Brain Injury:

A Guide for Families About School

Brain Injury Association of New Jersey, Inc.

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This publication is a project of the Children and Adolescents Committee, formerly the Education System Advisory Group, of the Brain Injury Association of New Jersey (BIANJ).

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Introduction

Members of the Children and Adolescents Committee of the Brain Injury Association of New Jersey (BIANJ), formerly known as the Education System Advisory Group wrote this guide to help families when their child enters or returns to school after a brain injury. The writers and members of the Committee include professionals who work in the field of brain injury, cognitive rehabilitation, regular and special education, school nursing, and parents.

This guide is for families who are looking for information and resources to help their child return to school and negotiate the academic system throughout their education. The authors hope you find this book useful and informative.

The terms, as used in this text, “parents” and “families” include biological, adoptive, single parent, extended and any other familial arrangement. This resource may be valuable for anyone who cares for a child with brain injury and may need some help understanding and negotiating the school re-entry process.

There are many people in schools who have contact with your child. The term “educators” is used to include anyone working within an educational setting, including administrators, teachers, aides, therapists, psychologists, counselors, coaches and many others. They all influence your child’s education in some way.

Brain injury affects each child differently. It is impossible to give all the answers for each situation. By familiarizing yourself with the educational system and learning what resources are available, you will be better able to find and choose those that best meet your child’s needs in school. This guide focuses on educational issues, but there are many other topics that can affect your child after a brain injury. There are references and resources at the end of this guide to help you find more information.

Our mission is to support and advocate for individuals affected by brain injury and raise public awareness through education and prevention. Brain Injury Association of New Jersey has committed its resources to a set of goals to provide services and programs urgently needed now and in the future. The current program and services offered by BIANJ include:

- information and resource service
- browse and borrow book and video library
- support groups for persons with brain injuries and their families
- a week-long summer respite and recreation program
- a supported employment demonstration project
- initiatives to help prevent brain injuries
- education about brain injury for educators, health care staff, human services personnel, and people affected by brain injury
- advocacy and legislative action
- care coordination services for individuals who sustain brain injuries and their families
- outreach to provide information about brain injury and resources in languages other than English and in alternate formats

BIANJ can provide information about professionals who are available to speak to school personnel about brain injury. They can provide you with guides designed for educators and school nurses to explain more about the impact of brain injury on your child's education.

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Chapter 1
What is Brain Injury?

The definition of brain injury has changed over the past 10 years. Brain injuries are described as traumatic or acquired based on the cause of the injury. Knowing what causes a brain injury is very important for researching effective treatment and developing prevention programs.

The Brain Injury Association of America (BIAA) has developed the following definitions:

Traumatic brain injury (TBI) is an insult to the brain, not of a degenerative or congenital nature, which is caused by an external physical force that may produce a diminished or altered state of consciousness, and which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning.

Traumatic brain injuries can happen during everyday activities. The most common causes of brain injuries among young children are falls, such as a fall from a changing table or down the stairs in a walker. Car crashes where the child is a passenger or is struck by a car are also major causes of brain injury. Physical abuse, such as hitting or shaking a child, is another. Skate boarding, rollerblading, falling off a bike or scooter, falling from a slide, and sports injuries are other common causes of brain injuries in older children.

Acquired brain injury (ABI) is an injury to the brain that is not hereditary, congenital or degenerative.

Acquired brain injuries are caused by some medical conditions, such as stroke, encephalitis, aneurysm, anoxia (lack of oxygen during surgery, drug overdose, or near drowning), metabolic disorders, meningitis, or brain tumors.

Although the causes of brain injury differ, the effects of these injuries on a child's life are quite similar. This guide generally refers to children with traumatic and acquired brain injuries as children with a brain injury. The term "traumatic brain injury" is used throughout the text when information provided is specific to traumatic injuries.

Why is brain injury called the silent epidemic?

Brain injury is called the "silent epidemic" because of the staggering number of people who are injured each year. As many as 1.4 million people in the United States have traumatic brain injuries each year, but only one sixth of them are admitted to hospitals. This does not even count the number of people with acquired brain injuries.

Brain injury is the leading cause of death and disability in children and young adults.

The majority of children who have mild or even moderate brain injuries may not even be hospitalized after being hurt. That means that many children and their families are not aware

that a child with a brain injury may need special attention. Family members, school personnel, and even medical professionals may have trouble figuring out why a child's behavior or abilities have changed when symptoms finally appear. Often what is really a brain injury is diagnosed as a behavioral or learning problem. Thus, the "silent epidemic" includes thousands of undiagnosed brain injuries.

Medical technology has advanced so greatly in the past twenty years that many people with brain injury, who formerly would have died, are now saved. Rehabilitation programs used to be primarily for restoring physical functioning – helping people walk and talk again. The increase in the number of "survivors" of brain injury has led to new and specialized treatment in hospitals and rehabilitation programs as well as services in the community. They are all part of the road to recovery after brain injury.

Brain injury is also "silent" because most children with brain injuries look "normal". Difficulties caused by the injury may not become apparent for months or years after the injury. As a child tries to learn new and more complex information in school, or make complicated and important moral decisions, difficulties may appear over time.

Degrees of brain injury

This guide has information about children with mild, moderate and severe brain injuries. If your child has been hospitalized for any length of time - a week to months - you probably have heard the terms "moderate" or "severe" to describe the injury. You have seen and experienced the physical, cognitive, and emotional effects of these injuries. As you have watched your child recover, there have likely been reports and explanations about the injury's effects.

For many children who have what is called a "mild brain injury" or concussion, there may have been no explanations. Often, these youngsters only visit the Emergency Department or a doctor's office and may be told that their symptoms will "go away". Sometimes, these difficulties continue and parents and their child become confused and frustrated by changes in mood, memory, personality, or headaches. Given that the effects of a mild brain injury most often appear in the school setting, information about mild brain injury, or concussion, is included in this guide.

What is mild brain injury or concussion?

You begin to see unexplained changes in your child. The teacher calls and asks if something is happening at home to explain your child's lack of attention, forgetfulness, and impulsive calling out in class. You have seen behavioral changes as well, but cannot explain why. You remember the fall your child took when roller blading or skate boarding and the bump on the head. Your child was shaken up, but seemed okay and went back to playing. Could there be a connection… Maybe?

> *My son fell off the monkey bars and hit his head. That was six months ago. It seems like now I'm on the phone every day about a problem.*

A child with a mild brain injury or concussion may not have lost consciousness. Children are less likely to lose consciousness from a brain injury than an adult. Loss of consciousness is not the best indication for mild brain injury or concussion. As a result, the injury often goes unnoticed or is not diagnosed. A few days or months later, there are some changes in the child's behavior. The child gets frustrated easily, has trouble sticking to tasks and gets distracted, or grades drop. More problems may result from a child's inability to understand these difficulties. A child may have trouble getting along with other children and become aggressive or depressed.

These behaviors can get worse when family, educators and friends do not understand these changes and don't know what to do.

Common causes of mild brain injury or concussion are:

- falls off bikes, swings, or skateboards
- collisions during sports activies such as soccer, football or baseball
- throwing or swinging a young baby
- whiplash injuries in a motor vehicle crash

You do not have to hit your head to sustain a mild brain injury or concussion

A mild brain injury or concussion usually results in a temporary change in the way the brain works. There may be a short loss of consciousness, but often there is no loss of consciousness. Rather, a child may feel confused, groggy or disoriented for a while. For example, a child may not remember what was happening just before the injury.

Some of the common symptoms or after effects include:

- headaches, nausea
- tinnitis or ringing in the ear
- slower processing of information or slow thinking
- trouble understanding written and spoken information
- distractibility or jumping from one thing to another
- difficulty changing from one activity to another
- sensitivity to lights and/or sounds
- changes in sleep patterns

A child may have one or more of these symptoms or show other changes not in this list. Every mild brain injury, or concussion, should be measured, monitored and managed for optimal recovery. Premature return to activity may prolong the recovery process and increases the risk of a second concussion. In a small percentage of children, symptoms continue for a long time and have serious effects at home and in school.

Over the summer, our family was in a minor car crash. My daughter hit her head and the doctor in the emergency room said she might have a mild concussion. He sent us home and told us to watch her for 24 hours. After three months, her school grades dropped dramatically although she was studying more. She was socializing less. She seems to be getting more depressed every day. What should I do? Who should I call?

Many times a child with a mild brain injury or concussion may appear to be fine until problems show up in school. Grades may drop for no apparent reason. Often, doctors are unable to find anything physically wrong, because mild brain injury is difficult to detect. There are usually no findings on a CT Scan or MRI to explain the symptoms. This is why education about mild brain injury is so important for your child, family and school staff.

My child was diagnosed as having Attention Deficit Disorder (ADD) in the first grade. After falling off his bike a few weeks ago, he complained of headaches. He had been doing very well in the program developed by his school. Now he seems to be getting forgetful and is always fighting with someone.

You can help by getting information about brain injury from the Brain Injury Association of New Jersey. You can also help by working closely with school staff to put together a plan to help your child adjust to these changes. For example, your child may need shorter homework assignments or extra time on a test. Support and information can help you and your child develop skills to manage any physical, cognitive and social/emotional changes at home and school. It may also prevent or minimize behavioral difficulties such as depression, temper tantrums, or acting out.

Jack sustained a concussion at soccer practice on Monday and sat for his SAT's on Saturday. He had difficulty focusing. He managed to continue, even with an increasingly painful headache and was unable to complete the exam. Jack and his family were dissappointed with his scores as they did not match his PSAT projection - and influenced what colleges he would apply to.

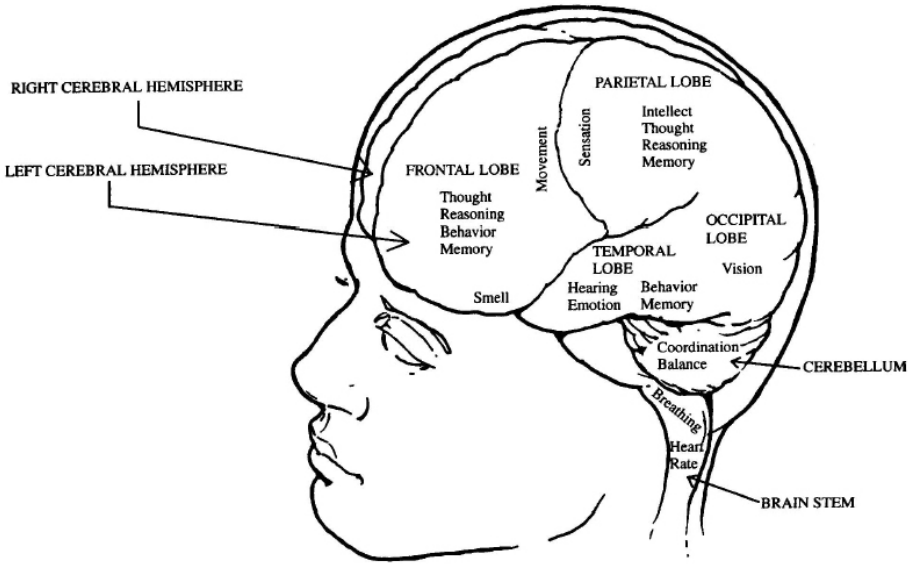
Just as accomodations are made for a sprained ankle, likewise a student with a mild brain injury or concussion needs support and assistance until the symptoms subside. A short term 504 plan may be appropriate.

Weeks or months of a school year can span more than one marking period. This can have devastating effects on your child's ability to develop the knowledge base for the entire school year. There may be rippling effects on the next year.

Education about brain injury and close contact with school staff are important for ANY student with a mild brain injury. They can reduce difficulties and failure in school and help avoid negative behavioral, emotional and academic consequences.

Anatomy of the brain

When your child's brain injury is described, you may hear about different areas of the brain. Each area is associated with functions or abilities that affect how your child navigates through daily life. Basic knowledge about what these terms mean can be helpful for understanding tests, such as neuropsychological evaluations. It can also help you better explain to school staff how your child's injury affects learning and participation in school activities.



This diagram reprinted with permission from: Acute Brain Injury: A Guide for Family and Friends The University of Iowa 2000

Common changes following a brain injury

Some of the most common changes or complaints that are reported after a brain injury are listed below. Many of these symptoms lessen over time, but some may be permanent. It is likely that your child has some of these symptoms, but it is unlikely that your child has them all. Use the checklist on the following page to describe your child.

Physical changes - does your child have ...

- ☐ fatigue or tiredness
- ☐ ringing in the ears
- ☐ blurred or double vision
- ☐ trouble walking or grasping objects
- ☐ slurred speech or trouble finding words when speaking
- ☐ unsteady balance (falls or bumps into things more)
- ☐ dizziness
- ☐ headaches
- ☐ sensitivity to lights and/ or sounds
- ☐ changes in sense of taste or smell
- ☐ nausea
- ☐ changes in sleep patterns
- ☐ endocrine or hormonal changes

Cognitive or thinking changes - does your child find it hard to...

- ☐ remember things
- ☐ concentrate
- ☐ do two things at once
- ☐ follow directions
- ☐ understand what is going on
- ☐ get the same grades as before
- ☐ solve problems and think abstractly
- ☐ get organized
- ☐ do things consistently
- ☐ read and understand at same speed as before
- ☐ recall previously learned information
- ☐ learn new things

Psychological or behavioral changes – is your child...

- ☐ irritable
- ☐ moody
- ☐ showing flat affect or little change in emotion even if very happy or sad
- ☐ self-centered or finding it hard to take another's point of view
- ☐ depressed, sad or with low energy
- ☐ fidgety
- ☐ impulsive, doing things without thinking them through

It is important that information about the cause, date, description and consequences of your child's brain injury be included in both medical and educational records. Because your child's brain is still developing, the effects of the brain injury may not be evident until your child is older and has difficulty performing more advanced tasks. Symptoms may change as a child passes through developmental milestones, such as puberty, or with transitions from one level to another, such as transition from middle school to high school. Should problems arise in the future, documentation of the injury can help educators identify causes of difficulty with learning in order to give help and support.

Brain injury affects the whole family

This is a very difficult time for you as you strive to learn about the education system, advocate for your child, and deal with the varied emotions that come along with a diagnosis of brain injury. When a child sustains a brain injury, the impact is felt throughout the family and can be expressed in different ways. Other children may begin to act out, marital relations can be strained and friends and community support can taper off, leaving a parent overwhelmed, anxious, and depressed. It is important to note that these and other emotions are normal and healthy and part of your own recovery and adjustment to brain injury.

There are supportive services available to you and your family to aid in the adjustment process. Family and/or individual counseling, sibling and family support groups and/or informal school supports are often positive steps in helping family members cope. If you do have other school

age children, it is important to maintain contact with their teachers and guidance counselors so they can receive extra support and understanding.

