

**Brain Injury Australia Inc.**

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1 December 2008

Dear National Disability Strategy,

Following is Brain Injury Australia's submission to the National Disability Strategy, the result of exhaustive consultations with our State and Territory member organisations – the Brain Injury Network of South Australia (BINSAs), Brain Injury Association of Queensland (BIAQ), Brain Injury Association of Tasmania (BIAT), The Victorian Coalition of ABI Service Providers (VCASP), Brain Injury Association of NSW (BIA NSW), Brain Injury Matters (BIM) and Somerville Community Services.

Brain Injury Australia would welcome any opportunity to be involved in any further consultations in regards to the further development and implementation of the Strategy and would be grateful for any further communication as to its progress.

Sincerely,

A handwritten signature in black ink, appearing to read 'Nick Rushworth', is written over a light blue horizontal line.

Nick Rushworth  
Executive Officer

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# **Brain Injury Australia: Submission to the Australian Government's National Disability Strategy**

**Nick Rushworth  
Executive Officer**

**December 2008**

Brain Injury Australia is the national peak Acquired Brain Injury (ABI) advocacy organization representing, through its State and Territory member organizations and network relationships, the needs of people with an ABI, their families and carers.

Brain Injury Australia advocates for Australian Government program allocations and policies that reflect the needs of people with an ABI and their families, and provides input into policy, legislation and program development through contact with Australian Government ministers, parliamentary representatives, Australian Government departments and agencies, and national disability organizations.

Acquired Brain Injury refers to the multiple disabilities arising from any damage to the brain that occurs after birth. Common causes of ABI include accidents, stroke, infection, alcohol and other drug abuse and degenerative neurological disease. Traumatic Brain Injury (TBI) is an ABI caused by a traumatic event, from an external force to the brain such as a motor vehicle accident, a fall or a blow to the head.

The consequences of an ABI can be profound, complex and multiple. The physical problems commonly reported by people with an ABI include headaches, fatigue, seizures, poor balance and coordination, visual and hearing disturbances, chronic pain, paralysis and epilepsy. Many people with an ABI experience cognitive problems, including poor memory and concentration, reduced ability to learn, plan and solve problems. Roughly two-thirds of people with an ABI exhibit shifts in behaviour post-injury, including poor impulse control and disinhibition, aggressive verbal and physical tendencies. In that context the psychosocial-emotional problems consequent to ABI can be debilitating.

## ***What do you think should be included in the National Disability Strategy?***

Based on the results of the Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers, Brain Injury Australia estimates that **over 500,000 Australians are living with an ABI** (see below, page 12). Further, almost 3 out of every 4 are aged less than 65 years, half of them between 15 and 34 years of age. **2 out of every 3 said that they acquired their brain injury when they were aged under 25 years.** 9 out of every 10 said their ABI was caused by accident or injury. **3 out of every 4 were men. 1 in 3 people with an ABI reported 5 or more health conditions, compared with about 1 in 8 of all people with disability and 1 in 4 reported four or more disability groups, compared with 1 in 18 of all people with disability.**

**Overall, ABI is 10 times as common as spinal injury and produces, on average, 3 times the level of disability.** Yet, of this large group of Australians – highly, multiply and complexly disabled – **less than 12,000 accessed Commonwealth State/Territory Disability Agreement (CSTDA)-funded services in 2004-2005.**

1. Brain Injury Australia firmly believes that, while people with a disability share concerns in common, ***any “National Disability Strategy” must reflect the needs and experiences of specific disabilities.*** This is not simply an argument from the size of the constituency Brain Injury Australia seeks to serve. It reflects the differing levels of community awareness about different disabilities, and that it's Brain Injury Australia's conviction that community awareness of ABI lags at least twenty years behind that of other disabilities. **The combined effects of relatively low levels of community awareness about ABI with the fact that ABI is commonly referred to as the “invisible disability” - because its consequences, even if observable, are often not associated with disability generally nor ABI specifically - with, in turn, the social isolation that is a specific effect of the disability are pernicious, especially for those whose ABI occurs in the prime of their lives; just as they are about to enter the world of work, embark on tertiary study, start a family etc.**

