

"A comprehensive system of care for children, adolescents and their families"

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The Mental Health Needs of Children with Traumatic Brain Injury

By Barbara Dively



Mental health professionals have an important role to play in helping children, families, teachers and schools cope with any brain injury that causes changes in cognition and/or behavior. Whenever a child acts abnormally, the professional must inquire into the possibility of a history of brain injury, because the effects are life-long, increase over time as demands increase and interfere with the maturation of the brain.

Prior damage to the brain may be revealed at any age through impaired

cognitive function and/or inappropriate behavior. Damage to the brain occurs through interference with the oxygen supply to the brain as a result of trauma, stroke, near drowning, near suffocation, drugs, alcohol, infection, surgery, tumor, aneurysm, poisoning, etc. Damage is cumulative, regardless of the cause.

Traumatic brain injury alone is the leading cause of both death and disability from birth to age 40. Some estimate that most prison inmates have a history of childhood traumatic brain

injury. According to Pennsylvania Department of Health statistics for 2004, 32,936 children under age 21 possessed a medical history that included prior hospitalization due to traumatic brain injury. About five times as many, or 164,680, had a history of emergency department discharge with this diagnosis. The Centers for Disease Control and Prevention projects an unknown but larger factor for children seeking no treatment, treatment at clinics or treatment with individual physicians. For each hospital admission for bicyclists, there were 27 bicycle-related visits to the emergency room. (See references at the end of the article for sources of this information.)

Mental health professionals have a life-long important role to play after any brain injury that changes cognitive and/or behavioral functioning.

- Classmates and teachers may need help to understand and relate to the recent survivor of traumatic brain injury, while dealing with their own shock and grief over losing the person they knew and loved.
- Children with brain injury and their families may need help as they experience grief over what has been lost, frustration with daily struggles and fear over what the future may hold.
- Families may need help to accept reality, maintain a strong family unit, build a support system and create a consistent home structure that promotes recovery.

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Meeting the Needs of Children with Traumatic Brain Injury

The Individuals with Disabilities in Education Act (IDEA) defines traumatic brain injury as "an acquired injury to the brain caused by an external physical force, resulting in total or partial functioning 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; psychosocial 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."

According to the Brain Injury Association of America, the age groups at highest risk for traumatic brain injuries are children ages birth to four, and teenagers ages 15-19. This makes the issue relevant for all those who work with children and adolescents, as well as those who specifically work with children and adolescents with mental health needs, since there are emotional and behavioral problems special to these age groups that can occur as the result of traumatic brain injuries.

The Department of Public Welfare has convened a Brain Injury Workgroup in collaboration with the Department of Health, to "address the barriers and gaps in services for children and adults with brain injury by developing, expanding and coordinating services across the lifespan." This workgroup identified a number of specific issues that cross programs and departments, as individuals and the system work with people with brain injuries:

- *Identification and screening:* Using a standardized brain injury screening tool has been identified as a means to ensure that everyone with a history of brain injury will be appropriated assessed.
- *Neuropsychological evaluation:* Such an evaluation would help to determine necessary accommodations for individuals with brain injuries.
- *Development of treatment standards:* Best practices for the treatment of brain injuries are needed for "appropriate cognitive and behavioral rehabilitation."

- *Training of staff in the service system:* This training would include especially school system and intermediate unit staff, some of whom administer screening tools.
- *Coordination of services across the service system:* The treatment standards should be implemented in every service system, with procedures for coordinating and collaborating among state departments and agencies serving individuals with brain injuries.
- *Lack of appropriate providers:* A sufficient number and variety of regionally available providers are needed to meet the rehabilitation and support needs of individuals with brain injuries.
- *Funding:* Flexible, available and timely funding is needed to "minimize neuropsychological disability and maximize personal independence."
- *Information:* Individuals, family members and the general public need to be informed about the symptoms and prevention of brain injury, as well as appropriate treatment, rehabilitation and services.