You are receiving a lot of information within this guide and probably throughout the onset of the brain injury. There are many people and agencies, including BIANJ, listed in the back of this guide, that are available to assist you in understanding brain injury and how it relates to you.

There are also glossaries at the back of this guide that define many medical and educational terms which you may be seeing or hearing.

Chapter 2
Going Back to School

Each family and child faces a different situation. Your child may have been in the hospital, been transferred to inpatient rehabilitation, or received outpatient rehabilitation. Your child may have only been treated in the emergency department and sent home. As a parent reading this manual, you may be trying to figure out what to do next. Although each of you has traveled different roads, you share the common goal of ensuring that your child goes back to school with an effective educational program.

How do I know what my child needs to successfully return to school?

There are many valuable types of assessments and evaluations that can be useful when your child returns to school. The type of evaluation depends on the severity of the injury and how it has affected your child. For instance, a speech evaluation is done when a student with a brain injury has problems using or understanding language; an occupational therapy evaluation when there is difficulty with fine motor movements (picking things up with hands); and a physical therapy evaluation when there is difficulty with gross motor movements (walking).

School child study teams (CST) will conduct testing that measure what academic and skill level a student is able to work at. There are also other tests that examine "cognitive" or "thinking" abilities. These are important for understanding how to address weaknesses in the brain's ability to process information. These tests also give information on how to use the student's strengths in cognitive abilities that remain intact after a brain injury. A neuropsychological evaluation is the primary method for assessing cognitive abilities after a brain injury.

Neuropsychological evaluation

It is important for a child with a brain injury to have a neuropsychological evaluation one or more times during the course of recovery. A neuropsychological evaluation is a comprehensive assessment of your child's thinking skills (cognition), behavior, and emotional status. The testing takes between six and twelve hours to complete. This evaluation gives information on how your child is learning and identifies your child's strengths and weaknesses. The results give information that is critical for developing an effective educational program.

A neuropsychologist is a doctorate-level psychologist with extensive training and experience in brain-behavior relationships. When a child is being evaluated, the neuropsychologist must be familiar with developmental neuropsychology. This is the study of how behavior and thinking develop and change as the brain matures over time. When choosing a neuropsychologist, it is important to find one who has experience with children and brain injury.

Most school districts do not have a neuropsychologist on staff. However, school districts are required by law to asses your child in all areas of suspected disability. A CST typically becomes

involved to determine what special services are needed. The CST may be uncomfortable authorizing and funding a neuropsychological evaluation due to the cost. The CST may also not understand the difference between a neuropsychologist and the school psychologist. However, as a parent, you have the right to ask for a neuropsychological evaluation.

The cost of a full neuropsychological evaluation varies, depending on geographic location and the length of testing. Because the neuropsychological evaluation gives information that is critical to planning the educational program, the school may pay for it. It is important that you know your child's rights under the law of special education and all possible sources of funding. A neuropsychological evaluation may be paid by the school, your child's medical insurance, or auto insurance (if the brain injury was due to a motor vehicle incident). The Brain Injury Association of New Jersey can help you with information and suggestions for funding.

Cognitive rehabilitation

Cognitive rehabilitation may be recommended after the neuropsychological evaluation. Cognitive rehabilitation can help a child process and use information more effectively. Information from the neuropsychological evaluation helps identify areas where help is needed. For example, family and teachers may help a student with very short attention learn how to recognize distractions and how to get back on task. A student with poor short-term memory might learn to use a daily checklist or log to help with recall.

Cognitive rehabilitation may be delivered in the home or in a rehabilitation center by specialized therapists. There are a number of creative ways that school and cognitive rehabilitation may be combined. For example, a child might attend a cognitive rehabilitation program in the morning and school in the afternoon. Ongoing communication among family, the cognitive therapist, and the student's teacher can help the student carry over the skills learned in therapy to home and school.

What kinds of services are available through IDEA and 504?

Creativity and flexibility at school can make the difference between your child's success or failure. The ongoing changes in your child's brain after an injury require flexible programs. The confines of the regular education system may limit the scope of services available. Differing degrees of supports or academic assistance can be obtained through the federal Individuals with Disabilities Education Act (IDEA) or Section 504 of the Vocational Rehabilitation Act.

The wording and laws about special education may be new to you and may feel overwhelming at times. As you continue reading this guide, you will develop a clearer understanding of what the terms and laws are and how they relate to your child's needs. The contact resources in the back of this guide can help you with questions and information about the educational system.

Understanding IDEA

The Individuals with Disability Education Act, commonly referred to as IDEA, is the federal law

which provides for a free and appropriate education for all students from birth through 21 in the least restrictive environment.

IDEA is the United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities from birth through age 21

The New Jersey special education regulations include "traumatic brain injury" as one of the specific disabilities that may be covered under IDEA.

Understanding 504 plans

Section 504 of the Vocational Rehabilitation Act-1973 was established before IDEA. It was the first anti-discrimination legislation that addressed people with disabilities.

Section 504 protects an individual who has a physical or mental impairment that substantially limits one or more life activities such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working. It protects persons of all ages, not only school aged children.

Almost every school in New Jersey receives federal funding of some type and is therefore obligated to adhere to Section 504 of the Vocational Rehabilitation Act. The Act also includes day care programs, before and after school programs, and recreational programs. The spirit of the law is to provide access through reasonable accommodations so all students benefit from their education.

An example of a reasonable accommodation....

After Tom's brain injury, he found it hard to keep up with homework because he processes information slowly. When material is read to him, he understands it and can learn at grade level. Under his 504 Plan, teachers break his homework reading assignments into smaller amounts per night and extend them over the weekend. Tom also has books on tape. He reads while istening to the tape for multisensory input. It also helps pace his reading.

There are many possible accommodations depending on what your child needs. Commonly, accommodations are used for test taking and work done in the classroom as shown by the following lists.

Test-taking accommodations

- allowing extra time
- dictating responses
- taking tests in a quiet setting
- having directions read, repeated or re-worded
- alternate formats, depending on a students specific needs

Classroom accommodations

- special seating
- use of an FM system (headphones that directly link the teacher to the child and screen out extraneous noise)
- equipment access (use of calculator, laptop computer, tape recorder, or note taker)
- modified assignments (shortening classwork and homework tasks)
- enlarged print

What decisions need to be made?

Your school district will determine whether or not your child meets the criteria to be eligible for IDEA or Section 504 services. Deciding whether or not you want your child to receive these services can be a difficult decision. Fear of classification, labeling, stigma, and concerns about being in the special education system are just a few of the concerns expressed by parents.

> *My child had a moderate traumatic brain injury last year and went through outpatient rehabilitation and cognitive remediation for six months. She lost a year of school and they say she needs to be classified. I don't want her classified, but I don't know what to do.*

Some adolescents may object to appearing "different" from their peers, particularly if they feel that the environmental accommodations of Section 504 or IDEA draw attention to them. Focusing on the extent of your child's injury and its impact on your child's ability to function in school can help you decide whether or not IDEA or 504 accommodations are necessary to meet your child's specific educational needs.

Additional support services, such as counseling, and a sensitive approach by school personnel can help you and your child develop a hopeful and positive approach. Children may be classified as eligible for special education and related services and receive special education supports and services in general education classrooms when appropriate.

The Individualized Education Programs (IEPs) that are required by IDEA and plans designed under 504 increase the responsibility and accountability of the school to provide specific services. The required documentation of your child's program is an advantage of these plans. This makes the school legally accountable for providing an appropriate educational program as developed in the IEP or 504 Plan. This also gives an organized way of passing on important information from year to year. It avoids depending on "word of mouth", thus insuring that valuable information about your child is not lost.

A student who is determined, through the evaluation process, to be eligible for IDEA services is entitled to receive related or ancillary services that are necessary to meet educational needs. These services may include, but are not limited to, physical therapy, occupational therapy, speech therapy, counseling and special transportation. The need for and frequency of related

services are assessed based on how the brain injury affects your child's ability to participate in activities at school. While the services discussed above may be provided under IDEA, they are not typically provided as part of a 504 Plan. A 504 Plan focuses on adaptations to a regular classroom, such as having tests without a time limit or taking a test orally instead of writing it. Please refer to the chart later in this chapter for some differences between IDEA and Section 504.

It is important to learn everything you can about special education in your district, and the services available. You may want to speak to people who have experience with school reentry after brain injury and find out what others have done. Call the Brain Injury Association of New Jersey or the Statewide Parents' Advocacy Network (SPAN). Speak to other parents whose children have faced similar situations.

The following three questions may help you understand how decisions are made regarding IDEA and Section 504. Keep in mind that no decision is absolutely final. If you start with a plan and later find that it is not working, you can revise it. It is vital to have frequent and accurate communications with teachers and school liaisons so that needed changes are not delayed. If you wait until the end of a marking period, catching up will be more difficult.

If any services become unnecessary, they can be stopped. One of the most important considerations for returning to school is to work or build from real successes, not failures. Many times a student with a brain injury has changes resulting in lowered abilities; focusing on *what cannot be done* can lead to a "deficit identity." Letting your child try school without any supports and waiting to "see what happens" should be considered with caution. While this may seem like a supportive approach as a start, it can backfire if your child has difficulties and then feels like a failure. A successful return to school requires a thorough assessment of a child's coping abilities, academic strengths, and weaknesses.

SOME DIFFERENCES BETWEEN IDEA AND SECTION 504

	IDEA	Section 504
Purpose	To provide a free, appropriate public education (FAPE) in the least restrictive environment	To provide people with disabilities, to the maximum extent possible, the opportunity to be fully integrated into mainstream American life.
Scope	Applies to all public schools (and charter schools)	Applies to any program or activity that receives federal financial assistance
Protection	Children and youth from birth through high school graduation who fall within one or more of the specific categories of qualifying conditions – Traumatic Brain Injury (TBI) is included as a category	Any person, child or adult, who (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment – Individuals with brain injury are protected in and out of school
Legal	Procedures for ensuring enforcement are specified under the federal Individuals with Disabilities Education Improvement Act regulations	Procedures for ensuring enforcement are specified under federal 504 and Americans with Disabilities Act regulations.
Eligibility	Requires that a child's disability affects his/her educational performance - All students who are eligible under IDEA are also eligible for Section 504	Not all students who are eligible for Section 504 are also eligible for IDEA
Evaluation	Requires that a child be comprehensively evaluated by a multidisciplinary team	Evaluation draws on information from a variety of sources and is documented
Resulting Document	Requires an Individualized Education Program (IEP)	Does not require an IEP, but does require a written plan
Annual Review	IEP must be reviewed once a year at minimum	504 plan must be reviewed periodically, but it is up to the educational agency or institution to establish procedures for review
Reevaluation	Required every three years or more frequently if needed, or at request of the parent, but not more than once a year, unless the district and parent agree	Required before significant change in placement for school-aged children – Post-secondary education requirements vary from school to school

How does IDEA work?

The basic steps to get special education services for your child are:

- referral
- identification
- evaluation
- determination of eligibility
- development of the Individualized Education Program (IEP)
- review

The referral

The parent or a teacher generally requests the referral. This is the first step toward obtaining special education services for your child. You will be asked to sign a release form so that your child can be evaluated. A pamphlet describing the special education laws and your rights as a parent usually accompanies the release form.

Sometimes a school Intervention and Referral Services (I & Rs) program may meet prior to a referral. This is a group from your child's school such as teachers, guidance counselors, or Child Study Team members. This group can meet at the request of a parent or teacher to informally discuss strategies to help your child on a short-term basis. If a teacher calls for this group to meet, the school is not required to notify you as the student's parents/guardians. The group usually meets again in 4 to 6 weeks to discuss your child's progress and to decide if IDEA or 504 recommendations are appropriate. Ongoing communication with the school can keep you updated on meetings.

Identification

Once a formal referral to determine eligibility for special education services is made, the child study team, the general education teacher, and the parent(s) meet to review data and determine whether an evaluation is warranted. If an evaluation is warranted, the group determines the nature and scope of the evaluation. The group may also determine that an evaluation is not warranted and, if so, determine other appropriate action.

Evaluation and eligibility determination

An initial evaluation consists of a multi-disciplinary assessment in all areas of the child's suspected disability. It must include at least two assessments and must be conducted by at least two members of the child study team. The child study team includes a school psychologist, a learning disabilities teacher-consultant (LDTC), and a social worker. (See glossary for definitions.) Other specialists may be added during the evaluation as needed, such as a speech and language pathologist, physical therapist, neuropsychologist, neurologist, etc. You, as a parent, are also a member of the IEP team.

The purpose of the evaluation is to gather information on your child's functioning in many areas including the following type of skills:

- academic
- physical
- cognitive
- social/behavioral

The information gathered during the evaluation is used to determine if your child needs special education and related services. Your child may have been tested during rehabilitation. Often the CST will accept some or all of these tests, including neuropsychological evaluations, which can reduce a great deal of stress and repeated testing.

It is very important for parents and educators to view test results cautiously. Brain injury is unique. A child with a brain injury typically can still recall and use knowledge and concepts learned prior to the injury. Scores on knowledge based tests, such as achievement tests, given after the injury may be similar to testing scores before the injury, as a student's old learning may remain intact. The ability to learn new information is often impacted after brain injury

Educational evaluations from the CST often do not challenge the student's ability to learn new information. Yet this is the ability that is most often affected by a brain injury. Specialized neuropsychological testing can detect changes in your child's new learning style. If you feel that the school's evaluation does not accurately describe your child, then you have the right as a parent or guardian to request an independent or second evaluation at the school's expense.

When the evaluation is completed, the IEP team meets to decide whether the student is eligible for special education services. If so, your child will be classified as "eligible" for special education and related services based on the criteria for a disability category that best fits your child's condition. Eligibility under IDEA is a tool to get services to meet your child's needs, not a lifelong label.

Knowing the differences in IDEA categories

Students with brain injury are unique in many ways. It is important to be aware of the many differences between your child with a brain injury and others who are eligible for special education. Eligibility based on traumatic brain injury (TBI) should be used if your child meets the criteria for the definition used by the NJ Department of Education.

> **"Traumatic brain injury" corresponds to "neurologically impaired" and means an acquired injury to the brain caused by an external physical force or insult to the brain, resulting in total or partial functional disability or psychosocial impairment, or both. 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.**

Some students with brain injuries are classified as eligible for special education and related services based on the criteria for TBI. However, within the special education system in New Jersey, students with brain injury are often categorized under other handicapping conditions that also qualifies them for special services under IDEA. This is because "TBI" as a descriptive category was added to the NJ code in 1998. Prior to this addition, a student with a brain injury was generally determined eligible for special education services under other categories. There is just beginning to be an accurate census of students with brain injuries in NJ schools.

