
- difficulty or an inability to change a train of thought leading to repetition or trouble seeing another's point of view, and not surprisingly

- the onset of depression, which is a very common emotional consequence that usually comes some time after the injury. This may be related to many factors including grief, loss of self esteem, confidence, social networks and/or employment, enforced dependency and a lack of appropriate support services.

The following examples related by individuals with an ABI capture some of the impact for the person and highlight the lack of community and professional awareness of ABI.

'...It took me twelve months of physio. and speech therapy and three months of practice at home to learn how to get on the bus and ask for an all day ticket. The first time I went out and tried I had some balance problems getting on (the bus) because I have to drag the right side of my body. It took a while to get the words out; my speech is a bit slurred because it's hard to make my tongue do what I want it to. The driver looked at me with disgust and had a go at me for being drunk that early in the day. It was awful; everyone was looking at me and I didn't try again for a long time.'

*'...Another time, early on when I was still in the wheelchair, I was having a meal at the pub with some friends when a man from a nearby table came up, smiled at me and said "You poor b*****. Here have one on me" and threw a couple of dollars in the coffee cup I was holding. I felt pretty angry, but my friends said to calm down and that he meant well even if he was a bit clumsy about it. I hated it, really hated it. I don't want charity! I still get angry when I remember it.'*

(George, a 33 year old man eighteen months after a severe stroke which resulted in acquired brain injury)

'...They keep giving me these forms to read and telling me that I have to go to this place and that place and be there at this time and that time on this day and that day. I'm too embarrassed to tell them I can't read the forms...they'll think I'm stupid. I used to go to uni... After I got out of the office I couldn't remember what she said I had to do next...'

(Jenny, a twenty-three year old woman who had been hit by a car while cycling)

4. Identifying the needs of people with an acquired brain injury

There continues to be a paucity of prevalence and service demand data for ABI. This is in part due to the way information is recorded in hospitals and health settings, and ongoing confusion about ABI, particularly in relation to cognitive impairment and its distinction from intellectual disability. However, some relevant data has recently been analysed by the Australian Institute of Health and Welfare.² Data was sourced from the 2003 ABS Survey of Disability, Ageing and Carers, the CSTDA disability service users in 2003–04 profile and hospital stays associated with traumatic brain injury.

The other significant source of data is consultation with individuals with an ABI, their families and service providers. BIA consults regularly with its membership and their constituents in each state or territory (refer to section 4).

The AIHW analysis of the 2003 ABS Survey of Disability, Ageing and Carers indicated that:

- Prevalence estimates for ABI in 2003 were:
 - **432,700** people (2.2% of population)
had ABI and some activity limitations or participation restrictions

² Presented by Nicola Fortune, AIHW at the BIA National Conference, Queensland May 2006

- **157,500** (0.8% of population) had ABI and a 'severe or profound core activity limitation' — i.e. needed help with self-care, mobility, or communication
- 28,700 people said that ABI was their main disability condition³
- Age at onset of ABI in 2003:
 - approx. 31% in 0-14 years age group
 - approx. 33% in 5-24 years age group
 - approx. 21% in 25-44 years age group
 - approx. 10% in 45- 64 years age group
- 90% of people said their ABI main condition was caused by an accident or injury
- ABI disproportionately affects males, with young men having the highest risk of sustaining a traumatic brain injury
- 14,500 people with an ABI had a primary carer aged 65 years or over
- Of the people with ABI who needed frequent support with core activities (self-care, mobility or communication):
 - 85,000 people needed daily help, with
 - 58,400 people requiring this at least three times per day or more

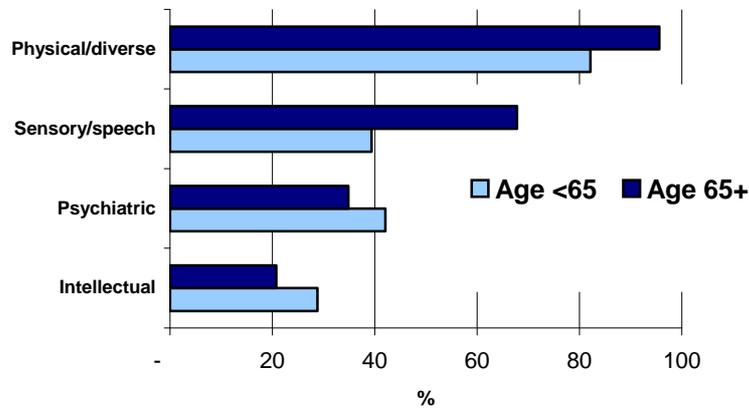
Figure 1: People with ABI who needed frequent support with core activities

