



**BRAIN INJURY AUSTRALIA:**  
**submission to the**  
**Australian Government Department of**  
**Education, Employment and Workplace**  
**Relations' Review of Disability**  
**Standards for Education 2005**

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## **Foreword:**

The submission that follows: firstly, noting the December 2010 Discussion Paper invites submissions that "may answer all or some of the questions" contained therein, mainly addresses questions 3 ("Access to education and training opportunities") and 5 ("Awareness and recognition") of the Discussion Paper; secondly, compiles arguments from Brain Injury Australia's long-standing interest in issues relating specifically to children with the disability, including its 2007-2008 and 2009-2010 policy papers - prepared for the Australian Government's Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) – on "Children, Young People and Acquired brain injury" and "Inflicted Traumatic Brain Injury in Children", respectively; and, thirdly, on a Brain Injury Australia's precursor, the Head Injury Council of Australia's (HICOA) submission to the Senate Employment, Workplace Relations and Education References Committee 2002 Inquiry into the Education of Students with Disabilities.

As per the Discussion Paper, Brain Injury Australia provides this submission as a "peak/community organisation". 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. The major components of Brain Injury Australia's role are: advocacy for Australian Government program allocations and policies that reflect the needs and priorities of people with an ABI and their families, and the provision of effective and timely input into policy, legislation and program development through active contact with Australian Government ministers, parliamentary representatives, Australian Government departments and agencies, and national disability organizations.

## **Background:**

**Acquired brain injury (ABI) refers to 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 applied to the head from an assault, a fall a motor vehicle accident. ABI is common in Australia. In 2003, 432,700 people (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions”<sup>1</sup> due to their disability.<sup>2</sup> 317,900 Australian children were living with a disability, about 1 in 12 of all Australian children. 162,800 children had “physical/diverse disabilities” - an estimated 22,800 of whom were children with an ABI.<sup>3</sup>**

Of the 432,000 Australians with an ABI:

- **One in four reported four or more disability groups**, compared with one in eighteen of all people with disability.
- **One in three people with an ABI reported 5 or more health conditions**, compared with about one in eight of all people with disability.
- **Only 12,000 of them accessed Commonwealth State/Territory Disability Agreement (CSTDA)-funded services in 2004-05.**
- People with an ABI accounted for 6% of all CSTDA service users.
- About half (51%) of service users with ABI had a carer, compared with 42% of CSTDA service users generally.
- More than two-thirds (68%) of service users with an ABI were male, compared with 56% of CSTDA service users overall.<sup>4</sup>

**The international literature shows that ABI is 10 times more common than spinal cord injury and produces, on average, 3 times the level of disability.**

**Nearly all of the children (90%) who were identified as having an ABI - as a “main” or “associated disabling condition” - had “severe or profound core activity limitations”;** 11,400 of 12,700 children. **A total of 38,382 children aged 0–14 years accessed CSTDA-funded services in 2003-04.** The vast majority (87%) of children with disabilities accessing CSTDA-funded services accessed community support services. The next most commonly accessed CSTDA-funded service was respite—accessed by 18% of children. Brain Injury Australia estimates that – from their proportion of the total identified as having “physical/ diverse disabilities” – **only 445 children with an ABI accessed CTSDA-funded services.**<sup>5</sup>

In 2004–05, there were **21,800 admissions to Australian hospitals for which a diagnosis associated with TBI** was recorded as either the principal or an additional diagnosis.

- **3,700 of those admissions were for children aged 0-14 years.**
- **Approximately 6,000 for young people aged 12-24.**
- **Males accounted for more than two-thirds (69%) of admissions.**

**“Over one-third of all deaths in Australia for children are from injury. About one in five people admitted to hospital due to injury in 2001-02 were children.** Falls were the most common cause (43%). Transport accounts for fewer cases (14%) but these tend to be severe. The special vulnerability of toddlers to injury is indicated by the prominence of drowning and pedestrian injuries in this age group. For older children, the prominence of injuries related to cycling and falls...reflects the exploratory and adventurous character of this stage of life.”<sup>6</sup>