2. ***The National Disability Strategy must include a genuine commitment to national level awareness-raising*** – utilising the expertise of advocacy organisations like Brain Injury Australia and its member organisations, targeting government services, employers, community organisations etc. - *across all disabilities.*

3. Brain Injury Australia acknowledges the National Disability Strategy's commitment to “outcomes”. Therefore, ***any and all efforts in awareness-raising about ABI must be measured in the extent and level of its recognition.*** For instance, Brain Injury Australia has recommended, in its May, 2008 policy paper for the Department of Families, Housing, Community Services and Indigenous

Affairs on “Children, Young People and Acquired Brain Injury” – in *recognition* of the 23,000 Australian children aged 0-14 with an ABI - that both the category “Cognitive Disability” and subcategory “Acquired Brain Injury/ Traumatic Brain Injury” be included in all Centrelink policy documents and publications relating to eligibility for income support for people with disabilities and their carers, especially in Centrelink’s “Lists of Recognised Disabilities”. Moreover, some State and Territory departments of *disability* – and the services they fund – continue to fail to recognise ABI as a disability qualifying for support. **A genuinely National Disability Strategy, committed to “a new whole-of-government, whole-of-life approach to disability issues” will make a nationally consistent recognition of specific disabilities one of its first outcomes.**

4. Brain Injury Australia – and its State and Territory member organisations – endorse Recommendation 2 of the Senate Standing Committee on Community Affairs inquiry into the “Funding and Operation of the Commonwealth State/Territory Disability Agreement [CSTDA]; namely “that the next CSTDA clearly recognise the complex and interacting needs of, and specialist services required by, people with dual and multiple diagnosis, and **people with acquired brain injury**. Along with the *recognition* in the next CSTDA of the specific needs of people with an ABI needs to be an acknowledgement *in funding* by Australian and States’ and Territories’ Governments of *specialist services* – including both *individual and systemic advocacy* – for people with an ABI. In almost every consultation conducted by Brain Injury Australia and its States’ and Territories’ member organisations, people with ABI with challenging behaviours, for example, are the first to be excluded from service provision. *The National Disability Strategy needs to state a commitment to specialist service and advocacy provision and training* (in the form, for example, of secondary consultations conducted by Brain Injury Australia and/ or its member organisations) in the specific outcomes from injury for people with an ABI, including challenging behaviours.

5. Brain Injury Australia welcomes the preparatory work the Australian Government has undertaken towards a national “disability insurance” scheme. ***The National Disability Strategy should clearly state that access to services and support should not discriminate on the basis of the cause of disability.*** For example, assaults are a leading cause of TBI in young Australians. But because they are not – unlike, for example, motor vehicle accidents – covered by States’ and Territories’ statutory schemes, (apart from modest “victims of crime”) compensation is unavailable. People with a non-compensable ABI go the back of the queue for services and support.

6. Brain Injury Australia notes proposals for a rearrangement of responsibilities between States, Territories and the Australian Government for aged care and disability services. ***The National Disability Strategy should clearly state that***

**access to services and support should not discriminate on the basis of the age of onset of disability.** As Australia's population ages, stroke remains the leading – and an increasing - cause of ABI hospitalisation. Low falls (of less than one metre, occurring mostly in the home, and in people aged 65 and over) now account for the majority of *Traumatic Brain Injury (TBI)* hospitalisations and their rates are expected to triple by 2050, requiring 750,000 additional hospital bed days, 3,320 additional residential aged care places and accounting for \$1.375 billion in total health care costs. The equivalent costs of stroke were \$1.3 billion, in 1997. Brain Injury Australia expects the demand for post-stroke and post-falls-related TBI rehabilitation and advocacy to accelerate likewise.

