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BRAIN INJURY AUSTRALIA

Policy Paper: Children, Young People and Acquired Brain Injury

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Acquired Brain Injury (ABI)

Acquired brain injury (ABI) 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)

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.

prevalence (the number of existing cases at a given time)

ABI is common in Australia. In 2003, 432,700 people (2.2% of the population) had an ABI with “activity limitations” or “participation restrictions” (see Glossary, below) due to their disability:

- **Almost 3 out of every 4 were aged under 65 years.**
- **160,000 had “severe or profound core activity limitations”.** (see Glossary)
- **2 out of every 3 were aged under 65 years, half of them between 15 and 34 years of age.**
- **3 out of every 4 were men.**

27,300 people with an ABI aged under 65 years experiencing “activity limitations” or “participation restrictions” said their ABI was the “main disabling condition” (see Glossary):

- **9 out of every 10 said their ABI was caused by accident or trauma.**
- More than 50% of them said the accident or injury occurred on a street, road or highway.
- 2 out of every 3 said that they acquired their brain injury when they were aged under 25 years of age.¹

prevalence - children

The Australian Bureau of Statistics *2003 Survey of Disability, Ageing and Carers* found that **317,900 Australian children** (see Glossary) **had a disability**, or 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.**²

multiplicity, complexity, severity, service use

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.³

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..

multiplicity, complexity, severity, service use - children

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 – from their proportion of the total identified as having “physical/ diverse disabilities” – that **only 445 children with an ABI accessed CTSDA-funded services.**⁴

incidence (the number of new injuries within a given period)

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.**

cause

“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.”⁵

The limitations that apply to national level data on the incidence of ABI (see “incidence” in Glossary) also apply to any assessment of the causes of ABI. The NSW Brain Injury Rehabilitation Program (NSW BIRP).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)⁶**
- **6% cerebral haemorrhage**
- **5% were sport-related**
- **16% were non-traumatic brain injury⁷**

“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.”⁸

Recommendation One:

Traumatic Brain Injury is highly preventable. Brain Injury Australia recommends that, as part of a whole-of-government approach to Acquired Brain Injury, the Department of Families, Housing, Community Services and Indigenous Affairs encourages the Department of Infrastructure, Transport, Regional Development and Local Government to direct the Australian Transport Council - comprising Federal and all State and Territory Ministers with transport responsibilities - to revise all subsequent National Road Safety Action Plans (constituting the National Road Safety Strategy 2001-2010; aimed at a 40% reduction in the number of road-related fatalities by 2010) to include children as a distinct target for its strategy to “Improve Equity Among Road Users”.

Recommendation Two:

Brain Injury Australia welcomes the Australian Government's promise of a "stronger prevention focus" in the recently proposed National Child Protection Framework – aimed at addressing the 45% increase in cases of child harm, abuse and neglect over the last five years – and recommends, given the circumstances of secrecy in which most child abuse occurs and the subtleties involved in detection of injuries such as Acquired Brain Injury, that the Department of Families, Housing, Community Services and Indigenous Affairs direct that Acquired Brain Injury be included in all current and future workforce training in child protection.

death and disability

Injury is the leading cause of death and a major cause of hospitalisation for Australian children. **Road transport accidents remain the most common external cause of death from injury among children**, despite a 35% decrease in motor vehicle accident deaths between 1995 and 2004. Initiatives such as road condition improvements, enhanced vehicle safety design, increased compliance in child restraint use, public education campaigns and improved trauma care services could account for the decline.⁹

However this reduction in road-related deaths has occurred at the expense of an increase in serious non-fatal TBIs. The heritage of research on the outcomes of TBI shows that roughly 1 in every 5 hospital admissions for TBI (above) will result in some permanent and/or profound disability. In Australia, about a 1,000 child passengers (aged 0–16 years) were seriously injured due to road crashes per annum between July 1999 and June 2002.¹⁰

