



BRAIN INJURY ASSOCIATION OF NEW JERSEY

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No Brain Injury is
Too Mild to Ignore,
or Too Severe to
Lose Hope

Learning about Special Education

By Marilyn Lash, MSW and Bob Cluett

Introduction

Where do I start? This is the question often asked by parents of recently injured children as they enter the complex special education system. Even parents who have some prior experience with special education are uncertain how to proceed because most schools have little experience with students with brain injuries. Many parents whose children have been in special education for many months or years since their brain injury still report that each school year feels like “starting all over again.”

Educating a student with a brain injury is a complex and challenging process that constantly changes over time. The child’s brain is still developing while it is recovering from the injury. Schoolwork is constantly changing as the student interacts with different teachers and classes through different grades and schools. Relationships with friends and classmates change. As one parent commented, “The only thing that remains the same is that, ‘Everything is always changing.’”

The Informed Consumer

Parents cannot be effective advocates if they are not knowledgeable. The federal law on education, the Individuals with Disabilities Education Act (IDEA), now includes a specific category of traumatic brain injury for students under special education. While the federal definition is limited to traumatic injuries to the brain caused by an external physical force (such as a blow to the head), many states have broadened this definition to include acquired brain injuries (strokes, tumors, encephalitis, meningitis, near drowning). Parents and others can find out how their state defines brain injury by contacting the state Department of Education or their local special education director.

The diagnosis of a traumatic or acquired brain injury does not automatically qualify a student for special education. The diagnosis is just a beginning. Once a referral for special education has been made, it is the school’s responsibility to conduct a multidisciplinary evaluation. This evaluation determines how the brain injury has affected the student’s ability to learn and function in school. Federal and state laws provide very specific procedures and timelines for this process.

Just as educators need to learn about how a brain injury can affect a student’s ability to learn and function in school, parents need to learn about the laws for special education and how to become effective advocates. The education law guarantees parents certain rights and responsibilities. This



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article identifies four important resources for parents, advocates and educators about special education and brain injury.

The National Information Center on Children and Youth with Disabilities (NICHCY)

NICHCY is an excellent place for parents of children with brain injuries to begin. This federally funded national clearinghouse provides information on disabilities in children and youth (birth to age 22). Its resources include fact sheets, guides and news written in clear and understandable language for parents. Many materials are free or are available for a minimal charge. NICHCY's Publications Catalog lists all products and is a gateway to information about special education, transition services and other national clearinghouses of information. NICHCY has a new four-page fact sheet on TBI that provides an excellent overview of the consequences of brain injury and its effects upon a student's learning. Sections include: What is TBI?, How Common is TBI? and Signs of TBI. The section on school describes how a brain injury can affect a student and provides tips for teachers and parents. Resources direct readers to books and manuals about students with brain injuries. You can even receive a list of resources in your state. Interested individuals can visit NICHCY's website at: <http://www.nichcy.org>, call (800) 695-0285 or (202) 884-8200, or write NICHCY at PO Box 1492, Washington, DC 20013-1492.

Special Education IEP Checklist for Students with Brain Injury

Once a student has been found eligible for special education, the school must develop an individualized educational program (IEP) to meet the student's special needs. This is the blueprint for his/her education. Parents are an integral part of this plan and must approve it before it can be put into effect. The IEP is not paperwork that sits in the student's folder. It is a flexible and critical tool that can change as the student's needs change, although it is only as effective as the content.

Because a brain injury affects each student differently, there is no set formula for the IEP of a student with a brain injury. This checklist identifies common changes after a brain injury and lists student accommodations or assistance that may be needed for thinking and communication, developing social skills and adjusting to physical changes. Possible changes that can be made in the classroom are then listed for teaching strategies, giving instructions and assignments and using adaptive aids. By using the IEP checklist, parents and educators can identify gaps in the student's educational plan, recommend accommodations and identify the skills, strategies and behaviors the student needs to learn and function at school. An IEP checklist is available from L&A Publishing at (603) 569-3826.



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Parent Training and Information Centers

Children with brain injuries are a new population of survivors, whereas children with birth-related conditions, mental retardation, chronic illness and cancer have well-established informational networks and advocacy systems. This includes a national network of federally funded Parent Training and Information Centers in each state. Although these centers are often overlooked by parents of children with brain injury because their focus includes children with birth-related or developmental disabilities, these centers are valuable resources for parents of children with brain injuries because they have identified the “special needs system” in each state, particularly the special education system. They are excellent resources for gathering information, asking questions and meeting professionals and parents. Many even provide special advocacy workshops for families, training programs, conferences, newsletters and support groups. The name and address of the Parent Training Information Center in your state is available from BIA’s Family Helpline at (800) 444-6443 or from the Federation for Children with Special Needs in Boston at (671) 482-2915.

Broadening your network

We all know the importance of networking. Never is this more important than for the parents of a child with a brain injury. Look beyond the diagnosis. Parents of children with other disabilities can be valuable mentors and sources of information. For example, parents of children with special needs have years of experience negotiating IEPs, finding funding for uninsured expenses, locating recreation programs, maneuvering through bureaucracy and filing appeals. Their savvy can help you understand how the “system” works and what to do when it breaks down. You bring the knowledge about how the brain injury has affected your child; other parents bring their knowledge about how to become effective advocates. You can learn from one another.

Marilyn Lash, MSW, co-chairs BIA’s Special Interest Group on Children and Adolescents with Brain Injury. Bob Cluett is the survivor of a childhood brain injury.

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*Additional information can be found at: Helpline: 1.800.444.6443
www.biausa.org*