Behavior after Brain Injury: Challenges for Children and Adolescents
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This publication is a project of the Children & Adolescents Committee of the Brain Injury Alliance of New Jersey (BIANJ). René Carfi, MSW, LSW, CBIST, Senior Director of the Brain Health Network and Justin Stanley, CBIS, Information & Resources Program Coordinator of BIANJ were the coordinators for this publication. Additional assistance was provided by Family Support Coordinator Paige Forsyth and Public Education Coordinator Joanna Boyd.

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BIANJ can provide information about professionals who are available to speak to school personnel about brain injury. In addition to this guide, BIANJ has also developed guides for educators, school nurses and families about the impact of brain injury on a student’s education. Please encourage educators, school nurses and parents to contact BIANJ to obtain these guides.
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Introduction

Purpose
Members of the Children and Adolescents Committee of the Brain Injury Alliance of New Jersey (BIANJ) wrote this guide to help parents identify, understand, and respond to the behavioral issues they may see in their child after a brain injury. The authors, who are members of the Committee, include parents and professionals who work in the field of brain injury, cognitive rehabilitation, general and special education, and school nursing.

This guide can also be used by general and special education teachers, school psychologists, educational consultants, social workers, guidance counselors, principals, speech and language pathologists, and other professionals who work with students with brain injuries.

While behavioral issues following brain injury are not uncommon, parents often receive little information and few avenues of support to address the changes in behavior that can dramatically impact their child at home and in school. These changes can also directly and indirectly affect their child’s future expectations and achievements. This guide provides a foundation for educating parents about what to look for and where to go to seek help. With this material, parents will gain an increased awareness and understanding of behavioral challenges. They will also have information on what to do when they begin to see behavioral issues.

Mission of BIANJ
Our mission is to support and advocate for individuals affected by brain injury and raise public awareness through education and prevention. The Brain Injury Alliance of New Jersey has committed its resources to provide services and programs urgently needed now and in the future.

The current programs and services offered by BIANJ include:
- Information and resource service
- Support groups for persons with brain injuries and their families
- A week-long summer respite and recreation program
- 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
Chapter 1

What is Brain Injury?

Brain injury is the most common form of injury in children and adolescents. According to the Centers for Disease Control and Prevention (CDC), among children aged 0 to 19 a yearly average of:
• 62,000 children sustain brain injuries requiring hospitalization and
• 564,000 are seen in hospital emergency departments following a brain injury.

In New Jersey, in one year (2007), the Center for Health Statistics recorded:
• 1,231 children aged 0-17 hospitalized with brain injury and
• 22,436 more seen in emergency departments following brain injury.

Brain injuries are described as traumatic or acquired based on the cause of the individual's injury. Knowing what causes a brain injury is very important for both treatment and prevention.

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 occur during everyday activities. Common causes of injury include:
• falls
• assaults
• sports injuries
• motor vehicle crashes.

Among young children, the most common causes of brain injuries are falls, such as a fall from a changing table or down the stairs. Tragically, physical abuse by hitting or shaking a child is another major cause in young children. Car crashes, in which the child is a passenger or is struck by a car, are major causes of brain injury among all ages. Falls or collisions while skateboarding, roller blading or biking, as well as sports injuries, are common causes of brain injuries in elementary school age children and adolescents.

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, including:
• stroke
• encephalitis
• aneurysms
• metabolic disorders
• anoxia (lack of oxygen during surgery, drug overdose, or near drowning)
• toxic exposure
• meningitis
• brain tumors

Although the causes of brain injury differ, the effects of these injuries on a child's life are quite similar. This guide uses the general term of “brain injury” to include children with traumatic and acquired brain injuries. The term “traumatic brain injury” (TBI) is used when information is specific to those types of injuries.
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 1.7 million people in the United States have traumatic brain injuries each year, but only one sixth of them are admitted to hospitals. This number does not include people with acquired brain injuries.

This epidemic 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 be hospitalized. This means that many children and their families are not be 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.

Brain injury is also “silent” because most children with brain injuries look “normal.” Some difficulties may not become apparent until the student reaches a developmental stage requiring more complex abilities. It is then that impairments from an earlier brain injury become evident. This may occur with new learning or when more complex thinking and learning is required. 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, even years after the injury.

Previously, individuals with brain injuries often did not survive. The advent of new medical technologies has greatly increased survival rates. Increasingly, even children with severe brain injuries eventually return home and go to school.

Epidemiology

Traumatic Brain Injury
According to the Centers for Disease Control and Prevention (CDC), an estimated 5.3 million Americans, a little more than 2% of the US population, currently live with disabilities resulting from traumatic brain injuries. Brain injury occurs every 23 seconds and sends more than one million individuals to the hospital each year.

Acquired Brain Injury
The incidence and prevalence of various types of acquired brain injuries that may be seen in children are as follows:

Tumors
Brain tumors of the central nervous system account for nearly 20% of pediatric cancers. This is much higher than in adults, where they constitute only 1% to 2% of new cancers. No pattern of inheritance is found in most cases. Survival rates depend on the type of tumor and its location. The survival of children with brain tumors has increased with the advent of improved imaging that gives earlier and more precise diagnosis and location of a tumor, new surgical techniques such as stereotactic surgery, and new chemotherapy agents and radiation protocols. Because children are living longer after the diagnosis and treatment of a brain tumor more children are living with acquired neurocognitive and behavioral changes.