Age	Daily	> 3 times/day
0-44	28,500	19,800
45-64	17,500	9,400
65+	39,500	29,300
All ages	85,500	58,400

- Care needs related to communication, cognitive/emotional, transport, mobility, meal preparation, paper work, property maintenance, self care, health care and housework were either only partly met or for some, not met at all
- The dominant source of assistance for the majority of care needs was informal assistance ie. family carers, followed by a combination of informal/formal assistance with formal assistance being the second lowest source of assistance. The only other source was 'none'
- Other reported disability groups for people with an ABI are summarised in figure 2

³ Please note there are a number of reasons why people are not comfortable to acknowledge an acquired brain injury

Figure 2: Other reported disability groups for people with ABI



- When compared with all disability groups, people with an ABI are more likely to have multiple conditions including mental health problems and substance abuse

The AIHW analysis of the CSTDA disability service users in 2003–04 profile indicated that:

- 187,800 people used services
- **11,500** service users had ABI — 6% of all service users:
 - 7,900 (4%) had ABI as their primary disability
 - 3,600 (2%) had ABI as an additional disability
- Service types most commonly used by service users with ABI:
 - Case management, local coordination & development— 4,730 (41%)
 - Open employment services— 1,920 (17%)
 - Learning and life skills development— 1,770 (15%)
 - Therapy support for individuals— 1,380 (12%)
 - In-home accommodation support— 1,160 (10%)
- In all areas in which service users required support (including communications, self care, interpersonal interactions, education, working, learning, domestic life and economic life), a higher percentage of people with ABI required assistance than for all other service user groups

5. Does the CSTDA meet the needs of people with an acquired brain injury?

When comparing the ABS population data and CSTDA disability service data from 2003 it should be noted that while

- 15% of people with *severe* or *profound* core activity limitation aged under 65 had ABI
- only 6% of CSTDA service users had ABI.

Further, data analysis also revealed:

- Multiple disability is characteristic of the population with ABI
- Survey data indicate substantial levels of unmet need for assistance

- Heavy reliance on informal assistance
- High rates of multiple service use among disability service users with ABI
- Complex support needs were characteristic of service users with ABI

Consultation with individuals with an ABI, their families, advocacy groups and service providers highlighted the extent to which the needs of this population are significantly unmet. Key areas of concern related to:

- Access
- Access to services and the appropriateness of generic and/or specialist service provision
- Accommodation, including young people in nursing homes
- Advocacy for people with ABI
- Children with an ABI and Education
- Individuals with an ABI involved in the Criminal Justice system
- Dual Diagnosis and complex needs *eg. ABI and mental illness, substance abuse*
- Employment and Welfare Reform
- National Insurance Policy
- Rural and Remote Issues – access to services
- Social Participation

This submission cannot do justice to the range of issues raised throughout the consultations in a single paper, but a small number are explained further in the pages which follow.

Advocacy and Information

The need for greater advocacy and information was emphasised by both people with ABI and their families and carers. Advocacy is required at two levels. Firstly, on a day-to-day basis people with ABI may require an advocate in order to obtain the services and assistance they require. The nature of an ABI disability means that it may be difficult for some individuals to represent themselves. Other individuals may need some assistance or support to self advocate. Secondly, people with ABI require effective systemic advocacy to ensure they have input into all levels of government decision making.

The future directions of the federally funded National Disability Advocacy Program are currently uncertain and this has added to the anxiety levels of people with a disability, their families and service providers. This potential threat to advocacy coincides with the introduction of the welfare to work policy and program which potentially threatens the income security of numbers of people with living with an ABI.

'We've supported a person with multiple difficulties including intellectual disability, ABI, substance use and personality disorder who has children. Mental health only offers case management associated with the mental health problem; child protection is extremely difficult and rarely sophisticated in its approach to people with complex difficulties. The coordination of multiple services - not only in content, but also in agreed approach - often appears to require the intervention of an advocate due to the difficulties professionals appear to have in establishing protocols for a lead worker.'

