HEAD INJURY COUNCIL OF AUSTRALIA

SUBMISSION TO THE

INQUIRY INTO THE EDUCATION OF STUDENTS WITH DISABILITIES

By the Senate Employment, Workplace Relations and Education References Committee

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The Head Injury Council of Australia is the peak national organisation representing the interests and needs of people with acquired brain injury

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HICOA welcomes the Senate Inquiry into the education of students with disabilities and is hopeful that this process will encourage Australian educational systems to be more aware of, and responsive to, the academic, environmental and emotional needs of students who have incurred acquired brain injuries.

This submission concentrates on primary and secondary school systems. This is because HICOA is cognisant of, and concerned about, the life long implications brain injuries can have for children and young people who do not receive a diagnosis and subsequent adequate support. HICOA believes that much more needs to be done within Australia's educational systems to improve assessments and support for children and young people with acquired brain injuries.

This submission has drawn on the experience of teaching and allied care professionals, literature on acquired brain injury, and the broad experience of professionals working in the acquired brain injury field. It particularly notes how children with acquired brain injury are being overlooked in school systems and therefore are not receiving the support they need. The submission concludes with recommendations which we strongly urge the Inquiry to consider.

We have endeavoured to keep this submission succinct and have structured it in the following way.

- Defining acquired brain injury
- The nature and causes of acquired brain injury
- The number of children with acquired brain injury
- Why children with acquired brain injury are overlooked in school systems
- The National Policy on Services for People with Acquired Brain Injury
- Long term implications of not providing support for children with acquired brain injuries
- Recommendations

DEFINING ACQUIRED BRAIN INJURY

Acquired brain injury can be defined as -

> *"neurological impairment which is acquired after birth. Hence, acquired brain damage can be distinguished from congenital brain damage subsequent to genetic disorders, acquired foetal infection, or toxicity and damage occurring as a result of degenerative or genetically predisposed conditions"*[1].

Therefore acquired brain injury is not the same as intellectual disability. "Children or adults with mild or moderate acquired brain injury can retain their intellectual abilities but still experience difficulty controlling, coordinating or communicating their thoughts and

[1] Kendall, Elizabeth (1991) Acquired Brain Damage : A review of Service Provision in Queensland, Headway Queensland.

actions[2]". We have emphasised this point because it is still not well understood by individuals in education systems or in the broader community. Children with acquired brain injury are often formally categorised with children with intellectual disability or developmental delay. This effectively conceals the number of children with acquired brain injuries in education systems as well as their support needs.

An earlier landmark report on acquired brain injury in Australia stated "amongst all disability types, acquired brain injury may be one of the most misunderstood"[3].

THE NATURE AND CAUSES OF ACQUIRED BRAIN INJURY

Falls and road traffic accidents are the major causes of brain injury amongst school aged children. However, research confirms that child abuse is the most common cause of serious head injury in children less than 1 year old[4]. In addition, "several studies have demonstrated that children who have incurred an acquired brain injury are likely to present with a psychiatric disorder, particularly ADHD (attention deficit disorder) or ODD (oppositional defiant disorder)"[5].

Brain injury results in cognitive dysfunction which can cause short term memory loss, perception and concentration difficulties, deficits in attention, organisation, problem-solving and reasoning. It may also produce changes in personality, behaviour and emotional control and physical and sensory impairments.

THENUMBER OF CHILDREN WITH ACQUIRED BRAIN INJURY

For many reasons, it is difficult to obtain accurate statistics on the number of children with acquired brain injury, not the least of which, is that many brain injuries are unidentified. Nevertheless, the Australian Bureau of Statistics' 1993 figures estimated that the number of children under 14 years with an acquired brain injury was approximately 70,000.

During 1997 and 1998 at the Women's and Children's Hospital in South Australia, "more than 350 children were seen for head injuries that were likely to result in some kind of residual effect but were not categorised as major traumatic injuries"[6]. The Hospital acknowledges that these figures *"do not include the potentially large numbers of children sustaining mild and moderate injuries who are discharged without follow-up or who were never admitted to hospital"*[7].

Similarly, another study (within Queensland and New South Wales) found that there is an *"under-representation of numbers of students with acquired brain injury when the records of educational authorities are compared with the annual hospital admission rates for acquired brain injury or head trauma …"* [8].

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2 Children with acquired brain injury: planning and support guide for schools, preschools and childcare services (2000), South Australian Department of Education, Training and Employment, Women's and Children's Hospital, Adelaide.

3 Kendall, E. (1991).

4 Includes Parker, R.S. (1994) Neurobehavioural outcome of children's mild traumatic brain injury. Seminars in Neurology, 14, 67-73; Carty, H., Ratcliffe, J. (Feb 1995) The shaken infant syndrome, British Medical Journal, 11, 344.