Encephalitis
Encephalitis is an inflammation of the brain and spinal cord that is usually caused by a viral infection. It is impossible to determine the true incidence or number of cases in the US because reporting policies are neither standardized nor rigorously enforced. Several thousand cases of viral encephalitis are reported yearly to the CDC. This is probably a fraction of the actual number.

Lead poisoning
According to the CDC, approximately 310,000 children ages 1-5 years in the US have levels of lead in their blood that are high enough to cause irreversible damage to their health. Even low lead levels can be harmful and are associated with lower intelligence, difficulty with thinking and learning, smaller stature and growth, and impaired hearing.
**Stroke**
Stroke is more rare in children than in older adults. However, certain groups of children are at risk for a stroke. Strokes can occur in utero or during pregnancy, as well as during or shortly after delivery. This places babies at risk for cerebral palsy and other complications. Strokes are slightly more common in children under the age of two. Premature infants are also at greater risk when there is concern about getting oxygen to the brain. Sickle cell disease affects one of every 500 African-American newborns and also places a child at risk for stroke. Approximately one quarter of all children with sickle cell anemia will have a stroke.

**Severity of traumatic brain injury**
Traumatic brain injuries are usually characterized as **mild**, **moderate**, and **severe**. Although definitions vary, the following guidelines describe these terms, which are often used in medical reports.

**Mild** brain injury:
- Brief (less than 1 hour) or no loss of consciousness (LOC)
- Possible symptoms of a concussion

**Moderate** brain injury:
- Coma lasting more than 1 hour but less than 24 hours
- Neurological evaluation finds evidence of brain trauma
- Possible positive findings on CT scan or EEG

**Severe** brain injury:
- Coma lasting more than 24 hours

**Mild brain injury**
Mild brain injuries occur much more often than moderate or severe injuries. These students are likely to be taught in a general education classroom.

When the injury is a “mild” one (also referred to as a mild brain injury or concussion), there is often no neurophysiological test that can confirm damage to the brain. The child is usually not hospitalized, and, if any neurological testing was done, the results are often negative or “normal”. The child and family are often told that there is “no problem” and there is no reason for further testing.

Many children have blows to the head in the course of their normal play and development. While the majority of these do not result in any lasting effects, there is evidence that a mild concussion can result in cognitive and behavioral changes. Studies have shown that multiple impacts or blows to the head, especially prior to recovery from the initial injury, can result in increased brain damage, cognitive and behavioral symptoms, and even death. Second-impact syndrome is the term used to describe this event. It can be prevented in athletes by following the appropriate return-to-play protocols under the supervision of a medical professional trained in concussion management. When cognitive and physical complaints and sometimes, behavioral changes, persist, they are a direct consequence of organic brain damage despite the “mild” degree of injury.

In most cases of a mild brain injury or concussion, children are told to rest, take medication for headaches, and return to school within a few days. Upon returning to school, they may not complain of any cognitive changes. However, they may conversely have decreased school performance and increased behavioral problems that did not exist prior to the injury. After a concussion the student may complain of headaches, dizziness, difficulty with processing language, memory problems, concentration difficulties, and poor judgment. These can affect classroom work and relationships. *Remember, if you know one child with a brain injury, you know one child with a brain injury. Every brain injury is different!*

Recovery or progress after a mild brain injury can be hindered or slowed by preexisting conditions that include: learning disabilities, personality disorders, substance abuse, impulsivity, and attention deficit disorders. These conditions are likely to alter outcomes for a student with any degree of brain injury.
**Moderate to severe brain injury**

Moderate to severe brain injuries occur less frequently than mild injuries. The child is more likely to be hospitalized following a moderate to severe injury. Inpatient and/or outpatient brain injury rehabilitation is also a possibility. If rehabilitation occurs, the brain injury rehabilitation team may help facilitate the child’s transition back to school. These children are more likely to be placed in a more restrictive environment outside the general education classroom. However, behavioral issues resulting from the brain injury may not be apparent initially, but can still appear months or even years later as the brain heals and develops.

**Anatomy of the Brain**

Some general knowledge about the anatomy of the brain can help parents and educators understand how changes and challenges in the student’s behavior relate to specific areas of the brain. Each area of the brain has specific functions, although many areas overlap. The following chart provides a summary of primary areas of the brain and how each affects cognitive, behavioral, and motor abilities.

<table>
<thead>
<tr>
<th>Region</th>
<th>Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain stem</td>
<td>Basic body functions (e.g. breathing, heart rate, sleep)</td>
</tr>
<tr>
<td>Cerebellum</td>
<td>Motor control</td>
</tr>
<tr>
<td>Mid brain (Center)</td>
<td>Transfer of information between brain regions, movement, basic drives including arousal, motivation, growth, hunger, thirst, emotional reaction, aggression, and sexual response</td>
</tr>
<tr>
<td>Posterior (Back)</td>
<td>Understanding or interpreting information</td>
</tr>
<tr>
<td>Anterior (Front)</td>
<td>Showing or expressing what one knows</td>
</tr>
<tr>
<td>Left hemisphere</td>
<td>Verbal abilities, sequential reasoning, detailed problem solving</td>
</tr>
<tr>
<td>Right hemisphere</td>
<td>Visual spatial abilities, understanding the “big picture”</td>
</tr>
<tr>
<td>Occipital lobe</td>
<td>Visual problems</td>
</tr>
<tr>
<td>Parietal lobe</td>
<td>Visual – spatial, sensory perception, awareness of deficits</td>
</tr>
<tr>
<td>Temporal lobe</td>
<td>Auditory understanding, memory and learning, receptive language and receptive nonverbal auditory input, behavior</td>
</tr>
<tr>
<td>Frontal lobe</td>
<td>Expression, attention, organization, planning, cognitive flexibility (e.g. changing plans or actions when problems arise), the ability to use feedback, and the ability to start and stop behavior</td>
</tr>
</tbody>
</table>