7. Brain Injury Australia is grateful for the five-year \$244 million commitment the Council of Australian Governments gave in 2006 to the Young People in Residential Aged Care Program in developing age-appropriate accommodation for the hundreds of young people with an ABI currently in, or at risk of admission to, residential aged care. The Young People in Residential Aged Care Program remains a part, albeit a crucial part, of the larger effort at designing, funding and building accommodation that meets the specific needs of people with an ABI. ***The National Disability Strategy, alongside a commitment to range of flexible options for accessible accommodation for people with other disabilities, should include an equal commitment to people with the physical, cognitive and behavioural challenges the consequence of ABI.***

8. Brain Injury Australia welcomes the Australian Government's commitment to social inclusion, led by the Prime Minister, the Deputy Prime Minister and the Australian Social Inclusion Board. In keeping with both the "social inclusion agenda's" core principle of allowing all Australians to "have their voices heard" and the Strategy's commitment to consultation, ***the Strategy's formulation and implementation should be underpinned at every stage by the direct participation of people with a disability, their family members and carers. Generally, people with a disability are experts in their own needs. And the National Disability Strategy should support a consumer participation that reflects the breadth and diversity of outcomes and lived experiences of people with an ABI.***

9. Almost universally, families report to Brain Injury Australia and its member organisations that their lives have been changed dramatically and irrevocably when a member experienced an ABI. Family members drew attention to their experiences of isolation, and emotional and financial stress particularly after the intensive post-acute rehabilitation came to an end. ***The National Disability Strategy needs to include a commitment to support carers, and to meet their needs for respite.***

10. Specifically, ***the National Disability Strategy must: include clear and distinct objectives, define the outcomes that will demonstrate that "families and carers are well supported" and how those are going to be quantified and***

***measured; include timeframes in the reporting framework; include performance indicators in the reporting framework; and include delineation of the roles and responsibilities for action on the implementation of the Strategy between Australian and State/ Territory governments.***

***What are the greatest barriers that people with disability face to participating fully within the community and what specific local or national actions could be taken to overcome these barriers?***

“Promoting social inclusion requires a new way of governing. Australia must rethink how policy and programs across portfolios and levels of government can work together to combat economic and social disadvantage in Australia.”

- [www.socialinclusion.gov.au](http://www.socialinclusion.gov.au)

**1. Social Disadvantage:**

***People with an ABI are drawn from the same populations as those at the greatest risk of any injury – of low socio-economic status: from poor housing; large family size; histories of abuse, neglect and marital breakdown; parental drug or alcohol abuse and substance abuse; mental illness and poor levels of education.*** For many of Brain Injury Australia’s constituents, their ABI serves to exacerbate social marginalization. Brain Injury Australia records that the National Disability Strategy is committed to a “whole-of-government, whole-of-life approach to disability issues” and, as such, should measure its success in the *prevention* of the injuries that can result in disability, including ABI.

**2. Social Participation:**

The barriers to full community participation of people with an ABI are both individual and systemic, each feeding the other. For example, in almost every consultation conducted by Brain Injury Australia and its State and Territory member organisations ***the lack of community awareness (addressed above - in the broadest sense; inclusive of government, service providers, community organisations, employers etc.) is cited as the single greatest obstacle.*** At the same time, the cognitive-behavioural challenges that many people with an ABI experience discourage them from social participation precisely because those challenges are not understood as being a function of their disability. Outright exclusion is the commonest consequence.