The limitations that apply to national level data on the incidence of ABI also apply to any assessment of the causes of ABI. The NSW Brain Injury Rehabilitation Program provides treatment to people with a severe TBI and other sudden onset ABI. Of the **261 new admissions of children aged 0-14 years to the NSW BIRP during 2006-07:**

- **27% were the result of a fall or dive**
- **9% were passengers in a motor vehicle accident**
- **9% were pedestrians hit by a motor vehicle**
- **7% were assault/non-accidental (largely the result of child abuse or domestic violence)<sup>7</sup>**
- **6% cerebral haemorrhage**
- **5% were sport-related**
- **16% were non-traumatic brain injury<sup>8</sup>**

“Children from low socioeconomic backgrounds and Indigenous Australian children...have a higher risk of injury and death from injury than other Australian children. Children from low socioeconomic groups are more likely to suffer injury from certain causes, such as house fire or assault, which are more often fatal than other causes of injury. The likelihood of a child being injured or killed has also been associated with single parenthood, low maternal education, young maternal age at birth, poor housing, large family size, and parental drug or alcohol abuse.”<sup>9</sup>

The consequences of an ABI in a child or young person 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 children and young people with an ABI experience cognitive problems, including **poor memory and concentration, reduced ability to learn, plan and solve problems.**

Even given the limitations in the incidence data detailed above, crucial to any understanding of the costs of ABI to individuals, families and communities is that **its incidence is highest in children needing to learn and form relationships and young people in the prime of life, coinciding with important events such as completing secondary education, entering further study or employment and establishing their own families.**

In that context the psychosocial-emotional problems consequent to ABI can be debilitating - emotional instability, irritability, and impulsive or inappropriate behaviour are common. These can, in turn, lead to the onset of depression and other mental illness related to many factors including grief, loss of self-esteem and self-confidence, the loss of friends and social networks and employment, enforced dependency and, in certain circumstances, drug and alcohol abuse, criminal activity and homelessness. But ABI is often referred to as the “**invisible disability**” because its consequences (above), even if observable, are often not associated with disability generally nor ABI specifically. This is especially the case with people with a mild or moderate ABI.

The Australian Bureau of Statistics' 2003 *Survey of Disability, Ageing and Carers* provides information on need for assistance across 10 “life domains” - three core activities (mobility, self-care and communication) and seven “non-core activities”. The area with which people with ABI most **commonly required assistance was cognitive and emotional tasks. Over 100,000 people, or more than one-third of all people with ABI aged under 65 years, reported needing help in this area.** Compared with people with disability generally, people with ABI were more likely to need assistance with mobility, self-care, cognitive and emotional tasks, paperwork, transport, health care and meal preparation. **Almost 30% of people with ABI aged under 65 years living in households needed help with at least one core activity, and 4% needed help with all three core activities. In comparison, 26% of people with disability generally needed help with at least one core activity, and 2% needed help in all three areas.**

Traditionally, children have been reported to have better outcomes from ABI than adults. This is thought to be due to the child's brain's increased plasticity – its capacity for repair. However, cognitive deficits and psychosocial-emotional problems may not become apparent until later in the child's development. These pose difficulties for parents, teachers and healthcare workers. There is often a poor fit between the needs of children with ABI, and both mainstream and “special” school educational programs. Parents and teachers often face many challenges, including coping with a child with an ABI's changed learning capacity and academic performance, changed behaviour and friendship networks, a changed self-identity.<sup>10</sup>

The socioeconomic profile of Australian families that have a family member with a disability indicates a strong association between the prevalence of disability and low income. **“In 1998, 70% of household-living Australians aged 15–64 years with a profound core activity restriction, and 56% of those with severe restrictions, were in the two lowest income quintiles, compared with 31% of people without a disability. Poverty rates almost double with the addition of a disabled child: 7.4% of Australian households without a disabled child are poor, compared with 12.3% of households with a disabled child.** Australian households with a disabled child are more than twice as likely to experience financial hardship, restricted social participation, unmet needs and a lack of support.”<sup>11</sup>