Recommendation Three:

Traumatic Brain Injury is a leading cause of death *and* disability. It is also highly preventable. Brain Injury Australia recommends that, as part of a whole-of-government approach to Acquired Brain Injury, the Department of Families, Housing, Community Services and Indigenous Affairs encourages the Department of Infrastructure, Transport, Regional Development and Local Government to direct the Australian Transport Council to revise all subsequent National Road Safety Action Plans (constituting the National Road Safety Strategy 2001-2010) to include, alongside the targeting of reductions in road fatalities and a commitment to the improvement of trauma, medical and retrieval services, recognition of injury and potential disability like Acquired Brain Injury as part of the accounting of the "road toll".

young people

Injuries were responsible for 76% of the 1,060 deaths in males aged 15-24 years, and 59% (230) of all female deaths in 2002. Nearly half of the injury deaths in that age group were motor vehicle accident-related. The injury death rate was more than three times higher for young men than for young women. The involvement of alcohol was indicated in 10% of injury deaths in this age group. Among young men the most prominent causes of injury admission were motor vehicle accident-related (21% of cases) followed by assault (13% of cases). The proportion of injury admission due to motor vehicle accident-related injury was similar for young women (21% of cases) but assault was less prominent (8% of cases).¹¹ Overall, between 1996–97 and 2004–05, hospitalisation rates due to assault increased by 7% among young people.

In 2003, there were approximately 249,300 young people aged 15–24 years (8.9%) with a disability in Australia. Between 1981 and 2003, the estimated proportion of young people with a disability increased from 5.7% to 8.9%. **There were: 38,000 young people with an ABI aged 15–24 with "activity limitations or participation restrictions"; 9,500 with "severe or profound core activity limitations" and 7,000 for whom an ABI was their "main disabling condition."**¹²

Recommendation Four:

Brain Injury Australia recommends that, as part of a whole-of-government approach to Acquired Brain Injury, the Department of Families, Housing, Community Services and Indigenous Affairs encourages the Department of Infrastructure, Transport, Regional Development and Local Government to direct the Australian Transport Council to revise all subsequent National Road Safety Action Plans (constituting the National Road Safety Strategy 2001-2010) that, as part of its commitment to the “Education” of “young road users”, include in all “public information initiatives”, “school-based programs” and “novice driver training” information about Acquired Brain Injury, its causes and consequences.

Recommendation Five:

Brain Injury Australia endorses the National Injury Prevention and Safety Promotion Plan: 2004 – 2014 – signed by the Australian Health Ministers in July 2005 and, in principle, its “Priority Activities” with “Youth and Young Adults”. Brain Injury Australia recommends that Priority Activities which “provide information about injury prevention and safety promotion among young people to...police, education, community services and occupational health and safety” include information about Acquired Brain Injury, its causes and consequences. Moreover, in regards to Priority Activities that “seek the advice and participation of young people in developing and conducting strategies to prevent the leading causes of death and disability in their age group”, Brain Injury Australia’s State and Territory member organizations can provide young people with direct experience of Acquired Brain Injury to assist with prevention initiatives.

the cost of injury

Premature death is measured by the years of life lost (YLL) due to disease or injury and non-fatal health outcomes are measured by years of “healthy” life lost due to disease, disability or injury (YLD). To combine these two health measures into a summary health measure, disability-adjusted life years (DALYs) has been developed to summarise the burden of disease and injury at a population level.