**What happens after a brain injury?**

The path of treatment and rehabilitation for a child with a moderate to severe brain injury usually begins with the emergency department and often moves to inpatient care at a local hospital or trauma center. This may be followed by transfer to an inpatient rehabilitation hospital and then to outpatient rehabilitation when the student finally returns home. Finally, the child may participate in home schooling, return to school for a partial day, and then transition back to a full day of school. However, not all children follow this path of services. Many return directly home from the hospital and go right back to school. In many cases, especially with mild brain injury, the child is only seen in the emergency department and is not admitted to the hospital.

For those who do go to a rehabilitation hospital, a typical day includes cognitive, speech/language, physical, and
occupational therapies, plus psychosocial support services such as counseling with a social worker or assessment by a psychologist. Some inpatient rehabilitation programs have a hospital-based school program with a special education teacher. This is sometimes the first academic experience that the child has following a brain injury and it serves as a baseline for cognitive and academic functioning.

For those children who have been hospitalized and are now living at home again, rehabilitation therapies may still be needed. Just when the child needs to take it easy, there are multiple demands to catch up in school, do homework, and attend out-patient therapies or work on a home therapy program. These children can end up having a longer day with greater demands than they did prior to their injury!

Brain injury is complex and unique. The road to recovery is a long process.

With rehabilitation and the support of family, friends and the community, many students with brain injuries are able to resume pre-injury activities. Recovery may take weeks, months, or years. Often recovery is slow and incomplete.

Factors that affect recovery include:
- Age when injured
- Time elapsed since the injury
- Length of coma, if any, and presence of post traumatic amnesia
- Personality characteristics prior to injury
- Intellectual and functional levels prior to injury
- Cause, location, and severity of injury
- Support systems
- Environment and treatment since the injury
- Overall medical health
Chapter 2

Brain Injury and Behavior

Changes in emotion, cognition, and behavior

Brain injuries may change a child’s cognition, emotions, behavior, and personality. Such changes may be subtle and evolve over time or they may be immediate, dramatic and obvious. After a period of recovery over days, weeks, or months, families and teachers may see that what appear to be minor changes in life at home or school have become more significant. At first, it may be thought that the changes are the child’s response to the trauma of the injury, part of the recovery process, or a difference in the way parents or teachers respond to the child. Or families and teachers may not associate the behavior or changes with the brain injury at all. In reality, the changes are a direct result of the injury to the child’s brain.

As a result of a brain injury, children and adolescents may undergo many changes in daily routines, life and educational skills, and relationships with friends and family members. Older children may remember how they were before their injury. Such memories may cause emotional reactions that alter their self-esteem and affect their behavior.

Certain areas of the brain, like the frontal lobes, monitor behavior and are highly susceptible to damage during a traumatic injury. As an example, a child who was easy-going, full of energy, and considerate before the injury now may appear impulsive and easily agitated. When a child sustains a brain injury, even if the frontal lobe damage is not specifically indicated on imaging tests, frontal lobe functions are often affected. The child may have difficulty with the following:

- managing anger
- temper
- starting or stopping actions
- feelings
- restlessness
- inability to stay focused or follow directions
- impulsiveness

Things that made the child happy before the injury may be over-stimulating afterwards or may be interpreted differently, resulting in disruptive or inappropriate behaviors. The child may not necessarily be “acting badly” but may be acting differently as a result of the changes the injury caused.

Behavior: What is part of typical development?

There are certain behaviors in childhood and adolescence that are considered to be a typical part of child development. As a result, parents may wonder if the behaviors they are seeing are typical or related to the injury. Below are behaviors that are typical for different age groups.

Typical behavior

- **Preschoolers**: Have difficulty controlling their emotions and temper and can occasionally exhibit acts of aggression. For example: They may not want to share their toys in class and may hit their classmate that tries to take their toy.
- **Grade School**: Can lack self-discipline and need support from adults in learning how to handle their frustration. For example: They may get frustrated with their homework and become upset.
- **Tweens**: Can be mildly oppositional and argumentative, and lack the ability to recognize long-term consequences of their actions. For example: They may refuse to do their homework and not understand the long-term consequences of not doing their homework.
- **Teens**: Can have trouble managing impulsivity, be moody, and act defiant. For example: They may skip class and talk back to their parents.
As a parent, how do you know when behavior is related to the injury or becoming problematic.
• Are you having difficulty managing your child’s emotional outburst, or are they having difficulty managing their emotional outbursts?
• Are they having difficulty managing impulses?
• Are they exhibiting behavior that does not respond to discipline?
• Is their behavior interfering with their schoolwork or school day?
• Is their behavior interfering with their social interactions with friends in or out of the classroom?
If the answer to any of these questions is yes then you should begin to seek out someone to help you identify the behaviors and determine a plan for addressing the behaviors. You know your child and family best. If it is too much to handle for anyone in the family it is time to reach out for help.