5 Max, J.E., Lindgren, S.D., Knutson, C., Pearson, C.S., Ihrig, D., Welborn, A. (1998) Child and adolescent traumatic brain injury: correlates of disruptive behaviour disorders. Brain Injury, Vol. 12(1), 41-52.

6 Children with acquired brain injury: planning and support guide for schools, preschools and childcare services (2000) p.4.

7 Ibid. p.4.

8 Sterling, Leith (1994) Students with Acquired Brain Injuries in Primary & Secondary Schools, HICOA Project Report.

These comments and findings are validated by overseas research undertaken in the field of child abuse, a significant cause of brain injury in children. Many of these brain injuries remain undiagnosed[9]. Further, children who incur brain injuries this way, are neuropsychologically evaluated far less than accident cases, despite often having sustained brain damage of equal or greater severity[10].

WHY CHILDREN WITH ACQUIRED BRAIN INJURY ARE OVERLOOKED IN SCHOOL SYSTEMS

HICOA, as the national peak representative organisation for people with acquired brain injury, is well placed to note the tendency by Federal and State government to expect models of support suitable for other people with disability to be suitable for people with acquired brain injury. This is problematic as the support needs and welfare of this group of people remain unaddressed and often hidden from service providers and policy-makers.

This is the situation that is being experienced by children with acquired brain injuries in Australia's school systems and it is mediating against their academic and psychosocial welfare.

We outline in the following text the three main reasons why children with brain injuries are being overlooked in school systems. These are because the majority of education jurisdictions do not have –

(1) a specific assessment category for children with acquired brain injury,
(2) interdisciplinary integration policies,
(3) professional expertise in acquired brain injury in school support units.

No Specific Assessment Category for Children with Acquired Brain Injury

One systemic reason children with this disability are being overlooked is because the majority of State education systems have no specific category for 'acquired brain injury' although they do for other types of disabilities. The following information provided by the Paediatric Acquired Brain Injury Network in Brisbane illustrates the problems with such policies.

- "Children with acquired brain injuries in schools often have complex and pervading difficulties for many years following their injury.

- A system of Statewide ascertainment is used in Queensland schools which allocates expert resources to children with

  - intellectual impairment
  - speech and language impairment
  - hearing impairment
  - vision impairment
  - autistic spectrum disorder

[9] Eg. Price, B.H., Daffner, K.R., Stowe, R.M. (1990) The compartmental learning disabilities of early frontal lobe damage, *Brain* 113, 1383-93; Eslinger, PLJ., Grattan, L.M., Damasio. H. (1992) Developmental consequences of childhood frontal lobe damage, *Archives of Neurology* 49, 764-9.

[10] Miller, Laurence (1999) Child Abuse Brain Injury: Clinical, Neuropsychological and Forensic Considerations, *The Journal of Cognitive Rehabilitation*, 17, Issue 2.

- physical impairment.

- Many parents, teachers, therapists, and affected students themselves believe that a number of these children do not have their needs met adequately in their school, since there is no ascertainment category specifically for brain injury, and therefore

  - Some children with brain injury fall across a number of ascertainment categories but are low on them all, although their aggregate disabilities may be major.

  - Some children cannot be ascertained at all because the cognitive, executive and emotional dysfunction, untreated, causes them to have major behavioural problems in school, and there is no ascertainment for this. In some cases, behaviour management specialists do not have the knowledge of acquired brain injury to deal effectively with these children.

  - Although there are individuals within the education department who are interested in acquired brain injury and have developed a level of expertise in the area, there is no recognised, centralised body of experts in the education system.

  - Recognition of acquired brain injury within the ascertainment system is necessary to improve resources, facilitate networking of relevant stakeholders, develop management techniques, create classrooms options, and support systems for both teachers and students".

Similarly, in Victoria the Victorian Coalition of Acquired Brain Injury Service Providers is aware that many students with acquired brain injuries are failing academically and have a low commitment to completing their education[11]. They believe reasons contributing to this include –

- "The fact that acquired brain injury is not recognised as an educational disability category. This has resulted in students with acquired brain injury developing problems in all areas of their lives, including academic, medical, social behavioural, " … which in turn creates developmental problems that typically require more effort and resources than would have been required by early preventative efforts"[12].

- The assessment tools used to determine eligibility for the Program for Students with a disability or Impairment (PDSI) do not identify the educational difficulties a student with mild-moderate acquired brain injury may experience.

  Given that acquired brain injury is not an educational disability category, internationally accepted and recognised, diagnostic tests available are not currently used in Victoria. Standardised tests mostly assess pre-injury, old, knowledge and students "…may

11 Submission to Victorian Department of Education, Employment and Training (2000) Victorian Coalition of Acquired Brain Injury Service Providers.

12 Ylvisaker, M. (1998) (2nd ed.) Traumatic Brain Injury Rehabilitation: children and adolescents. Butterworth-Heinmann, Massachusetts.

score at misleading high levels on tests of academic achievement because of knowledge and skills preserved from before the injury"[13]. The assessments are presented in a structured, out of context environment, with few distractions and with continual monitoring and feedback from the tester.