Premature mortality was responsible for 41,032 YLL among young Australians aged 15–24 years in 2003. Injuries were the leading cause of premature mortality, accounting for two-thirds of the total YLL among young people. Within the injury category, motor vehicle accidents were responsible for 29% of the YLL. **The economic cost of motor vehicle accidents has been estimated to be in the order of \$17 billion per annum, approximately 2.3% of the Australia’s Gross Domestic Product (GDP)**¹³. Though there is no direct estimation for the lifetime costs of transport accidents involving children and/or young people that result in TBI, actuarial work conducted by Pricewaterhouse Coopers (“No-Fault Long Term Care Costing Study”) for the NSW Government’s Lifetime Care and Support Scheme calculated **the average annual cost per person - whose ABI was caused by a motor accident requiring care for more than 2 hours per day for life – at \$123,000.**

about Brain Injury Australia

Brain Injury Australia (BIA) is the national peak ABI advocacy organization representing, through its State and Territory member organizations and network relationships, the needs and interests of people with an ABI, their families and carers. A major component of BIA’s role is:

- 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.

the impact of ABI on children and young people

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 (see Glossary), 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.¹⁴

impacts - families and carers

In 1981, 3,500 children (9% of all children with a disability) were living in institutional care. By 1993, that number had declined to 500. With almost all children with a disability now living in households, provision of care has become increasingly the domain of family caregivers. **In 2003, an estimated 54,600 people were primary carers of co-resident children with a “severe or profound core activity limitation”; and the vast majority (91%) were mothers**. Over half of these carers spent more than 40 hours a week engaged directly in the care of a resident child with a disability.

The majority (62%) of mothers who were primary carers of children aged 0–14 years with a disability were not in the labour force. This compares with 36% of other mothers of children of the same age. Around 53% of primary carers of children with a disability felt they needed more support, particularly in relation to financial assistance and respite care. Of these **primary carers, 40% reported more respite care as their greatest need and 34% reported financial assistance as their greatest need**.¹⁵ There is some evidence that the circumstances of caring for a child with a severe ABI may contribute to marital

breakdown. A recent United Kingdom study of the school performance of 82 children post-TBI examined the correlation between behavioural problems the consequence of the TBI and separation and divorce. 27 children in the study had parents who were divorced or separated - 5 occurred after their child's injury. Of these children, 16 (59.3%) exhibited behavioural problems at school compared to only nine (22.5%) of the 40 children whose parents were not divorced or separated. The study concluded that, whatever contribution a child's behavioural problems may make to parent-carer stress, the absence of one parent may place a child vulnerable to their exacerbation.¹⁶

services, assistance and other care arrangements

Most carers of children with disabilities receive the Carer Allowance ("a payment for carers who, because of the demands of their caring role, are unable to support themselves by participating substantially in the workforce"¹⁷) as their main disability-related support payment, with a smaller proportion receiving the Carer Payment ("a supplementary payment available to parents or carers who provide daily care and attention for adults or children with a severe disability or medical condition" - Centrelink¹⁸). **In 2003, 133,000 carers were in receipt of a Carer Allowance in relation to a child with disability and 75,937 people were receiving the Carer Payment. Three-quarters of Carer Payment recipients also received the Carer Allowance.**¹⁹ CSTDA-funded support services are a primary source of formal support for children with disabilities in Australia. Community support, including services such as therapy support, early childhood intervention and behaviour/specialist intervention, was the most common support service received, followed by respite services. □

socioeconomic profile

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."²⁰

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.²¹ 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.²²

"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."²³ 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.

Recommendation Six:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs, via its recent evaluations of both the Child Disability Assessment Tool (CDAT) and the Adult Disability Assessment Tool (ADAT), reexamines the policy settings that inform – and the rates of – income support for parents of children with disabilities.

unmet need

The Australian Bureau of Statistics' *2003 Survey of Disability, Ageing and Carers* asked people whether their needs for help with different activities were met. **The highest levels of unmet need for people with an ABI were associated with self-care and property maintenance. More than 10% of those who needed help in these areas didn't receive any. Almost one in three people with ABI (32%) who needed assistance with cognitive or emotional tasks received some help, but needed more.** Lower proportions of people with ABI than with disability generally had their needs fully met in the areas of mobility, property maintenance, transport and meal preparation.²⁴

Centrelink's "Lists of Recognised Disabilities" and the Child Disability Assessment Tool

Ever since 1994, when the Commonwealth and State governments agreed on a "National Policy on Services for People with Acquired Brain Injury", ABI has been recognized – by name - in most legislative and administrative contexts as a distinct disability. Most notably, 1998's first (and all subsequent) Commonwealth/States/Territories Disability Agreements cite ABI as a distinct disability group.