What do behaviors look like at different ages?

Very Young Children
Emily is a happy, energetic toddler who fell at age two from a shopping cart onto the floor of a supermarket. She was treated in the emergency department and sent home. The next week Emily’s mother took her to the family physician because she thought Emily might have an ear infection. She had been acting cranky, getting up all times of the night and giving the babysitter a hard time. She was difficult to console and seemed to be more impulsive than was normal for her.

Grade School
Sara is ten years old; she was adopted at age three years. Unknown to her adoptive parents, Sara had a traumatic brain injury from domestic violence by her biological father. Sara’s mother has been contacted by the child study team because Sara was having a difficult time in the fourth grade in several areas. The team met with Sara’s mother to discuss her behavior and the results of the evaluations. The classroom teacher attended the meeting and reported that Sara is often disruptive in class by calling out instead of raising her hand to answer questions. She is typically a step behind her classmates in academic discussions and, when she doesn’t have an answer or gives a wrong answer, she acts out. She gets in trouble for attempting to start conversations with her classmates and asks for very frequent bathroom breaks. While Sara is a charming child, her behavior negatively impacts her academics. She is having a particularly difficult time with math, reading comprehension, and writing.

Adolescence
Russell played soccer since before he entered kindergarten. He had several concussions over the years but always recovered within a week or two. His last concussion was just a month ago when he fell and hit the pavement while trying out his friend’s new skateboard. He didn’t tell anyone that he fell because he figured it would just go away. Russell’s mother and father came home from running errands on a Saturday afternoon just prior to the beginning of the school year to find him sleeping on the couch when he was supposed to be raking leaves. They woke him up and sent him out to do his chores.

Russell had just begun the eighth grade and receives special education in school for Attention Deficit Disorder; he has an IEP but is mainstreamed in regular classes with his peers. He is well liked in school and neighborhood and is a star player on the community’s soccer team.

Over the next month, his mother began to notice that Russell was spending an increasing amount of time sleeping and less time on his homework. He began to have a difficult time paying attention in class and his teacher contacted his mother to ask if anything was going on at home. He visited the nurse’s office with increasing frequency over the next few months complaining of headaches. His teacher contacted his mother several more times explaining that Russell was falling behind in his schoolwork and was annoying his classmates during class. By the time school recessed for the holiday break, Russell was failing two subjects and had been suspended for fighting with a classmate.

Late Adolescence
William was in a car crash when he was twelve years old. He was in the back seat of the car and wasn’t wearing a seat belt. He had a traumatic brain injury and was in an outpatient brain injury rehabilitation program for six weeks following the injury.

As he moved up to high school, he began to lose many friends. William had trouble fitting in, as
the friends he had grown up with didn’t know what to make of the changes in his behavior. He became socially isolated and eventually fell in with the wrong crowd. He began sneaking out of his house to drink and smoke pot with his new friends. As high school graduation approached he was getting in trouble in and out of school. His parents blamed that “gang” he hangs out with after school.

His grades were below average regardless of how much time his parents spent studying with him. William intended to go to the community college after high school, but his falling grades and a recent arrest were making his future look bleak. The truth was that he just couldn’t take it anymore. His parents didn’t understand how hard it was. He just wanted to belong to something. He felt different from everyone else and he was getting tired of always faking it. Faking that he understood the conversation; faking that he was only joking when he answered that stupid question in science class today. Everything had become so hard for him since he entered high school.

Growing into an injury

Changes that result from brain injury may not become evident for a long period of time, as an injury can also affect how the child’s brain develops. For example, the result of an injury to the frontal lobes may not become apparent until the child reaches adolescence, when frontal lobe functions, such as higher level reasoning and social problem-solving develop. Injury to other areas of the brain, like those that control reading and writing, may not become apparent until the child needs to use those skills in school. Because children are still developing cognitively, the brain injury may have a long-lasting impact and changes in behaviors may appear later in the child’s development.

“A child’s brain continues to develop until he or she reaches his or her early 20s... The full impact of an injury on a child’s brain becomes evident over time as the brain fails to mature in line with the child’s physical growth and development... These delayed or latent effects can create lifetime challenges for living and learning for children, their families, schools, and communities.”


Adolescence, the period between puberty and adulthood, presents many challenges for the child with or without a brain injury. During this period of growth and development, every child undergoes extensive physical, psychological, emotional, and personality changes. Additional challenges during this period can occur in the child with a brain injury. Puberty may begin early if certain areas of the brain have been affected. Hormonal changes may cause an increase in mood swings and emotionality. Damage to the frontal lobes may make it difficult for the child to manage emotions and inhibit words and actions that may be inappropriate. The child may not be able to process his or her thoughts and consider the result of his or her actions, before expressing them. Thus some young people may behave in a disinhibited way and appear to be unable to calm down and show self-control. They may engage in inappropriate touching or make inappropriate comments. This behavior, especially if accompanied by poor social skills and awareness, may make it difficult to develop positive relationships and can make the child vulnerable to social isolation. It may also lead to peer rejection or unwarranted punishment at school. The presence of brain injury makes the challenges of adolescence even more demanding.