Brain Injury Australia urges the authors of the National Disability Strategy, in their pursuit of a social inclusion agenda for disability policy and service delivery, not to underestimate the genuinely social in *social* inclusion. Australian Governments could learn from the results of the longest long-term study ever conducted in Australia of the outcomes of ABI – a 20-26 year follow-up of 100 men with Traumatic Brain Injury admitted to Sydney’s Lidcombe Hospital between 1976 and 1981. Apart from the fact their needs for support were ongoing so long post-injury - 85% had used at least one service in the preceding twelve months – their greatest unmet need (for 73% of them) was for some form of “*social participation activities*”. For many of the people with an ABI who are the intended targets of the National Disability Strategy, their first engagement with a government service, with a community organisation or a sporting club may be their very first

engagement with the wider world *per se*. Which is why the nature of that first engagement with – how disability-inclusive *and* how ABI-aware it is – is absolutely crucial. Because failure, because of systemic barriers, risks permanent exclusion.

An example of a “local action” that addresses such barriers: 75% of traumatic brain injuries in New South Wales are caused by motor vehicle accidents; 70% of those injuries happen to men; and 40% to men aged between 17 and 25. And while traumatic brain injuries represent less than 2% of claims made on the state’s Compulsory Third Party (CTP) scheme, they account for half of the Motor Accidents Authority of New South Wales’ large claims and nearly one-fifth of the scheme’s total cost. Their average cost is roughly \$1 million. In partnership with Rotary’s Youth Driver Awareness (RYDA) program, Brain Injury Australia’s New South Wales member organization - the Brain Injury Association of New South Wales - has established a 40-member Speakers’ Bureau; of people with a traumatic brain injury who share their experience of road trauma with high school students. Over 50,000 students have participated in RYDA since its inception in 2000. The benefits of such a program are manifold. Firstly, the Bureau caters to the enormous community enthusiasm for road safety information. Secondly, the Bureau satisfies Rotary’s objectives of community benefit and aids the socially disadvantaged. Thirdly, low community awareness about Acquired Brain Injury is raised. Fourthly, injury prevention moneys are available to the Bureau to match community interest in road safety. Fourthly, and most importantly for the Association’s mission, the benefits to the speakers of sharing their experience of ABI, of simply being heard, are immense. A survey conducted of speakers involved in a similar program - Sydney’s Westmead Hospital “Think Twice” - found that while none were working or studying at commencement, 60% had left the program after 18 months to commence full or part-time work or study. For many of the speakers, their involvement in the program represented their first social venture since their ABI.

The Australian Institute of Health and Welfare’s (AIHW) 2007 report into “Current and Future Demand for Specialist Disability Services” found that, despite an increase between 1998 and 2003 of 25,300 people aged 15–64 years with severe or profound core activity limitations who were not in the labour force, unmet demand for Commonwealth State/Territory Disability Agreement (CSTDA)-funded Community Access Services - providing opportunities for people with a disability to enhance their social independence by accessing services and facilities generally available in the community (like the “speakers” programs, above) – had actually decreased by around 4,500 during the same period, though the AIHW report warns that “in coming years, demand for community access services may be expected to increase, due to growth of the CSTDA target population.” Moreover, “among people aged 0–64 years, the broad disability groups with the highest projected growth rates are physical/diverse disability (6%) and *Acquired Brain Injury* (5%)”. In terms of “national actions” that can be written into the National Disability Strategy, ***Brain Injury Australia is***

***convinced that a commitment by Australian Governments to additional funding of Community Access Services will act to break down barriers to social engagement for not only people with an ABI, but people with a disability generally.***

### 3. Education:

Brain Injury Australia's precursor, the Head Injury Council of Australia (HICOA) was commissioned in 1994 by the then Commonwealth Department of Employment, Education and Training (DEET) to write a comprehensive survey of the experiences of students with an ABI in Australian primary and secondary schools. HICOA's report noted that the "definitions of disability vary in each state, as do the criteria for determining eligibility for special education services". Work completed for the Commonwealth Department of Education, Science and Training (DEST) six years later confirmed "a lack of uniformity across Australia in the way in which students with disabilities were identified with different criteria being used for operationalising the definitions across the states and territories. Our findings also suggested it was possible for students who are not in the DETYA [Commonwealth Department of Education, Training and Youth Affairs] categories to be unidentified or for there to be under-identification." Furthermore "most states and territories did not have a definition of disability *per se*, and most education departments referred to students with disabilities as a group or to categories of disability...There was considerable variability as to which categories of disabilities were provided for".

