

Addressing Educational Challenges Following Pediatric Acquired Brain Injury

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Abstract

Children with acquired brain injury (ABI) can face a broad array of challenges that can endure over their lifetime, making this a complex area of specialization for life care planners. Education is a primary component of children's lives. Therefore, it is important when attempting to determine supports and services, to identify key impacts of the brain injury to a child's current and future functioning. Comprehending the nuances that may occur over time when an ABI is superimposed on a developing child's brain is key. Understanding the nature, diversity, effects and remedies for these potential long-term challenges requires the expertise of numerous specialists, including, educational specialists with specific training and experience in educating children with ABI.

Keywords: traumatic brain injury, non-traumatic brain injury, acquired brain injury, concussions, education, school, academics, students, brain development, brain maturation, neurodevelopment

The Centers for Disease Control identifies brain injury as a leading cause of disability for children and adolescents in the United States (Faul, Xu, Wald, Coronado, & Dellinger, 2010). A World Health Organization (2006) report states that neurological disorders are "seriously underestimated by traditional epidemiological and health statistical methods that take into account only mortality rates but not disability rates" (p. 1). Children and youth who sustain a brain injury may experience specific and complex learning, social, and communication issues that potentiate significant educational ramifications that can require enduring lifetime supports. A combination of medical, rehabilitation, school, and family supports and services, may be required both initially and over time, to promote successful outcomes.

Acquired brain injuries (ABI) occur after birth, not before or during, and encompass both traumatic (caused by an external force) and non-traumatic (caused by an internal force) brain injuries (Brain Injury Association of America, 2018). There are many different taxonomies for describing the levels of severity of traumatic brain injury (TBI). For example, for purposes of initial treatment, TBI onset is frequently triaged into three different levels of severity based on the duration of alteration or loss of consciousness (LOC). This includes mild (less than 30 minutes LOC – sometimes no LOC but an alteration of consciousness), moderate (less

than 24 hours LOC), and severe (greater than 24 hours LOC). Concussion is one form of mild TBI. Contrary to common misconceptions (McKinlay, Bishop, & McLellan, 2011), functional outcome is inconsistently correlated with the initially diagnosed severity of the brain injury (Bernard, Ponsford, McKinlay, McKenzie, & Krieser, 2017; Dettmer, Ettl, Glang, & McAvoy, 2014; Haarbauer-Krupa et al., 2017). It is important to determine the mild, moderate, or severe impacts that the brain injury inflicts upon the child's life.

Each brain injury is unique, and multiple factors can affect functional outcomes. This includes but is not limited to: age at injury onset (Anderson & Moore, 1995; Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005; Catroppa, Anderson, Mores, Haritou, & Rosenfeld, 2008); location and severity of injuries (Anderson et al., 2005; Catroppa et al., 2008; Catroppa et al., 2017; Steyerberg, Mushkudiani, Perel, & Butcher, 2008); premorbid capacities and limitations (e.g., Babikian, McArthur, & Asarnow, 2013; Fay et al., 2010; Satz, 1993; Stern, 2009); co-morbid injuries; initial access to treatment following injury onset (e.g., Goldstein, Mayfield, Thaler, Walker, & Allen, 2016; Ylvisaker et al., 2005); and social, family and cultural issues (e.g., Anderson et al., 2001; Anderson, Morse, Catroppa, Haritou, & Rosenfeld, 2004; Hawley, Ward, Magnay, & Long, 2009; Hoofien, Vakil, Gilboa, Donovan, & Barak, 2002). Understanding these factors is critical for successful case formulation.

Not every child who experiences a brain injury will develop symptoms or sustain disability. The onset of dysfunction, however, may also not always be immediate or directly obvious. For example, a student diagnosed with a concussion may return to school experiencing daily migraine headaches and short-term memory issues that require immediate school intervention. Another student with TBI may return to school and initially function remarkably well. However, this initial presentation may not be representative of long-term functioning. Latent neurological damage along with the increasingly complex environments that children face as they age may later reveal a variety of diverse challenges that impact capacities to learn, communicate, maintain friendships, and lead a productive life.

Medical to School Transition Planning

Brain injury is often referred to as an invisible injury because the resulting cognitive impairments can be hidden in a child who physically appears to have returned to normal.