Behavior as Communication

Sustaining a brain injury can change how someone receives, understands, and expresses information. Behavior is a mode of communication, just like spoken and written language. Changes can occur right after a brain injury or develop over time as a child or adolescent “grows into deficits” sustained from the injury. If the behaviors are inappropriate, they can interfere with a child’s or adolescent’s daily life.

Behaviors that can appear include angry outbursts, acts of aggression, and destructiveness. Behaviors can also represent emotions such as confusion, frustration, withdrawal, fear, anger, depression, anxiety, and grief. These behaviors are distressing both to experience and to witness. They disrupt the child’s family and social relationships. Children and adolescents with brain injury and those closest to them may feel helpless in controlling unfamiliar distressing behaviors and initial efforts to stop them may not work. There may
be confusion as to why the behaviors are happening, what to do about them, and how long the behaviors will last. Sometimes behaviors occur at predictable times; for example, they may occur every day before school. Other times, the behaviors seem to happen for no obvious reason. One of the most frightening aspects of behavior changes for the child and family is the perception of loss of control. However, there are many types of interventions that can be used to manage negative behaviors and these are discussed next.

There are many reasons why behaviors change after a brain injury. A first step is to look at how others view the behavior. Initially assuming the behavior is willful, stemming from a lack of respect, or from a loss of love for family members can lead to increased anger among everyone involved. This is often how children and teens with brain injury are characterized, especially if there are no obvious physical signs of the injury. This view can be counterproductive, particularly with children and adolescents who may act out more in response to the perception of being treated unfairly.

Instead, behaviors should be seen as a signal that a person’s brain is not sending accurate messages about appropriate responses to a situation or emotion. This perspective leads to objective assessments of what triggers the behavior and how to manage it. By approaching negative behavior in a therapeutic way, the focus can be on helping the child develop new skills to compensate for changes in brain functions.

How cognition affects behavior

Some behaviors can interfere or make it difficult for the child to do expected tasks or responsibilities. What happens before (precipitant) a negative behavior occurs can be related to changes in how the child or adolescent with a brain injury thinks and learns (cognition). Changes in the child’s ability to self-monitor or regulate emotions can lead to outbursts, disinhibition, withdrawal, and perseveration (repetition). Physical impairments can include hemiparesis (one sided weakness) and other limitations in fine and gross motor functioning or movements. These can restrict a child or adolescent’s functional independence and can lead to feelings of fear, vulnerability, frustration, and loss. Challenging or stimulating environments such as too much noise, actions, or light can also trigger inappropriate disruptive behavior.

Families may be puzzled when negative behaviors arise after their child returns home from the hospital. This is especially true given the common perception that recovery will rapidly once the hospital stay has ended. The return home actually presents a dramatic change from the adapted physical environment and structure that was present in the hospital or rehabilitation program. Often families don’t feel and witness the full impact of the child’s cognitive, behavioral, and emotional changes until the child returns home and reenters the community where things are much less structured. Other changes that families may see after the child comes home are tantrums and acting out behaviors, particularly in younger children who have not developed sophisticated coping skills yet. These may be related to the child’s inability or difficulty expressing or coping with overwhelming emotions. Grief can envelop an entire family, not just the child or adolescent with a brain injury.

It can be enormously frustrating for a child or adolescent with a brain injury to be confronted with the inability to act and do everything that was second nature prior to the injury at home and in school. Family and friends may not have learned how to readjust their behaviors and routines to the child’s needs. This may lead to the child feeling neglected and lonely. It is not just the child or adolescent who needs to change and learn after a brain injury, but those who interact with the child need to change as well. It is difficult work for everyone involved to suddenly have to change how they speak and act in relation to the child’s post-injury needs.

How different life is after brain injury becomes clear when the child returns to a familiar environment. Students who previously functioned well in school may now become aware of how much harder it is to do the same work. Peer social groups may shift in their absence while hospitalized. Adolescents with increased independence who hold a job or drive may feel infantilized or experience a profound change in perception of identity if they are no longer able to do so. Conversely, moving into an unfamiliar setting such as a new classroom is harder after a brain injury and can also trigger incidents of inappropriate behavior. Taking the time to understand how daily living has changed after the brain injury, what coping skills a child and family need to develop, and what supports can be added are some of the first steps to managing behavior changes after brain injury.
Chapter 3
Brain Injury and Families

Adjustment to Brain Injury

Brain injury often happens in an instant, but affects a family for a lifetime. Just as each brain injury is unique, the impact it has on the family will be unique for each individual within that family. Adjusting to the injury will occur in each family member’s own time and own way. Most families and individuals go through stages that are similar to the stages of grief experienced following a loss. They often grieve the life they had prior to the injury, and the person their family member was before the injury, including all the hopes and dreams they had for their loved one prior to the injury.