Brain Injury Australia believes that access to educational supports for students with disabilities should be consistent between jurisdictions, not the least reason for which is the need for portability of benefits - families of children with disabilities should be able to move interstate as freely as any other. Almost 15 years after HICOA's report, Brain Injury Australia notes that little progress has been made towards uniformity, even with the passing of the Disability Standards for Education in 2005 that; mandated "reasonable adjustments" be made by all public and private educational institutions, primary and secondary schools, and tertiary institutions such as Technical And Further Education(TAFE), private colleges and universities to meet the terms of the Disability Discrimination Act, 1992 (DDA) and made it unlawful for an educational authority to discriminate against someone on the basis of their disability.

***Brain Injury Australia recommends the National Disability Strategy include the following "national actions": that the Department of Education, Employment and Workplace Relations to standardise the definitions of disability across all Australia's States and Territories - applying equally to both Government and Non-Government education providers - to ensure students with disabilities are not discriminated against purely on the basis of where they live and also to ensure the portability of access to educational supports across jurisdictions.***

As Brain Injury Australia believes there should be uniformity in eligibility for educational supports for students with an ABI between States and Territories and that access to those supports should not be at a jurisdiction's discretion, it also believes in equality of access to those same supports *across disability types and categories*. Brain Injury Australia could not find an educational jurisdiction that either; named ABI as a qualifying *subcategory* for access to Australian Government-funded Literacy, Numeracy and Special Learning Needs or Non-Government Centres Support (NGCS) or indicated "Cognitive Disability" as a non-categorical major grouping alongside, for example, "Intellectual Disability" or "Autism Spectrum Disorder"/ "Asperger Disorder".

***Brain Injury Australia recommends the National Disability Strategy include the following "national actions": that the Department of Education, Employment and Workplace Relations standardise the definitions of disability across all Australia's States and Territories - applying equally to both Government and Non-Government education providers - to include the category "Cognitive Disability" as being eligible for Australian Government-funded programs for students with disabilities and that category subsume "Acquired Brain Injury", by name.***

In correspondence that formed part of the preparations for Brain Injury Australia's May, 2008 policy paper for the Department of Families, Housing, Community Services and Indigenous Affairs on "Children, Young People and Acquired Brain Injury" a number of States' and Territories' education departments wrote that eligibility for educational supports for students with an ABI "varies depending on the level of impact of the ABI and many students are ineligible." Brain Injury Australia remains unconvinced that Australian schools are always able to access the expertise to judge either the severity or impacts - short or long-term - of ABI in students. The Head Injury Council of Australia's 1994 report noted that "traditional school-based psychological testing...has been found to be inadequate in thoroughly describing the cognitive, behavioural and psychosocial function" of students with an ABI. In circumstances where a student's ABI is identifiable from, for instance, the report of a health professional a comprehensive neuropsychological assessment – comprising measures of intelligence, emotion and behaviour, attention, memory and learning, planning and organization, language, perceptual and motor abilities – is the only valid and verifiable tool for evaluating the educational (and other) needs of a child or young person with an ABI. In spite of the mandate provided by the Disability Standards for Education in 2005, that all "education providers...must take reasonable steps" to "ensure that the student has access to...*specialized support services necessary* for the student to be able to participate in the activities for which he or she is enrolled", the same consultations (above) have demonstrated that a neuropsychological assessment for students with an ABI is not the norm and that the default assessment tool for a student with an ABI is an Intelligence Quotient (IQ) test. IQ tests have been shown to fail to pick up the "specific neurobehavioural domains that are particularly vulnerable to the impact of ABI, for example, attention, speed

of processing, memory and learning.” Moreover, “IQ measures are unable to detect the subtle shifts occurring as a consequence of mild TBI” (the majority of TBIs, above) and “often place the performance of students with an ABI within normal limits, despite the presence of ‘significant processing and learning disorders.’”