A large population-based study of 8,000 families in the UK found that couples who have a child with a disability were at an 80% increased risk of living in poverty. Three-quarters of UK families with a disabled family member are located in the bottom half of income distribution. Three-quarters of British families with a child with a disability surveyed during 1985 and 1988 reported not having enough money to care for their child. They face, on average, three times the financial costs of parents who do not have children with a disability.<sup>12</sup> Another UK study of parents of 100 children with a TBI found that majority of them had either taken significant unpaid leave or given up work entirely within twelve months of their child’s injury.<sup>13</sup>

“Research estimating equivalence scales for Australian households - comparing the relative financial wellbeing of those with, versus without, a disabled member - found that when taking the cost of disability into account, the poverty rate for households with a disabled adult jumped from being 1.2 times that of households without a disabled adult to 6.6 times. The resulting poverty rate of 29.7% amongst households with a disabled adult suggests a major public policy failure.”<sup>14</sup> Both the findings of the Australian research and results of the UK studies, described above, directly coincide with the response to the extensive consultations with parents, carers and service providers conducted by Brain Injury Australia as part of the preparations for this paper.

## **Education:**

In 2003, 97% of children with a disability aged 5–14 years were attending school - 89% of them in mainstream schools and 9% in “special” schools. While the mainstreaming of children with disabilities within the education system has increased substantially over the last 20 years, the proportion of students with disabilities attending mainstream schools in the government sector varied greatly between jurisdictions, from 95% in Tasmania and the Northern Territory to 66% in Victoria. Similarly, in the non-government sector, the

proportion attending mainstream schools varied from 88% in New South Wales to 100% in the Northern Territory.<sup>15</sup>

1. ***“Question 5 Awareness and recognition” of the Review’s Discussion Paper*** asks; “do you think the Standards have raised awareness and increased understanding of the issues affecting people with disability and their rights to access and participate in education and training?” Brain Injury Australia believes that public understanding of ABI lags around 20 to 30 years behind that of other disabilities. ABI is often referred to as the “hidden” or “invisible” disability. This operates in at least four ways. Firstly, at the level of population; in official estimates of prevalence significant numbers of Australians with an ABI are simply unknown to government. For example, one of the fundamental documents in estimating the prevalence of disability in Australia - the Australian Bureau of Statistics’ Survey of Disability, Ageing and Carers (last conducted in 2003) - significantly underestimates the number of people living with an ABI. The ABS Survey’s sample comprised “14,000 private dwellings and 300 non-private dwelling units”, covering “people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia.” Estimates of the prevalence of ABI in Aboriginal and Torres Strait Islander (ATSI) communities generally, and in the Northern Territory specifically (where ATSI comprise 30% of the population) indicate rates up to three times that for non-ATSI communities. The ABS Survey estimated that 432,700 Australians (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions” because of their disability. Due to the deficiencies in the ABS Survey’s sampling, Brain Injury Australia is confident that over 500,000 Australians have an ABI. Secondly, due to the severity, multiplicity and complexity of disability experienced by children with an ABI, or the circumstances in which their brain injury was acquired (physical abuse during their first year of life, for example), many children “hidden” from such government surveys may not know that they have a disability. Conversely, HICOA’s 2002 submission noted that ABI-specific services “believe there are much larger numbers of children with milder head injuries who still have significant learning and behavioural issues resulting from these injuries. It is unlikely that many of these children will come to the attention of these services or the education system, certainly not without a proactive approach including education and awareness training of school staff”. Thirdly, due to the circumstances in which their brain injury was acquired, or as a function of the resulting disability, many children with an ABI may have a reluctance to disclose their disability. Feelings of embarrassment, guilt or shame are powerful deterrents to talking openly about disability. The ABS Survey recognised this: “A number of people may not have reported certain conditions because of: the sensitive nature of the condition... [and]