The lack of good statistical information on children and brain injury is not unique to the New Jersey Department of Education. The Center for Health Statistics of the NJ Department of Health

and Senior Services reports that there were more than 2,000 children who sustained brain injuries resulting in hospitalization during 2000, the last year for which complete data are available. These numbers do not include children who were only seen in emergency departments, clinics, doctors' offices, or not at all.

These figures, and those available from the pediatric rehabilitation hospitals that specialize in brain injury rehabilitation, tell us that thousands of children with brain injuries severe enough to require inpatient rehabilitation are hidden among the population of students receiving special education services. These numbers do not reflect the many thousands more students with mild brain injuries who never received rehabilitation or other medical interventions. Part of the process of establishing an accurate census for TBI within the education system is making sure that students, who are categorized under some other condition but actually meet the criteria for TBI, have their eligibility criteria changed.

Despite meeting the TBI criteria, some districts may identify a student with a brain injury under categories such as "specific learning disability", "cognitively impaired" or "emotional disturbance". Further, determining eligibility of such students on the basis of their brain injury helps insure that statistics on the incidence or numbers of students with traumatic brain injuries are accurate. This can lead directly to more appropriate funding, research, prevention strategies, and better ability to develop effective school programs. Although students with brain injury may have characteristics similar to other disabilities they also have unique challenges that require specific strategies and accomodations.

Communication is the key

Communication is an important part of a successful return to school, especially if your child has a severe brain injury. Your child may still be receiving therapies outside of school, such as occupational therapy, physical therapy, speech therapy, and counseling. As you work on developing an effective educational program, remember that communication among you, the teachers, and therapists is critical for effectiveness and consistency at home and in school.

> *My son spent a whole year in a rehabilitation hospital after his brain surgery. We've been through so much. He's getting special services but he is very unhappy in school. The teacher doesn't seem to know what to do with him and he is just getting more frustrated and depressed. What can I do?*

You may need to initiate communication and stay involved to be sure that communication is established and continued. You might suggest that monthly progress reports with specific goals and strategies be exchanged between therapists and school personnel. By encouraging ongoing cooperation among everyone, progress can be regularly reviewed and any necessary changes can be made.

If your child is more severely injured, early contact with the school, while your child is still in the hospital, helps set up an open line of communication between the hospital and school. This

also starts the process of educating the school about your child's needs. Once your child is ready to begin schoolwork, the hospital social worker or case manager can be a liaison or link between the hospital and school. As a parent or guardian, you are the primary contact with everyone. Your role is vital in the coordination of services and the communication of information.

Individualized Education Program (IEP)

Some key areas addressed in the IEP include:

- present levels of academic achievement and functional performance
- how the disability affects involvement and progress in the general curriculum
- a statement of measurable academic and functional goals and benchmarks or short-term objectives
- the special education and related services and supplementary aides and services to be provided to the child.
- supports for school personnel

The IEP also includes any program modifications or supports for school personnel that help your child reach the stated goals and objectives. The supports are to help your child participate in the general, extracurricular and other nonacademic activities. The supports also help your child be educated with other children in the general education class.

The IEP is a legal document that the school must implement. Parents are an important part of the team that develops this document. The Statewide Parent Advocacy Network (SPAN) and the NJ Department of Education provide trainings and periodic workshops on IEP development to help families work with members of the IEP team to develop an effective IEP document.

The first part of the IEP states that your child is eligible for special education and related services based on the criteria for TBI or Other Health Impaired. The IEP will state the dates for beginning the program and any related services (such as occupational, physical or speech therapy). It also states how often, how long and where these services will be provided.

The IEP also includes a list of annual measurable academic and functional goals and objectives for each academic subject and other areas to be addressed. Many schools use a menu type of computerized IEP form where goals and objectives are chosen from a pool or list. Sometimes these goals and objectives do not meet the unique needs of your child. If you have a goal for your child that is not in the pool of computerized goals, it is within your rights to ask the IEP Team to write in the goal.
The IEP must state specific strategies, techniques, and activities. It also lists any special equipment or instructional materials that your child needs. Any special equipment or materials (such as a computer) that must be provided by the school should be specifically written into the IEP so that the school's responsibilities are clear.

You may feel intimidated, anxious or uneasy about the IEP process the first few times you participate. While it is very familiar to school staff, it is very new to you.

You can invite somebody to attend an IEP meeting with you. You do not need to attend alone.

It is a good idea to invite an advocate who is familiar with the special education system or another helpful professional (such as a rehabilitation staff member or neuropsychologist) to go with you. They can help you decide if the program being offered is the most appropriate for your child. If you can not arrange for an advocate to go with you, you can bring anyone who can provide you with moral support and act as a notetaker. If no one is available to accompany you to the meeting you can request to change the date of the IEP meeting. If you must go to the meeting alone, it is a good idea to bring a tape recorder so that you can review the meeting at home when you are more relaxed. Be sure to notify the district prior to the meeting that you plan to tape record the meeting.

In most cases, you may agree with the content of the IEP. You do not have to sign the IEP at the meeting. Never sign a blank IEP form that is to be filled in later. Wait until the goals and objectives and instructional supports and accomodations are written, then read it and sign if you agree. It is always a good idea to bring the document home and review it thoroughly. If you agree with the IEP after carefully reviewing it, you can sign it and return it to your child's case manager.

Each local child study team identifies one person to be the child's case manager. This person is the liaison between the school and the parents and ensures that everyone involved in implementing the IEP gets the appropriate information. Sometimes the case manager is the social worker, other times it is the psychologist or LDT-C.

If you disagree with your child's school district about any part of your child's evaluation, educational program, or placement, try to work out the problem informally by talking with staff. If you can not work it out, you can have your case formally reviewed by a third party. The first step is to return the unsigned IEP with a letter stating why you do not agree **within 15 days of the meeting**. Then refer to the special education law or call an advocate for further help. If needed, call BIANJ or SPAN for more information.

Placement in the Least Restrictive Environment

The IEP team is responsible for where your child's education program will be delivered, based on the results of the evaluation and what is written in the IEP. By regulation, placements should be in the "least restrictive" settings. For one student, the "least restrictive" setting may be in a general education class without any supports or accomodations. On the other end of the continuum, the services that another student needs to be educated may necessitate a residential, out of district setting.

The optimal placement is to give your child the opportunity to participate with the regular school population as much as possible with reasonable help or supervision. Generally a student receives services through one, or a combination of, the following programs:

Inclusion in a general education class... a child with special needs participates in general education class with or without additional in class support detailed in the IEP.

Resource programs... individual and small group instruction provided to students with disabilities by a certified teacher of students with disabilities. Resource programs may be provided in general education class or in a pull-out session.

Special class program... Small group setting within the local school district. Student usually has most if not all subjects in this classroom.

Approved Private School for Students with Disabilities... An incorporated entity approved by the NJ
Department of Education to provide special education and related services to students with disabilities placed by the district board of education responsible for providing their education

Home instruction... One-to-one tutoring at home or in the hospital.

Residential... An out of home and district placement that provides highly specialized services such as behavior modification for students with severe impairments.

As a member of the IEP team, you have an important role in determining your child's placement, but you do not do it alone. Consideration of all the information about the student, plus creativity and flexibility, are crucial for a successful placement for any child with a brain injury.

If you and the team cannot find or develop an appropriate placement in your school district that can meet your child's needs, then there are private out-of-district schools that may or may not be suitable for your child. Deciding on an out of district placement can be a difficult process. If an out-of-district placement is appropriate for the student, it is important for you to make appointments and visit any school that is recommended. Make sure to visit when school is in session so that you can observe students and staff together. It helps to make a list of questions for staff ahead of time.

Although a private out-of-district placement may be needed for your child initially, your child may be able to enter a less restrictive placement months or years later. It is also sometimes appropriate for a child with a severe brain injury to be placed in the home neighborhood school. This placement almost always requires that the school be educated about your child's specific injury and needs. The school can have an in-service training for staff to educate them about brain injury and to prepare them to meet and understand your child's needs.

A placement within your home school district can still be flexible and creative. Reviewing your child's needs that have been outlined in the IEP can help you figure out if the suggested placement will meet those needs in the least restrictive manner. You can meet the teachers and staff that would be working with your child. Your informed participation in the placement decision-making process is very important.

Remember that you know your child best.

How can the school nurse help?

The school nurse can be an important person in your child's reentry to school. The nurse's medical background helps monitor your child's recovery. Your child may see the nurse regularly for medication or if other ailments occur. Your child may become anxious and develop stomachaches or headaches. Your child may even visit the nurse when feeling cognitively overwhelmed, fatigued or having trouble with a specific subject.
By being included in the communication network, the school nurse can spot a problem early and help address it. It is always advisable to keep the nurse informed and request the nurse's presence at the transition meeting when your child reenters school. You may wish to request that your school nurse attend IEP meetings, given their important role in your child's school routine.

Whenever there is a change in your child's medication (even if the medication is not given at school), or a change in your child's medical condition, it is important to contact the school nurse.

If your child sustains a fall, injury or any change in behavior, it is important to keep in touch with the nurse regularly and ask that this information be given to other staff. If you want the school nurse to communicate directly with your child's doctor, you must give written consent. You can limit this consent to information about your child's injury or any illness that affects abilities and activities in school.

Sports and prevention of brain injuries

When a student is preparing to return to school after a brain injury, a common question is about participation in gym, playing sports and other physical activities such as biking, rollerblading, and skiing. Your child's doctor will be able to recommend what activities your child can engage in, based on your child's medical condition.

Concern about preventing an additional brain injury will influence your child's choice of activities, particularly in the first year of recovery. Multiple brain injuries, even mild ones, or one concussion after another, can have a cumulative negative effect on the brain. If your child was actively involved in sports prior to the injury, it may be difficult to accept limits on activities.

You are in the difficult position of enforcing those limitations. Deciding whether to deny your child an activity that brings pleasure and builds self-esteem versus protecting your child from the chance of another injury can be a difficult task. A second injury can worsen the effects of the first brain injury. To help make this decision and to help your child adjust to any changes, talk with doctors and therapists treating your child and discuss the level of injury and your child's current abilities. There are non-physical ways for your child to participate on a team (keeping score). It is also helpful to gather information about protective gear and how it works.

Bicycle helmets are a well-known form of protective head gear. NJ law requires that children

under age 17 wear them while riding. Helmets also protect children while skiing, rollerblading, skateboarding and riding a scooter. Statistics have shown that, when worn correctly, a properly made helmet can significantly reduce the severity of a brain injury. This can mean the difference between a fatal or severe injury and a milder one.

A helmet alone will not completely prevent an injury. Children and adolescents need to learn safety skills and how to reduce risky behaviors. For bicycle safety, the Centers for Disease Control recommend a combined approach of wearing appropriate protective gear, teaching safety skills, and developing safe riding environments. These principles can be applied to any sport or physical activity that carries the risk of sustaining a brain injury from an impact or collision.

As awareness of the serious effects of sports-related brain injuries has increased, many elementary and high school physical education teachers and coaches are learning more about the prevention and screening of injuries. If the teachers and coaches in your school have not had this training yet, you may want to let them know that such training is available.

The Brain Injury Association of New Jersey can help you find speakers on the prevention of sports injuries to educate school personnel. It is a lot easier for any child with a brain injury to fit in when the whole team or class plays safely. You can contact BIANJ for more information about how to bring prevention into your child's school.

Important things to know about the Special Education Law

Private or parochial schools have more limited special education services.

Children from birth to age 3 years old are entitled to services through statewide Early Intervention Programs (EIP). An application to your county's Special Child Health Services can help your child receive therapies and identify other funding for medical needs.

Children ages 3 – 5 years old can receive special education and related services through your local public school. To be eligible for these programs, you must request that your local public school district evaluate your child for eligibility for special services.

Children ages 5 to 21 are serviced through your local school district. The principal of your assigned school can direct you to the Special Services Department.

For adolescents ages 14 years and above, the IEP must reflect goals for the transition from school to adult life. It is important to plan and prepare for what the adolescent will do after high school. Two key agencies that help with adult services are the Division of Developmental Disabilities (DDD) and the Division of Vocational Rehabilitation Services (DVRS).

Delaying graduation makes it possible for your child to receive important special educational services through age 21 in some instances. When a student graduates, the responsibility of the school system for providing special education services is over, and

thus, there may be a gap in services. For example, in some cases, DVRS may not take over until age 21, if the child is no longer in school. Graduation should be considered very carefully. Your child may want to graduate at age 18 years. You can explore having your child participate in commencement exercises without actually graduating or receiving a diploma. This may ease your child's anxiety or sense of loss by including your child in this important event.

Thoroughly investigate all program options to consider what each has to offer your adolescent educationally, vocationally, emotionally, and socially in order to prepare for adulthood. If you have questions about delaying graduation, be sure to talk to everyone involved.

It is a parental right to have an advocate who can help you prepare for and attend school meetings. An advocate can help you understand information, provide support, and ask critical questions about special education laws and your specific situation. Your local child study team is required to provide you with a copy of your parental rights.

You also have the right to have a translator present who is fluent in your native language The translator can help you participate in the IEP process and read and explain the IEP to you in your native language.

Considering assistive technology is a required part of the IEP process. Assistive technology is a device or service your child needs to access or benefit from educational programs. It goes from low technology to high technology and includes assessment, purchasing, training, and follow-up.

Your school district cannot require you to pay for the device and services, but you can share the cost if you choose. By considering options and benefits from alternate sources such as Medicaid and health insurance, you can share the cost among several payers. DVRS is another possible source of funding for assistive technology, but only during the transition to work or post high school education/training and only for school or work use.

When the school district pays the entire cost of assistive technology, the district owns the equipment. This does not mean that your child has to keep the devices at school. It can be worded in the IEP that your child can move the assistive technology from class to class and to home. During the transition process, parents can ask the school district to discuss transferring ownership or selling the assistive equipment or services to the new provider of services for your child that may be funded, if appropriate, by DVRS or DDD.

Some examples of assistive technologies include:

Books on tape... Your child can read along or just listen. Books on tape give multisensory input, compensate for slower reading speed, low reading level, or difficulties with sounding out words *(*decoding).

Text reader programs... These may have study skills options. They include computer programs that read material. Your child can highlight the main points, vocabulary etc., to be printed out as notes. They can help your child compensate for

physical issues affecting writing speed or legibility and also help with slow speed of processing.

Other technology may include a voice recorder to put assignments in a notebook, word prediction programs or a note taker.