***Brain Injury Australia recommends the National Disability Strategy include the following “national actions”: that the Department of Education, Employment and Workplace Relations ensure that the services of a neuropsychologist - to provide comprehensive assessments of students with an Acquired Brain Injury - are made available across all Australian States and Territories’ educational jurisdictions and to both Government and Non-Government education providers.***

#### 4. Employment:

Brain Injury Australia’s 2002 study into ABI and employment included detailed individual interviews and focus groups conducted with over 50 people with an ABI (as well as family members and carers). They represented men and women aged 20 to over 60 of different cultural, educational and socio-economic backgrounds and types of ABI. The results of the consultations proved that, while employment was clearly crucial to social inclusion, employers represented the largest barrier to people with an ABI gaining meaningful work. ***Brain Injury Australia recommends that the National Disability Strategy include as “national actions” provisions for training and incentives for employers, specifically to counteract negative stereotyping of people with a disability as being too difficult, too time-consuming or too expensive to employ.***

Many people with an ABI do not readily disclose their disability. And there may be a host of reasons for secrecy – the age at which a person acquired their brain injury, its causes, its consequences etc. ***Brain Injury Australia argues that disclosure is almost always a two-way street, that: as much as government agencies and employment services providers, for example, may expect that is the person’s responsibility to acknowledge their disability, they have at least an equal responsibility to make their practices – and their staff – disability-aware enough for the client environment to be conducive to disclosure. Brain Injury Australia believes that the kinds of “national actions” called for to remove these barriers derive from the dedicated awareness-raising strategies detailed above.***

Where a person feels comfortable to disclose their ABI they may not necessarily have a high awareness of areas in their post-injury capacities that require additional support for finding and keeping employment. Unrealistic employment goals and a lack of insight are some of the characteristics of people with ABI often described by service providers and more generally in the research literature. Some people with an ABI are unable to recognise the behaviours which are not acceptable in workplaces.

Where a person feels comfortable to disclose their ABI, their Job Capacity Assessment may not reflect the level of pre and post-placement supports they may need and/ or their Job Network or Disability Employment Network may not be able or willing to put such supports in place. ***Brain Injury Australia believes that the kinds of “national actions” called for to remove these barriers to successful employment placement derive from awareness-raising strategies targeting government and employment services, specifically Job Capacity Assessors, Centrelink, Job Network and Disability Employment Network staff and vocational rehabilitation providers.***

Many people with an ABI (especially in the moderate or mild categories) do not see themselves as having a disability and, thus, as candidates for the disability employment system. Brain Injury Australia’s 2002 study uncovered a pattern of people with an ABI moving in and out of the general employment market seeking to use their abilities, often self-initiating job applications, and often finding their new incapacities irreconcilable with the kind of work they undertook before their ABI. The costs of these initial failures – in damage to self-confidence and, importantly, in an entrenched reluctance to re-engage with the job market are very considerable.

Disability employment services were seen as the “last resort”, particularly employment services where groups of people with different types of acquired and developmental disabilities were working together. This was because of the association with people with other disabilities – especially intellectual disability, with which ABI is regularly confused - and the perceptions by people with an ABI of the low expectations attributed to workers with disabilities in these settings. This failure to accept the existing disability employment service options could sometimes be interpreted as people with an ABI lacking insight, being unrealistic. Perhaps so, in certain cases, but from a client-of-a-service’s perspective their experience remains valid.

## ***What areas of research do you think should be a priority to better inform the National Disability Strategy?***

### 1. Prevalence:

***Brain Injury Australia believes that the best beginnings of research in the area of disability are accurate counts of populations, crucially but not solely, by disability type.*** The survey ordinarily cited as the authority on disability *prevalence* is the Australian Bureau of Statistics' Survey of Disability, Ageing and Carers – which, in 2003, arrived at an estimate of 432,700 people (2.2% of the population) living with an Acquired Brain Injury with “activity limitations” or “participation restrictions”.