A student with a mild-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.

- Program Support Groups (or Student Support Units) are currently not resourced or supported with adequate acquired brain injury specific information to enable them to make informed decisions on how to best allocate funding provided under the PSDI to achieve optimal education outcomes for students with acquired brain injury."

The three main services in Brisbane providing rehabilitation for children with acquired brain injury all report a distressing lack of support by the educational system for many of these children, most of whom have experienced severe head trauma.

Similar to the above comments by the Women's and Children's Hospital in South Australia, these 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.

[13] Ibid. p. 369.

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,
- Their resulting distress has been so great that they have wanted to leave school[14].

These experiences are well known to acquired brain injury rehabilitation specialists linked with school systems. The Brisbane Paediatric Acquired Brain Injury Network is aware that children they have been supporting have dropped out of school because of a lack of support from the education system.

THE NATIONAL POLICY ON SERVICES FOR PEOPLE WITH ACQUIRED BRAIN INJURY

This national policy developed by Commonwealth, State and Territory Governments states that

> *"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"* p.12.

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.

LONG TERM IMPLICATIONS OF NOT PROVIDING SUPPORT FOR CHILDREN WITH ACQUIRED BRAIN INJURIES

The long term implications of children with acquired brain injuries not receiving the support they need while they are young should be sufficient to encourage Australian governments to increase the knowledge and skills level of teachers and to ensure there are well-resourced support programs for these children.

The attached Fact Sheets provide brief but succinct detail of the life long implications associated with acquired brain injury for many people. The worst scenario, and research supports this, is that children and young people, particularly those with undiagnosed brain injuries and violent backgrounds, are at risk of developing lifestyles potentially injurious to themselves and to others.

As the attached Fact Sheets show there is a strong association between acquired brain injury and homelessness, the overuse of alcohol and other drugs, juvenile delinquency, partner abuse, and the criminal justice system.

HICOA therefore urges the Inquiry to consider the recommendations in this submission.

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[14] Backhouse, M. (1997) The Development of a Service Model to Assist Young People with Acquired brain Injury in the Transition from School to Employment. A project funded by the Commonwealth Department of Health and Family Services.

RECOMMENDATIONS

(1)

HICOA RECOMMENDS that a specific assessment category for children with acquired brain injury be immediately instituted in each State educational jurisdiction.

(2)

Ideally, protocols should have been developed by now between school systems and paediatric rehabilitation teams specialising in acquired brain injury. However, the feedback we have received suggests that this type of early intervention is patchy and inadequate throughout Australia.

As the Victorian Coalition of Acquired Brain Injury Service Providers has pointed out, "the last decade of experience in rehabilitating and educating children with traumatic brain injury has convinced practitioners in the field that a collaborative, interdisciplinary approach to educational interventions is the best practice and results in cost-effective success on accepted achievement tests, state competency tests, dropout and retention rates, referral to self-contained special education and family satisfaction with school services"[15].

Indeed studies conducted by experts in acquired brain injury recommend that early psychosocial assessment and interventions aimed at increasing a child's coping may attentuate the emotional consequences of paediatric brain injury[16].

HICOA RECOMMENDS that interdisciplinary integration programs be immediately established in accordance with best practice models evident in New South Wales and the USA and that those currently operating be evaluated on their adequacy and effectiveness for students with acquired brain injury in metropolitan and rural/remote areas.

These evaluations should consider whether–

- education systems have formal planning protocols in place, ie, the steps that should be taken by school and health professionals in helping children who have incurred brain injuries to re-adjust to school life and allocated roles and responsibilities.

- resources in terms of staff and funding of the support needs of students with acquired brain injuries are adequate.

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15 Ylvisaker, M. (1998) (2nd ed.) in Submission to Victorian Department of Education, Employment and Training (2000) Victorian Coalition of Acquired Brain Injury Service Providers.

16 Luis, C.A., Mittenberg, W. (2002) Mood and anxiety disorders following paediatric traumatic rain injury: a prospective study, *Journal of Clinical Exp. Neuropsychology*, 24(3):270-9.

- children with acquired brain injuries have prematurely left school because of a lack of, or inadequate, support.
- children in rural and remote areas receive adequate and ongoing support.
- children receive regular follow-up assessments.

(3)

HICOA believes it is vital that children with undiagnosed acquired brain injuries should, as much as possible, be identified by school systems and receive the necessary support. This will not happen if educational and clinical support staff have little or no knowledge of acquired brain injury.

HICOA RECOMMENDS that Student Support Units incorporate clinical expertise in acquired brain injury to ensure that students receive useful and accurate assessments of their support needs.

(4)

HICOA RECOMMENDS that school education systems be proactive in providing regular in-service training for teaching staff on acquired brain injury and how these can impact on the student within the various educational settings.