

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

Organisation: GMCT: Brain Injury Rehabilitation Directorate (BIRD) and NSW
Brain Injury Rehabilitation Program (BIRP)

Name: Dr Adeline Hodgkinson and Ms Barbara Strettle

Position: Chair and Network Manager

Date received: 19/02/2010

LEGISLATIVE COUNCIL GENERAL PURPOSE STANDING COMMITTEE NO. 2:

New Inquiry

The provision of education to students with a disability or special needs

**Response by the GMCT: Brain Injury Rehabilitation Directorate (BIRD) and
NSW Brain Injury Rehabilitation Program (BIRP)**

<u>CONTENTS</u>	page
1. Background Information regarding Acquired Brain Injury (ABI)	1
1.1 Prevalence of Brain Injury in Children and Youth in Australia	1
1.2 Impact of Brain Injury on Children and Young People	3
2.0 SUMMARY OF ISSUES STRATEGIES AND POTENTIAL SOLUTIONS TO IMPROVE EDUCATIONAL OUTCOMES FOR STUDENTS WITH DISABILITIES and including students with disability following acquired brain injury (ABI)	5
3.0 RESPONSE BASED ON TERMS OF REFERENCE FOR THE INQUIRY	9
APPENDIX 1: Taken from the "NSW Department of Education and Training DISABILITY CRITERIA (school sector) May 2003"	21
APPENDIX 2: Background to the Academic Competence and Evaluation Scales (ACES)	22
APPENDIX 3: References	23

LEGISLATIVE COUNCIL GENERAL PURPOSE STANDING COMMITTEE NO. 2:

Response by the GMCT: Brain Injury Rehabilitation Directorate (BIRD) and NSW Brain Injury Rehabilitation Program (BIRP) regarding The provision of education to students with a disability or special needs

We welcome the opportunity to provide feedback to this inquiry regarding issues in managing the disability and special needs of children with brain injury in the education system. The GMCT: Brain Injury Rehabilitation Directorate (BIRD) has collated feedback for this response and collaborated with clinicians in the NSW Brain Injury Rehabilitation Programmes (BIRP) from:

- The Children's Hospital at Westmead
- Sydney Children's Hospital at Randwick
- South West Brain Injury Rehabilitation Service (The Kids' Team) at Albury
- New England Brain Injury Rehabilitation Service
- Brain Injury Team at Kaleidoscope, John Hunter Children's Hospital
- The Paediatric Reference Group, an advisory group supporting the work of the NSW Brain Injury Rehabilitation Programme and the Greater Metropolitan Clinical Taskforce (GMCT) Brain Injury Rehabilitation Directorate which comprises the state-wide network for brain injury rehabilitation services within NSW Health. For more information about the network please refer to <http://www.health.nsw.gov.au/initiatives/birp/index.asp>

NSW BIRP clinicians value the opportunity to work collaboratively with the Department of Education and Training (DET) to maximise outcomes for students with brain injury. Our overall experience is that schools are willing to work with external staff although the model of working in partnership could be strengthened so it is consistent across the state. In compiling this response we have reported the current issues and identified potential strategies and solutions that address the special education needs of students with disabilities from ABI, interagency collaboration and improving the interface between the NSW BIRP and DET. Your consideration of this information is an important factor in improving the provision of education for students with acquired brain injury that will maximise learning outcomes and social inclusion for children and young people after acquired brain injury (ABI).

Structure of Report

The report provides background information on the prevalence and impact of acquired brain injury for children and young people as a foundation for the following key issues and potential solutions. The latter is based on the experience of NSW paediatric BIRP staff that support children with ABI to start school, return to school or change schools after the ABI, children who leave school early and the teachers who work with students with disabilities from ABI. Many of the solutions include strategies that are working in some schools but are not consistently available across the state for what may be a number of different factors. After the issues and potential solutions is a more detailed response structured on the terms of reference and provided with a focus on students with brain injury.

1. Background Information regarding Acquired Brain Injury (ABI) (References in Appendix 3)

1.1 Prevalence of Brain Injury in Children and Youth in Australia.

The Australian Institute of Health and Welfare (AIHW) published two reports describing the prevalence of childhood disability in 1998 (published in 2004¹) and 2003 (published in 2007²) taken from Australian Bureau of Statistics disability survey data. These figures revealed an increase in the prevalence of brain injury for 0-14 year olds over the time. In 1998 12,700 children had acquired brain injury (ABI) related disability, representing 0.5% of the Australian population, and 3% of all children with disability in Australia. Nearly all of the children in this group with acquired brain injury (90%, N= 11,400 children) were considered to have a severe

¹ Taken from <http://www.aihw.gov.au/publications/dis/cda/cda.pdf>

² Taken from <http://www.aihw.gov.au/publications/aus/bulletin55/bulletin55.pdf>

disability. In 2003 the statistics suggested prevalence was on the increase when a slightly larger proportion of Australians aged 0-14 (0.5 % = 20,100 children) had ABI with disability but only 12,900 of these were children with brain injury (which represents 64%). The 2003 data also included statistics for ABI disability prevalence for 15-24 years old Australians². Prevalence was much higher compared to the younger children at 1.4% of the population which included 38,000 children. A smaller proportion of this age group experienced severe disability at 25% of this group.

Australian Bureau of Statistics data (2009) suggests that 32.5%³ of the Australian population live in NSW. From this it could be assumed that approximately 6,353 (32.5% of 20,100) children in NSW have a brain injury. Based on the estimated number of children in NSW with a brain injury with brain injury at least 4,066 (64% of 6,353) children aged 0-14 and 9,500 young people aged 14-25 experience severe disability.