Stages of grief

- Denial: After the initial injury, many family members deny the long-term effects of the injury. Denial can often be a healthy coping mechanism to allow family members to get through the initial trauma they feel after the injury. Family members may say, “My child will be fine and fully recover. The doctors don’t know what they are talking about. They don’t know my son (or my daughter).” Denial only becomes a problem when a family member, or the person with the injury, does not move on from this stage and refuses to acknowledge or get help for the consequences of the injury.
- Anger & Frustration: After the initial stage of denial, many family members feel justifiably angry and frustrated that this has happened to their child and their family. The anger can be directed at doctors, family, friends, and even at oneself. Family members may say, “No one is helpful. I can’t get a straight answer from the doctor.” Again, anger and frustration are healthy, as long as the family member, or the person with the injury, moves on from this stage.
- Depression & Withdrawal: This is a very difficult and painful stage of recovery for all family members as they move towards accepting the long-term effects of the injury. This stage can be extremely painful for family members as well as the individual and can include restlessness, sleep disturbances, lack of appetite, difficulty concentrating, trouble making decisions, and trouble remembering things. Family members may say “What’s the use? Nothing will ever be the same again.” Again, this a healthy stage, as long as the family member, or person with the injury, moves out of this stage.
- Acceptance: As time passes, individuals and families can come to accept the changes that have taken place. Nothing can make life as it was before, but life can be new and worthwhile. It is important to remember that the timing of this stage may vary for each person in the family and members may not be on the same timeline. For example, a mother may get to this stage long before a father reaches this stage, or vice versa. In addition, acceptance may not always be the end of grief. Family members can move back into grief during stages of transition or important milestones; for example, when their child should be going to college, or getting married, or learning to drive, but is not. While acceptance is the final stage, it is not uncommon for family members to experience grief stages again after coming to acceptance of the injury.

How families adjust to brain injury when it occurs in childhood

Brain injury can happen at any point throughout the lifespan and, just as each injury is unique, it will affect each family differently depending on the age of the child. Unlike that of an adult, a child’s brain continues developing into his or her early twenties. Any injury to the brain can disrupt this brain development.

For those children injured before school age, there are significant concerns about how they will acquire new learning. Research has shown that information that has been previously learned often remains accessible to a child after a brain injury; however, acquiring new learning can be much more difficult. For a young child who has not yet entered elementary school, basic reading and math skills have not been fully developed, even if the child is in preschool. An injury during this stage can negatively impact school performance in all subject areas. Likewise, preschool aged children are also learning self-regulation and how to control their behavior in response to rules set by adults and peers. Preschoolers do not have abstract language to describe emotions, and this combined with other effects of the brain injury, can lead to behavioral problems. Yet, for parents the hope is often that the child will “grow out” of the injury.
The concept of “plasticity” may be construed as complete cure. What seem to be opposing messages—“your child will grow into his or her deficit”, and the brain is “plastic” or capable of compensating for deficits—may be confusing to parents. Denial about the effects of a brain injury or conversely, being vigilant for information or actively seeking resources can be a singular focus for some parents. However, these views frequently co-exist in families at different phases of time and among different family members at the same time they are dealing with the stages of grief.

In families with young children, twenty-four hour care is the norm. For families with a child with a brain injury, people outside the family may not realize that more support is necessary for both child and parents. Family members may become isolated from their communities as they try to adapt to the effects of a child’s injury. Sometimes, a family may withdraw from participating in social events for fear that others will not understand their child’s situation. For siblings, community isolation and the increased attention to the child with a brain injury can reinforce feelings of sadness, grief, and anger. A sibling can develop behavioral issues or feel pressure to be a “perfect child” in response to the family’s struggle to adjust to a brother’s or sister’s brain injury. Alternatively, siblings may also develop behavioral problems in response to the additional attention received by a brother or sister with a brain injury. Parents may also find themselves dealing with “dueling” behavioral outbursts between siblings as a way to gain attention and seek security.

Adapting to the effects of a brain injury also means that families may need to be aware of maintaining age-appropriate roles and finding ways to tend to all members of the family. The flow of attention in a family typically circles around the family member who is injured and most needy, but this can lead to others feeling drained and stressed. This increased stress and exhaustion can trigger behavioral issues in the young child with a brain injury as family members may be less consistent in setting behavioral limits, or the child may mirror the emotions of other family members.

Part of the positive adaptation process is for parents and siblings to learn that it remains okay, even when the child with a brain injury is very young, to take care of themselves. Parents and siblings may feel guilty about thinking of themselves, feeling they are being selfish. However, if a family is to persevere through difficult times, the feelings and needs of each person in the family need to be recognized, no matter what their age or relationship. This means allowing family members to express emotions such as frustration or anger and to express their needs openly and to have support. Learning to maintain a balance between the needs of the family and the needs of the child with a brain injury is an ongoing process. It can change as the child grows and it can also change as family members have new responsibilities and expectations in their lives.

For those injured after the school years have begun, families are thrust into a potentially new system of special education services. Students who were once able to function independently in the classroom may now be considering alternative settings. Words and phrases such as Individualized Education Plan (IEP), Section 504, special education, accommodations, and child study team (CST) may be new. Learning new timelines and processes for getting services can provide an additional strain on already taxed family resources. Families and schools often struggle to understand the new needs of students with brain injuries. Parents are pressured to advocate for their children just as they are in the middle of the grieving process.

School districts can help families by understanding the grieving process and the additional strain that has been placed on family systems. Helping parents walk through the special education maze by informing them of their rights to appropriate education, timelines for evaluations, plan developments, review meetings, and options for educational accommodations and placements can ease the burden. A family should request this information when informing the school of their child’s injury.

The Brain Injury Alliance of New Jersey developed two free guides for families.