Eligibility for income support for parents-carers of children with a disability (**Centrelink's Carer Payment and Carer Allowance**) is centrally determined by the use of two instruments – Centrelink's "Lists of Recognised Disabilities" (LORD) and the Child Disability Assessment Tool (CDAT). Even given that "Acquired Brain Injury" is used as an umbrella term to describe a range of disabilities arising from any damage to the brain acquired after birth and even given that ABI presents uniquely in the individual and may be difficult - especially in young children - to delineate from intellectual disability, or behavioural or conduct disorder, **Brain Injury Australia continues to be disappointed that neither of these instruments recognises Acquired Brain Injury, by name.** This is especially disappointing since: 23,000 Australian children live with an ABI, the "invisibility" of ABI (above) can mean that children with the disability, especially in its mild or moderate form, go unrecognized, undiagnosed and other cognitive disabilities that also occur on a spectrum of severity but have lower prevalence - "Autistic Disorder or Asperger's Disorder", for example - appear on the LORD.

The beginning and end of Brain Injury Australia's work is building awareness of ABI. Therefore, it is also disappointing that the **lack of recognition of ABI in the very tools used by the Australian Government to assess carer need** is reinforced in its "Social Security and Family Assistance Legislation and Policy Guides": the CDAT is used to assess eligibility for the Carers Allowance "if a child does not have a recognised disability or medical condition" and to "determine whether the care receiver is a child with a disability or medical condition which results in functional impairment or special care needs". The "responses from the [Health Professional and Customer] Questionnaires [about "functional ability", "behaviour" and "special care needs"]...calculate a score indicating the level of *physical, intellectual or psychiatric disability*."

Moreover, **there is no natural fit between many ABIs in childhood/ young adulthood and any of the four major disability groupings on Centrelink's "Lists of Recognised Disabilities". Many ABIs in childhood will incontestably produce "moderate to severe multiple disability or moderate to severe physical disability" but not necessarily "where the child is, or is likely to be, dependent for mobility indoors and outdoors from the age of 3 onwards." Many ABIs in childhood will result in "severe multiple or physical disability" but not necessarily "requiring constant care and attention where the child is less than 6 months of age". And only around 5% of ABIs in childhood will cause epilepsy, even fewer that are "uncontrolled while on medication".**

Recommendation Seven:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs includes the category "Cognitive Disability" in all Centrelink policy documents and publications relating to eligibility for income support for people with disabilities and their carers, specifically in its "Lists of Recognised Disabilities".

Brain Injury Australia also recommends that the same policy documents and publications name "Acquired Brain Injury/ Traumatic Brain Injury" as a subcategory of "Cognitive Disability".

As the dominant source of care for the majority of children and young people with an ABI is the informal assistance of family members, Brain Injury Australia welcomes the recent announcement by the Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, of a House of Representatives Standing Committee on Family, Community, Housing and Youth “Inquiry into Better Support for Carers”. Brain Injury Australia also welcomes the independent Taskforce’s report on the Review of eligibility criteria for the Carer Payment (Child) – though, again, it is regrettable that while the report uses the Australian Institute of Health and Welfare (AIHW) as its guide on grouping disabilities by type, it did not follow suit by examining the fit between the eligibility criteria for the Carer Payment (Child) and the 23,000-member subgroup of the “Physical/ Diverse” category identified by the AIHW as being often the most profoundly disabled – children with an ABI.²⁵

It has been Brain Injury Australia’s experience from consultation with parents and carers of children - especially those with a mild or moderate ABI - that, where they do not miss out on appropriate income support altogether, **Centrelink’s “Lists of Recognised Disabilities” and the CDAT remain blunt instruments for adequately reflecting the care needs of their child with an ABI.** For example, a parent of a child with challenging behaviour the result of an ABI can still score poorly on CDAT’s “Customer Questionnaire” because their intensive management of their child *is working*. Their child may never be at risk of, for example, self-harm only because behaviour is so closely monitored. If a carer aims to be eligible for income support, the CDAT can place them in an unenviable position.