Based on the 2003 data the number of children and young people aged 0 – 24 in NSW with severe disability due to ABI exceeds 10,400. The prevalence of childhood disability due to other conditions is much higher (Figures for 0-14 reported as being: intellectual disability and physical disabilities= 3.7% of the population each, Sensory and speech disabilities at 3.1% and psychiatric disabilities at 1.1%) but a higher proportion of children with brain injury experience severe disability. Both AIHW reports (2004; 2007) also document that people with brain injury of all ages experience several types of disability and usually more than one health condition, indicative of more complex needs. The prevalence of NSW children and youth with brain injury is an estimated 58,100 with 10,400 estimated to experience severe disabilities is a substantial number. Children and youth within this age bracket include those who will start school in the future, are currently at school and students in post school (including TAFE) options. All of these students are likely to have special education needs to achieve learning outcomes and may currently be falling through the supportive pathways and processes due to rigid criteria.

The number of students with disabilities in NSW sets the scene for this inquiry. In 2002 20,670 FTE students (the actual number of enrolled students may be slightly higher) attended government schools (16,755 in mainstream and 3,915 in special schools) and an additional 9,060 attended non government schools (7,955 in mainstream and 1,105 in special schools)(AIHW, 2004). In 1998 7.1% of students attending school had a disability (all causes). Of children and youth aged 5 – 20 years old (1981–1998; AIHW, 2004¹) 5.7% have disability due to ABI (3.1% severe). From this group school attendance is varied with 3.5% in normal schools, 1.6% in special classes in normal schools and 0.6% in special schools. In a separate report into students with ABI in primary and secondary schools in Australia (Starling, 1994) an estimated 2000 new cases of children with ABI are reported each year.

Based on analyses of the Australian Bureau of Statistics' (ABS) 2003 Survey of Disability, Ageing and Carers the AIHW report (2007) reports:

- ABI is common: around 1 in 45 Australians (432,700 people) had ABI with activity
- limitations or participation restrictions due to disability including about 20,000 children aged under 15 years had ABI
- People with ABI tended to have complex disability. They reported more disability groups and more health conditions than the average person with disability.
- More than one in four (26%) people with ABI reported four or more disability groups, compared with one in eighteen (5%) of all people with disability
- Age at onset figures suggest 33% sustain their brain injury aged 14 or under and 34% sustain their brain injury whilst aged 15-24

1.2 Impact of Brain Injury on Children and Young People

Children and young people with brain injury usually present with a complex mix of cognitive, physical and psychological problems. The adverse impact of paediatric brain injury on cognitive, motor and psychiatric functioning is well documented (Ewing-Cobbs and Bloom, 1999; Hawley, 2004; Anderson et al, 2006; Bloom et al (2001)). Cognitive impairments include reduced general

³ Taken from

[p://www.abs.gov.au/AUSSTATS/abs@.nsf/ProductsbyCatalogue/FBAC8C9AFBC52291CA25765100098272?OpenDocument](http://www.abs.gov.au/AUSSTATS/abs@.nsf/ProductsbyCatalogue/FBAC8C9AFBC52291CA25765100098272?OpenDocument)

intellectual functioning (though not in all cases and not to the same degree found in children with intellectual disability), reduced memory, concentration and importantly impaired executive functioning - the ability to organise, plan and monitor performance and behaviour (Glang et al, 2004). Behavioural changes as a consequence of brain injury can include aggression, disinhibition, socially inappropriate or oppositional behaviour or apathy, which can be confused as inappropriate student behaviours. In a study on the psychiatric sequelae of brain injury in children over 76% had lifetime psychiatric diagnoses including ADHD, ODD, anxiety disorder and others, with over 60% of these developing after brain injury (Bloom et al, 2001). These behaviours can impact not only on a student's academic achievement but also their ability to function in the classroom including answering questions, study skills, engagement in classroom activities, social skills in and outside class (DiPerna, 2006). It should be noted a student with brain injury may be variable in performance in the classroom, over the course of a day and week and certainly longer term, which makes recognition of ABI issues more challenging in the classroom setting (Glang, et al, 2004).

A further complication of brain injury sustained as children is related to their age at injury and the interruption of the course of normal childhood development. "The child's course of recovery is superimposed on normal developmental processes, thus having a potential impact not only on previously learned skills, but also on the development of future skills" (Glang, et al, 2004). Changes in demands through the lifespan for children, including starting school, transition to high school and the increased demands of exams as they near the end of schooling can highlight or exacerbate previous problems. Social and emotional demands also change over time (Glang et al, 2004). Thus some children injured at a young age may not experience significant problems until they reach high school where increased competence and independence are required.

Children and youth with brain injury are more likely to have adverse outcomes for education, social participation, quality of life and long term economic self sufficiency (Hawley, 2004; Anderson et al, 2006). Although educational outcomes are the focus of this response the longer term impact of paediatric brain injury needs to be reported. After school a reduced number of people with brain injury complete further education and they tend to have a greater proportion of part time and menial or unskilled jobs compared to the general population. Additionally, they are more likely to be unemployed. People who sustain brain injuries as children or youth are also less likely to live independently so the burden on family and the community persists.

In a recent Australian study children who sustain their injuries prior to starting school are slower to recover and have been found to have persistent problems at least 5 years post injury with poorer cognitive outcomes including ability to learn, intellectual skills, attention and language skills which would detrimentally affect school and overall performance (Anderson et al, 2009). Students who sustain their brain injury while in high school also have poor outcomes, although the impact and nature of difficulties may be different to those who sustain their injuries at an earlier age. Sharp et al (2006) reported adolescents with brain injury have significant trouble fitting back in at school, and the success or failure to do so was influenced by "the extent and quality of organisation, communication and support from parents, school teachers and the rehabilitation team". Adolescents who failed to fit in and experienced inadequate support often left school (Sharp et al, 2006). It should be noted that where students who are not recognised by DET as having a disability are unable to access post school option programmes. For those that stay at school changes experienced after brain injury include downgrading of educational and vocational goals, subjects are changed, poorer relationships with peers and reduced participation in extracurricular activities (Stewart-Scott and Douglas, 1998). Each student's "educational disability" is influenced by the nature of the injury, the student's premorbid abilities and personality, family supports, the school and external environment (Schutz et al, 2008). School related factors that impact on educational outcomes include educational level, nature of classes and classroom structure, perceptions of the student's classroom behaviour and the availability of support can all affect performance in different classrooms and playground (Schutz et al, 2008; Hawley, 2005). A specific understanding of the sequelae of each child's brain injury, including behavioural and cognitive impairments, as well as other factors influencing their performance is essential to design appropriate educational interventions to maximise a student's academic outcomes (Telzrow,

1987). Without adequate understanding of the impact of an individual student's brain injury, teachers may implement routine classroom 'management' strategies (from a discipline perspective) which may reduce the student's behaviour but will fail to improve their classroom participation and educational outcomes.