These issues have been formulated into specific recommendations which have so far received broad – but not specific – approval. The Department of Public Welfare will also soon release a DVD resource, entitled "Brain Injury and the Challenges of Life Ever After." Contact Ginny Rogers at virrogers@state.pa.us for more information. Additional sources of information about traumatic brain injury include:

- Brain Injury Association of Pennsylvania, www.biapa.org
- Brain Injury Association of America, www.biausa.org
- International Brain Injury Association, www.internationalbrain.org
- National Brain Injury Research Treatment and Planning Foundation, www.nbirtt.org

Harriet S. Bicksler, editor

Transition Planning after Traumatic Brain Injury

By Douglas A. Della Toffalo, Ph.D., ABSNP

Most individuals who suffer a traumatic brain injury (TBI) should be referred for a specialized type of evaluation known as a neuropsychological evaluation. This evaluation uses a mixture of fairly common instruments (such as individually-administered IQ and achievement tests) as well as more specialized instruments that are designed to measure a variety of information-processing skills. Simply put, a comprehensive neuropsychological evaluation seeks to find the very specific ways in which a person's thinking, learning and behavioral patterns may have been affected by his or her head injury.

Such evaluations should ideally be conducted early in the recovery phase in order to provide a "baseline" measure against which future progress in recovery can be compared. Re-evaluation with neuropsychological measures is generally recommended at one or more points in the recovery process that may be as much as two years post-injury or more. While adults generally display the bulk of recovery from TBI within 18 months, children display progress in recovery that can be ongoing for as much as five years or more (Lezak, Howieson, & Loring, 2004). Some deficits (such as in "executive functions" or certain higher-order reasoning skills) resulting from TBI in young children may not be fully evident until the child is more than 12 years of age.

Traumatic brain injuries (as well as other neurologically-based disorders such as Attention Deficit Hyperactivity Disorder, autism spectrum disorders, seizure disorders, Fetal Alcohol Syndrome, etc.) often leave individuals with a pattern of very unevenly-developed cognitive skills. Precise measurement of such unique patterns of strengths and weaknesses in information-processing skills is a critical step in the process of recovery, especially when planning for re-entry into the school setting and preparing for postsecondary education or vocational training. Comprehensive neuropsychological evaluations generally examine the way a person performs in the following cognitive skill areas: attention/executive functions (including behavioral control), language skills, motor functions, sensory-perceptual skills and memory. By using a variety of measures that are sensitive to multiple aspects of functioning in each of these areas, neuropsychological evaluations provide an array of

performance data that cannot be captured by traditional IQ or achievement tests alone. Assessments that rely upon traditional IQ and/or achievement tests alone often yield scores that tend to obscure educationally and vocationally-relevant strengths, weaknesses and needs (Semrud-Clikeman, Kutz, & Strassner, 2005).

With more than 40 percent of all head injury patients being below the age of 18 years (Bigler, 1990), it might seem logical to assume that schools must be rather accustomed to, and adept at, working with children who have suffered a TBI. Generally speaking, however, this is not so. Even though "Traumatic Brain Injury" is specifically included in one of the dozen or so educational categories of disability that can qualify a student for special education services, it is one of the least often identified types of educational disability. Schools tend to reserve the use of this educational diagnosis for only those students who have a clearly documented history of a brain injury. In reality, a much greater number of students displaying behavioral or cognitive symptoms of TBI are either not receiving any form of special education programming, or they are receiving such services after having been identified as a student with a learning disability or "Other Health Impairment" (which is often used as the category of educational disability when ADHD is suspected or has been diagnosed). This can be problematic because, without proper attribution of a student's learning and/or behavioral problems to the effects of TBI, the student's difficulties are more likely to be attributed to "laziness/poor effort" or poor discipline.

Evaluations completed in schools are conducted for the very specific purpose of determining whether or not a student displays eligibility and need for special education services. The types of medical or psychiatric disabilities that can qualify a student for such services are seemingly endless, but they must be translated into one of a dozen or so rather vague educational categories of disability such as learning disability, mental retardation, autism, visual impairment, orthopedic impairment, traumatic brain injury, speech or language impairment, and so on. These categories are necessarily vague, as they are meant solely to determine eligibility for special education services and not to determine a specific set of interventions or accommodations.

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Three Family Stories of Coping with Traumatic Brain Injury

Brain Injury: Challenges and Victories

By Kathleen Larson

My son, who is now 16 years old, received a brain injury from a near-drowning incident when he was three years old. His injury is not as severe as others I have known; however, this has its own pros and cons. Because he does not look like he has a disability it has been extremely difficult to get schools, doctors and others to give him the opportunities and understanding he has always needed. It took me awhile myself to accept the truth about him. Be sure you seek your own emotional support as well as support for your child.