You can contact your local school district or the Department of Education to get a copy of the special education law or to get more information about any of the items listed above. You can also visit the Department of Education website at http://www.state.nj.us/education

Chapter 3
Coordinating Your Child's Services

Over time, the professional coordinator of your child's services will change. If your child has a severe brain injury, a case manager from the hospital or a rehabilitation nurse provided by the insurance company may initially help you coordinate services. With the increased use of managed care plans through health insurers and the institution of case management by New Jersey auto insurers, you may be drawn into the often confusing domain of accessing benefits very early in your child's hospitalization. Financial counselors are also available at most acute care and rehabilitation hospitals to gather information on your benefits and to explain the needed steps to acquire non-emergency services such as Primary Care Physician (PCP) referrals.

You may hear the term case manager in many settings, for example, case manager of medical insurance, case manager of rehabilitation services and /or case manager within the school. The term, case management refers to the coordination of services; in these cases, within the specific environments where the case manager works.

You are always the best advocate for your child. You know your child the best and are the only constant among the many professionals involved in your child's recovery.

If your child has a mild brain injury, there may be a lag time between an accurate diagnosis and assignment of a case manager. You may be the only person who knows all the people and issues involved in your child's case. This may put you in the position to communicate information to and from all parties. Coordinating this information makes you a case manager.

If your child has a moderate or severe injury and is eligible for special education through IDEA, a member of the child study team will be assigned as the educational case manager. If your child is receiving accommodations in school through a Section 504 plan, the guidance counselor may be the contact person for your child's needs at school.

If your child is registered with the Division of Developmental Disabilities your child may be eligible for care coordination services from a Family Support Specialist through the Brain Injury Association of New Jersey. The Family Support Specialist could assist you in finding, obtaining and advocating for the supports and services your child needs. This could include accompanying you to IEP meetings.

There is a great deal for you to learn about your child's changing medical, emotional, and intellectual needs. You are the one constant in a parade of professionals. You knew your child before the brain injury. You have overseen the entire recovery process. You know how your child is functioning today. You are the most qualified to advocate and coordinate services for your child. Case management is something you and many parents have been doing all along. You have just not been called the "case manager".

You develop and plan activities for your child and help with schoolwork. You keep files on doctor visits and school progress reports. Case management for a child with a brain injury is the same basic process. It is the newness and unfamiliarity of the medical and educational information that can be intimidating, not the case management. The number and type of decisions you are making since your child's brain injury may be the most challenging part of being a case manager. To simplify the process, it is helpful to become organized early and keep important information where it can be easily found.

A useful way to begin organizing information about your child's brain injury and school reentry is to get a large 3 ring binder (with some blank paper for note taking), a 3-hole punch, and a calendar. Add documents as they arrive to the binder in order by date. Use the calendar to note important meetings and phone calls. Keep notes from important phone conversations (including records of all attempted calls or messages) and notes from all meetings.

As the information in the binder grows and you gather more information, it is wise to keep files of the following information along with your binder:

- A list of everyone (people from school, rehabilitation services, hospital or doctor's office) involved at any time with your child. Include the name, address, and telephone number for easy reference. You can later transfer these names into a separate telephone directory and cross-reference them with a description. For example you can enter the neuropsychologist in 3 or 4 places; the name, practice or agency name, under the heading "neuropsych", or under any other name that helps you find the person quickly.

- Copies of all "written consent to release information" forms.

- A list of your child's testing with dates and names of who did the testing.

- Copies of all written reports and medical tests, rehabilitative progress reports and evaluations, school reports including IEP's, etc., filed under corresponding categories.

You can get copies of reports from professionals over the course of your child's recovery. Having copies available in one place eliminates a great deal of stress when someone asks for a copy of a specific report.

- Keep an ongoing list of questions regarding you child's medical condition, medication, benefits, programming etc. Be prepared to ask them on the next contact or meeting.

- Keep a separate file where you put written explanations, informative guides and pamphlets, even if you are not ready for them yet. By collecting and filing this information now, it will be easier for you to find it when you need it later.

Learn the lingo to get through the system

To be an effective advocate for your child, it is important to understand clearly the terms and conditions of your insurance and any other sources of funding for your child's care. The following are some of the frequent issues that parents encounter when trying to access services for their child after a brain injury.

Personal injury protection

Personal Injury Protection (PIP) is a benefit of no fault auto insurance policies in New Jersey. If your child has a traumatic brain injury as a result of a motor vehicle crash, PIP benefits from your car insurance policy are the usual source of funding for medical and rehabilitation services. Most policies have a $250,000 cap or limit on medically necessary expenses that result from the incident. The amount may be different if you have requested a higher limit, available from only a few insurers, or if you have chosen a lower cap in order to reduce your premiums.

If your child is covered by health insurance benefits as well as PIP benefits, one set of benefits will be considered primary and the other secondary. This usually depends on which you chose to be primary when the auto insurance was purchased. It is important to notify both insurance companies of the injury as soon as possible. PIP benefits and health insurance do not always have equal coverage conditions. For example, health insurance normally has very limited coverage for rehabilitation services, whereas PIP may be more liberal.

Funding for services is a complicated and very important area. You may want to consider consulting an insurance case manager or an attorney very early on during your child's hospitalization or rehabilitation in order to maximize the funding for needed services. In some cases, both insurance companies have voluntarily agreed to coordinate payments to maximize benefits. This is referred to as "marshalling the assets" and may be available and appropriate under certain circumstances.

Know the rules

Be sure that you are clear about the conditions and limits of your insurance policies, particularly which services require precertification or preapproval from the case manager. If you have an HMO, be sure you know when a referral is needed for services.

Ask about the appeals process if a therapy or program has been denied. Initial denials can be based on the premise that the service is "not medically necessary". However, appeals can be pursued through the insurance company and, depending on the type of insurance, through independent reviewers outside of the insurance company.

You may have questions or feel errors have been made on financial matters. To avoid this, ask for explanations in writing from insurance companies and other funding sources so that you have a direct source to refer to when pursuing resolutions.

Medically necessary

The phrase "medically necessary" is a term often used by payers. What seems so vitally medically necessary to you, as a parent of an injured child, may not seem medically necessary

to the insurance representative. That is why it is very important to ask for decisions in writing, to consult with medical professionals, and not to be afraid to seek an appeal. Seeking the advice of an attorney may also be advisable if you feel that your child has been inappropriately denied the benefits/ coverage stipulated in your insurance policy. Often, an initial denial of a service is overturned during an appeals process as more information is reviewed about the case.

Importance of 60 days

Health insurance policies generally have limits on the number of days and/or sessions of rehabilitation therapies covered under the policy, particularly those provided on an outpatient basis. Ask to have terms such as "60 days" clearly explained.

For example, does 60 days mean 60 consecutive days of treatment or 60 sessions. Is the limit of sessions per calendar year or for the lifetime of the policy? Knowing the conditions of your insurance is extremely important so that you can coordinate therapies provided by school and insurance to maximize benefits for your child.

Special education law

A free and appropriate education must be provided to students under the special education law. This is not the same as providing rehabilitation to reach maximum recovery from an injury or illness. This is illustrated in the difference between "medically necessary" versus "educationally related" services.

Physical, occupational, and speech therapies can be provided as related services when included in the IEP, if your child has been found eligible for special education and related services within your local school district. Augmentative and assistive devices (see glossary) along with transportation to and from the school program can also be provided through your school district.

Special education regulations state that the requested therapies must be "required for the student to benefit from the educational program" in order to receive these services through a school district in New Jersey. This means that the disability or impairment must impede or affect your child's ability to participate in the learning environment.

Example of coordinating school and health insurance resources:

> *Your child's physician prescribes physical therapy three times a week to improve independent walking. The school says it is not necessary to provide the therapy at this frequency if the child can sit in class and attend to task. The child study team recommends PT only once a week to improve movement throughout the school and to increase inclusion. You choose to advocate for more therapy time in school and/or use your health insurance to provide the additional sessions. This is an example of how important it is to know the limits of your benefits and how to coordinate legally mandated educational services with insurance benefits. As a result, your child has the greatest likelihood of receiving all the assistance needed.*

Advocacy groups and alternative funding sources

There are parent founded advocacy groups as well as many relevant services that are available through state and county departments of human services in New Jersey. There are also free and low cost legal services.

Suggestions for resources....

- go to the Resources section in this guide.
- contact the Brain Injury Association of New Jersey's Information and Resources Family Helpline at 1-800-669-4323.
- check the local phone book.
- explore the Internet.
- contact the Department of Education for a free booklet, "Parental Rights in Special Education" (PRISE) that lists advocacy services and resources.
- attend conferences on special education and advocacy, such as BIANJ's annual seminar and SPAN's annual conference. These are opportunities to obtain current information on education, funding options, and resources, and to network with other family members of children with special needs.
- join an advocacy organization and receive their informative newsletters and e-mail communications.

Chapter 4
Personal stories

How life changed for Katie, Kevin, Eric and their families

Three personal stories show different options and interventions for children with mild, moderate and severe brain injuries. They show how information in this guide can be used to make a difference.

Katie's mild brain injury

Katie was in second grade when she brushed up against a moving school bus. She bounced back from the bus, bumping her head on the curb. Katie bruised her ribs and shoulders and lost consciousness for about one minute. Afterwards, she was dazed, held her head, and kept saying that her head ached.

She was taken to the local hospital's emergency department and had skull and chest x-rays. The results were normal and she was sent home. Katie continued to complain of neck and head pain, nausea, and a ringing or buzzing noise in her head. Her family took her to their chiropractor who performed some spinal adjustments.

Katie was out of school for one week. Upon returning to school, she still complained of head pain and ringing in her ears. She reported that the pain and noise distracted her and made her a little tired. These symptoms lessened over the first three months following the accident.

In first grade before her injury, Katie scored between the 75th and 98th percentile ranks on her achievement testing and had been a good student. Three weeks following the accident, she took her second grade achievement tests and scored much lower, between the 30th and 50th percentile. Reading and arithmetic scores had the most dramatic decline. The teacher noticed that Katie found it hard to retain new information and that she read more slowly. She often had to reread material, sometimes several times, to understand the information. Katie also had some difficulty with writing.

Her family had noticed changes too. They noticed that Katie was unhappy, irritable and more withdrawn. Her family had consulted an attorney about the accident. As the attorney gathered information about Katie's injuries, she recognized the symptoms of post-concussive syndrome. She referred Katie to a neuropsychologist, who confirmed the presence of cognitive slowing and attention difficulties due to a traumatic brain injury.

The neuropsychologist recommended to Katie's family that they write a letter to the Child Study Team (CST) at her school to request an evaluation for special services to help her with schoolwork. The neuropsychologist also recommended that Katie receive outpatient cognitive rehabilitation services. Specifically, rehabilitation was suggested to help Katie understand and deal with the changes she was going through from the concussion. She also needed help to develop compensatory strategies to cope with these changes in order to be successful at school again.

The Child Study Team evaluation was completed and determined that Katie did not require services under IDEA. They suggested that the rehabilitation center and school work together to develop a 504 plan. The CST gave information about 504 to Katie's family. They discussed how the strategies that Katie needed could be spelled out in a 504 plan and carried out by the classroom teacher.

Katie's parents were confused and sought help to understand what was the best thing to do for their daughter. They contacted the Brain Injury Association of New Jersey and were put in touch with an advocacy group. An advocate attended the school meeting with Katie's parents and helped them to work out a 504 plan that was clear, but flexible. This seemed important because Katie's needs were not completely understood but she was continually improving.

Many aspects of the first month were rocky. Katie did not follow through with homework for school and was tired by the time she got to her twice-weekly rehabilitation appointments in the afternoon. A meeting was called where the rehabilitation therapist attended and brainstormed with Katie, her parents and the school staff. A modified plan was developed that increased Katie's rehabilitation hours. Even though this sounded like a step backwards to Katie's parents, they agreed to try it because the rationale made sense. The rehabilitation therapist's plan was to use Katie's homework as part of the therapy content and to develop routines, organizational study skills and attention and learning strategies within the sessions. Recognizing that Katie experienced periods of mild fatigue at school, she was scheduled to rest in the nurse's office twice a day. Communication between the rehabilitation therapist and school staff was set up on a regular basis to address problems immediately.

The 504 plan was updated and revised, initially every six weeks and then once each marking period after Katie's performance improved and held steady. The same was true with the rehabilitation services. After one month, Katie's time in rehabilitation was cut back to two hours a week. Then it was weaned to once a week, every other week, and finally down to telephone check-ins over a period of three months. What had felt like a lifetime was a school year. Katie and her parents still notice some minor cognitive changes that remain, but Katie is active and successful in school after a year. The 504 plans were discontinued in mid-third grade, with the knowledge that reevaluation and rewriting of a 504 plan would be done if any problems occurred.

Comments

This case shows the importance of not being afraid to seek out and use community resources to help a student's reentry to school after an injury. Parents often hesitate to disagree with a school's recommendation or are afraid to bring others into the school's territory. Here, the combination of an informed lawyer, a neuropsychologist's recommendations, help from an advocate, and the rehabilitation staff's involvement were all important pieces in the success of Katie's return. Even though information is available about brain injury, not all school systems have expertise in this area. Most school staff will work cooperatively with community resource people because it is in the best interest of a student.

Kevin's moderate brain injury

At the time of his injury, Kevin was 16 years old. He was a junior in high school and was considered by his family and teachers as a "good kid" who took a lot of risks. Kevin was a C student and had run-ins with other kids now and then, as well as detention for minor offenses. Kevin was a passenger in a car driven by his best friend when they were involved in a motor vehicle crash. Kevin was thrown several feet after the crash. His friend died.

Kevin was in the hospital's Intensive Care Unit for one week, spent two weeks in a Brain Trauma Unit and then had outpatient rehabilitation for 8 weeks. He was unconscious for 20 hours and had seven days of post-traumatic amnesia. The CT scans showed bruising and swelling of frontal, temporal, and parietal lobes in his brain.

After he was discharged from the hospital, Kevin found it hard to remember things, follow directions, organize his thoughts, express himself, and plan his time. It took him longer to process information and respond to people than before his brain injury.

In addition, his parents worried about how he was reacting to the death of his friend. Because expressing himself was harder for Kevin after his injury, it was difficult to know how he felt about both the loss of his friend and his own loss of memories and abilities.

Kevin's parents contacted the school right after the accident. They gave permission to the staff at the brain trauma unit and cognitive rehabilitation program to have ongoing contact with the school to provide updates on his progress and plan for his return to school. Rehabilitation staff went to the school and provided brain injury education for Kevin's peers.

It was suggested to Kevin's parents that he be classified to receive special education services to better meet his needs. Kevin's parents sought other professional opinions and were put in touch with the Brain Injury Association of New Jersey and with a parent advocacy group, SPAN, to help them. They made the decision to take advantage of special education services and they felt that turned out to be a positive move. As part of the Individualized Education Program (IEP) process, an initial transitional plan was also proposed.