Research suggests that the learning needs and behaviour of students with TBI are different from students with other diagnoses and require different assessments and interventions (Glang et al, 2004; Telzrow, 1991). Telzrow (1991) recommends assessments need to be clinically useful, include functional observation and be ongoing to meet the unique needs of students with brain injury and support successful educational reintegration intervention. Glang (2004) suggests that "at the very least, awareness of the existence of TBI [ABI] presents the necessary opportunity to gather information and consider brain injury in assessment, program planning and interpretations of outcomes".

Recognising that students with ABI require different intervention strategies to achieve improved educational outcomes is a vital and urgent need and would be consistent with national and state policy changes. Acquired Brain Injury is recognised as a major disability group in the Commonwealth State/Territory Disability Agreement (AIHW 2004). Ageing, Disability and Home Care (ADHC), of the Department of Human Services NSW, included ABI as a separate eligibility criteria for services in 2009.

2.0 SUMMARY OF ISSUES STRATEGIES AND POTENTIAL SOLUTIONS TO IMPROVE EDUCATIONAL OUTCOMES FOR STUDENTS WITH DISABILITIES and including students with disability following acquired brain injury (ABI)

It is vital a review of the system supports ALL students with disabilities, including those with disability from acquired brain injury so they receive the appropriate support to meet their individual learning needs. The following issues strategies and potential solutions address both education and rehabilitation service issues and are made with this aim in mind.

Overall the primary suggested solution is to identify students with ABI as a separate disability group in the eligibility criteria for Department of Education and Training (See Appendix 1 for current criteria).

- This strategy would enable students of all ages with ABI as their diagnosis and who are currently falling through the gaps to access education that meets their special needs.
- The following information highlights the issues that require specific strategies and solutions to improve education outcomes and achieve social inclusion for individual students with ABI.

2.1 Issues and suggestions related to DET:

1. In the absence of ABI as an identified disability group then **the current eligibility criterion need to be applied more flexibly** to include students with severe disability after ABI and who have learning needs so they can access support consistent with their learning needs.
2. DET needs to be **more flexible and responsive to the changing needs of children with ABI**. The course of acquired brain injury in children is that the impact may only become apparent years after brain injury was sustained when the child fails to meet developmental milestones and additional learning needs are identified. Additional challenges are experienced for the teachers, student and family at these times.
3. There is an essential need for **transparency in decision making** for all concerned – the school, parents, rehabilitation staff etc. at all stages in the education process for:
 - a. Why a student is and is not approved as meeting eligibility criterion
 - b. How decisions regarding resources allocation are made
 - c. How the funding translates into everyday help for their child in the school setting (who is providing the support, how and for how much of the day).

Transparency in decision making is essential for all children with disabilities. It is vital when education decisions appear inconsistent with the care and support of the child or young person with ABI at home and in rehabilitation.

4. **Processes to support a consistent approach to decision making when working with students with brain injury are needed** which include those for:
 - a. Determining eligibility
 - b. Available educational supports within local and regional levels
 - c. Reviewing applications to support students return to school with appropriate support in timely manner.
 - d. Improve transition planning for school leavers with brain injury by describing the process for early identification of those students needing referral to transition co-ordinators.
 - e. Interagency working with education and health services should be included as a routine practice for students with disabilities including brain injury. E.g. include BIRP workers in Individual Education Plan (IEP) planning and review meetings.
 - f. Qualifications of Learning Support Officers (LSO) plus boundaries regarding their role; level of training and support they receive
 - g. Roles of staff within schools to facilitate open consistent communication e.g. who should be contacted? Regarding student with brain injury, who needs to be involved in meetings etc
 - h. Communication and dissemination of information within schools which includes guidelines when relief teachers are involved and for high schools where many teachers are involved.
 - i. Support routine collaboration between brain injury rehabilitation professionals and education staff to identify an individual student's learning needs and develop and monitor individually tailored strategies to meet the needs of each student with brain injury receiving rehabilitation.

Processes need to be agreed and disseminated at both regional and local school level to support management of students with brain injury within individual services and involving interagency collaboration as the partners may differ from the usual partners for other disability groups.

5. **Adjustments to the education and training curriculum** are required to provide to education staff including teachers, LOS and teachers aides (as appropriate) with the skills they need to work effectively with children and young people with ABI:
 - a. Regarding the nature of acquired brain injury and the multi-faceted and complex, long-term needs of students with a brain injury including managing challenging behaviour.
 - b. Regarding applying and monitoring impact of specific strategies often used for students with brain injury.
 - c. Modifying curriculums to suit needs of individual students with brain injury and other diagnoses.
 - d. How to maximise the presence of a LSO/ teachers aide in the classroom (it is unclear if this is already provided).
 - e. how to work with therapy services
 - f. Identifying individual learning goals when the student is unable to achieve class learning goals.

Options to provide training need to be explored but could incorporate existing opportunities including Teacher Education Day provided annually by The Children's Hospital Westmead which is open to teachers, LSO s and schools counsellors. An interagency working group could explore further options and develop new material.

6. **Ongoing support** should be available to teachers, LOS's and teacher aides working with students with disabilities and particularly disability from ABI as this is not a traditional area of knowledge and skill development.