(worker from specialist ABI advocacy service)

Appropriate Assistance and Support

People with ABI require practical assistance to complete rehabilitation, develop social networks, obtain employment, and participate in their communities.

'I think people with ABI merit assistance in their daily living from creative and compassionate people who are well versed in the subtleties and complexities of ABI.'

(participant in BIA consultation workshop 2005)

Given the complexity and diversity of the services that may be required (an average of over four different types, according to one recent study), it is unlikely that a single service provider can meet all the needs of a person with ABI. Very few services exist that are able to respond to the high quality of case management that is required to coordinate access to the services which are needed. In many states, the capacity of community organisations to support people with ABI who have complex needs is severely limited.

Because of the multiple needs of many individuals with an ABI, cohesive, cross program strategies are essential to ensure appropriate care and support is provided. Of particular concern are:

- ongoing difficulties gaining access to mental health and substance abuse specialist services, with people falling through the gaps and being placed in high risk situations which may result in serious injury, homelessness or in severe cases, imprisonment;

'I think mental illness is difficult enough for people with full brain capacity to manage and steer themselves through. To leave people with ABI to negotiate the current system is draconian. Specialist services are needed to cater for the needs of people with both ABI and mental health issues.'

(participant in BIA consultation workshop 2005)

- long waiting lists for the few, small specialist ABI programs that are available in each state;
- the lack of specialist ABI services in rural and remote area. Rehabilitation and support services for people with acquired brain injury in rural areas are virtually non-existent;
- not all service types being equally available (for example, counselling and social support programs in particular are limited);
- those whose support services are purchased by their insurer have access to a wider range of services, on a fee for service basis, than those relying on government-funded services, and the
- lack of interface between the acute hospital setting (the entry point for the majority of individuals sustaining a brain injury) and the community sector when planning for the immediate and longer term support needs of individuals leaving hospital.

Access to Appropriate Accommodation

Finding appropriate accommodation after rehabilitation is a key issue for many people with an ABI and their families. Meeting housing needs is at the heart of many impediments to social participation and access to services. Consider the following example provided by an ABI advocacy organization:

Frank is a young man with ABI who wishes to marry his girlfriend but faces a 10 year wait for public housing. He currently lives in a bungalow at the back of his parent's home but his parents do not wish to take on the additional supports associated with his fiancé living on the property. He is unable to get a priority or supported housing arrangement because he has no access to ongoing support (case management is all short-term and this prevents people with ABI being able to access community or Priority 2 housing)

Participants commented that compatibility rather than disability should be the prime consideration when developing housing options for individuals with an ABI.

'... After all, why should people with disability be clumped together completely apart from others? Why should we be deprived of interaction that is more reflective of the mainstream?'

(participant in BIA consultation workshop 2005)

Due to the limited options available, people with an acquired brain injury who have high support needs, are rarely given a choice. Some will end up in group homes, while others will be placed in a hostel. In both cases, the facility they call *home* is likely to have been designed for a different cohort of people with a disability e.g. people with an intellectual disability or a mental illness. Staff of such facilities are generally unable to respond appropriately to the complex issues surrounding acquired brain injury, and rarely is the service provided with sufficient resources to do so.

Staff, trained to support very different conditions are ill-equipped to meet the unique needs of residents with ABI. Consequently, people with an ABI are refused access because of the perceived complexity of their support requirements. Younger people with an ABI are inappropriately placed in aged care facilities because there is nowhere else to go.

When asked what he wanted in life, a 26 year old man living in a nursing home in country Victoria unable to access disability supports or to attend day programs because it is considered "double dipping" said two memorable things:

'I just want to get to Melbourne and meet some wheelie chicks - and - I just want a life...'

Employment

Many people consider holding down a job an important measure of their ability to lead a normal life. This is of particular concern for people with an acquired disability. People with acquired brain injury, however, face a number of barriers in returning to work including:

- cognitive impairment e.g. short-term memory loss, poor concentration;
- fatigue and other physical problems e.g. dizziness and headaches;
- poor control over emotions e.g. impulsivity, anger management, depression;
- loss of confidence and motivation.

Overcoming these barriers requires an appropriate level of support from an employment support or rehabilitation service. Employment services that respond to the needs of people with ABI are few in number and generally lack the resources to provide the intensive, one-on-one support required.