a lack of awareness of the presence of the condition on the part of the person reporting..." Also, "the need for help may have been underestimated, as some people may not have admitted needing help because of such things as a desire to remain independent..." Fourthly, lack of societal awareness compounds the problem. The majority of children with an ABI make a good *physical* recovery and often they will show no outward signs of disability. The common effects of injury, such as poor short-term memory, fatigue or irritability can be misinterpreted as simply flaws in the person. Children are often mistaken as unintelligent, uncooperative, unmotivated or alternatively aggressive and unpredictable. Brain Injury Australia believes that public understanding of ABI lags around 20 to 30 years behind that of other disabilities. Such a lack of public understanding of ABI is doubly disabling for the child affected: not only are these "invisible" disabilities not recognised as resulting from an ABI, they are seen as a function of who the person really is.

Even if Brain Injury Australia thought "awareness" and "understanding of the issues affecting" students with an ABI had "increased" since the introduction of the Standards, it would remain pure speculation. There is little, if any, data to measure changes, even in the *inclusion* of students with specific disabilities.

As part of the preparation of its 2007-2008 paper for FaHCSIA on "Children, Young People and Acquired brain injury", Brain Injury Australia contacted the "students with disabilities" section of each State's and Territory's department of education as well as the relevant non-government schools' representatives requesting information about: their numbers of students with an ABI and enrolment information and eligibility criteria for their Australian Government-funded Literacy, Numeracy and Special Learning Needs (LNSLN) Programs – that "improve the literacy, numeracy and other learning outcomes of disadvantaged students, including those with disability" - and Non-Government Centres Support (NGCS): funding "targeted to support learning and educational development opportunities for children with disability who are below school age to prepare them for integration into regular pre-schools or schools; assist school-aged children with severe disability by improving their access to educational programs; or assist children with disability in residential care."<sup>16</sup>

**No government or non-government primary or secondary education body collected statistically reliable information about students with disabilities by disability type.** A 2002 survey of Australia's Vocational Education and Training (VET) students conducted by the National Centre for Vocational Education Research (NCVER) found that: 2.0% of all students with a disability (1856 students

of 91, 439) “reported that they had” an ABI; a “very high proportion of students” with ABI reported multiple disabilities; the proportion of students with ABI who completed an Australian Qualifications Framework (such as diplomas or certificate IIIs) was “markedly lower” than that for all VET students and their employment rate was “lower than that for most other disability categories”.<sup>17</sup>

Brain Injury Australia’s 2007-2008 policy paper recommended that, in order to assess whether Australian Government-funded programs are meeting the needs of all students with disabilities, FaHCSIA work with the Department of Education, Employment and Workplace Relations to ensure that all State and Territory Government and Non-Government education providers maintain records on the numbers with students with disabilities, *by disability type* – including, by students with acquired brain injury.

2. **“Question 3 Access to education and training opportunities” of the Review’s Discussion Paper asks:** “have you or a person you know with disability, experienced difficulties enrolling in an educational institution or participating in educational activities on the same basis as people without disability?”

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”**.<sup>18</sup> 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”**.<sup>19</sup>

Brain Injury Australia’s 2007-2008 policy paper recommended that FaHCSIA work with DEEWR 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.

**Brain Injury Australia also 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 17 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.

However, "while the Australian Government provides substantial funding to the States and Territories for schools, including targeted funding to support educationally disadvantaged students, the State and Territory education authorities determine how these funds should be used and are responsible for the day-to-day operation of their schools and related student support services."<sup>20</sup> **As with the eligibility criteria for income support via Centrelink, Brain Injury Australia, while not having evidence (apart from the anecdotal experience of parents) for the *systematic exclusion* of students with an ABI from access to the educational supports required under the legislation, neither has any evidence of the *positive inclusion* of students with an ABI in any educational jurisdiction. 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 LNSLN or NGCS supports or indicated "Cognitive Disability" as a non-categorical major grouping alongside, for example, "Intellectual Disability" or "Autism Spectrum Disorder"/ "Asperger Disorder". Brain Injury Australia is not reassured by promises that students with an ABI are "usually identified under the broad disability types listed above"<sup>21</sup> when its consultations with parents prove otherwise, when *community awareness about ABI is low and there is little teacher training in general disability, and even less specifically in ABI*. As one NSW paediatrician**

put it during the consultations that inform this paper, the only teacher training available is “having one [a student with an ABI]”.