Kevin's school reentry began with home tutoring in combination with outpatient rehabilitation. (He began tutoring the second week he was in the rehabilitation program.) The rehabilitation team and the tutor met weekly to exchange information. It was during this stage of recovery that Kevin also began individual counseling with a psychotherapist to help him cope with loss and grief issues and to adapt to internal changes. He was also receiving medication for depression.

Kevin progressed to a half day at school followed by outpatient rehabilitation therapies (OT, PT, and Speech) in the afternoon. After two months, Kevin was ready to increase his time at school. He began to stay for lunch and gym class.

Staff at school began to see that Kevin was having more difficulty with social interactions. He was experiencing altercations with peers and sometimes with teachers and other school staff.

Especially when fatigued, he became verbally abusive. School staff met with Kevin and his parents to explore strategies to help him with the extended school day and how to handle the less structured activities that had been added to his schedule.

Kevin's psychotherapist was also consulted. Together with the child study team, Kevin, and his parents, a plan was developed to address his behaviors. Kevin's behavior began to improve with his increased awareness of what he was doing and consistent feedback about his behavior. At the close of Kevin's junior year, he was in school two-thirds time. He attended an extended school year program to increase his skill level and complete credits for his junior year. Kevin's goal for his senior year was to develop his vocational direction and be a full-time student with a half-day of academics and a half-day of workstudy. These goals were added to his IEP and transition plan as part of the ongoing revision process. Kevin's child study team also contacted the Division of Vocational Rehabilitation Services to consult with them about post high school services available to Kevin.

Although Kevin was making good progress in the vocational program, it was evident that he was not ready, vocationally or academically, to enter the work world. After reviewing his skills and needs, Kevin, his parents, and the child study team decided to hold off graduation for one year. Special arrangements were made for Kevin to attend the graduation ceremony and related activities without receiving a diploma. This meant he could be part of this big event but not lose his educational benefits.

Kevin, currently 19 years old, attends two academic classes and a vocational training program each day. His social skills and ability to self-monitor his behavior have continued to improve as well as his reading and math skills. While continuing to feel sadness at times over the effects of his own injury and the loss of his friend, Kevin has been able to express that he is not overwhelmed by this and has "graduated" from seeing a counselor once a week for support. He has referrals to brain injury support groups as well as a "clubhouse" type social group if he wishes to explore these resources.

Comments

Kevin's experience illustrates the steps involved in going through the rehabilitation stage, school reentry, and transition processes with sensitivity to the effects that cognitive impairments, grief, and personal adjustment can present for an adolescent with a brain injury. This example demonstrates good communication among the family, rehabilitation staff, school personnel, and DVRS. Delaying graduation allowed Kevin time to develop his academic and vocational skills in order for him to be better equipped to enter the work world. It also demonstrates how a coordinated effort to address behavioral issues in a positive way can have a beneficial outcome for the student.

Eric's severe brain injury

As a result of an auto accident, 14 year old Eric, was propelled from a car and had a traumatic brain injury and severe chest trauma. He was hospitalized for several months and spent six months in a low-level coma. After his transfer to a rehabilitation hospital, Eric received physical, occupational and speech therapies, and later cognitive rehabilitation.

He regained his speech eight months post injury and started academic tutoring shortly thereafter. A child study team from his local school district became involved in his case once tutoring was requested. At that time, Eric was deemed eligible for special education services under the category of traumatic brain injury. One year after his accident, Eric had progressed to reading, writing, and simple mathematics. He was walking with a walker and was able to eat enough on his own to have his feeding tube removed.

Progress continued, and as discharge from the rehabilitation hospital neared, Eric's child study team case manager began to attend the monthly case conferences to plan for the transition to school. Eric's parents obtained the services of a private consultant, specializing in brain injury. This consultant instructed his teachers about Eric's unique needs and helped develop an appropriate program at school. She helped school personnel understand the effects of Eric's brain injury and introduced strategies to maximize his classroom instruction.

Once discharged from the hospital, Eric attended an outpatient cognitive rehabilitation program four days a week, followed by cognitive/academic tutoring and therapies (OT, PT, and Speech.) On Fridays, he attended a full day at his home high school where he received all academic instruction in the resource room, plus some speech therapy. He had an instructional aide to help him navigate the halls and provide extra help in class.

Eric's IEP included assistive technology. His primary assistive device was a laptop computer with word prediction software, a screen reader and scheduling/date book software. Eric was mainstreamed into a computer class where he typed any notes or assignments necessary for his other courses into his laptop.

At that point, Eric was considered a ninth grader operating on a $4^{th} - 6^{th}$ grade level. Before his accident, Eric had functioned well above grade level. Much time was taken to modify his curriculum, develop appropriate goals and strategies and put together a transition plan. Frequent meetings among his parents, child study team members, and the TBI consultant were held to review progress and update the IEP as needed.

The following September, almost two years after his accident, Eric attended a resource program science class daily in addition to his other classes. He continued to receive his related therapies after cognitive rehabilitation therapy sessions and attended school all day on Friday. After the second semester that year, Eric's inschool program was increased to three periods with two periods of resource program science and history and one period of computers. Transition planning was continually updated with special attention to services Eric might need after graduation.

After a year and a half of services in a rehabilitation center, Eric was discharged. He returned to school the following September as a full-time junior. He was included in general education classes for art and computers, and continued his resource program for academics. He also had three periods of one-on-one speech therapy in school per week. He received PT and additional academic support along with speech therapy at home. He became involved in community reentry activities with a recreational therapist. Again due to his progress, Eric's transition plan in his IEP was updated to include new possibilities after high school.

By mid-junior year, testing revealed that Eric's academic achievement scores were between the 7th and 12th grade level. His functional cognitive performance remained impaired, especially in memory, the ability to organize his thoughts, and problem solving. The school nurse identified absence seizure activity and Eric was subsequently placed on anti-seizure medication by the neurologist.

Programming in school had become a bit more problematic because his resource program curriculum generally tapped into Eric's prior knowledge and did not challenge him with new material. One regular academic class had been added to his schedule with the additional support of an aide and a supplemental class to reinforce and modify the regular class materials. Programming for his senior year included three general education classes with extra support built into his program. His IEP clearly stated what modifications would be made to the general education class curriculum, what accommodations would be required and who would be responsible for its
day-to-day implementation. Accommodations written into the IEP included alternative test materials, modified assignments, tape-recorded classes for later review, study guides, and note takers.

As Eric's developing abilities changed his future educational needs, options were investigated at the post-high school level focusing on colleges and other post secondary schools with Section 504 accommodations and support programs. Eric, his parents and the rest of his child study team obtained information on possible programs and Eric and his parents visited various schools. They ended up choosing a county college with 504 accommodations.

Comments

This case illustrates the slow, steady and creative school reintegration process. It also demonstrates the flexibility a school offered and the positive results for the student. By looking at Eric's unique needs, planning and following through, programming went relatively smoothly.

References

Cohen SB: Adapting educational programs for students with head injuries. *Journal of Head Trauma Rehabilitation* March 1991;6(1):56-64.

DePompei R, Blosser J: Preparing education professionals for meeting the needs of students with traumatic brain injury. *Journal of Head Trauma Rehabilitation* March 1991;6(1):73-83.

Lash M, Cluett R: *A Manual for Managing Special Educationn for Students with Brain Injury*. Wake Forest, NC: Lash and Associates Publishing/Training Inc., 1998.

Lehr E: *Psychological Management of Traumatic Brain in Children and Adolescents.* Rockville, MD, Aspen Publishing, 1990.

Milton SB, Scaglione C, Flanagan T, Cox J, Rudnick FD: Functional evaluation of adolescent students with traumatic brain injury. *Journal of Head Trauma Rehabilitation* March 1991;6(1):35-47.

New Jersey Administrative Code, Title 6A, Chapter 14 Special Education, 2000.

Savage RC, Wolcott GF, Eds.: *An Educator's Manual: What Educators Need to Know About Students with Traumatic Brain Injury.* Washington, DC: Brain Injury Association, 1995.

Tyler J, Mira M: *Traumatic Brain Injury in Children and Adolescents: A sourcebook for teachers and other school personnel*. 2nd edition. Austin, TX: Pro-Ed, 1999.

Wagner, M, Stenger, K. Eds.: *Acute Brain Injury: A Guide for Family and Friends.* University of Iowa, 2000 (New Jersey edition).

Inclusion: The placement of students with disabilities in general education buildings and classrooms.

Independent Evaluations: Similar to the evaluation done by the school, but given by a trained person or team employed outside the school system. You may request an independent evaluation at the expense of the school system if you are not satisfied by that done by the school. This independent evaluation must be considered in planning for your child's educational needs.

Individualized Education Program (IEP): The basic plan including an instructional guide written by the child study team prior to the pupil's placement in a program. The plan states the pupil's eligibility for special education and related services, states current educational status, outlines goals, and describes the pupil's educational program.

LeAnomia: The inability to name an object that one recognizes and understands. A symptom of receptive aphasia.
Cerebellum: The portion of the brain that is located below the cortex. The cerebellum is concerned with coordinating movements.

Source: Chew, Lyn. *Head Injury: What Educators Need to Know. A Guide for School Nurses.* Edison, NJ: Brain

Injury Association of New Jersey, 1992.

Glossary of Educational Terms

Academic and Functional Goals: Measurable goals that shall, as appropriate, be related to the core curriculum content standards through the general education curriculum unless otherwise required according to the student's educational needs, or appropriate, student specific, functional needs. For all students, the annual academic and functional goals shall be measurable and apprise parents and educational personnel providing special education and related services to the student of the expected level of achievement attendant to each goal.

Advocate: A person, often a professional or trained parent, whose primary responsibility is to defend and speak for the best interest of a child.

Approved Private School for Students with Disabilities: An incorporated entity approved by the New Jersey Department of Education to provide special education and related services to students with disabilities placed by the district board of education responsible for providing their education.

Assessment: An observation and/or tests designed to determine a child's abilities in specific areas.

Assistive Technology Device: Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability.

Assitive Technology Service: Any Service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device.

Augmentative Communication: Assistive technology devices that enable individuals who are nonverbal or who have limited speech to communicate.

Case Manager: The identified member of the child study team who is responsible for coordinating the development, monitoring and evaluation of the effectiveness of the IEP. The case manager also facilitates communication between home and school and coordinates the annual review and reevaluation process.

Child Study Team (CST): An interdisciplinary group of certified persons, including a school psychologist, a learning disabilities teacher-consultant and a school social worker, who are responsible for evaluating students; participating in the determination of eligibility of students for special education program and service; providing services to the educational staff with regard to techniques, materials, and programs; consulting with and supporting families.

Due Process: The principle of law that ensures fair procedures will be followed during the special education of a child.

Early Intervention: Provision for implementation of programs provided to children with a handicap between birth and age three.

Educational Evaluation: An assessment conducted by the Learning Disabilities Teacher-Consultant (LDT-C) to determine a child's academic level of performance, including learning strengths, weaknesses and learning styles.

Educational Objectives: A set of measurable skills, accomplishments or tasks for a child that are written into the IEP.

Free, Appropriate Public Education (FAPE): Consists of special education and related services that are provided at public expense under public supervision and direction and without charge to the parents; meet state and federal requirements; include preschool, elementary, or secondary school education; and are provided according to an Individualized Education Program.

IDEA: The Individulas with Disabilities Education Act requires free and appropriate public education for students with certain learning disabilities.

IEP Team: The group of individuals who are responsible for the development, review and revision of the student's individualized education program.

In-Class Support: (Resource program option) A program of instruction where regular and special education teachers are planning and implementing special education. Instructional responsibility is shared between the two teachers as described in the student's IEP. Support instruction is at the same time and in the same activities as the rest of the class.

Independent Evaluations: Similar to the evaluation done by the school, but given by a trained person or team employed outside the school system. You may request an independent evaluation at the expense of the school system if you are not satisfied by that done by the school. This independent evaluation must be considered in planning for your child's educational needs.

Individualized Education Program (IEP): A written plan that sets forth present levels of academic achievement and functional performance, measurable annual goals, and short-term objectives or benchmarks and describes an integrated, sequential program of individually designed instructional activities and related services necessary to achieve the stated goals and objectives. the plan establishes the rationale for the student's educational placement and serves the basis for program implementation.

Individuals with Disabilities Education Act (IDEA): The United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. It addresses the educational needs of children with disabilities from birth through the age of 21.

Learning Disabilities Teacher-Consultant (LDTC): The child study team member who works with students who are experiencing academic difficulty or who have diagnosed learning differences. The LDT-C identifies learning styles, administers, analyzes, and interprets educational tests, reviews other pertinent information, and prescribes specific, appropriate, and practical learning strategies. he/she may also help in the areas of time management, organization and study skills.

Learning Strategies: Specific approaches or methods a student uses to work on a task.

Least Restrictive Environment (LRE): Sets the standard that, to the maximum extent appropriate, students with disabilities are educated with children who are not disabled. It means that special classes, separate schooling, or other removal of students with disabilities from the general educational environment should occur only when the severity of the disability is such that education in general education classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Mediation: A voluntary process available to resolve disputes between school districts and families.

Native language: The language or mode of communication normally used by a person with limited ability to speak or understand the English language. In the case of a student, the native language is the language normally used by the parents. Except that in all direct contact with a student (including evaluation of the child), the native language is the language normally used by the student in the home or in the learning environment. The IEP team shall determine the language of the student.

Neuropsychological Evaluation: An assessment using psychological tests, interviews, and behavioral observation, to determine a person's cognitive, emotional, and behavioral status, with particular emphasis on deficiencies in intellect, personality, and behaviors as outcomes of a brain injury. Such assessments attempt to determine brain behavior relationships, location of injury and brain systems involved.

Non-Discriminatory Testing and Classification: The methods used to test must be suited to your child's condition. A professional who understands the nature and unique aspects of your child's injury should do the testing. For example, a child who writes very slowly because of difficulty holding a pencil due to a muscle or nerve problem in the hands cannot be expected to take a written test in the same time period as a child with normal hand use.

Out of District Placement: When a child attends a school program outside his home school district.

Private Placement: Placement in private school, paid for by student's home school district.

Psychological Evaluation: A series of tests given by a school psychologist to determine your child's ability to learn and his social and emotional development.

Related Services: Transportation, and such developmental, corrective, and other suppotive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education.

Residential Placement: Program that provides not only the required school educational setting, but also a 24 hours a day, 7 days a week living situation.

Resource Programs: Individual and small group instruction provided to students with disabilities by a certified teacher of students with disabilities. Resource programs may be provided in a general education class or in a pull-out classroom. When a resource program is provided, it shall be specified in the student's IEP.

School Case Manager: The person on the child study team assigned to an individual student to coordinate the development, monitoring, and evaluation of the effectiveness of the IEP, as well as to facilitate communication between home and school and coordinate the annual review and evaluation process

School Psychologist: The child study team member who is licensed to administer, analyze and interpret intellectual and psychological tests.