Planning and consistent communication among the medical, rehabilitation, education, and family sectors does not always systematically occur upon transition from medical rehabilitation to school (Andersson, Bellon, & Walker, 2016). This lack of collaboration can adversely affect the student's learning potential (Discala, Osberg, & Savage, 1997; Glang et al., 2008). Many children with ABI return to school soon after injury before effective supports can be instituted. Additionally, some parents may not notify school staff about their child's brain injury, in hopes that everything will return to normal and the brain injury can be forgotten (Davies, Wade, & Wu, 2008). Any of these underlying factors can lead to ineffective educational planning, both initially and over time.

The Developing Brain

A child's brain is different than an adult's brain. It is not until adulthood that the human brain is fully anatomically and operationally developed (Casey, Giedd, & Thomas, 2000). Research indicates that children's brains do not simply bounce back after injury (Giza & Prins, 2006). An adult has a plethora of prior experiences and knowledge to support recovery in the event of brain injury; whereas injured children do not have these same reserves of experiences and skills. Unlike adults with brain injury onset, youth often face the challenge of amassing and developing critical skills with impaired abilities.

Because pediatric brain injury occurs while the brain is still developing (Whateley Driscoll, Quinones-Pagen, Savage, & Riddick-Grisham, 2011), the younger damaged brain is more at risk for lifelong adverse effects (Babikian, Merkley, Savage, Giza, & Levin, 2015; Ewing-Cobbs et al., 2004; Giza & Prins, 2006). Children who sustain a brain injury may experience "significant and persistent consequences in the development of intellectual and academic functions as well as deleterious effects on academic performance" (Ewing-Cobbs et al., 2006, p. 297). During child and adolescent development, defined regions of the brain undergo episodic periods of maturation and development (Casey et al., 2000; Gogtay, Giedd, & Lusk, 2004; Sowell, Delis, Stiles, & Jernigan, 2001). When neurological damage occurs to a child, it is superimposed on a developing brain (Babikian et al., 2015; Savage, 2009; Savage, 2010). Prior knowledge typically is not disrupted, but the child's future learning, emotional and adaptive capabilities can be compromised (Savage, 2009, Savage, 2010; Ewing-Cobbs et al., 2004). Babikian et al. (2015) found that there are "chronic aspects of medical/health, cognitive/academic, emotional/behavioral, and family/social outcomes after pediatric TBI" (p. 1849). Increasing demands as one matures following brain injury can create future challenges.

One example of latent effects is a kindergarten student who sustains a frontal lobe injury. The frontal lobes are where executive functions are housed. The kindergartener might

return to school and appear to function reasonably well. The frontal lobe region of the brain does not undergo rapid development until the middle school years and achieves full maturation in adulthood (Gogtay et al., 2004). Since students in early elementary grades are not required to perform higher-level cognitive tasks that involve executive functioning, deficits may not be immediately apparent. Over the years, as injured areas of the brain are relied upon to perform more complex, higher-level cognitive activities, new deficits may emerge. Whateley Driscoll et al. (2011) summarized the following regarding brain injury in students, "If we thought algebra was challenging in secondary school, try marriage, and if we thought that history studies were difficult, try competitive work" (p. 482). Therefore, it is important to continue monitoring students over time following brain injury.

Pediatric Brain Injury and Schools

A child's job is to be a student and school is where they spend the majority of their time working. Brain injury is considered a low incidence disability in schools (National Center for Education Statistics, May 2017; United States Department of Education, 2010), even though brain injury is a leading cause of disability among youth (Faul et al., 2010). This discrepancy is a national educational issue (Glang et al., 2016). It is crucial that professionals working with families to support children and adolescents following a brain injury ensure the school is not only aware that a brain injury occurred but that the school is also informed of possible supports and services that may assist the creation of an appropriate educational plan.

Many school staff exhibit misconceptions about students who have experienced a brain injury (Canto, Chesire, Buckley, Andrews, & Roehrig, 2014; Duff & Stuck, 2014; Ettel, Glang, Todis, & Davies, 2016; Hooper, 2006; Linden, Braiden, & Miller, 2013). A few common misconceptions include: all students recover from brain injury; outward physical recovery signifies full cognitive recovery; concussions do not result in long-term learning deficits; and neurological damage did not occur if neuroimaging scans are clear. One reason school staff harbor misconceptions is because most have not received adequate information and training about brain injury (Davies, Fox, Glang, Ettel, & Thomas, 2013; Glang et al., 2008; Glang et al., 2016; Glang, Dise-Lewis & Tyler, 2006; Glang, Ettel, Tyler, & Todis, 2013; Glang, Todis, Sublette, Eagan Brown, & Vaccaro, 2010).