Brain Injury Australia is grateful that Minister Macklin’s experience of the 4000 carer submissions to the Review has resulted in her acceptance that the eligibility criteria were “inequitable and restrictive” and looks forward to the introduction of “new fair and sensible assessment requirements” for the Carer Payment (Child) beginning 1 July, 2009.²⁶

Recommendation Eight:

Brain Injury Australia recommends that, in the Department of Families, Housing, Community Services and Indigenous Affairs’ implementation of the recommendations of the Review of the independent Taskforce into the Carer Payment (Child), that any revision of the Payment’s eligibility criteria, of the Child Disability Assessment Tool (CDAT) or the effectiveness of the payment reflects the specific needs of parents-carers of children with an Acquired Brain Injury.

Brain Injury Australia also recommends that implementation of the recommendations of the evaluation of the Adult Disability Assessment Tool (ADAT) also reflects the specific needs of parents-carers of children (over 16 years of age) with an Acquired Brain Injury.

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.²⁷

In the preparation of this paper, 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.”²⁸

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".**²⁹

Recommendation Nine:

Brain Injury Australia recommends that, in order to assess whether Australian Government-funded programs are meeting the needs of *all* students with disabilities, the Department of Families, Housing, Community Services and Indigenous Affairs works 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.

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"**.³⁰ 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"**.³¹

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.

Recommendation Ten:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs works with 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.

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.”³² As with the eligibility criteria for income support via Centrelink (above), 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”³³ 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]”.

Recommendation Eleven:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs works with 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 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.”³⁴ Based on the extensive consultations conducted as part of the preparations for this 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. 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”³⁵ (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.’”³⁶

Recommendation Twelve:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs works with the Department of Education, Employment and Workplace Relations 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, social 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.³⁷ 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".³⁸ 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.³⁹ **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."⁴⁰

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."⁴¹

Results published last year from a Commonwealth Department of Education, Employment and Workplace Relations-funded (DEEWR) 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."⁴²

Recommendation Thirteen:

Brain Injury Australia recommends that the Department of Families, Housing, Community Services and Indigenous Affairs works with the Department of Education, Employment and Workplace Relations 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.

criminal justice system

People with an ABI are radically over-represented in the nation's prisons. The 2001 NSW Inmate Health Survey found that 39% of women and 45% of men surveyed had sustained an ABI that resulted in a significant loss of consciousness and, of those inmates, 41% of women and 23% of men continued to have side-effects such as memory loss, anxiety or depression, poor concentration and behavioural changes. These prevalence rates have been broadly replicated by similar studies conducted by the Centre for Health Research in Criminal Justice (2006) and Victoria's Department of Justice (2007) - between 40 and 60 per cent of people in custody in NSW and Victorian prisons have experienced an ABI. These local study results conform to results from overseas. Two US studies of death row inmates found that 75% had a history of "brain damage" and 100% had a history of TBI. Another study of prisoners in US county jails found that 87% of inmates had a TBI.