School Social Worker: The child study team member who gathers information regarding the academic, social, and developmental histories to provide background information related to the child's education.

Social Evaluation: An evaluation of family, school, and community patterns as they may affect your child's adjustment at school, arrived at jointly by the parent and the school social worker.

Special Class Program: A program that serves students who have similar intensive educational, behavioral and other needs related to their disabilities in accordance with their individualized education programs. Special class programs offer instruction in the core curriculum content standards unless the IEP specifies a modified curriculum due to the nature or severity of the student's disability.

Special Education: Specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability, including (a) instruction conducted in the classroom, in the home, in hospitals, and institutions, and other settings; and (b) instruction in physical education.

Speech-Language Specialist: A professional who is licensed to identify and work with students who are experiencing a speech disorder in articulation, phonology, fluency, voice, or any combination, unrelated to dialect, cultural differences or the influence of a foreign language, an/or a language disorder which adversely affects a student's educational performance.

Transition planning: The process of planning for the student's transition from adolescence to adulthood and from school to life after school. Under UDEA, this process begins when the student reaches age 14.

Transition Services: A coordinated set of activities for a child with a disability that (a) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (b) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and (c) includes instruction related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.

Vocational Counselor: Assists teenage students in evaluation and placement in appropriate future work settings. Includes formal testing and interview of interests and abilities of students.

Zero Reject: No child between the ages of 3 and 21 years can be denied an appropriate education because of a physical disability.

Glossary of Medical and Rehabilitation Terms

Ablation: Cutting and removing a section of tissue. Cerebral ablation: cutting and removing part of the brain.

Acalculia: An inability to carry out simple arithmetical calculations.

Acquired Head Injury: Traumatic head injury that is caused by an external physical force or by certain medical conditions such as stroke, encephalitis, aneurysm, anoxia, or brain tumors – with resulting impairment that can adversely affect psychosocial, motor, communication, vocational, and cognitive/academic performance.

Affect: The emotional state of an individual at any given time.

Agenesis: Failure of tissue or an organ to grow and develop normally.

Agnosia: Inability to recognize the significance of sensory stimuli.

Agraphia: Inability to express ideas in writing.

Akathisia: Body restlessness, the urgent need for movement.

Akinesia: Loss of normal movement.

Alexia: Inability to comprehend written language.

Amentia: Sub-normal mental capacity that is congenital.

Amnesia: Loss of memory for periods of time. Several types have been noted: Anterograde Amnesia: Inability to remember events beginning with the onset of the injury; essentially, severely decreased ability to learn. Retrograde Amnesia: Loss of memory of events preceding the injury. Post-Traumatic Amnesia: The period of anterograde amnesia following a head injury. The person is unable to store new information.

Aneurysm: The dilation of the wall of an artery.

Anomia: The inability to name an object that one recognizes and understands. A symptom of receptive aphasia.

Anisocoria: Pupil inequality.

Anosognosia: Unawareness of paralyzed limbs in hemiplegia; the neglect of the paralyzed side.

Anosmia: Loss of sense of smell; indicates impaired olfactory nerve function.

Anoxia: Loss of oxygen to the brain that can lead to brain damage.

Apraxia: Inability to carry out precise movements, inability to carry out voluntary acts without loss of motor power.

Aphasia: An inability, partial or complete, to understand or express language whether written or spoken, because of injury or disease of the language centers of the brain.

Areflexia: Loss of reflex activities.

Ataxia: Impaired neuromuscular coordination in voluntary muscle movements.

Athetosis: Involuntary neuromuscular movements and facial grimaces as in cerebral palsy, caused by brain lesion(s).

Atrophy: The wasting away of live tissue.

Attention: The ability to focus on one part of a complex experience.
Aura: A sensory warning preceding a seizure.

Babinski's sign: Stroking the lateral aspect of the sole of the foot from the heel to the toe with a blunt instrument causes the great toe to plantar flex (a negative Babinski sign). If the Babinski sign is positive, the great toe dorsiflexes (extends upward) and the other toes fan out. The latter is an abnormal response, and is a pathologic sign indicating contralateral pyramidal disease.

Bitemporal hemianopsia: Blindness of each temporal field of vision.

Blepharospasm: Involuntary, forcible, rapid, spasmodic contractions of the eyelids.

Brain Stem: The lower portion of the brain that connects it to the spinal column. The brain stem coordinates the body's vital functions (breathing, blood pressure, and pulse). It also houses the reticular formation that controls consciousness, drowsiness, and attention.

Broca's Area: The Brain center for motor speech, located in the posterior portion of the third frontal convolution, anterior to the lowest part of the motor cortex.

Bruit: A sound or murmur, especially and abnormal one.

Bulbar: Pertaining to the medulla.

Causalgia: A burning pain.

Cephalagia: Headache

Cerebellum: The portion of the brain that is located below the cortex. The cerebellum is concerned with coordinating movements.

Cerebral Edema: An increase in the interstitial fluid within the brain; swelling of the brain.

Chorea: Jerky, violent, rapid, uncontrollable movements.

Clonic: Rapid alternate spasms of contraction and relaxations as in epileptic seizures

Closed Head Injury: The brain is damaged within the skull, without external penetration.

CNS: An abbreviation for the Central Nervous System.

Cognition: A general concept embracing all of the various modes of knowing: perceiving, remembering, imagining, conceiving, judging, and reasoning.

Cognitive Rehabilitation (Cog-Re): Therapy programs that aid people in the management of specific problems in thinking and perception. New strategies and skills are taught to help improve function and/or compensate for deficits.

Coma: A state of profound unconsciousness from which one cannot be aroused. The depth and duration of the coma are important indicators of prognosis in closed head injuries. Termination of coma is commonly measured by attainment of a simple command level by the patient.

Concussion: The common result of a blow to the head usually causing unconsciousness, either temporary or prolonged. Physiologic and/or anatomic disruption of connections between some nerve cells in the brain may occur.

Confabulation: The fabrication of experience recounted to fill in and cover up gaps in memory.

Contralateral: Pertaining to the opposite side of the body or brain. An antonym for ipsilateral.

Contrecoup Injury: An injury occurring in a part of the brain opposite the point of impact; this is often the site of more serious damage.

Contusion: A bruising of the brain resulting from a blow to the head. This bruising causes tissue damage and bleeding within the brain.

Convergence: Coordinated inward rotation of the eyeballs and contraction of the pupils when focusing on a near object.

Convolution: An irregular convex formation in the brain; a gyrus.

Corpus Callosum: Wide bands of neural fibers interconnecting the two cerebral hemispheres.

Cortex: The convoluted outer layer of gray neural tissue that covers the brain. For convenience the fissure of Rolando and the fissure of Sylvius divide it into the frontal, parietal, temporal, and occipital lobes. Both the left and right hemispheres are similarly divided.

Corticospinal tract: Motor pathway from precentral gyrus to the anterior horn in the spinal cord; the pyramidal tract.

Coup Injury: An injury to the brain on the same side as the impact.

CT Scan (Computerized Tomography): A series of computerized x-rays taken at different levels of the brain. A scan is done soon after the injury to determine whether surgery is needed. A CT scan shows the more obvious changes, such as hematoma, enlarged ventricles, of atrophy.

Decerebration: A rigid state resulting from destruction of the cerebrum. Higher centers no longer exert an inhibiting influence on the primitive brain stem and spinal reflexes. Upper limbs are extended and hyperpronated, lower limbs are extended.

Decortication: A rigid state resulting from destruction of the cerebral cortex. Upper limbs are flexed, lower limbs are extended.

Dementia: Reduced mental capacity that is acquired due to disease, trauma, degeneration, etc.

Demyelination: Destruction or loss of the myelin sheath.

Denervate: To deprive of nerve supply.

Diplegia: Paralysis affecting both sides of the body (both arms or both legs)

Diadochkinesia: Ability to perform rapidly alternating antagonistic movements, a cerebellar function.

Dichotic Listening: A technique for stimulating simultaneously both ears of a subject with different words, usually with similar initial sounds and lengths. This is used to investigate cerebral dominance for language.

Diplopia: Double vision.

Dura Mater: The tough, fibrous outer layer of membranes surrounding the brain.

Dysarthria: Defective articulation.

Dyscalculia: Faulty calculation ability; a mild or moderate aculculia

Dysesthesia: An irritating sensation.

Dysgraphia: Impaired ability to express ideas in writing.

Dyskinesia: A defect in voluntary movement.

Dysmetria: Inability to control the range of voluntary movements.

Dysnomia: Faulty word finding ability; a mild or moderate anomia

Dysphagia: Difficulty in swallowing.

Dysphasia: An impairment of speech; sometimes used as a synonym for aphasia.

Dysphonia: Hoarseness.

Dysrhythmia: Abnormal rhythm of electrical charges in the brain; detected by an electroencephalogram.

EEG (Electroencephalogram): A recording of the brain's pattern of electrical activity used to identify abnormalities.
Encephalopathy: Any disorder of the brain.

Epileptogenic Foci: Focal areas of pathological brain tissue that appear to be related to epileptic seizures.

Evoked Potential: The measurement of electrical changes in the brain or central nervous system following environmental stimulation; e.g. light flashes in a subjects eyes will evoke sharp electrical changes in the posterior parts of the brain, and staccato sound patterns will evoke sequentially similar electrical changes in the temporal lobes.

Executive Functions: Planning, prioritizing, sequencing, self-motivating, self-correcting, inhibiting, initiating, controlling, or altering behavior in response to feedback; setting goals.

Extradural: Outside the dura.

Extramedullary: Outside the spinal cord.

Extraocular movements (EOMI): Extraocular eye movements intact. Eye muscles are moving in the correct direction due to intact cranial nerves.

Extrapyramidal System: Motor pathways that regulate voluntary and reflex movements.

Fasciculation: Involuntary twitching of the muscle groups.

Field Cut: A defect in the visual field

Flaccid: Without muscular tone.

Frontal Lobe: The area of the brain located at the front of the head on both left and right sides. The frontal lobe contributes to the control of emotions, motivation, social skills, expressive language, and inhibition of impulses. The left side of the frontal lobe is known as Broca's area. The motor strip controlling movement and motor integration runs along the posterior (back) of the frontal lobe.

Fundus: The back portion of the interior of the eyeball that allows visualization of the retina, retinal arteries and veins, and the optic nerve head.

Galea: Fibrous connective tissue of the scalp, connects the fleshy portions of the occipitofrontal muscle.

Gestalt Psychology: A school of psychology that originated in Germany in 1912 and that stressed perception and a holistic view of behavior.

Glasgow Coma Scale: An observational scale used for rating the severity of injury by assessing a child's responsivieness in three areas: motor response, eye opening, and verbal response. A severe injury is a score from 3 – 8, a moderate injury is a score form 9 – 12, and a mild injury is a score from 13 – 15.

Gyrus: A convolution or convex fold of tissue.

Haptic: Sense of touch; recognition of three-dimensional objects; sterognosis.

Hard Signs: these refer to the unequivocal, medically documented signs of brain damage, such as brain surgery, cerebral bleeding, hemiplegia, brain tumor, or penetrating head injury.

Hematoma: A localized collection of blood in an organ, space, or tissue that can be diagnosed by a CT scan. In brain injury, three types of hematoma are common: epidural (outside the brain and its fibrous covering, but under the skull); subdural (between the brain and its fibrous covering); and intercerebral (in the brain tissue). Most hematomas must be removed by neurosurgical procedures.

Hematomyelia: Bleeding into the spinal cord.

Hemianesthesia: Loss of sensation of one side of the body.

Hemianopsia: Blindness of one-half of a field of vision.

Hemiplegia: Paralysis of one side of the body.

Hemorrhage: Bleeding that occurs following trauma. Bleeding may occur within the brain when blood vessels in the skull or brain are damaged.

Homolateral: Pertaining to or on the same side.

Homonymous Hemianopsia: Blindness of the same side of the field of vision of each eye.

Hyperreflexia: Increased action of the nerves.

Hyperesthesia: Overly sensitive sensation of touch.

Hyperthermia: Abnormally high body temperature.

Hypertonia: Increased muscle tone.

Hypesthesia: Decreased sensation of touch.

Hyporeflexia: Diminished action of the reflexes.

Hypothalamus: A portion of the thalamus contiguous to the optic chiasm; is related to the control of many visceral processes and emotional behavior.

Hypotonia: Reduced muscle tone.

Idiopathic: Of unknown cause.

Increased Intracranial Pressure (IIP): An increase in pressure within the cranial cavity. Intracranial hypertension.

Infratentorial (Subtentorial): Below the tentorium (brain stem and cerebellum).

Intracranial Pressure: A measure of pressure within the skull; it must be closely monitored following a brain injury since prolonged increases in intracranial pressure can result in more damage to the brain tissues.

Intradural: Within the dura.

Intramedullary: Within the spinal cord.

Ipsilateral: On the same side; antonym for contralateral.

Kinesthesis: Awareness of the body and body parts in space; includes awareness of balance and motion.

Lasegue's Sign: Leg raising sign. Pain aggravated in back and leg when attempting to extend flexed muscle.

Limbic System: A set of cerebral structures, inside the brain and above the brainstem, believed to be involved in emotional behavior and short-term memory. It may include the cingulate gyrus, isthmus, hippocampal gyrus, and uncus.

Locus: Place, site, or location. Used in medicine to indicate a specific area or point in the body.

Lower Motor Neuron: The neuron from the brain stem or anterior horn cell of the spinal cord to the muscle. Its destruction results in flaccid paralysis.

Magnetic Resonance Imaging (MRI): A diagnostic procedure that uses magnetic fields to create pictures of the brain's soft tissue. MRI can provide a more detailed picture than the CT scan.

Maturation: The process of becoming mature.

Meningioma: A slowly growing tumor in the meninges or membranes covering the brain.

Meningismus: Signs and symptoms of meningeal irritation occurring in the absence of infection.

Memory: Assimilation, storage, and retrieval of previously experienced sensations and perceptions when the original stimulus is no longer present; learning new material; may be visual of auditory.

Micrographia: Small, cramped, handwriting that becomes smaller as it continues.

Monoplegia: Paralysis of one extremity.

Motor Aphasia: Loss of the ability to express one's thoughts in words; excessive aphasia. Caused by a lesion in Broca's area.

Myasthenia: Muscular weakness.

Myopathy: Any disease of the muscle.

Neoplasm: New and abnormal growth of tissue; tumor.

Neuralgia: pain along the course of a nerve.

Neurons: Specialized cells that conduct nerve impulses.

Neuropathy: Any disease of a nerve.

Neuropsychology: The branch of psychology that attempts to test different specific components of cognition as memory. The neuropsychologist looks into the site and mechanism of damage to specific functions.

Nystagmus: Rapid, involuntary movement of the eyeball, indicates abnormality of eye muscle control.