7. **There is a need to provide opportunities for DET to explore an expansion of services and policies:**
 - a. Introduce the life skills curriculum in primary schools
 - b. Enable flexible attendance models for students e.g. part time enrolment
 - c. Flexible curriculum for early or extended access to work experience for students with special needs.
 - d. Introduction of a routine standardised assessment such as the Academic Competence and Evaluation Scales (ACES). The ACES provides an objective indication of the teachers perception of a student's learning needs based on classroom performance that are not related to diagnoses or other impairment based tests. Such an assessment should be explored for use by teachers for all students with disabilities. The NSW paediatric BIRP has utilised this assessment tool and can provide feedback and information regarding students with ABI.
8. **There is a need for greater capacity** (funding) to ensure that all students with disabilities receive appropriate education and training support to meet their individual needs and achieve meaningful outcomes in mainstream schools. Budget issues should not be the guiding factor in determining needs and providing supports. This means that there is a greater need for school counsellors, teacher aides, IM classes, behavioural support and tutorial centres in mainstream schools and access to special school placements for students who are not able to manage mainstream education targets.
9. **Routine consideration of alternative strategies** to in class supports should be considered and decisions made on each student's needs. Options include teacher training, teacher release, and modified curriculum.

2.2. Interagency Issues and potential solutions

There is a need to establish an interagency approach to manage education planning that involves the student their family and social environment and addresses the complexity of cognitive and behaviour change after ABI. Partner agencies would include the Department of Education and Training, Department of Human Services (children services) and NSW Health for specialist acquired brain injury paediatric services. An interagency working party would be welcomed to develop and implement a co-ordinated and systematic state-wide service system that meets the learning and education needs of students with disability from ABI.

The ad hoc arrangements currently in operation results in children and young people being excluded from education support services or situations where some children and young people are intermittently accessing essential education support or leaving school early when their individual special needs are not being met.

1. **Interagency training** could be identified and available across education, children's services and health to improve awareness of resources appropriate to children and young people with disabilities from ABI (within and external to education, improve collaborative working relationships, share understanding of disability, developing collaborative approaches to supporting the student, agree common terminology).
2. **Awareness of the resources** within health education and children's services could be shared to identify gaps, utilise existing material and develop new resources where required. This could include clarity of roles, services offered, eligibility criteria and pathways, resources and contact/ access information so staff from each agency understands what is available and how to access support across agencies for individual students.
3. Children and young people with ABI often require specialised testing performed by neuropsychologists in NSW Health as the pattern of cognitive impairment is different from other childhood disabilities. An interagency working group would **develop practice guidelines for neuropsychological assessments and explore strategies to**

include this information in individual education planning and class room teaching strategies.

4. An interagency approach is able to address **the broader family and social issues** that can impact on learning outcomes of children and young people with ABI.
5. An interagency approach can enhance working relationships and processes with external organisations and government departments for **consultation** about key issues and service planning. Consultation processes that involve the NSW BIRP and other specialist health services would be a valuable addition to existing consumer organisation consultation process as currently exists with the Brain Injury Association of NSW.

2.3 DET and the NSW BIRP

There is an identified need for the NSW BIRP to work collaboratively with DET to achieve appropriate learning outcomes for students with disability from ABI across NSW. Currently this primarily occurs on an individual student and single school basis as there is a lack of processes and pathways to interface health knowledge and skills with the knowledge and skills in the education sector.

There are difficulties utilising this approach for all students in all areas of NSW due to a lack of resources in the greater metropolitan and rural areas of the NSW BIRP. However, the lack of identification of ABI as a disability group exacerbates the difficulties.

1. The NSW BIRP has collaborated with DET on **resources for school children with ABI** that are not well distributed and available so teachers can improve awareness and knowledge about ABI and how to adjust education strategies for students with ABI.
2. Qualified education staff would benefit **from the involvement of NSW BIRP rehabilitation staff** when developing individual students' programmes to ensure that the physical, communication cognitive and behavioural issues are known and appropriate strategies are included to maximise learning targets and achieve individual education outcomes. Teachers need acknowledgement that this approach takes additional time and requires ongoing meetings as the students may have high support needs and may be slow to progress.
3. NSW BIRP rehabilitation staff **need a greater understanding of the curriculum** in order to effectively support teachers develop IEP's. In situations where there are difficulties identifying individual learning goals then the student is unable to achieve class learning goals.
4. **Capacity** of the NSW Brain Injury Rehabilitation Programme for students with brain injury needs review. In some rural areas no dedicated BIRP paediatric co-ordinator/ case manager position is funded to facilitate school pathways after ABI. The burden on staff from the NSW BIRP and NSW DET for implementing agreed strategies will need consideration. Identifying changes that will improve outcomes for students with ABI and are within current capacity and those that would need additional resources is critical. A business case that provides a rationale and cost analysis for increased capacity for health and education services may be required to address resource gaps.
5. The NSW BIRP has found the **position of special school counsellor (brain injury)** to be an important interface between health and education. The incumbent is a member of the paediatric reference group for the statewide network (GMCT: BIRD) and integral to identifying issues and working on solutions at a state wide level.