It should be noted that: the 2003 Survey's sample was small (“14,000 private dwellings and 300 non-private dwelling units...36,241 people for the household component and 5,145 people for the cared-accommodation component...”); the Survey's estimates were based on respondent's *self-reporting* (which, given the circumstances in which many people acquire their brain injury – often associated with embarrassment, shame, guilt and grief – would have resulted in significant underestimation); the Survey had no capture of “those living in remote and sparsely settled parts of Australia” (which, given the numbers of Indigenous Australians living with an ABI – around three times the non-Indigenous rate – would have resulted in significant underestimation); the Survey had no capture of prison or homeless populations (where people with an ABI are radically over-represented – comprising between 40% and 80% of the former and 10% to 30% of the latter); and the Survey acknowledged systematic underestimation of those with multiple disabilities (where one in four people with an ABI reported four or more disability groups - compared with one in eighteen of all people with disability – and one in three people with an ABI reported 5 or more health conditions, compared with about one in eight of all people with disability).

Brain Injury Australia and its State and Territory member organisations believe that it is reasonable to expect, from the above, that the true number of Australians living with an ABI easily exceeds 500,000.

Brain Injury Australia welcomes the commitment by the July, 2008 Community and Disability Services Ministers' Conference of an additional \$6.5 million to enhance the next iteration of ABS' Survey of Disability, Ageing and Carers, including doubling the sample size. Brain Injury Australia hopes that the additional funding will enable a greater level of sophistication in the design and use of the Survey's instruments to detect ABI in circumstances where respondents (or their surrogates) are reluctant to disclose or minimise their levels of impairment resulting from their ABI.

## 2. Data Collection:

***The beginning and end of Brain Injury Australia's work is building awareness of ABI. Any attempts at "top down" awareness raising via the evidence-based arguments contained in submissions like this is hamstrung while "bottom up" government services data collection fails to allow (privacy provisions notwithstanding) for the recording of client information by disability type.***

For example, in its submission to The Australian Government's Green Paper "Which Way Home? A New Approach to Homelessness", Brain Injury Australia related its frustration that, given the difficulties in detection and the reluctance of many people with an ABI to disclose their disability, throughout the twenty-three years in which the Australian Government's Supported Accommodation Assistance Program (SAAP) has been in operation, its National Data Collection Agency (NDCA) – managed by the Australian Institute of Health and Welfare (which, peculiarly, recognises and records ABI specifically in every other avenue of its research) – still does not invite self-report of ABI in its "Client Form", thought it does for intellectual and physical disability and while offering "psychological", "specialist counselling" and "psychiatric services" as well as "drug/ alcohol support or intervention" as "specialist services" in its "support to client".

## 3. Outcomes Studies:

The body of local research into ABI is blessed with strong outcomes studies from longitudinal surveys. Their results are uncontroversial, and consistent – that people with an ABI generally make a good "physical" recovery but retain significant cognitive and psychosocial impairments (and the extent of both is positively correlated to one broad measure of injury severity - length of Post-Traumatic Amnesia).

For example, the longest long-term follow-up study of the outcomes of ABI ever conducted in Australia - of 100 men admitted with TBI to Sydney's Lidcombe Hospital between 1976 and 1981, referred to above - found that 85% had used at least one service relating to their ABI in the preceding 12 months and that their unmet needs remained high, "especially in the social participation (73%), vocational (67%), and respite (38%) areas...restrictions in social participation were prevalent (e.g., 66% for employability, 54% for interpersonal relationships)".