Obtunded: Blunted alertness, dulled behavior.

Occipital Lobe: The posterior (back) part of each side of the brain, involved in perceiving and understanding information.

Occupational Therapist (OT): Provides activity based treatment in keeping with the goal of achieving maximum independence in daily living skills. This therapist evaluates and treats cognitive and physical deficits, including limited functional use of the upper body, decreased visual-perceptual and motor difficulties with daily living skills, such as grooming, dressing, and writing.

Optic Chiasm: The structure formed by the place of crossing of the optic nerve fibers from the nasal halves of the retina. It is located in front of the pituitary gland.

Opticokinetic: Pertaining to the movement of the eyes.

Opthalmoplegia: Paralysis of the eye muscles.

Otorrhea: Discharge from the ear; drainage of cerebrospinal fluid (CSF) from the ear.

Palsy: Paralysis.

Papilledema: Loss or impairment of motor functions.

Paraplegia: Paralysis of the lower extremities.

Paresis: Partial or incomplete paralysis, motor weakness.

Parethesia: An abnormal sensation without objective cause such as numbness, tingling.

Parietal Lobe: The upper middle lobe of each side of the brain, involved in receiving and understanding sensations and closely linked to speech fluency and writing.

Parosmia: A disorder of the sense of smell; perverted sense of smell, indicates impaired olfactory nerve function.

Penetrating Head Injury: The brain is penetrated from the outside, as in a bullet wound (also referred to as an open head injury). Penetrating injuries tend to damage localized areas of the brain, which result in fairly discrete and predictable disabilities.

Periocular Edema: Swelling of the eyelids and surrounding tissue.

Photophobia: Unusual sensitivity to light.

Physiatrist: A physician (MD) who specializes in the area of medicine and rehabilitation. While physiarists may treat a wide variety of illnesses, the emphasis is always on the evaluation of functional disability and prescription of treatment through therapies, orthotics, medication, and other modalities.

Physical Therapist (PT): Primary emphasis is on motor functioning. This therapist evaluates your family member's range of motion, strength, coordination, balance, endurance, and mobility skills. The physical therapist will show you how to assist your family member with an exercise program and daily activities. The need for equipment, such as a wheelchair, walking aid, or bathroom equipment in monitored and recommended by the physical therapist.

Pons: A connecting center in the brain stem for motor and sensory nerves.

Post-Concussive Syndrome: Is a specific set of circumstance that occurs following a blow to the head involving minimal or brief loss of consciousness. Symptoms of post-concussive syndrome include headache, dizziness, ringing in the ears, blurred vision, difficulties in complex attention and simultaneous processing, and decreased mental speed and memory problems. Also, there is frequently seen a personality change, such as irritability.

Post-Traumatic Amnesia (PTA): A loss of memory that occurs immediately after the injury and which may continue for weeks or months. During this time many patients are unable to organize or retrieve information. The length of PTA is regarded as an indicator of eventual recovery.

Post -Traumatic Epilepsy: A seizure disorder occurring in greater than five percent of patients who suffer head trauma. The more severe the injury, the greater the likelihood that seizures will appear.

Post-Rolandic Area: The area just posterior to the fissure of Rolando; the sensory strips, parietal, occipital, and temporal lobes.

Premorbid: Prior to the onset of illness or injury.

Proximal Instability: Impaired strength or muscle tone of the trunk, shoulder girdle, or hip girdle. This can cause poor posture, abnormal movement of the limbs, inability to sit up, and inability to hold one's head up. Caused by damage to the motor strips of the brain.

Psychosocial: Refers to the combined psychological and social factors. This is often used in the discussion of psychological and social factors.

Ptosis: Drooping of the upper eyelid.

Quadriparesis: A weakness that involves all four limbs.

Quadriplegia: Paralysis of the upper and lower extremities.

Recall: The act of remembering, reconstructing, and initiating that which has been stored.

Receptive Aphasia: Impaired understanding of language, whether written or spoken.

Recognition: Realizing that you have seen, heard, touched, smelled, etc. before and are connecting to that object.

Related services/ Support Services: These terms refer to counseling for pupils and parents,speech-language services, recreation, occupational therapy, physical therapy, transportation, and any other appropriate developmental, corrective, and supportive services required for a pupil to receive education as outlined in his IEP.

Respite Care: Care provided by a professional or community agency to enable the primary caretaker an interval of rest or relief.

Retrieval: Bringing back from storage for the purpose of communication.

Retrograde Amnesia: Loss of memory for events and periods of time before the injury or accident.

Romberg's Sign: Inability to maintain balance while standing with eyes closed and feet together. Indicates cerebellar dysfunction.

Scanning Speech: Slow hesitant speech characterized by pauses between syllables.

Sciatica: Pain along the course of the sciatic nerve.

Scotoma: A blind area in the visual field.

Semicoma (Light Coma): An altered state of consciousness in which the patient responds only to painful stimuli.

Sensorium: The state of an individual in regard to his mental awareness.

Sensory Aphasia: Loss of the ability to comprehend spoken language; receptive aphasia. Caused by a lesion in Wernicke's area.

Soft Signs: Refer to minimal behavioral deviations in a child, reported by the neurologist, where the traditional neurological examination shows no clear sign of brain damage or dysfunction. These indications, such as neuromuscular clumsiness, involuntary twitching movements of the hands, and poor directional sense, are strongly suggestive of abnormal functioning of the central nervous system, but such a diagnosis is not supported by the usual neurological examination techniques. Consequently, these are suspected neurological signs.

Somnolence: Sleepiness, unusual drowsiness.

Spasm: A sudden violent, involuntary contraction of a muscle or a group of muscles.

Spastic: Abnormal increase in muscle tone.

Spasticity: An abnormal increase in muscle tone, causing the muscles to resist being stretched. A patient with "spasticity" may look curled up, with his arms held close to his chest, or he may appear stiff.

Spinothalmic Tract: Sensory pathways from the gray dorsal column of the spinal cord terminating in the thalamus.

Spontaneous Recovery: The recovery that takes place naturally as the brain heals; this type of recovery occurs with or without rehabilitation, and it is often difficult to know how much improvement is spontaneous and how much is due to rehabilitative interventions. It occurs early in the recovery process.

Sterognosis: The ability to recognize objects by touch.

Strabismus: Inability of the eyes to perform coordinated movements.

Stupor: An altered state of consciousness, in which the patient is very difficult to arouse, responds poorly to verbal stimuli.

Sublaxation: A partial or incomplete dislocation.

Supraretorial: Above the tentorium (the cerebrum).

Temporal Lobe: The lower middle part of each side of the brain, involved in receiving information from the auditory system and involved in memory.

Tentorium: The fold of the dura mater between the occipital lobes and the cerebellum. Supports the cerebrum, separates the posterior cranial fossa from the remainder of the cranial cavity.

Tic: An involuntary twitching of a muscle.

Tone: The normal degree of tension in a muscle.

Tonic: Rigid convulsive movements characterized by simultaneous contraction of opposing muscles.

Traumatic Head Injury: See acquired head injury.

Trigger Zone: Refers to a part of the face which when stimulated precipitates an attack of trigeminal neuralgia (tic douloureux).

Uncal Herniation: Herniation of the uncus through the tentorium causing compression of the oculomotor nerve and the brain stem.

Uncus: Extreme medial portion of the temporal lobe.

Upper Motor Neuron: The neuron from the motor cortex to the brain stem or anterior horn cell of the spinal cord. Its destruction results in spastic paralysis.

Vegetative State: An altered state of consciousness in which only involuntary or unconscious body functions remain intact.

Ventricles: Four cavities in the brain that are filled with cerebrospinal fluid, serving as a cushion when the brain is impacted. These cavities may enlarge when brain tissue is damaged.

Visual Field Deficit: Inability to see objects located in a specific area of the visual field. Often the blind area includes everything in either the left or the right half of the visiual field, but may involve a quarter of the visual field.

Wada Carotid Amytal Test: Refers to the test of speech dominance first developed by Dr. JuhnWada in 1949. When amytal is injected into the left carotid artery it is carried to the left cerebral hemisphere in a matter of seconds, where it has an anesthetizing effect. In most patients this produces temporary interference with all language processes. When injected into the right carotid artery amytal usually interferes with a patient's ability for picture interpretation and spatial perception.

Wernicke's Aphasia: Receptive aphasia.

Wernicke's Area: The cerebral cortical area, usually in the left temporal area, believed to be involved in the understanding of language. It is believed to include one-third of the left superior temporal gyrus and part of the middle temporal gyrus.

Statistics

The Centers for Disease Control and Prevention (CDC), in the United States, estimates that:

- at least 5.3 million Americans (approximately 2% of the U.S. population) live with disabilites resulting from brain injuries.
- A brain injury occurs every 21 seconds in this country, and sends more than one million people to the hospital each year.
- Of this one million:
    - 230,000 will be hospitalized and survive
    - 80,000 will experience an onset of disabilities resulting from their brain injuries
    - 50,000 will die

Traumatic brain injury and children – national statistics

- Brain injury is the most frequent cause of disability and death among children and adolescents in the United States (CDC, 1999; Lehr, 1990).
- Males are twice as likely to sustain a brain injury as females, due to differences in risk exposure and lifestyle. 14 to 24 year old males are at highest risk. (CDC, 1999; Kraus, 1993).
- The leading causes of brain injury in children are motor vehicle crashes, violence and falls (CDC, 1999).
- Among children ages 4 to 14, motor vehicle crashes with children as passengers is the number one cause of brain injury. Unrestrained or improperly restrained children of any age are much more likely to incur a brain injury and/or die in motor vehicle crashes than children who are restrained properly (National Safe Kids Campaign, 1999).
- Every two hours in the United States a child is killed with a loaded gun (American Academy of Pediatrics, 1994). In 1992, firearms surpassed motor vehicles as the number one cause of brain injury fatalities in the United States (Sosin et al., 1995).

Traumatic brain injury and children - NJ statistics

The Center for Health Statistics in New Jersey has compiled the following statistics for children ages 0-21 who were hospitalized in 1997 with a traumatic brain injury (Center for Health Statistics, February, 2001). These statistics do not include those individuals who were seen in emergency rooms and not admitted, or those who never went to the hospital at all. These numbers do not represent those with acquired brain injury.

In New Jersey,

- Males sustain approximately twice as many brain injuries as females. The ratio increases further when traumatic brain injury from assaults is examined, with 90% of brain injuries from assault occurring in males.
- Children in high school and post high school (ages 15-21) sustain almost half of all traumatic brain injuries in the birth to 21 age group.
- Motor vehicle collisions are the cause of the largest number of brain injuries.
- Brain injuries from falls occur more often in younger children and taper off as children get older.
- Brain injuries from assaults and motor vehicle crashes occur more often in the high school and post high school years (15-21).

References

Centers for Disease Control and Prevention. *Surveillance Report.* April, 1999.

Center for Health Statistics, Department of Health and Senior Services, Trenton, NJ, February, 2001.

Kraus JF: Epidemiology of head injury. In: *Head Injury.* PR Copper (Ed.) Baltimore: Williams & Wilkins, 1993.

Lehr E: Incidence and Etiology. In: *Psychological Management of Traumatic Brain Injuries in Children and Adolescents.* E Lehr (Ed.) Rockville, MD: Aspen Publishers, 1990.

Resources

There are many sources of information on brain injury, advocacy, special education, and many other topics addressed in this guide. The sources listed below are good places to begin searching when you need information about a specific topic. The Brain Injury Association of New Jersey's Information & Resources Helpline can provide you with additional information on available resources.

Brain Injury Association of New Jersey, Inc.
☎(800) 669-4323 (Family Helpline) ☎(732) 745-0200 Web: www.bianj.org
BIANJ provides a number of services to assist individuals with a brain injury and their families.
(See page 2 for more information)

Brain Injury Association of America
☎(800) 444-6443 (Help Support Line) ☎(703) 761-0750 Web: www.biausa.org
BIA provides information about brain injury and resources throughout the United States. The web page provides dozens of links to brain injury information sites.

Statewide Parent Advocacy Network (SPAN)
☎ (800) 654-7726 Web: www.spannj.org
SPAN provides information, training, and advocacy for parents of children with disabilities.

New Jersey Protection and Advocacy
☎ (800) 922-7233 Web: www.njpanda.org
This program protects and advocates for the rights of citizens with disabilities.

Education Law Center
☎ (973) 624-1815 Web: www.edlawcenter.org
This agency provides help for families with issues related to the education system.

Community Health Law Project
☎ (609) 392-5553 Web: www.chlp.org
This project advocates for the health care needs of individuals with disabilities.

Association of Schools and Agencies for the Handicapped-New Jersey
☎ (877) 287-2724 Web: www.asah.org
This organization provides information about private schools in NJ, which provide specialized services for students with special needs.

Families and Advocates Partnership for Education (FAPE)
☎ (952) 838-9000 Toll-free:☎ (888) 248-0822 Web: www.fape.org
The Families and Advocates Partnership for Education (FAPE) project is a partnership that links families, advocates, and self-advocates to information about the Individuals with Disabilities Education Act (IDEA).

HEATH Resource Center
Web: www.heath.gwu.edu
A resource center of the George Washington University, Graduate School of Education and Human Development, and the national clearinghouse on postsecondary education for individuals with disabilities.

Family Support Center of New Jersey
Toll-free: ☎1-800-372-6510 Web: www.fscnj.org
The Family Support Center is a "One-Stop Shop" clearinghouse, offering the most up-to-date information on all types of disabilities as well as national, state and local support programs and services for individuals and families seeking such information.

Lash & Associates Publishing/Training Inc.
708 Young Forest Drive, Wake Forest, NC 27587-9040
☎ (919) 562-0015 Web: www.lapublishing.com
This company has a comprehensive array of written materials and resources about brain injury.

National Dissemination Center for Children with Disabilities
PO Box 1492, Washington, DC 20013-1492
☎(800) 695-0285, ☎(202) 884-8200 Web: www.nichcy.org
Clearinghouse with a large selection of clearly written, free or low-cost information.

National Safe Kids Campaign
1301 Pennsylvania Ave., NW Suite 1000, Washington, D.C. 20004-1707
☎(202) 662-0600 Web: www.safekids.org

SOME NJ GOVERNMENT AGENCIES/PROGRAMS

Office of Special Education Programs
☎(609) 292-0147 Web: www.state.nj.us/njded/specialed
This state office is responsible for providing special education and related services.

Learning Resource Centers
Web: http://www.nj.gov/njded/lrc/
The Learning Resource Centers are supported through the New Jersey State Department of Education, Office of Special Education Programs and provide services to parents and educators serving pupils with disabilities ages 3 to 21, including information services, books and videos that can be borrowed, and consultation and training services.