3.0 RESPONSE BASED ON TERMS OF REFERENCE FOR THE INQUIRY

1. Best approach to determine allocation of funding:

- i. Please note that "functional capacity" and "disability" are related issues, as they represent the level of both ability and disability within a person.
- ii. We understand that there can be wide variation in functional ability based on diagnosis, but consider that both elements may be useful. The Department of Education and Training (DET) criteria already includes a combination of diagnostic and capacity criteria (See Appendix 1, page 12 for a summary), yet students with brain injury repeatedly struggle to meet these rigid criteria despite having significant learning needs. The current impairment based criterion including language, physical disability, intellectual impairment, mental health, deaf/ blind, hearing and visual impairment often fail to appropriately identify students with brain injury as having learning support needs. Brain injury is not included as a separate eligibility criterion which would enable this client group to readily meet criteria when their learning needs are described as for other diagnostic groups e.g. learning disabilities and mental health. Whilst the option to make individual determinations of eligibility on a case by case basis is available this is time consuming, the reasons for decisions are not always transparent and is an inappropriate waste of resources for children receiving specialist brain injury rehabilitation that have clear needs. This places extra burden on rehabilitation staff and also on parents who are already caring for a disabled child within the family to prove something that is obvious to those working and caring for the child. The impact of this is that many children with brain injury don't get access to the educational support they need to learn including Transition to employment etc. Any review should provide criteria that set clear boundaries for eligibility but are not so rigid as to block access for students with genuine learning support needs.
- iii. Despite the complexity of problems for student with ABI in accessing curriculum and support, ABI is not a recognised as disability for funding purposes. The challenge for students with an acquired brain injury is that often their issues and needs blend into the range of similar sequelae seen in other children with different causality. Whilst the impact of brain injury on a student's functioning and education needs can vary we recommend that eligibility criterion should include Acquired brain injury of moderate to severe range. Children with moderate to severe brain injuries almost always have a complex mix of impairments, disabilities and restrictions in participating in normal activities. Often the combination of effects reduces a student's ability to learn and engage in education and criteria that is too rigid currently means many students with brain injury struggle to meet eligibility criteria. Current criteria results in many students with brain injury not accessing the services they need to achieve education goals).
- iv. The deficits arising from acquired brain injury tend to be life long challenges that exacerbate over time as the cognitive demands of the school setting increase and disability becomes more evident as developmental milestones are compromised. The ability of the student with an ABI to 'keep up' with same aged peers is often confounded by changes to the demand for attention, concentration, behaviour and self monitoring of their own participation in social and learning environments. Sometimes this means a student with brain injury may not have clearly identified needs until some time after their brain injury, such as starting high school where demands are greater, but the more severe the brain injury means cognitive, behavioural, social and learning problems are likely to be experienced immediately after injury, and certainly once they return to or start school. Brain Injury is a life long condition and is comparable to a child with autism or Down Syndrome, rather than an isolated incident from which a child may be 'cured'.
- v. The terms Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI) can be confusing. ABI refers to brain injury or damage that is acquired after birth and

includes TBI as well as brain injury caused by anoxia (lack of oxygen to the brain), brain tumours and other neurological conditions. Traumatic brain injury is a more specific group that includes injury caused to the brain as a result of direct trauma or injury, although the exact aetiology of damage may vary. TBI can be caused by motor vehicle accidents, falls, sporting injuries, non accidental injuries (including shaken baby syndrome) and assaults. Both ABI and TBI describe global diagnoses but offer no understanding of the individual impact and specific nature of the injury in the FUNCTIONAL outcome of the student. Diagnostic terminology does not reflect the significant range of outcomes (cognitive, social, behavioural, emotional, physical) that may impact individual students but moderate and severe brain injury will impact on a student in a variety of these areas.

The BIRP clinicians report that overall in NSW there is not a consistent, nor accurate understanding or a sound knowledge base of the nature of acquired brain injury. As a result, the multi-faceted and complex, long-term needs of students with a brain injury are often not met consistently within the public and private education system.

- vi. In regards to eligibility criteria the following issues need to be considered in relation to ABI/ TBI:
 - a. We support a diagnostic criteria to include moderate to severe traumatic brain injury but acknowledge that the functional impact of the TBI would be required to identify the nature and amount of support a student required. The long term nature and developmental challenges for a student with brain injury need acknowledgement. The ability of students with a brain injury to access the curriculum and participate in normal everyday arenas of school, home and the community are diminished where appropriate support is not provided.
 - b. In some cases the severity of the TBI has not been determined at the time of injury. Measuring injury severity is unclear for children who are under 8 years of age at the time of injury. International work is ongoing to improve measurement of injury severity for the very young. Measurement of Post Traumatic Amnesia (PTA) is the most reliable approach to measuring injury severity and is not routinely carried out by all emergency departments, trauma units etc. When this occurs the functional impact of injuries often signals the need for brain injury rehabilitation at a later stage.
 - c. The aim of acknowledging Acquired Brain Injury as a specific disability group is to enhance inclusion, access and participation in normal everyday learning arenas.
- vii. Limitations in assessment tools need to be acknowledged for students with brain injury.
 - a. Most assessment tools do not recognise learning profile or difficulties subsequent to TBI.
 - b. BIRP tried to introduce a standardised objective assessment called the Academic Competence and Evaluation Scales (ACES). The ACES is an objective assessment regarding school functioning and performance including learning, academic skills, interpersonal skills and participation in the classroom. It is an assessment developed by education staff to identify learning needs of students with a range of disabilities. We believe the ACES assessment encourages improved collaboration between education and health staff to support delivery of effective rehabilitation and academic support for these students. However the return rate by teachers was so poor we have largely discontinued using this valuable assessment. See Appendix 2, page 13 for more information about the ACES assessment.
 - c. Students with brain injury with any scaled score <70 on full scale IQ to be eligible for funding with diagnosed TBI.
 - d. Need to recognise that adaptive behaviour scores may be more valuable than IQ scores for some children with ABI. Usually the child has been identified as having difficulty coping with the curriculum before referral to school counsellor or health professionals. Consider starting with functional assessment rather than standardised battery of assessments.