Brain Injury Australia’s 2007-2008 policy paper recommended that the FaHCSIA work with DEEWR to 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.

A number of jurisdictions responded 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.”<sup>22</sup> Based on the extensive consultations conducted as part of the preparations for its 2007-2008 paper, **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. Furthermore, HICOA noted “a student with a mild-to-moderate acquired brain injury can perform relatively well in this kind of contrived situation and therefore is not considered ‘severe’ enough to require any student services support. However, within a classroom situation, where there are distractions, where they are left to work alone and are required to initiate, organise, plan and judge, a student with an acquired brain injury is unable to adequately access the curriculum or engage in the education opportunities provided within the classroom. These students, the quiet ‘non-achievers’ who pose no problems but fail to achieve their personal best, or the ‘behaviour problems’ who are aggressive, frustrated and incorrectly labelled, begin their downward spiral at school, often ending in truancy and low student retention and participation.”

The lack of recognition of the impact of brain injury on educational outcomes quite often means that appropriate low-cost, early intervention strategies are not implemented in a timely manner. 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 demonstrated as failing 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”<sup>23</sup> (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.’”<sup>24</sup>

Brain Injury Australia’s 2007-2008 policy paper recommended that that FaHCSIA work with DEEWR to 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.

Brain Injury Australia is unaware of any local studies examining the frequency of outcomes from ABI in childhood that result in difficult or “challenging behaviours”; impulsivity, overactivity, verbal and physical aggression, disinhibition etc. A British study of 70 school-age children with TBI found that two-thirds of students with an ABI “exhibited significant behavioural problems...significantly more” than control groups of children without ABI. Moreover, the study found a “strong link” between school performance and behavioural problems, over three-quarters of children identified by teachers as having serious behavioural problems also had difficulties with schoolwork.<sup>25</sup> A US study of 190 children found that TBI was “associated with an increased rate of behaviour problems that persisted for several years after the injury” and that those problems “were a significant predictor of...deteriorated classroom academic performance”, even when accounting for race, socioeconomic status, and the child’s “academic skill”.<sup>26</sup> The difficulties Australia’s teachers experience in managing the challenging behaviours of students with disabilities *have* been well researched. A 2001 study of 571 primary school teachers in Queensland found that the **difficult or challenging behaviour of students with “special needs” was not only a significant stressor but also represented an occupational health and safety issue for teachers** who reported a wide range of serious and sometimes dangerous situations with which they had to cope on a daily basis.<sup>27</sup> **However, educational outcomes for students with an ABI like those recorded in the High Court of Australia’s 2003 decision in Purvis v New South Wales (Department of Education and**

**Training) may have been avoided if education staff training in ABI was made available.** A two-year long survey of 8 Australian families of adolescent students returning to school after an ABI found that hospital rehabilitation teams, school executive staff, counsellors and parents needed to “teach the teachers” about what they may expect: “participants reported that many classroom teachers did not have a sufficient level of understanding of ABI and consequent academic needs.”<sup>28</sup> HICOA’s 2002 submission noted “many young people who have not been linked in with school-based support services or allied health consultation services have reported that: their teachers have not understood them or their needs; they have experienced bullying and discrimination; and their resulting distress has been so great that they have wanted to leave school.”