When he first started really exhibiting severe behavior—violence (chasing people with knives, throwing furniture at school), failing at school and not being able to read—he was in second grade. I was so confused, I really did not understand it. Even when he spent 30 days at a children’s hospital being evaluated and even though he came back with an abnormal EEG, the doctors still did not diagnose his traumatic brain injury. It was only when a good neuropsychologist took an MRI of his brain that we saw the scar tissue and realized what we were dealing with. It was so important to know where the scar was and what portions of his brain were affected and therefore what specific manifestations of his disability we could expect.

I still had regular and constant battles with schools to obtain any kind of help for him. It is not an understatement to say that most teachers and educators are greatly uneducated when it comes to TBI. They do much better with other disabilities. I think TBI still remains unrecognized and confusing for them. Finally by seventh grade, after another failing report card for my son, I threatened the school with a lawsuit for compensatory education and other remuneration for their clearly inadequate and negligent treatment of my son. While I do not recommend this except as a last resort, I finally got the school district to pay for a complete neuropsychiatric evaluation, something I could never have afforded and which insurance will not cover. It was 26 pages long and done by a highly qualified private neuropsychiatrist.

Finally, everything was all on paper. After that I used that report extensively every time I encountered any resistance at all to the things I felt he needed to be successful. Because the school knew I was educated in the law and had the medical evidence to back it up, their resistance almost completely faded. I cannot stress enough the



need for a complete neurological evaluation. It is such a powerful tool. Now my son is a junior in high school. He gets a B average and receives all the benefits available through special education and other agencies and specialists. I do not think there is anything I have requested these last two years that I did not receive, including a specialized training course about TBI for every teacher, counselor, principal or other school employee who might come into contact with him. That was especially helpful since finally everyone at the school began to take seriously the real disability Rob struggled with, in spite of appearing “normal.”

The only truth I have to offer is that every victory is always hard fought for, but well worth it. There is so much law on the parents’ side, but many parents are not aware of these laws. As I work with parents as an advocate, I am still astounded how many parents are stunned to learn about the amount of benefits they can receive. Parents have to be involved and educate themselves or they will never be able to give their children what they should have and deserve, but it is worth the effort. To every parent I would say all the tears, frustration, anger and agony are worth the light in a child’s eyes when he comes home with that first great report card or first victory of any kind. Never give up and never give in! I wish every parent much deserved rewards for all their efforts. To say it is easy would be a lie, but to say it is always, eventually, so well worth it and so rewarding is a truth I would offer with the greatest hope for success.

Coming Back from a Severe Brain Injury

By Kim Wolf

My daughter was in a coma for one and a half years following a motor vehicle accident in March 2001 when she was almost 12 years old. As she came out of the coma, she began special education in the form of occupational and physical therapy. By the end of the school year, she also received music therapy. As she came back to life, she began with a special education teacher and speech therapist. She has had homebound services for the past four years.

This year, our daughter has had a lot of medical setbacks such as severe osteoporosis, kidney stones and gall stones, causing us to put occupational and physical therapy on hold due to her pain. Although she has had over 50 medical appointments this year, she has continued music and speech therapies, and increased her hours with the special education teacher.

Our daughter is on more than 15 medicines besides formula feeding through a pump. She cannot eat by mouth, walk or talk, but she understands. Her left hand moves

slowly to answer questions but her eyes always scan to the correct answer first.

She had 15 fractures to the left side of her head, so the right side of her body doesn't work. She uses diapers and a wheelchair, has had seizures and lacks any self-help skills. Homebound services have worked the best for her since she tires very easily and has all these health issues.

Our daughter is presently trying communication devices, sign language and cards. We always give her choices and have provided a communication board. Every day we post the date, her appointments that day, the weather, and who will visit her that day—all in order for her to be a part of today.

Our school district has done an excellent job implementing her Individualized Education Plan, helping her extended summer schooling go smoothly.



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Support Needed for Resilience after Brain Injury

By Barbara Dively

Children with brain injury experience the world in a different way, and require support to develop resilience and assure optimal functioning in adult life. Their parents often cannot get any help, but instead face procedural barriers within and between systems, while their children's developmental years pass by.



One parent, who prefers to remain anonymous, hopes to help others by sharing her family's experience. Her son is high functioning but has neurological issues and a history of acquired brain injury from surgery on his skull when he was a baby. As a result, he experiences "mild anxiety, mild behaviors, cognitive difficulties, visual disorders, sensory impairment, and some behaviors that come and go."

Her son struggles each day with frustration and anxiety in the school setting, but has not been identified by the school system and does not have an IEP. This boy is uniquely aware of his personal limitations on a daily basis, but cannot understand or articulate the difficulties he is having.