A prior brain injury may not be linked to newly emerging cognitive or behavioral issues for several reasons. First, there may be no documentation of a student's past brain injury in the school records. Second, school staff may not know how to monitor the student for latent onset deficits. Lastly, parents may not have received information from medical and rehabilitation providers about potential future effects their child may experience over time. These reasons can lead to

misdiagnosis, ineffective educational planning, iatrogenic treatment, and further learning challenges for the student. This can be especially deleterious if a student's educational plan is created based on the misassumption that the she or he has a psychiatric disorder, intellectual disability, autism, social-language disorder, attention deficit hyperactive disorder, or other disability or disorder. Studies have found that lack of appropriate supports and services may lead to dropping out of school (Barrat et al., 2014), drug and alcohol abuse (Ilie et al., 2015), and criminal involvement (Williams et al., 2015). Hughes et al. (2015) found that up to 72% of incarcerated youth had sustained a prior TBI, and 100% of juveniles who were on death row had experienced a prior TBI (p. 94). Hence, the chronic nature of brain injury requires long-term surveillance.

Developing an effective educational plan is a multi-factored and multi-disciplinary effort. Whateley, Driscoll et al. (2011) stated, it is possible to "predict long-term deficits and needs of individuals" (p. 485) after a pediatric brain injury. However, numerous factors must be investigated, including, but not limited to the child's age at the time of injury, current age and functioning, prior developmental progress, family support, school support, access to healthcare services that includes rehabilitation, and a history of modifiers (i.e., learning difficulties, migraines, prior brain injuries). Collecting these data requires a comprehensive review of all available records, including medical, social, educational, legal, unique event files; comprehensive on-site parent, student, and school staff interviews; direct observation of the student at both home and school; and detailed communication with professionals and other sources. This information is compiled into an in-depth report that includes specific information regarding recommended educational supports and other treatment modalities; supported by the latest peer-reviewed research from the field.

Records Review

First, a thorough records review should be conducted that includes all past and current medical, rehabilitation, neuropsychological, educational and other records of significance such as unusual life events, legal issues, family issues such as divorce or other stressors, with particular attention paid to critical issues that can impact learning and development. Critical issues can include, but not be limited to brain injury location and severity, seizures, pain syndromes, premorbid learning capacities, prior injuries and illnesses, and behavioral changes. Additionally, topics that require follow up during the on-site interviews and observations are noted at this time.

School, Parent, Student Interviews and Observations

Interviewing parents, school staff, and the child, as well as conducting observations at school and home are essential when constructing a comprehensive picture of the child's prior and current functioning. Both settings provide excellent

opportunities to correlate medical diagnoses, neuropsychological test results (e.g., cognitive and behavioral deficits) and other clinical findings with functional performance. In addition, these natural environments may reveal other strengths and limitations that the child experiences that were not evident in the controlled environmental settings where most clinical evaluations occur.

Record reviews, interviews, and observations can help to create a comprehensive picture of the student's current functioning. In some cases, the compiled information warrants involvement by other professionals. For example, a child who has continuing headaches while viewing a computer screen, watching television, becomes dizzy when walking up stairs, frequently reports that his eyes feel tired and has trouble reading sentences because the words jump around may suggest the need for a vestibular-ocular evaluation. Teacher reports of a student's frequent episodes of daydreaming, parent reports of spacing out at home, and classroom observation of these episodes may suggest the need for a neurological evaluation.

Teachers can provide valuable information regarding residual deficits (if they understand brain injury) because of the daily time they spend with students. School staff interviews should also include teachers the student had prior to the brain injury, if possible, to compare pre and post-injury function. In some instances, even though current teachers recognize the student has learning disabilities, they may be unaware that the student experienced a prior brain injury until the interview and observation take place. This is also the time when the evaluator can determine what school staff know about the effects of a brain injury and how to appropriately support such a student at school.

When interviewing teachers, it is essential to ask teachers more than generalized questions such as "How is the student doing in school?" Probing questions based on information discovered during the record reviews are also required such as:

- Do you adjust the student's academic supports based on her performance?
- What type of formative and summative assessments do you use in your class? How does this student perform?
- How does this student's academic performance compare to her peers?
- If you knew the student before her brain injury, how was she the same or different in comparison to now?