The 2003 Young People in Custody Health Survey, conducted by the NSW Department of Juvenile Justice, found that 40% of young men had sustained an ABI resulting in significant loss of consciousness. Most ABIs were the result of being struck by an object or person during fights (63%). Memory loss (19%) and poor concentration (18%) were the most common unresolved side-effects from reported ABI by young men.⁴³

While studies have consistently found high levels of ABI among prisoner populations, they are equivocal on a causal link between ABI, the personality and behavioural results of ABI and subsequent offending behaviour; whether the ABI itself is the cause of offending behaviour or whether the life circumstances of offenders who subsequently report ABI are perhaps criminogenic. Prisoners almost universally report low socio-economic status, histories of abuse and neglect and substance abuse, mental illness and poor levels of education. Regardless, compelling evidence is emerging that brain injuries of such severity are a distinct risk factor for re-offending. Moreover, the appropriate care, support and management of people with a brain injury in contact with the criminal justice system is thus not only a core responsibility of the nation's Departments of Attorneys-General, Juvenile Justice and Corrective Services - in recognition of the equal rights of people with disabilities - but also potentially an exercise in crime prevention.

Glossary:

activity limitations

Activity limitations are “difficulties an individual may have in executing activities” such as learning to read (Australian Bureau of Statistics’ 2003 *Survey of Disability, Ageing and Carers* [SDAC])

child

For the purposes of this report, a child is aged 0–14 years, corresponding to standard definitions used by both the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW).

disabling condition

A disabling condition is a “disease, disorder or event that leads to an impairment or restriction that has lasted or is likely to last for at least 6 months”. [SDAC]

incidence (the number of new cases within a given period)

National-level information about the incidence (new “cases” each year) of ABI/ TBI is unreliable. Hospital admission data is compromised by the fact that not all people who suffer an ABI/ TBI are hospitalized. It is estimated that 70%–85% of all TBIs fall into the mild category and “while they rarely require inpatient rehabilitation, patients commonly report cognitive and behavioural changes” lasting 3–6 months. 10%–15% of people with mild TBI “remain symptomatic in the longer term with a persisting post-concussion syndrome: physical complaints including headache...changes in taste and hearing; difficulty with attention and memory; and irritability, insomnia and sleeping difficulties. Interpersonal relationships and work may also be affected. This large group of people with TBI can face many years of impairment, possibly affecting health, education, occupation, and social and emotional functioning.” (“Medical Journal of Australia Practice Essentials – Rehabilitation 4: Rehabilitation after traumatic brain injury”, Fary Khan, Ian J Baguley and Ian D Cameron *Medical Journal of Australia*, 2003, 178 (6): 290-295) Furthermore, even given new statistical linkages between different hospital datasets, ABIs requiring multiple hospital admissions are susceptible to double-counting.

main disabling condition

A “main disabling condition” is, in circumstances where multiple conditions are, the one reported as causing the most problems.[SDAC]

participation restrictions

Participation restrictions are “problems an individual may experience in involvement in life situations” such as attending school or participating in recreation. [SDAC]

young people

This paper uses the Australian Institute of Health and Welfare’s (AIHW) “young people” as those aged 12–24 years. (Defining young people as those aged between 15 and 24 years is also a widely accepted statistical convention and is used by many studies on youth.)

Endnotes:

¹ Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers [ABS SDAC] Dr Louise O'Rance and Nicola Fortune, Australian Institute of Health and Welfare 2007. Disability in Australia: acquired brain injury. Bulletin no. 55 [BULLETIN 55] Canberra: AIHW.

² Australian Institute of Health and Welfare (AIHW), Children with disabilities in Australia, [CWD] Canberra, 2004, BULLETIN 55 and Disability Updates: Children with Disabilities (Bulletin no.42), Australian Institute of Health and Welfare, Canberra, 2006.

³ ABS SDAC, BULLETIN 55 (see above)

⁴ CWD (see above)

⁵ National Injury Prevention and Safety Promotion Plan: 2004 – 2014.

⁶ "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.

⁷ "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.

⁸ 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.

⁹ Ibid.