Carers

The current expectation of high levels of informal assistance and support, evidenced previously in this submission, is not an acceptable or reasonable strategy in responding to the needs of individuals with an ABI. When the primary carer is a family relation – a parent, spouse, sibling, child or close friend – this can have a significant impact and jeopardise the quality of the relationship. Adults do not generally wish to be in a situation of enforced dependency, where everyday support needs are met by ageing parents, partners or siblings; however well intended. Those parents or family members who do undertake the primary caring and support role report extreme difficulty in accessing respite services. An extraordinary number of carers report that, for many years after the injury, they continue to feel anger and grief over the failure of the system to understand and support them. They report feelings of helplessness over the continued battles they face trying to identify and access services capable of responding to the needs of their loved one.

Looking to the future

Issues for improvement raised during BIA's consultations included:

- Clear pathways to support, less referrals and transitions, more consistency
- Information from forums such as the BIA consultations need to be publicised and made relevant to ALL life domains, ie., employment, accommodation, education, support, leisure etc
- Fair and equal conditions, such as pay, within employment settings

- Less handballing!!
- Legalities and systems are currently too fussy and complicated. They need to be tailored to allow greater access and eligibility for people
- More sensitivity and cultural understanding for indigenous communities, especially in appreciating indigenous culture and ABI, providing cultural education and awareness
- Staff and professionals being more positive and proactive with services, everyone will be better off emotionally and physically
- Encouragement, positivity and a long-term approach
- Facilities for families to “live” with not “care” for members with an ABI
- Support for carers – respite, refreshment, professional training
- More rural services – less isolation
- Greater publicity and increased community awareness of ABI
- Seeing ABI as a long-term process
- More person-centred, emotional support from staff rather than a clinical approach
- Support for families during the onset of the trauma, hospitalisation and rehabilitation
- On site and ongoing support within employment

6. Conclusion

Although further research is required into unmet needs, this submission provides irrefutable evidence that people with an ABI and their families are significantly disadvantaged under the current funding and program arrangements of the Commonwealth, State Territory Disability Agreement (CSTDA).

The lack of a whole-of-life, whole-of-government strategy, including comprehensive planning and policy development within and between Commonwealth and State/Territory governments, has resulted in an ad hoc and unsatisfactory approach to supporting the needs of people with an ABI.

What is clear from the experience of individuals with an ABI, their families and service providers is the barriers and negative legacy that have unwittingly been created by a narrow portfolio focus on ‘disability’ rather than a broader strategy focussing on the person and their needs within the context of their total environment and their life aspirations.

Planning needs to be multi-pronged and include key portfolio areas such as of health, mental health, transport, education and justice.

Brain Injury Australia believes that every individual with an ABI has the right to access the supports and resources required to optimise social and economic participation.

- Where is the whole-of-government, whole-of-life approach to supporting the needs of people living with an ABI, and people with a disability more generally?
- What are the barriers within government structures or bureaucracy which prevent the development of cross program, multi-faceted policies and service development?
- What are the opportunities for people with an ABI and organizations such as Brain Injury Australia to work with government to collaboratively shape a more effective and responsive framework and system which provides quality support and access when it is needed and where it is needed?

Brain Injury Australia and its member organizations in each state would welcome the opportunity to meet with the Senate Community Affairs References Committee to speak further to our submission.

Appendix 1 : Membership and role of Brain Injury Australia

Member Organizations

Brain Injury Association of New South Wales
Brain Injury Association of Queensland
Brain Injury Association of Tasmania
Brain Injury Options Co-ordination (BIOC) South Australia
Headway Victoria
Somerville Community Services Inc (Northern Territory)

BIA's role

- Advocate for government program allocations and policies that reflect the needs and priorities of people with acquired brain injury and their families
- Provide effective and timely input into policy, legislation and program development through active contact with Federal Government ministers, parliamentary representatives, Federal Government departments and agencies, and national disability organisations
- Initiate and coordinate national projects
- Increase national public awareness of acquired brain injury through the implementation of public information programs
- Monitor Federal Government consumer consultation processes to ensure that these are of a quality that is meaningful and inclusive of people with acquired brain injury and their families
- Develop strategic alliances that support and enhance the achievement of BIA's strategic objectives.