*Brain Injury: A Guide for Families About School* helps families understand how to navigate the education system following a child’s brain injury. *Brain Injury: A Guide for Educators* helps educators and school personnel understand the needs of students with a brain injury. You can request free copies of both guides at [info@bianj.org](mailto:info@bianj.org) or download electronic copies at [www.bianj.org](http://www.bianj.org).
In addition to learning about a new educational system, families may also find that new strategies are needed for their child to learn and function in school. There may be gaps in the child's knowledge of previously learned material. The child may struggle to complete tasks that require skills such as planning and organizing information and materials, initiating assignments, completing assignments on time, or note taking. The child may have difficulty demonstrating and retaining knowledge. It can be a challenge for families and schools to recognize the need for compensatory and remediation strategies and to develop and implement these strategies. A neuropsychological assessment and/or a cognitive rehabilitation consultation can help guide appropriate school placement and programming. Continued consultation and evaluation of a student’s educational plan is also recommended.

Remember, educational plans are fluid documents that need to be evaluated and modified as the needs and abilities of the student change and as the recovery process progresses.

How families adjust to brain injury when it occurs in adolescence

For those injured during adolescence, the injury comes at a time when most families and adolescents are adjusting to the many changes that come during adolescence and are preparing for the transition to adulthood. Adolescence can be a very tumultuous time for any adolescent and parents, as the adolescent begins to assert independence, has changes in behavior and emotions, learns to drive, plans for college, or makes other plans for after high school. The adolescent with a brain injury faces even more stressful and complex changes. The injury may occur when the child is still adjusting to the transition to high school or it may occur close to or following graduation just as preparations are underway for moving on and away from family. Adjusting to the injury is never easy for the family, but certain transition points can make the experience more difficult. For example, a family may find it more difficult when adjusting to the injury, during the transition to high school, and during the transition to special education services, or when faced with the pressure from the school to graduate their child with the rest of their class even though he or she might benefit from further schooling up to age 21.

Family Dynamics & Adjustment to Brain Injury

Existing family dynamics also affect how each family and each family member will respond to an injury and ultimately adjust to the changes the injury brings. Family dynamics can involve:

- the roles that family members play (for example, one family member might carry more responsibilities than others);
- how they communicate with one another, or if they communicate with one another;
- how they deal with conflict (working together, avoiding conflict, coping through substance abuse);
- how parenting is handled in the family and who is responsible for parenting; and
- how stable or unstable the family is.

However, even in the most stable family, adjustment can be a difficult process that is uniquely experienced by each member of the family.

How family dynamics affect how families address behavior

Dealing with changes in behaviors can be difficult and challenging for any family. Each family has patterns and responses that will affect how behaviors are managed in the home, in social situations, and between family members. One family may be struggling with how to stop the child with a brain injury from interrupting conversations; another family may be dealing with a child who becomes enraged and physically challenges siblings. There may be a long list of difficult behaviors by the child and the family may find it impossible to address all of them at the same time.

It is helpful for a family to discuss what behavior is the most troubling and then decide how to work on improving that behavior. It is important to agree on how each family member will respond when the behavior occurs. Only in the perfect family will family members never give in to the behavior, never ignore the behavior, and never escalate or challenge the behavior being addressed.
Siblings

Brothers and sisters come in all sizes and ages. Each has a unique relationship with the child with a brain injury. Regardless of these differences, each sibling will grieve, feel extraordinary pain, and above all want things to go back to “normal”. In the midst of coping with changing dynamics in the family, siblings are trying to deal with their own emotions which are often conflicting. Simultaneously there is love for their brother or sister who has been injured, anger that this injury has happened, frustration that recovery is taking so long, and fear of what the future holds for them and their sibling. Younger children will have difficulty expressing these emotions; older children may express them loud and often! Some siblings experience “survivor guilt” or a sense of responsibility because they could not protect their sibling from this injury.

Parents, understandably, are often so focused on recovery of the injured child and caring for their needs that other children in the family are initially taking second place – and feeling it. Siblings have a need to understand what has happened and have their questions answered in a timely and age appropriate manner. They also need to be protected from behavior that is aggressive or harmful, verbally or physically. Parents’ resources are extraordinarily stretched in terms of time, patience, and energy. It is very difficult to find the few minutes each day to focus on others in the family, yet, a few minutes each day that parents spend with siblings is critical for them to feel safe, secure, and cared for. It may be necessary for parents to schedule individual time to spend with each of the other children, one at a time.

Extended Family

Although almost everyone knows of someone with a brain injury or has met someone with a brain injury, it is difficult to understand the effect that brain injury has on a family unless they have personally experienced it especially when it is a child who is injured. Even in the most supportive families, most relatives expect that this is a crisis that will pass in time. There is an abundance of information about brain injury on the internet and the Brain Injury Alliance of New Jersey has a library full of books and information that extended family members can use.

Sometimes relatives are too far away to help with the physical demands; however, they can probably help with research and communication chores. If they cannot help with things directly related to the brain injury they may be able to help with the routine things like paying bills or communicating with insurance companies. Relatives who are geographically closer can assist with shopping chores, transportation to siblings’ activities like sports and birthday parties. Family dynamics change for the extended family also. Often parents find support from an extended family member that they might never have expected. Often one of the most difficult challenges for parents is to ask for help. It takes planning and practice to determine what to ask for and who to ask; it also means being prepared for someone saying “no” and not taking the refusal personally.

Sometimes there is no extended family or the extended family has made it clear that this crisis is not their problem. Parents often become resourceful and develop new relationships with those who show an interest in helping such as church acquaintances and neighbors. These individuals became like family over time.