¹⁰ Wei Du, Caroline F Finch, Andrew Hayen and Julie Hatfield "Trends in hospitalisation rates for road traffic injuries in child motor vehicle passengers in New South Wales", Medical Journal of Australia, Volume 187, Number 9, 5 November 2007. "...Mortality is just the tip of the iceberg. In Massachusetts, the 1980 statewide injury prevention program found that for every death, there were 44.4 hospital admissions and over 1200 presentations to emergency. This statistic seem to translate well to the situation in NSW where in 2000, there were 603 fatal accidents and around 28,000 significant injuries (48 admission for every death)", Susan Adams (Sydney Childrens Hospital), "Road Crashes and Child Injury Trends: Road Safer Kids", presentation to the Motor Accidents Authority of NSW, 10th March 2003.

¹¹ The National Injury Prevention and Safety Promotion Plan: 2004 – 2014.

¹² Young Australians: Their Health and Wellbeing, Australian Institute of Health and Welfare, Canberra, 2007 and BULLETIN 55.

¹³ Luke B. Connelly, Richard Supangan (Australian Centre for Economic Research on Health and Centre of National Research on Disability and Rehabilitation Medicine) “The economic costs of road traffic crashes: Australia, states and territories”, Accident Analysis and Prevention, 38, 2006: “In this paper, we obtain detailed data on road traffic crash (RTC) casualties, by severity, for each of the eight state and territory jurisdictions or Australia and use these to estimate and compare the economic impact of RTCs across these regions...We converted the Bureau of Transport Economics (BTE) 2000 estimates, which are expressed in \$A1996 to \$A2003 values...”

¹⁴ Fary Khan, Ian J Baguley and Ian D Cameron, MJA Practice Essentials – Rehabilitation 4: Rehabilitation After Traumatic Brain Injury, MJA, 2003.

¹⁵ “Disability updates: children with disabilities”, Bulletin No. 42, Australian Institute of Health and Welfare, Canberra.

¹⁶ Carol A. Hawley (Centre for Health Services Studies, University of Warwick, Coventry), “Behaviour and school performance after brain injury” Brain Injury, Vol. 18, No. 7 (July 2004), 645–659.

¹⁷ Centrelink

¹⁸ Centrelink

¹⁹ CWD

²⁰ 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.

²¹ CWD

²² 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.

²³ 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.)

²⁴ BULLETIN 55.

²⁵ See page?, above: “Nearly all children (90%) who were identified as having an ABI (as a “main” or “associated disabling condition”) had severe or profound core activity restrictions (11,400 of 12,700 children)” CWD.

²⁶ Jenny Macklin, Minister for Families, Housing, Community Services and Indigenous Affairs, speech to the “Every Child Matters” national conference, Melbourne, 15 May 2008.

²⁷ “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)

²⁸ 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)

²⁹ “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.

³⁰ Leith Sterling, Students With Acquired Brain Injury In Primary And Secondary Schools, Head Injury Council of Australia, Canberra, 1994.

³¹ Christa van Kraayenoord et al. “Literacy, Numeracy and Students with Disabilities”, Department of Education, Science and Training, Canberra, 2000.

³² 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, 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.)

³³ Correspondence from Trisha Winter, Director, Disability And Statewide Programs, Department of Education and Children’s Services (DECS), South Australia.

³⁴ Correspondence to Brain Injury Australia from Bill Daniels, Executive Director, Independent Schools Council of Australia.

³⁵ Vicki Anderson, Elizabeth Northam, Julie Hendy, Developmental Neuropsychology: A Clinical Approach, Psychology Press, 2003-02, p. 160,161

³⁶ 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.

³⁷ 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.

³⁸ 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.

³⁹ 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.

⁴⁰ 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.

⁴¹ Correspondence from Carolyn Rennie, Principal Education Officer - Students with Disabilities, Student Programs. Learning Services North, Department of Education, Tasmania.

⁴² 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.

⁴³ "2003 Young People in Custody Health Survey Key Findings Report", Psychological and Specialist Services Unit, NSW Department of Juvenile Justice, Haymarket, 2003.