Purvis v New South Wales (Department of Education and Training) related to a 13 year-old boy, Daniel Hoggan, whose encephalitis at six months of age left him with a severe ABI, vision impairment, epilepsy and “challenging behaviours” that resulted in six suspensions then finally expulsion from a NSW high school - for verbal and physical aggression towards other students as well as teachers. The Human Rights and Equal Opportunity Commission (HREOC) found that the State had discriminated against Hoggan on the grounds of his disability. The State sought judicial review in the Federal Court of Australia, which set aside HREOC’s decision. The Full Court of the Federal Court unanimously dismissed the foster father’s (Alexander Purvis) appeal and his appeal to the High Court upheld the Full Court’s verdict. Initially, HREOC’s Hearing Commissioner had found that ignorance and a prejudicial bias had informed Hoggan’s “**Individualized Behaviour Management Plan**” and that it had been developed by the school without seeking expertise, specifically, in behaviour management or, generally, in special education. The Commissioner’s view was “if schools are able to receive accurate and informed advice on the current nature of a student’s disability and the educational needs of each student then stereotypical assumptions are less likely to impinge on decision-making.” In light of the Purvis case, Brain Injury Australia remains concerned that, in some jurisdictions like Tasmania, determination of eligibility of students with an ABI for Australian Government-funded programs like LNSLN and NGCS continues to be “discussed and negotiated at the school level, involving personnel within the school and support personnel.”<sup>29</sup>

Results published in 2007 from a DEEWR-funded survey of a 103 teachers from all States and Territories and from primary, secondary and post-compulsory sectors recorded a need for professional development in “special education”; that is “provided by experts and/or other teachers to directly support their current needs” and “involves learning from others’ experience through networking, visiting

and observing.”<sup>30</sup> 1994’s *National Policy On Services For People With Acquired Brain Injury*, developed by Commonwealth, State and Territory Governments stated: “effective service delivery depends on staff expertise and understanding of the special problems – physical, cognitive, social and behavioural – of people with acquired brain injury. Not only should curricula for health and community service workers incorporate packages on ABI, but in addition, short briefing courses should be available for staff, such as school teachers and home care workers, to assist them in dealing with one-off situations.” HICOA’s 2002 submission commented; “this statement is a clear recognition of the need for education programs for staff training in acquired brain injury as well as relevant professional expertise within student support units.”

Brain Injury Australia’s 2007-2008 policy paper recommended that that FaHCSIA work with DEEWR and with Brain Injury Australia - and its State and Territory member organisations - to make teacher-training (undergraduate, postgraduate and in-service) in Acquired brain injury available in all State and Territory educational jurisdictions and to both Government and Non-Government education providers.

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<sup>1</sup> Participation restrictions are “problems an individual may experience in involvement in life situations” such as attending school or participating in recreation. (Australian Bureau of Statistics’ 2003 Survey of Disability, Ageing and Carers)

<sup>2</sup> Brain Injury Australia considers the Australian Bureau of Statistics’ 2003 Survey of Disability, Ageing and Carers significantly underestimates the real number of Australians with an ABI. The survey’s sample comprised “14,000 private dwellings and 300 non-private dwelling units”, covering “people in both urban and rural areas in all states and territories, except for those living in remote and sparsely settled parts of Australia. The exclusion of these people will have only a minor impact on any aggregate estimates that are produced for individual states and territories, with the exception of the Northern Territory where they account for over 20% of the population.” Estimates of the prevalence of ABI in Indigenous communities generally, and in the Northern Territory specifically (where Indigenous Australians comprise 30% of the population) indicate rates up to three times that of non-Indigenous communities. The survey had no capture of the criminal justice system or the homeless where estimates of the prevalence of ABI range between 40%-80% and 10%-30% respectively. The survey’s results were “based, wherever possible, on the personal response given by the respondent. However, in cases where information was provided by another person, some answers may differ from those the selected person would have provided.” Brain Injury Australia considers that, given the circumstances in which many ABIs occur – especially in the young, disclosure of the nature and level of impairment, let alone ABI itself, to a government-appointed surveyor may be difficult. The survey recognises this: ““A number of people may not have reported certain conditions because of: the sensitive nature of the condition...[and] a lack of awareness of the presence of the condition on the part of the person reporting...” Also, ““The need for help may have been underestimated, as some people may not have admitted needing help because of such things as a desire to remain independent...” Given the multiplicity and complexity of disability that many people with an ABI experience, cited above, the following statements of survey are also noteworthy: “as certain conditions may not have been reported, data collected from the survey may have underestimated the number of people with one or more disabilities” and “as certain conditions may not have been reported, data collected from the survey may have underestimated the number of people with one or more disabilities.” Brain Injury Australia is grateful that the July, 2008 Community and Disability Services Ministers’ Conference agreed to inject \$6.5 million to enhance the next iteration of ABS Survey of Disability, Ageing and Carers, including doubling the sample size, due for release in 2010.