- e. Concern has been expressed by clinical Neuro-psychologists working in the area of Brain Injury regarding the use of raw scores from testing to determine the support needs of the student in the school environment. Testing scores alone do not give sufficient information about the functional needs of the student– more analysis of function is needed for students with special needs and disabilities. It is generally felt that it is the functional needs of the student should be used to determine the need for support services rather than testing scores that allocate funds on a of students within the school environment or based on diagnostic grouping. It is recommended that the process of using raw scores to determine support be reviewed so that process is sufficiently sensitive to allow student with a ABI/TBI to get the support they need. Recommend that DET and neuropsychological clinicians get together to put together a more strategy to look at how the testing numbers are used and the rationale behind using scores without using the clinical interpretation
 - f. Children with a brain injury can get assessment results within the intellectually normal IQ range, but have severe limitations in executive functioning, reduced attention and concentration, slowed processing and challenges of behavioural and social skill changes which impede their ability to manage at school. Students with brain injury without full scale IQ score < 70 but in presence of specific cognitive and behavioural deficits will need significant support in school, although this group does not readily fall within current criteria. Use of the neuropsychological and speech/language testing tools – not meeting the need of the kids as the results are not being interpreted suitably to capture the true needs of the child – school counsellors will benefit from increased liaison with health professionals administering these tests in their expert area to seek greater clarification of functional need and greater understanding of brain injury.
- viii. The current system is ad hoc arrangement by local services. An interagency approach that includes NSW Education, ADHC (children services) and specialist acquired brain injury health services would be welcomed to develop a co-ordinated and systematic state-wide approach to meeting the learning and education needs of students with disability from ABI currently excluded or intermittently accessing essential education support. It is worth noting that Ageing, Disability and Home Care (ADHC), NSW Department of Human Services, has acknowledged acquired brain injury as a diagnostic criteria for ADHC provided and funded services for adults. An interagency agreement involves ADHC NSW Health, brain injury specialist services, mental health, drug and alcohol services to reduce barriers to service access and ensure client needs are met without people falling between the limiting remit and criteria of individual organisations.
- ix. There is a lack of transparency in how funding decisions are made.
In the instances where a student with a brain injury does meet criteria, it is often challenging to identify how support funding is allocated and difficult at times to influence the use of the funding to meet the specific need of the student with a brain injury. Families and supporting agencies cannot easily determine what criteria have been used by a school to make the decision to fund a student. There appears to be a large difference between the types of support that is provided by schools to students with apparently similar needs. For example, one girl with a physical disability and a Traumatic Brain Injury has had major environmental modifications approved at the school she attends in addition to full-time access to a teacher aide. In contrast other students with similar levels of physical disability (or worse) and Traumatic Brain Injury get almost no teacher aide support. So, it seems like a kind of lottery at the moment as to who will get support in the public schooling system.

In addition workers expressed the following:

Families often express frustration at not having a clearer picture of how the funding translates into everyday help for their child in the school setting (who is providing the support, how and for how much of the day). As an external agency, Brain Injury Services are often not privy to why support is or isn't provided in school. This is

extremely frustrating as the rejection for funding does not provide sufficient rationale to assist services to adjust their applications and often then delays the students' legitimate return to school. Funding appears to be dependent on the experience, skills and creativity of the school staff and those who can manipulate the funding and applications for funding. These decisions can result in programs that are part time with reduced school hours with a reliance on families to bridge the gap by providing home based family activities, support and supervision. A lack of school education support can result in disadvantage to the child when they leave school early.

In circumstances where insurance is able to pay for teachers aides there is often reluctance by schools to include these strategies and utilise the time specifically for the injured child.

x. Allocation of funding

It is difficult to sense how much funding gets attached to an individual student to support their needs and how this translates to face to face support. This is a difficulty for Brain Injury Services who are able to advocate for additional funding for students who are compensable or have access to funding from Life Time Care Scheme. Brain Injury workers are required to communicate current support levels and argue for additional funding – without this information justification for enhancement is impeded.

It is understood that schools once they have the funding have some degree of 'flexibility' as to how they use these funds, but can choose to use the funds without consultation and hence miss opportunity to target students with special needs with appropriate intervention and input from health professionals

Students with physical needs often easier to gain services because the disability is more concrete and visual but it is the longer term implication of the cognition etc that needs in class support in the long term

xi. Language Criteria

There are an insufficient number of classes and too few students that meet the criteria – their skills are too diverse across the board 1st and 2nd percentile. The Speech Pathologists working within BIRP can provide more information if required.

2. Level and adequacy of current special education places

It is the experience of the Brain Injury Services of NSW that the overall preference of parents is to have their children return to mainstream classes with suitable support to make this a positive experience.

Where this is not possible due to the nature of the student's disabilities, or where there is a lack of appropriate support in mainstream schools, Brain Injury Services across NSW have experienced greater difficulty placing students with significant sequelae following their brain injury into the school setting due to a decline in the availability of special class & special school placements.

In addition, the options available for an individual student are not always the most appropriate placement to meet their needs but limitations in funding prevents more intensive input for the student in the mainstream school setting. This has been noted particularly in:

- IM classes,
- behavioural units
- tutorial centres

The removal of specific support classes for students with Mild intellectual disabilities and language-based difficulties continues to present a challenge.

3. Adequacy of support services for children with a disability in mainstream school classes

i. Access to in school support:

- a) Parents (and health professionals) unfamiliar with education supports within local and regional levels. In some cases staff within the schools are unaware of their own resources beyond school counsellor.
- b) Heavy load (within and across schools) of school counsellors limits access.
- c) Over reliance on provision of teacher aides in preference for other forms of resourcing e.g. teacher training, teacher release, modified curriculum. Risk for children who have aide support for a long time to become dependent on the one to one support. In some of our complex cases teacher aide has guided the development of the child's program rather than supported implementation of the teacher's program. Usually due to limited knowledge, time and very slow progress of the child.
- d) Parents (and health professionals) are unfamiliar with education supports within local and regional levels. In some cases, staff within the schools are unaware of their own resources beyond the school counsellor.

ii. Process of Applying for School Support

- a) The point of return to school after acquiring a severe brain injury is a vital and very demanding time on both the returning student, their school and family. Efficient and forward, cooperative planning is the key to the success of this transition. Frustration continues to be expressed by both health care workers and school staff regarding the limitations imposed on applying for appropriate funding to meet the needs of students with an acquired brain injury and facilitate timely return to school.
- b) Many times where the student with a brain injury with 'return-to-' school support needs does not meet and cannot be made to 'fit into' the funding criteria, the undesirable situation arises where:

- Students are returned to school without sufficient support in place. This may mean a teachers and class needs to adjust to the returning student with out extra help in class. The returning student must struggle in class without the physical support of a worker to help with the adjustment process (social, physical, behavioural and cognitive).
- Students may be delayed from returning to the school system in a time frame that suits their abilities

- a. Health care organisations should be able to submit applications for funding support on the **basis of the functional needs of the student** for which they are advocating, **without applications being blocked** for consideration because the student does not fit the limited criteria currently accepted by Department of Education. Allowing all applications for support for consideration allows the DET to develop a broad understanding of the complexity of needs that their school communities are reporting and allow them to plan and provide for services accordingly. The criteria should be flexible enough to cope with applications from specialist health services.