Because this child is high functioning and has unfamiliar medical conditions, it has been difficult for his parents to obtain medical care, services or educational supports. He does not fall into any service category because of the lack of severity of the issues. His mother has faced almost insurmountable barriers trying to obtain the necessary referrals from the medical system to get to the appropriate medical specialists. Finally connecting with neuropsychologists was an enormous benefit: "These are the people that have provided me with the support and diagnoses that we needed. Pushing through the medical world to get access to the specialists was not easy. Obtaining neuropsychological testing is helpful to find the problem areas and what needs to be done for the child. Finding

providers is a very difficult task and insurance plans do not want to pay for this specific testing.

"As a parent, my attempts to advocate and fight for my child's rights have been continually met with additional discrimination and retaliation targeted against my child. It is frustrating to lose battle after battle, with each system that is supposed to offer a

service or support and provide help. It is an all-too-common plight. If you speak to other parents of children with a disability, they too have similar stories of such hardships and retaliation. It happens more often than one would ever imagine.

"The systems need to be more open to including and providing services to all children with disabilities." The systems "need to be more willing to work around all schedules and provide services after school hours. The educational system is based on a failure model. A child with a disability must have a disability and be in need of specialized services. Then, they must fail, in order to demonstrate their individual need for supports and specialized instruction. Alternatives need to be established to close the gaps and provide needs specific to one's disabilities. More needs to be done."

This child and all children with disabilities need support as they cope with their limitations. This parent and all parents of children with disabilities need support, not opposition, as they satisfy their complex responsibilities: caring for a child with a disability, securing educational supports, finding the right outside services, maintaining the child's medical care, earning a living to support the family, meeting their own personal needs, meeting the needs of their other children, and maintaining their marriage and family life.

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- While children with disabilities are entitled to Medicaid, families need support and encouragement to take this step.
 - While Section 1396 (d)(r)(5) EPSDT of federal Medicaid law guarantees reimbursement for whatever services are needed to promote recovery—such as occupational therapy, speech therapy, communications systems, physical therapy, vision therapy, etc.—families need support to find and use these services.
 - While eligible children are entitled to assistance under federal Individuals with Disabilities in Education (IDEA) law, Section 504 of the Rehabilitation Act, and the Gaskin Settlement, families need support to find and use these benefits.
- What happens without help?**
- Children gradually fall behind and are not in regular classes by the third year following a brain injury.
 - Families disintegrate due to the stress
 - Unaddressed behavioral impairments from brain injury carry a heavier price as life become more complex. These impairments may include lack of impulse control, mood swings, irritability, anxiety and difficulty understanding how personal behavior affects others.
 - Unaddressed failure to understand one’s own deficits creates an increasing gap between self and peers when combined with faulty brain maturation, and exaggerates the impact of any cognitive and/or behavioral impairments.
- Through steady, kindly interactions, emphasizing patience and encouragement, mental health professionals can promote a climate of recovery and maximize the resilience of all who are touched by this tragedy.

Barbara Dively, Ph.D., is coordinator for the Acquired Brain Injury Network of PA, Lansdale, PA. She and several colleagues will be presenting a session at the Children’s Interagency Training Conference in April on “Putting the Pieces Together...After Traumatic Brain Injury.” Conference information is online at <http://pacassp.psych.psu.edu/docs/2007conferenceoverview.htm>.

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Once a student's eligibility for special education is established through an evaluation, they may never again undergo individual testing with IQ, achievement or other measures. Rather than conducting comprehensive re-evaluations with additional diagnostic instruments, schools are generally able to make the necessary periodic adjustments in special education services and related services, interventions and accommodations (and meet legal requirements for conducting mandatory re-evaluations) through collecting and reviewing classroom performance data. While this process can result in the delivery of appropriate disability-related supports within the schools, it does not provide the level of diagnostic specificity or intervention information required by postsecondary settings such as trade schools or colleges.

Disability support coordinators in postsecondary settings generally require recent (within one to three years of postsecondary enrollment) diagnostic evaluation data that, among other things, include updated IQ and individual achievement test scores as well as more specific diagnoses than can typically be provided through school systems. Resources for obtaining appropriate neuropsychological evaluations of individuals with TBI (or other neurologically-based disabilities) for

postsecondary purposes include neuropsychologists in private practice, including a network of approved evaluators contracted by the Pennsylvania Office of Vocational Rehabilitation (OVR).

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