<sup>3</sup> Australian Institute of Health and Welfare (AIHW), Children with disabilities in Australia, Canberra, 2004, Bulletin 55 and Disability Updates: Children with Disabilities (Bulletin no.42), Australian Institute of Health and Welfare, Canberra, 2006.

<sup>4</sup> ABS SDAC, BULLETIN 55 (see above)

<sup>5</sup> CWD (see above)

<sup>6</sup> National Injury Prevention and Safety Promotion Plan: 2004 – 2014.

<sup>7</sup> “Although deaths from assault are relatively rare among children, fatal outcomes from intentionally inflicted injuries or homicide provide an indication of the nature and extent of extreme interpersonal violence in this age group. Interpersonal violence, including domestic violence and child abuse, is often associated with parental drug and alcohol misuse and mental health problems. Hospitalisation rates for assault capture serious incidents of intentional harm inflicted by other people. This group includes hospitalisations for injuries from domestic violence and child abuse.” (CWD) “Key national indicators of children’s health, development and wellbeing: indicator framework for A picture of Australia’s children 2009”, Canberra, 2008. Moreover, “some children have brain injury as a result of domestic violence, which is unlikely to be disclosed by the family, and the child may never have their brain injury correctly diagnosed. Fortune N and Wen X, The Definition, Incidence And Prevalence Of Acquired brain injury In Australia, Australian Institute of Health and Welfare, Canberra, 1999.

<sup>8</sup> “The data is useful and representative of the injury patterns of severe ABI. Analysis of a case load of the BIR Program to look at the range of severity, the overall outcome and the impact of the disability is not available. ED presentations would give a very different picture. But as the majority of TBI is mild and commonly results in minimal long term disability that data needs to be interpreted differently.” Correspondence to BIA from Robert Bosi, Network Manager, NSW GMCT Brain Injury Rehabilitation Directorate.

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<sup>9</sup> Australian Institute of Health and Welfare, Key national indicators of children's health, development and wellbeing: indicator framework for A picture of Australia's children 2009, Canberra, 2008.

<sup>10</sup> Fary Khan, Ian J Baguley and Ian D Cameron, MJA Practice Essentials – Rehabilitation 4: Rehabilitation After Traumatic Brain Injury, MJA, 2003.

<sup>11</sup> Saunders, P (2005) Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies, SPRC Discussion Paper No. 145, University of NSW. The author is grateful for direction to this research from Dr. Paul Henman from the School of Social Work and Human Services at The University of Queensland.

<sup>12</sup> CWD

<sup>13</sup> F/N Hawley et al. (North Staffordshire Rehabilitation Centre, Stoke-on-Trent, Staffordshire) "Parental stress and burden following traumatic brain injury amongst children and adolescents", Brain injury, 2003, Volume 17, Number 1.

<sup>14</sup> Peter Saunders, "The Costs Of Disability And The Incidence Of Poverty", Social Policy Research Centre Discussion Paper No. 147, UNSW, 2006. (Cited by Henman, above.)

<sup>15</sup> "These data, however, may reflect jurisdictional variation in the availability of special schools, and in enrolment integration policies based partly on definition of disability, which impedes any comprehensive discussion or comparison of what is happening across Australia." (CWD)

<sup>16</sup> Correspondence to Brain Injury Australia Judy Gordon, Acting Director, Students with Disability Section Student Access and Equity Branch, Department of Education, Employment and Workplace Relations (DEEWR)

<sup>17</sup> "As a whole, students with a disability in VET have prior schooling education levels strikingly far below those for all other VET students. About 55% of all people with a disability had left school at or before the end of Year 10, compared with 40% for all VET students. This suggests that developing educational pathways before Year 10 for people with a disability is important as part of an early-intervention approach." Cavallaro et al. "People with a disability in vocational education and training: A statistical compendium", National Centre for Vocational Education Research (NCVER), Adelaide, 2000.