***Brain Injury Australia believes that, given the consistency in results of local outcomes studies (and their consistency with results from overseas) and given the natural limitations to research funding on disability, that a focus of research on the psychosocial results of ABI and building an evidence base of "what works" in the areas of social and workforce participation for people with an ABI is needed – e.g. studies into take-up rates and/or barriers to entry for people with an ABI to CSTDA-funded Community Access Programs.***

#### 4. Criminal Justice System:

People with an ABI are radically over-represented in Australia's prisons. A 2003-04 survey of 200 New South Wales inmates found that 82% had experience of Traumatic Brain Injury (TBI), with 65% reporting a loss of consciousness and, of those, 52% said they had ongoing effects (headaches, memory loss, personality or behavioural change, anxiety or depression etc.) and 22% had sustained four or more TBIs. These kinds of prevalence rates have been broadly replicated by similar studies conducted by the NSW's Department of Juvenile Justice, its Corrections Health Service, the Centre for Health Research in Criminal Justice and Victoria's Department of Justice. Overall, somewhere between 40 and 60 per cent of people in custody in NSW and Victoria report ABI. And these local survey results conform to results from overseas.

***But Brain Injury Australia is aware of only two jurisdictions - South Australia and the Australian Capital Territory – that screen prisoners for a history of ABI at reception. Brain Injury Australia is also unaware of any jurisdiction that screens detainees in juvenile justice for a history of ABI at reception.***

The Australian Institute of Health and Welfare's 2007 report into prisoner health noted that "there is no routine injury surveillance within Australian correctional systems. Jurisdictions report rates of 'prisoner on prisoner' and 'prisoner on staff' assaults as part of the annual Report on Government Services published by the Productivity Commission. However, this is simply a tally of the number of 'Governor's Reports', is administrative in nature, lacks detail, is likely to underreport injury, and does not aim to serve any public health purpose." This is in spite of the fact that in New South Wales prisons, for example, assaults are the second most common injury treated in prison clinics. Whether a prisoner brings their ABI with them into prison or acquires one while there, the potential consequences – in cognitive function, in changed behaviour etc. while detained or post-release – and the resultant increased risk of re-offending is the subject of an emerging body of international research evidence. ***Brain Injury Australia believes that local research examining the relationship between ABI and offending (and recidivism) rates – underpinned by universal screening for ABI at reception and better injury surveillance in corrective services – is a priority, alongside pre- and post-release programs for prisoners with an ABI.***

#### 5. Indigenous Australians:

Brain Injury Australia acknowledges the recognition given in the "Discussion Paper for Consultation" to the higher prevalence rates of disability among Indigenous Australians. There are no reliable estimates for the rates of ABI in Indigenous communities. However, it is almost universally accepted that, especially given the extent of alcohol and other drug abuse, that they would be significantly higher than that in non-Indigenous communities. Specifically: the

transport injury rate for Indigenous Australians is up to three times that of non-Indigenous Australians; a recent study demonstrated the rate of “head injury” due to assault in the Indigenous populations of QLD, WA, SA and the NT was more than 20 times that of non-Indigenous populations (the rate of head injury due to assault in Indigenous women was almost 70 times that for non-Indigenous women); even given its relatively young population, the median age for stroke in the Northern Territory (where Indigenous Australians account for 30% of the population) is 20 years below the national average and between 1999 and 2006, 60 Indigenous Australians in the Northern Territory have died from petrol-sniffing and a further 120 have suffered permanent “brain damage”. ***Brain Injury Australia insists that ABI in Indigenous communities become a research priority for informing the National Disability Strategy.***

Generally, Brain Injury Australia believes that: data collection on disability should be undertaken in conjunction with national censuses and household surveys and in close collaboration with universities and other research facilities; disability-focused and general health and welfare research should be integrated through the establishment of a forum where researchers and the disability sector can exchange information related to disability and research; a national publicly-accessible database should be established on disability-related research with the aim of identifying gaps in the knowledge base; and the National Disability Strategy should include provision for the facilitation of the publication of market-relevant and significant research findings.