iii. School Support roles

a) Learning Support Officers (LSO) /Teachers Aides

There is great support from Brain Injury Services of NSW to maintain learning support officers/teachers aides in the school setting as they provide the intensive one to one support that a child with a significant brain injury benefits from in the classroom. While there is not empirical evidence that provision of an in class teacher support worker can provide better learning outcomes for the student, the aides do provide a range of outcomes that benefits the student in the schools setting and supports the teachers and other students in that placement. They:

- Implement range of educational & therapeutic programmes under supervision of teacher and therapists
- Allows the teacher to target specific learning areas with greater intensity and opportunity for revision
- Psychologically enhances the child's positive experience of school
- Helps child to access the school environment & curriculum e.g. safety, movement around school, social support, cognition, behaviour, physical, personal care, task initiation, learning at the students pace
- Where augmentative aids do not meet the needs of the student e.g. slowed writing/typing provision of a scribe assists the student stay engaged and on task
- Mental health outcomes

However there is much room for improvement and enhancing the current system of providing LSO to students with special needs. Some concerns raised by clinicians include:

- Lack of transparency in how the recruitment of LSO takes place and what formal training and support is given to staff in these positions
- Unclear how much training teachers have in how to maximise the presence of a LSO in the classroom. Opportunity to enhance teacher training in how to use an aide and work with therapy services.
- LSO where not adequately supported can 'over step' their boundaries with the student – training, supervision and support would assist to minimise this
- Recommend schools take opportunity to train aides specifically about acquired brain injury and the strategies that can be employed to support the student and enhance the intervention of the workers e.g. The Children's Hospital Westmead invites teachers, LSO s and schools counsellors of NSW to a Teacher Education Day each year. A combination of teaching and practical strategies to support the student.
- There does not seem to be any formal initial or ongoing support / training for aides in school. Without clear understanding of the nature of brain injury, it is very difficult for the educational worker to facilitate learning and maximise the participation of the student in that environment.

b) Specialist School Counsellor (SSC - Brain Injury)

Brain Injury Services NSW has worked with several educational staff in the role of SSC (Brain Injury). This role has proven itself to be a keystone in the vital interface between the health system and the Department of Education. The role enhances both health worker understanding of the educational options and process and similarly provides Educators with a colleague with enhanced skills in understanding how a child with a brain injury can re-enter the school system.

The Acquired Brain Injury Specialist Counsellor, Jean Kidd, provides a valuable role in the provision of appropriate support to the student with a brain injury starting or returning to school. The SSC (Brain Injury) is a very strong advocate of students following a brain injury – the SSC (Brain Injury) understand the complexity of brain injury outcomes and long term support needs and offers an important interface with the

Department of Education system. The role assists workers in both educational and health areas to clarify terminology and understand the constraints of their respective systems, and allows both to work cooperatively towards the best educational and rehabilitation outcomes for the student with a brain injury. Currently this role is very limited and there is inequity of access across NSW to this specialist support within schools.

iv. DET developments regarding school supports

Inviting health services such as the NSW Brain Injury Rehabilitation Programme to participate in formal consultation processes regarding managing the needs of students with disabilities would support collaborative working.

e.g. BIRP would have welcomed the opportunity to respond to and understand the " School Learning Support Program" which was out for consultation in mid 2009:

<http://www.schools.nsw.edu.au/media/downloads/schoolsweb/studentssupport/programs/disability/consultation.pdf>

4. Provision of suitable curriculum for intellectually disabled and conduct disordered students (discuss cognitive impairment)

- Difficulty accessing modified curriculum due to:
 - Lack of teacher experience/ skills (see above)
 - Life skills curriculum not available in primary school
 - Eligibility criteria in high school relies on IQ score or diagnosis of mental illness – criteria too rigid to meet needs of most students with ABI/TBI
- Lack of flexible attendance models for students. Limited options to enrol part time in mainstream and special schools.
- Inadequate transition planning for school leavers. (We acknowledge that there are some fantastic Transition Coordinators employed through DET however in many cases students are not referred proactively to prepare well in advance for transition).
- Inflexible curriculum for early or extended access to work experience.

5. Access to professional support services, such as speech therapy, occupational therapy and school counsellors

- Allied health not employed (or contracted) by education in NSW; therefore rely on individual children accessing health or ADHC services. The cut off ages at many community health centres prohibits access for older primary and high school students.
- Inconsistent lines of communication across schools – who should be contacted? Who needs to be involved in meetings etc
- Health, ADHC and education work under different models, use different language. There are limited opportunities for interagency training to improve awareness of resources (within and external to education, improve collaborative working relationships, share understanding of disability, develop collaborative approach to supporting the student.
- In some cases this results in outside services being seen as additional to the students learning support team leading to lack of collaboration, duplication or different directions.

6. Adequacy of pre-service and post-service teacher training

- Many teachers lack relevant training and do not have skills to develop modified curriculum for individuals. They have difficulty identifying individual learning goals when the student is unable to achieve class learning goals. Many of our schools look to therapists to guide development of individual education program. Therapists lack sufficient knowledge of curriculum to do this.
- Teachers have limited knowledge of alternative behaviour management strategies. Limited access to specialist behaviour teachers.
- Need for increased access to training and support for teacher aides.

Training for education staff is outside of our area of expertise, however there would be a benefit of formal under and post –grad training in the area of Acquired Brain Injury with specific input from clinical rehabilitation teams providing some education, strategies and real examples of students entering the education system after a severe injury. NB: The Children’s Hospital Westmead invites teachers, LSO’s, schools counsellors and other teaching staff of NSW to a Teacher Education Day each year. A combination of teaching regarding acquired brain injury, the range of outcomes and practical strategies to support the student. It is envisaged that increased teacher awareness of ABI issues would enable education staff to be more proactive in identifying both the needs of individual students and appropriate resources and strategies to meet the needs of these students at an individual, school and regional level given the education context which rehabilitation staff won’t be fully aware of.