<sup>18</sup> Leith Sterling, Students With Acquired brain injury In Primary And Secondary Schools, Head Injury Council of Australia, Canberra, 1994.

<sup>19</sup> Christa van Kraayenoord et al. "Literacy, Numeracy and Students with Disabilities", Department of Education, Science and Training, Canberra, 2000.

<sup>20</sup> Correspondence to Brain Injury Australia Judy Gordon, Acting Director, Students with Disability Section Student Access and Equity Branch, Department of Education, Employment and Workplace Relations (DEEWR). "For example, the criticism extends to the distortion of schools' understanding of disability, the exclusion of some disability groups from the jurisdictions' operational definition of disability (e.g. learning disability, severe behaviour problems, language disorder), and the discretionary power given to the jurisdictions to decide who may be eligible to receive special education services, and as a consequence, who may have a disability. The lack of consistency in the definition of students with a disability in Australian schools is also causing difficulties in achieving the National Goals of Schooling for these students. However, there have been some recent initiatives that may assist in achieving improved consistency in definition...The proportion of school students with a disability in Australian schools rose from 2.6% in 1996, to 3.5% in 2001. While the DDA has increased awareness of disability in regular schools, which may account for at least some of the increase in the identification of disability, the Act has had a minimal impact on the definition of disability by schools, on enrolment patterns for students with a disability,

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and on regular classroom practice.” (Ian Dempsey (Centre for Special Education and Disability Studies, University of Newcastle), “Recent changes in the proportion of students identified with a disability in Australian schools”, Australia, 2003.)

<sup>21</sup> Correspondence from Trisha Winter, Director, Disability And Statewide Programs, Department of Education and Children’s Services (DECS), South Australia.

<sup>22</sup> Correspondence to Brain Injury Australia from Bill Daniels, Executive Director, Independent Schools Council of Australia.

<sup>23</sup> Vicki Anderson, Elizabeth Northam, Julie Hendy, Developmental Neuropsychology: A Clinical Approach, Psychology Press, 2003-02, p. 160,161

<sup>24</sup> Baxter,R., Cohen, S., Ylvisaker, M.Comprehensive Cognitive Assessment in Ylvisaker (ed.) Head Injury Rehabilitation: Children and Adolescents, San Diego, CA, College-Hill, 1985 cited in Sterling, L. et al (1995), Students With Acquired brain injury In Primary And Secondary Schools, Head Injury Council of Australia, AGPS: Canberra.

<sup>25</sup> Carol A. Hawley (Centre for Health Services Studies, University of Warwick, Coventry, UK) “Behaviour and School Performance after Brain Injury”, Brain Injury, Vol. 18, No. 7, July 2004.

<sup>26</sup> Keith Owen Yeates and H. Gerry Taylor, “Problems in School and Their Educational Correlates Among Children With Traumatic Brain Injury”, Exceptionality, 14(3), 141–154.

<sup>27</sup> Murik et al. (2005), cited in Shaddock et al. “Project to Improve the Learning Outcomes of Students with Disabilities in the Early, Middle and Post Compulsory Years of Schooling”, Australian Government Department of Education, Employment and Workplace Relations, Canberra, 2006.

<sup>28</sup> Nicole L. Sharp, Rosalind A. Bye, Gwynnyth M. Llewellyn, Anne Cusick, “Fitting back in: Adolescents returning to school after severe acquired brain injury”, Disability and Rehabilitation, June 2006; 28(12): 767 – 778.

<sup>29</sup> Correspondence from Carolyn Rennie, Principal Education Officer - Students with Disabilities, Student Programs. Learning Services North, Department of Education, Tasmania.

<sup>30</sup> Shaddock’s et al. (2005) “Project to Improve the Learning Outcomes of Students with Disabilities in the Early, Middle and Post Compulsory Years of Schooling”, Australian Government Department of Education, Employment and Workplace Relations, Canberra, 2007.