Division of Disability Services
Toll free Information Line ☎(888) 285-3036 Web: www.state.nj.us/health/dds/index.html
The Division of Disability Services is an excellent resource for disability-related information, and also oversees the Traumatic Brain Injury Fund and Traumatic Brain Injury Medicaid Waiver. Call for a free resource guide.

Division of Developmental Disabilities
☎(609)631-2200 Web: www.state.nj.us/humanservices/ddd/index.html
This organization provides services for households that include an individual with a developmental disability or brain injury sustained before the age of 21.

Division of Child Behavioral Health Services (DCBHS)
24-hour Access Line: ☎1-877-652-7624
Web: www.state.nj.us/humanservices/dcbhs/aboutdcbhs.htm
The Division of Child Behavioral Health Services (DCBHS), serves children and adolescents with emotional and behavioral health care challenges and their families across all child-serving systems.

Division of Vocational Rehabilitation Services
☎(609) 292-5987 Web: www.state.nj.us/labor/dvrs/vrsindex.html
DVRS provides services to individuals with work-related disabilities to help those individuals become employed.

Commission for the Blind and Visually Impaired
☎(973) 648-3333 Web: www.cbvi.nj.gov
This program provides vocational rehabilitation services for people who are blind or visually impaired.

New Jersey Traumatic Brain Injury (TBI) Medicaid Waiver Program
☎(888) 292-4800 Web: www.state.nj.us/health/dds/index.html
This program provides services in the home and community for those injured after the age of 21 who qualify financially and medically.

New Jersey Traumatic Brain Injury (TBI) Fund
☎(888) 285-3036 Web: www.state.nj.us/health/dds/index.html
The Traumatic Brain Injury Fund, administered by the Division of Disability Services, allows New Jersey residents who have survived an acquired brain injury to obtain the services and supports they need to live in the community.

Special Child, Adult and Early Intervention Services
☎Telephone: 609-777-7778 Web: www.state.nj.us/health/fhs
Special Child Health Services provides case management to ensure that children with special health care needs receive quality services that will prevent or reduce the effects of developmental delay, chronic illness or behavioral disorder.

Catastrophic Illness in Children Relief Fund
Toll Free: ☎1-800-335-FUND Web: www.njcatastrophicfund.org
Financial help is available from this fund if your child is 21 years old or younger when the medical expenses were incurred; your family has lived in New Jersey at least three months prior to application; and in any prior, consecutive, 12 month period, dating back to 1988, eligible expenses must exceed 10% of the family's income, plus 15% of any excess income over $100,000. Covered expenses include, but are not limited to, special ambulatory care, acute or specialized in- or out-patient hospital care, medical equipment, medically-related home modifications, home health care and medical transportation.

NJ Family Care
Toll Free: ☎(800) 701-0710 Web: www.njfamilycare.org
NJ FamilyCare is a federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians to have affordable health coverage.

BIANJ Publications

The Brain Injury Association of New Jersey provides a number of free publications for families and professionals, all of which can be obtained by calling the Association at 1-800-669-4323 or (732) 745-0200. Publications can also be ordered online at www.bianj.org. The following are just a few of the publications available through the Association.

Brain Injury: A Guide for Educators - This booklet assists all educators in working with children with brain injury.

Brain Injury: A Guide for Families about School - This booklet is geared for family members to assist with their child's transition back to school following a brain injury.

Brain Injury: A Guide for School Nurses - This booklet assists school nurses in understanding the unique needs of children with brain injury.

Acute Brain Injury: A guide for family and friends
This booklet provides basic information about brain injury and its treatment. It describes the brain, how it functions, and what happens when it is hurt in clear terms. It is especially useful for understanding medical care and rehabilitation in the early stages of recovery. It has a helpful section of NJ resources. Also available in a Spanish translation.

Brain Injury, When the Call Comes: A Congregational Resource
This 24-page booklet provides clergy with information about brain injury, how it impacts the person, family and community, and how the congregation can help.

Browse & Borrow Book & Video Catalog
The Association maintains a library of over 200 books and 40 videos that New Jersey residents can borrow free of charge. This catalog lists all books and videos available, complete with descriptions and borrow forms.

Making Life Work After Brain Injury: A Family Guide for Life at Home
This book will help readers' families, persons with brain injury and professionals -- through the new, unchartered territory of brain injury -- physical, cognitive and behavioral symptoms – including answers to questions family members commonly ask.

New Jersey Brain Injury Resource Guide
This 20-page booklet contains information on brain injury resources around the state, including support groups, rehabilitation programs, national and state brain injury associations, and state and county organizations and agencies that assist people with brain injuries.

Traumatic Brain Injury & NJ Special Education
This fact sheet assists families in understanding Traumatic Brain Injury as it is defined within the NJ Special Education system, along with symptoms and statistics related to children and brain injury.

When Your Child's Head Has Been Hurt (available in English and Spanish)
This colorful flyer describes what parents should look out for following their child's mild brain injury and how to get help.

Brain Injury Prevention Materials
The Association also provides a number of materials to raise awareness of the preventability of brain injury, including fact sheets, posters, coloring books and brochures.

Books & Videos

It can be difficult to find information that is practical and understandable. The following books and videos are clearly written for families and educators and are helpful for understanding brain injury and special education. All books and videos are available through the Brain Injury Association of New Jersey's Browse & Borrow Book & Video Library, and can be borrowed free of charge. A complete listing of books and videos available to be borrowed through the Association is available by calling 1-800-669-4323 or (732)-745-0200. A complete listing is also available online at www.bianj.org.

Children with Traumatic Brain Injury: A Parents' Guide
Edited by Lisa Schoenbrodt
Published in 2001 by Woodbine House in Bethesda, MD
☎800-843-7323 Web: www.woodbinehouse.com
A comprehensive reference book written by a multidisciplinary team of professionals, this book provides parents with medical, rehabilitation, educational and legal information and support to help them and their child navigate through brain injury.

Pediatric Brain Injury: The special case of the very young child
Written by Carole Wedel Sellars, Candace Hill Vegter, Susan Sivertsen Ellerbusch
Published in 1997 by HDI Publishers, PO Box 131401, Houston, TX 77219 ☎(800) 321-7037
Using an exceptionally concise, clear and understandable writing style, the authors give an excellent overview of the effects of brain injuries on infants, toddlers and preschoolers. Remarkably free of complex medical jargon, it reviews the development of the child's young brain, compares normal development with changes that can result from a brain injury, and gives case studies. The challenge of designing therapy programs for young children is explained fully to help parents understand goals and treatment principles.

A Manual for Managing Special Education for Students with Brain Injury
Written by Marilyn Lash, Bob Cluett
Published in 1999 by Lash and Associates Publishing/Training, Inc.
708 Young Forest Drive, Wake Forest, NC 27587 ☎(919) 562-0015 Web: www.lapublishing.com
Skills used by professional case managers are adapted for parents and applied to special education. They are...
Assessment... How has the brain injury affected this child?
Information gathering... What do I need to know?
Referral... When do I involve a specialist?
Service Coordination... How do I put this all together?
Advocacy... How can I help others understand?
Evaluation... How do I know if this is working?

An Educational Challenge: Meeting the needs of students with brain injury
Written by Dana DeBoskey
Published in 1996 by HDI Publishers, PO Box 131401, Houston, TX 77219 ☎(800) 321-7037
This manual gives a basic overview with a lot of information about the brain and how it works in very clear, non-jargon writing that is readily understandable for educators and parents. Common cognitive needs are described with lists for interventions and strategies in the classroom. Types of assessment batteries and achievement tests used by schools are listed. Final chapters address the often overlooked topics of teacher reactions and vocational planning.

Signs and Strategies for Educating Students with Brain Injuries
Written by Marilyn Lash, Gary Wolcott and Sue Pearson
Second edition published in 2001 by Lash and Associates Publishing/Training, Inc.,
708 Young Forest Drive, Wake Forest, NC 27587 ☎(919) 562-0015
This book gives a basic overview of the consequences that brain injuries can have on a child's learning, behavior and adjustment in school. It explains common changes and gives strategies for the classroom and at home. A special section on transition strategies helps prepare the student for moving from teacher to teacher, grade to grade and school to school with lots of worksheets for families and educators.

Brain Injury and the Schools: A Guide for Educators
Written by Anne McDonnell
Published in 2005 by the Brain Injury Association of Virginia
☎(804) 355-5748 Web: www.biav.net
This manual provides an overview of brain injury and its cognitive, behavioral, and physical consequences. It provides many resources for teaching and non-teaching personnel: strategies for addressing the issues these students may have relative to education and transition and where to find additional information. This manual was written for school personnel (regular and special education teachers) instructional assistants, psychologists, social workers, and school nurses.

Educating Educators about Acquired Brain Injury
Produced by Brock University and the Ontario Brain Injury Association in 2003
E-Mail: obia@obia.on.ca Web: www.abieducation.com
This manual is intended as a resource to anyone involved in the education of a student who is living with the effects of an acquired brain injury. This manual covers topics such as brain and function in the context of ABI, understanding ABI from a developmental perspective, working with ABI in the school, teach approach and assessment and the role of parents. An appendix is included which has acronyms, a brain injury quiz, glossary and resource/reference list.

Learning and Cognitive Communication Challenges: Developing Educational Programs for Students with Brain Injuries
Written by Roberta DePompei & Janet Tyler
Second edition published in 2004 by Lash and Associates Publishing/Training, Inc.,
708 Young Forest Drive, Wake Forest, NC 27587 ☎(919) 562-0015
This manual explains the relationship between cognitive processes and classroom behavior. By understanding the effects of these challenges on learning and behavior in the classroom, educators and therapists can develop more effective educational strategies and accommodations. Written in clear language and filled with practical checklists and student examples, this user-friendly manual expands on the already popular educational tip cards by the authors. Chapters Address: cognitive-communicative challenges, effect of cognitive-communicative challenges on learning and behavior in the classroom, treatment of cognitive-communicative strengths and needs using an integrative approach, assessing teaching strategies, and transitioning students with brain injuries.

Returning to School Following Brain Injury: A Guide for School Personnel
Produced in 1993 by the National Resource Center for Traumatic Brain Injury
Web: www.neuro.pmr.vcu.edu/material/2005catalog/index.htm
This video will help family members, counselors, and teachers more effectively advocate for students with brain injury. This insightful three-part, 60-minute videotape addresses the causes and consequences of TBI, eligibility requirements and curriculum considerations, and classroom strategies for promoting academic success following traumatic brain injury. Professionals, survivors of TBI, their family members, and students help educators understand the need for family-educator-professional partnerships in preparing the student with TBI for his/her return to the school setting. Topics highlighted include: effective educational programming and individual educational plans, common obstacles to learning and recommended action steps, environmental adaptations and special education services, and placement options.

TAKE TWO After Traumatic Brain Injury
Produced in 2001 by Project BRAIN, Tennessee Disability Coalition
Available through Lash and Associates Publishing/Training, Inc.,
708 Young Forest Drive, Wake Forest, NC 27587 ☎(919) 562-0015
Three families openly discuss the effects of traumatic brain injury. The youths talk about the physical and cognitive changes that altered their abilities in school, relationships with others, and plan for the future. Professionals in rehabilitation, mental health and education, comment on the challenges typically faced by families when a child has a brain injury. This video shows the educational challenges by following these three youths as they return to school. It describes the strategies and supports that helped them return to the classroom and resume their education. Their wide age span demonstrates the developmental impact of a brain injury and the different educational issues in elementary and high school.

Pathways to Successful Transition for Youth with Disabilities
Written by Gary Greene and Carol A. Kochhar-Bryant
Published in 2003 by Pearson Education, Inc.
The goal of this book is to provide the reader with an understanding of the possibilities and potential of transition services, as well as philosophy and practices for the benefit of students with disabilities. In this book, the authors present prevailing as well as contrary views on transition, then emphasize those that are held by the majority of researchers and practitioners. This book is not intended to be an encyclopedia or exhaustive review of transition research and services, but rather an overview of those areas in which there is agreement on principles and where controversy is based on easily understood differences in reasons or opinion.

Further Reading

The Brain Injury Association of New Jersey maintains both an online library of articles, many of which are clearly written for families and educators. The following articles are available at www.bianj.org.

Questions Often Asked About Behavior After Brain Injury by Marilyn Lash, MSW and Ronald Savage, EdD. TBI Challenge! (Vol. 4, No. 4, 2000).

Questions About Speech and Communication After Brain Injury by Marilyn Lash, MSW and Roberta DePompeii, PhD. TBI Challenge! (Vol. 4, No. 4, 2000).

Brothers and Sisters: Brain Injury is a Family Affair by Carolyn Rocchio. Family News and Views.

Helping Brothers and Sisters by Marilyn Lash, MSW. TBI Challenge! (Vol. 3, No. 4, 1999).

School to Work: Moving From Adolescence to Adulthood by Marilyn Lash, MSW. TBI Challenge (Vol. 4, No. 1, 2000).

Back To School by Marilyn Lash, MSW and Bob Cluett. TBI Challenge! (Vol. 3, No. 5, 1999).

Learning About Special Education by Marilyn Lash, MSW and Bob Cluett. TBI Challenge! (Vol. 3, No. 2, 1999).

Teaching Accommodations for Students with Brain Injuries by Marilyn Lash, MSW. TBI Challenge! (Vol. 4, No. 2, 2000).

Testing Accommodations for Students with Disabilities by Jill Adams. TBI Challenge! (Vol. 4, No. 1, 2000).

Young Adults with Brain Injury and College by Jen Bunch. TBI Challenge! (Vol. 4, No. 2, 2000).

The following are articles that can be obtained by contacting the Brain Injury Association of New Jersey or can be downloaded online from the cited website.

Students with Traumatic Brain Injury: Identification, Assessment and Classroom Accommodations by Mary Hibbard, Wayne A. Gordon, Tamar Martin, Barry Raskin, Margaret Brown. Premier Outlook (Vol. 3, Issue 3, Summer 2002). Available online at www.premier-outlook.com.

School Integration: Addressing Behavioral Needs of Students Following Brain Injury by Janice Opella, M.Ed. Premier Outlook (Vol. 4, Issue 2, Summer 2004). Available online at www.premier-outlook.com.

Student with a Brain Injury: Achieving Goals for Higher Education by HEATH Resource Center. Available online at www.heath.gwu.edu.

Additional articles for families and educators are available in hard copy from the Brain Injury Association of New Jersey on a range of topics. For more information, contact one of the Association's Information & Resource Specialists at 1-800-669-4323 or (732)-745-0200.

Please Give Us Your feedback

BIANJ needs your help! Your feedback is essential to our on-going development of information and resources about brain injury.

Please take a moment to help us evaluate this guide. When finished, please cut and fold this page in thirds, affix first class stamp, tape shut and mail.

Thank you.

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