After a brain injury, a student may know the correct answer to a test question one day, but not the next. Does the teacher know if this is a retrieval issue or a comprehension issue? Teachers without adequate training may see this as an issue of *not knowing the answer* rather than an information retrieval issue. A teacher might view a student's daily acts of defiance as willful disobedience and take away daily recess as punishment because he or she does not know that a prior

brain injury can impact behaviors years later. With appropriate brain injury training, the teacher may learn to track and modify the antecedents triggering a student's behavioral outbursts to facilitate educational success (Bruce, Gurdin, & Savage, 2006; Feeney & Ylvisaker, 1995).

A student with brain injury may look exceptionally well on paper when educational tests, homework, quizzes, and report card grades are reviewed. However, a different picture may emerge when the learning support plan is reviewed, academic work samples are gathered, and teachers are interviewed. It may be discovered that the student takes all tests using an open book, has no deadlines for work completion, is excused from writing all papers, or takes all tests and quizzes in a separate room in conjunction with cueing by the teacher. In such instances, working with school staff to employ scaffolding strategies is important to facilitating new learning, as well as teaching the student self-advocacy skills to prepare for the post-high school graduation transition. The key issue is to understand the processes that are promoting or encumbering current performance in order to make salient long-term recommendations.

As students prepare to transition from high school to post-secondary education, work, and community living, it is vital to determine the potential barriers she or he may experience when these abundant academic supports are no longer in place. Many students with brain injury may fall through the cracks after they graduate from high school because these previously available services are no longer available. Dr. Ron Savage explained that "students [with brain injury] who have left high school no longer receive six hours a day of support in a safe (school) environment. Post-graduation, work accommodations are minimal, and community supports are not funded" (personal communication, January 27, 2018).

Formal Education Supports

All students with disabilities in the United States have access to a Free Appropriate Public Education (FAPE). FAPE is guaranteed by the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973. In some cases, a student may need a Section 504 Plan or an Individualized Education Program (IEP) to access these services. Parents can request that the public school conduct an evaluation. This requires the school to initiate a multifaceted evaluation process to determine if the student qualifies for formal supports and services. Although a medical or rehabilitation provider cannot medically require the school to provide a 504 Plan or IEP, the academic planning decisions for a student should always be informed by other outside information when available. Outside medical, rehabilitation, psychological, neuropsychological, or educational evaluations provided to the school must be considered by the school team, but this information does not automatically dictate services and supports. Determining the

need for a 504 Plan or an IEP, and associated services is ultimately a school team decision. There can be differences between what services the school team offers and what parents, outside professionals or others recommend.

Formal Academic Accommodations-Not Special Education

Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law enforced by the Office of Civil Rights to prevent discrimination against individuals with disabilities. This law can protect students who qualify as having a physical or mental impairment (e.g., brain injury) that substantially limits one or more major life activities (e.g., thinking, concentrating, reading, sleeping, learning) (Section 504 of the Rehabilitation Act of 1973). The key emphasis in this definition is that the impairment (in this case brain injury) must have a *substantial* impact on a major life function. A 504 Plan is created by the school team to provide formal academic accommodations so that a student with a disability can access and learn the same curriculum content as other students. This is intended to "level the playing field" (Lerner, 2004, p. 1045) between students with disabilities and their peers. However, the learning expectations and curriculum remain the same. A few common academic accommodations may include but not be limited to extra time for testing, testing in a separate room, copies of teacher notes, and audiobooks.

Formal Academic Accommodations and Modifications-Special Education

The school team evaluation may determine that a student needs both formal academic accommodations and academic modifications. Academic modifications are provided through special education and signify that the student's academic curriculum needs to be adjusted or changed relative to the standard general education curriculum. Students requiring this higher level of service are then assigned to a primary exceptionality category recognized by the federal special education law, Individuals with Disabilities Education Act (IDEA). In 1990, the category of Traumatic Brain Injury was added to IDEA and specifies that a TBI is:

"...an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psycho-social behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma" [34 *Code of Federal Regulations* §300.8(c)(12)].

Students with non-traumatic brain injury who are found in need of special education cannot be included under the federal IDEA definition of TBI. Instead, these students may qualify for special education services under a different IDEA special education category such as Other Health Impaired. However, it is important to check with the state Department of Education where the student resides, as several states have adapted the definition to include all ABIs.