Note that access to training package for those working with people with brain injury using web based system is scheduled to be made available to ADHC staff across NSW. This will include at least 2 modules relevant for paediatric brain injury specifically. A similar option for education staff could be explored as a relatively low cost readily accessible system for teachers. Thus would address the issues raised above where, “The BIRP clinicians report that overall in NSW there is not a consistent, nor accurate understanding or a sound **knowledge base** of the nature of acquired brain injury. As a result, the multi-faceted and complex, long-term needs of students with a brain injury are often not met consistently within the public and private education system”.

7. Other Issues identified by NSW BIRP

a) Communication within schools:

Communication regarding the needs of children with brain injury can be variable. Scenarios may include:

- Where there is a relief teacher for a mainstream class information about the student with special needs may not be passed on
- Dissemination of information particularly in high schools where many teachers are involved.
- BIRP workers are not always included in Individual Education Plan (IEP) planning and review meetings.

Numerous strategies are implemented in a range of schools to tackle these issues – however there is not a consistent policy that is implemented to ensure that communication stays at an optimum level – consistent policy implementation in both special and mainstream school and across primary and secondary levels would strongly enhance the provision of support to the student with special needs.

A known and recommended procedure adopted state wide would additionally assist external service providers such as Brain Injury Services to interact with the correct school personal and engage the correct applications as it interacts with schools across NSW. Vital roles such as the Specialist School Counsellor, Brain Injury provides an important buffer and support between the health and school system.

b) Positive Interagency Experiences

- Schools are generally very welcoming – the model of working in partnership is strongly advocated by BIRP workers
- Dept of Education and education staff in independent and private school are overall very willing to work with external staff e.g. therapy / BIRP
- School based meetings work well and allow BIRP staff to access a number of key school staff at one time
- Collaboration completing assessments such as ACES, other non standardised checklists to support rehabilitation.
- BIRP workers value the opportunity to work collaboratively and cooperatively for the needs of the children to enhance participation, access to curriculum and functioning outcomes e.g. IEP, pre-enrolment meetings etc
- Schools that allow health workers and therapists to provide direct support and information giving to the teacher and teacher's aide facilitate the quality of the information exchanged and allow both parties to work in a responsive timely manner.
- BIRPS can cite many positive experiences where the school has provided physical space to allow for therapy services to occur in the school setting and have then taken direct interest in the intervention – a better model than those wanting the student removed and 'fixed'

APPENDIX 1: Taken from the "NSW Department of Education and Training DISABILITY CRITERIA (school sector) May 2003".

Language: Students must have an assessed receptive or expressive language disorder which is documented within a current speech pathologist's report (in general, the report should be less than 12 months old). At least one of the scales (either receptive or expressive) must indicate a standard score of 70 (second percentile) or less.

Physical Disability: The student must have a current physical condition involving the motor system that significantly limits the student's level of functioning and independence in mobility, personal care, and/or ability to physically undertake essential learning tasks.

Intellectual Disability: To meet criteria for intellectual disability, students must have a full-scale IQ score on an approved individual test of intelligence of approximately:

- two to three standard deviations below the mean for mild intellectual disability
- three to four standard deviations below the mean for moderate intellectual disability
- four standard deviations or more below the mean for severe intellectual disability

There must be information on the assessment of adaptive skills and school performance (where applicable) consistent with, or below this range of scores.

Hearing Impairment: Students must have a current audiogram and report from *Australian Hearing* which indicates a sensori-neural or permanent conductive hearing loss of 30 decibels or more in both ears.

Vision Impairment: Students must have a current diagnosed vision impairment, which details a permanent vision loss that is 6/24 or less in the better eye corrected, or less than 20 degrees field of vision.

Deaf/Blind: Students must have a vision and hearing impairment, both at levels that severely impact on their ability to learn, and which result in unique educational needs.

Mental Health Problems: Students must exhibit behaviour(s) that is characteristic of mental health problems at a level of frequency, duration and intensity that seriously affects their educational functioning and emotional well-being. The behaviour(s) must be evident in the home, school and community environments.

Autism: Students with autism must have a current report from a specialist medical practitioner or registered psychologist with appropriate clinical experience.

General Notes

Where there is evidence that a student has a significant disorder or malfunction that is not adequately described by one or more of the above criteria and the condition is impacting greatly on educational outcomes, the Coordinator Student Counselling and Welfare together with the Coordinator Special Education will consider all available documentation and make a determination on a case by case basis.

When considering support class placement for students with more than one disability, it is important to ensure that the disability having the most significant impact on educational outcomes is addressed and any other disability supported in an appropriate manner.

APPENDIX 2: Background to the Academic Competence and Evaluation Scales (ACES).

The ACES has robust psychometric properties and has been developed in accordance with the Standards for Educational and Psychological Testing which is published jointly by the American Educational Research Association, American Psychological Association and the National Council on Measurement in Education (Di Perna and Elliot, ACES Manual, 2000). It was primarily designed for teachers and school based practitioners, along with community staff to support work with children and adolescents. The Academic Competence Evaluation Scale or ACES⁴, needs to be rated by the teacher or teachers involved with the student. It is scored by the rehabilitation clinician but joint interpretation is recommended.

The ACES has 73 items which measures the teachers perception across two domains, Academic Skills, related to academic performance which are taught explicitly in the classroom including reading, maths and critical thinking, and Academic Enablers, which are skills and behaviours that support academic performance (e.g. study skills (e.g. paying attention in class, completing homework), interpersonal skills, engagement (e.g. volunteering in class, assuming leadership) and motivation (e.g. persists when task is difficult). The teacher does not need to score the form. The items are rated according to the proficiency or frequency of a behaviour, skill, or attitude compared to grade level expectations over the past month rated the importance of the behaviour, skill, or attitude in each teacher's classroom.

We hope to evaluate whether the ACES provides clinically useful information that can also be objectively analysed. Information from the ACES will provide:

- Objective information on how a child is currently performing academically and in the school community.
- Support clinical reasoning to identify the rehabilitation goals the client wants to achieve at home and in the classroom and what intervention/ support will assist goal achievement.
- Enable a student's progress to be monitored over a school year

The ACES is completed by the child's teacher who rates the child's participation in the classroom which takes around twenty minutes to complete.

⁴ DiPerna and Elliot (2000)

APPENDIX 3: References

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