Special education is provided in the form of an IEP that specifies individual goals for the student's education. School staff are required to monitor the student's progress towards reaching those goals during the academic year. The school-based IEP team, which includes the parents, determines what academic services and supports the student requires to be successful in school (not for medical improvement) and incorporates them into the IEP. A student may also benefit from extended school year (ESY) services from the school district. Many students following a brain injury benefit from ESY services over the summer months, so that regression of learning does not occur. The school team determines the need for ESY, following a school-based data collection process. Parents should be informed that this is a possible service their child.

Neuropsychological evaluations. It can be valuable for a qualified neuropsychologist to conduct an evaluation and provide recommendations to the school team to help inform educational planning. A properly administered neuropsychological evaluation can help reveal the student's strengths and impairments by investigating cognitive processes such as short and long-term memory, attention, speed of processing, and executive functions, to name a few. The school team should work in collaboration with the neuropsychologist and any other current health care providers to create an appropriate individualized educational plan. However, it is important to note that schools are not required to pay for a student's neuropsychological evaluation or other outside examinations. Often, this cost falls to the family or the medical insurance. If parents disagree with the school-based assessment findings, the parents can provide a written request asking the district to pay for an independent educational evaluation before the evaluation occurs. The school will either 1) provide the parents with information regarding local evaluators to contact or 2) refuse the request and commence a special education due process hearing.

Medically-based versus school-based therapies. Medical rehabilitation therapy follows a medical model. School-based therapy follows an educational model. Because a student had previously received medically-based rehabilitation therapy (e.g., physical therapy, occupational therapy, speech therapy) it does not mean that the student will automatically qualify for those same therapies in the school setting. The school team determines if the student is experiencing an educational impact that requires the related service of a school-based therapist to enable the student to receive equal access to an education. As previously noted,

there may be other challenges that the student continues to experience outside of school, which are typically deemed unrelated to educational performance, that do not qualify for school-based services.

Students who sustain a brain injury often have unique needs. Some school-based therapists may not have familiarity working with students after a brain injury. If the student is receiving both community-based and school-based therapies, it is vital that the therapists communicate so the goals are reinforced in all settings. Contacting the state's Brain Injury Association or Brain Injury Alliance can be one way to identify local medical and rehabilitation providers with experience in brain injury.

Expert Educational Planning

Comprehensive compilation and assimilation of the medical, rehabilitation, educational, social, and other information is required to develop viable and effective resources that can aid a student with educational challenges following brain injury onset. Expertise in the fields of special education and brain injury is crucial to helping others involved in the student's support system understand and navigate the full scope and limitations of a school system. This professional should also maintain astute proficiency in educational law. In addition to recommending requisite educational services and supports, it is also important to identify how to access local resources to promulgate desired functional outcomes such as assisting families in obtaining services from the Department of Developmental Disabilities. A Brain Injury Educational Specialist is one type of professional who has extensive clinical experience working with students with brain injuries coupled with background training, education, and certification coursework in the combined fields of special education, brain injury, and child development.

These specialists can serve as the expert in the neurodevelopmental aspect of brain injury as it relates to education, transition planning, peer relations, home and community involvement due to their ability to concisely determine pre-and post-injury functioning of the child both at home and school and operationalize associated supports and services that may be required.

The expert professional assessing and compiling recommendations for the educational supports and services following pediatric brain injury should be able to understand and operationalize the neurodevelopmental aspects of brain injury as it relates to education, transition planning, peer relations, home and community involvement, navigation of school systems, proper data collection and monitoring required by school staff, and strategies for the development of effective educational plans. When considering life care plans created for forensic cases, the professional must also be able to be qualified as an expert within court requirements. This can vary across jurisdictions, but at a minimum requires professional documented clinical experience, education,

ongoing training, and contribution to the field of pediatric brain injury.

Conclusion

Brain injury is considered a chronic disease process that evolves over time (Babikian et al., 2015; Institute of Medicine, 2009; Masel & DeWitt, 2010). Therefore, it is crucial that children and adolescents be monitored for as long as possible to account for any deficits that manifest over time. Medical, rehabilitation, and educational providers are unable to change the primary effects of a brain injury (e.g., the area of the brain damaged, the severity of the injury). However, it is possible for these providers to positively impact the potential chronic outcomes following pediatric brain injury if appropriate supports and services are available to children and adolescents both initially and over time.

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