Extended families can add even more stress when their expectations are based on misinformation or lack of it, yet they still offer opinions about the family dynamic or how to “discipline” the child with a brain injury. They may be focused on obvious or physical improvements and not understand the full consequences of the injury or the fact that it is life altering for everyone in the family. Ultimately families adjusting to brain injury will determine how to best find the help and support they need whether it is from relatives near and far or “new” relatives who respond to their needs with kindness, energy and support.
You Know Your Child Best

When a child has a brain injury, there will be a lifetime of changes and challenges to consider. Because the brain is still developing in your child, the effects of the injury may not be evident until your child is older and has difficulty performing more advanced tasks. As parents you know your child best and can use your knowledge to drive the services and supports that will maximize the outcomes as your child grows and develops.

The best way to become an advocate for your child is to be informed. Meetings and appointments regarding your child can bring about uncertainty and anxiety, particularly when you are unfamiliar with the system and process. For example, an initial evaluation with the child study team or a neuropsychologist can be intimidating. Getting information about what to expect in advance can help reduce your fear and uncertainty. It can also be helpful to bring an objective third party with you, whether it is an advocate, a family friend, or a family member. Preparing a list of questions in advance is usually helpful and do not be afraid to ask for explanations of things you are unsure about. After steps for your child’s program have been put into place, it is important for parents to go back and review how things are going to ensure that the agreed-upon plan is resulting in the desired outcomes.

Questions to Ask

While it is difficult to determine the extent of a child’s rehabilitation needs over time, securing the services to maximize long-term rehabilitation is essential. There are many questions that family members can ask that will guide the process from diagnosis and initial treatment through discharge and return to home, school, and community. Actively participating in treatment team meetings in the hospital or rehabilitation program will help parents make decisions about a child’s care and lay the groundwork for seeking supports when the child returns to school and community activities.

Below are some sample questions to ask the treatment team. However, there might be additional questions to consider, depending on the needs of the child and family.

1. Will my child need any in-home services?
2. Will my child need any specific medical equipment? If so, where can I get it?
3. Will my home need to be changed or modified in any way?
4. What kind of special accommodations might my child need upon returning home and to the community?
5. Are there any support groups or other resources that I should be aware of?
6. Are there any resources for caregivers or family members?
7. Will my child need to be on any special medication?
8. Who will communicate my child’s needs to the school or community?
9. What follow up care should I expect? How often should my child get a check-up?
10. Will my child need to see a specialist? If so, what kind and how often?
11. What problems should I be looking for?
12. Who should I call if problems arise?
13. Should my child be working on anything specific at home to help rehabilitation?
14. Are there any financial resources for my family?
It is important to ask for everything in writing. A lot of information is usually given at once and it is most helpful to have everything on paper to read and review later.

Discharge planning and behavioral issues

The most important point to remember is that you should have every question answered in clear and understandable language. Each member of the treatment team should be able to explain his or her role in the treatment process and how they work with other members of the team. Parents should be given an explanation of how the injury may affect the child’s ability to learn and process information, feel emotion, and behave. They should be encouraged to seek as much information as needed to work effectively with the staff who is caring for their child. Doctors and therapists should provide information on the child’s progress; parents should ask how that relates to “what’s next” in the process. The social worker or discharge planner is a key resource for community services, insurance and financial concerns, and family support services. Parents should keep notes on the information received and feel comfortable in referring to these as the child progresses through treatment or an educational program.

Whether the child receives services as an inpatient or is sent directly home from the emergency department, it is essential for parents to request medical records that identify the brain injury, outline treatment received, and explain the child’s status and needs. Medical records will support the request for appropriate services in the school setting and provide the basic information needed to guide future services. Parents should also look for resources for advocacy and information on their child's behalf should they require additional support and help in securing services in the future.

The Brain Injury Alliance of New Jersey maintains a Helpline to assist those affected by brain injury, as well as those assisting them. If you have questions or don’t know where to turn for help, contact the Helpline at 1-800-669-4323, 732-745-0200, or info@bianj.org.
Chapter 5
Managing Behavior at School & Home

Parents and teachers manage behavioral issues continually at home and in school. When a brain injury has affected behavior in a negative manner, it can disrupt home and school life for everyone. Managing difficult behaviors is not a perfect science; there isn’t a lesson plan to follow or a book telling teachers and parents exactly what to do and how to do it. The school setting provides structure and has staff to evaluate and manage behaviors therapeutically. However, there needs to be continuity among all individuals in the child’s life in order to improve behavior. This means that schools, clinicians, and parents need to communicate with each other on a regular basis. This continual communication is important to effectively track changes in a child’s behavior patterns over time. In cases where a child has had rehabilitation services, it is most likely that several (if not numerous) assessments and evaluations have been performed. The information in these reports is invaluable to parents and school staff to better understand the consequences of the brain injury and to provide insights into behavioral issues.

Neuropsychology, Cognitive Rehabilitation, and Behavior
A complete neuropsychological evaluation assesses strengths and weaknesses of a child’s cognitive functioning or how the child thinks and learns. This includes assessing attention, memory, visual and language processing, and executive functioning. A child’s inappropriate behaviors or acting out may be related to cognitive impairments. The neuropsychologist may be able to provide insight into triggers for certain behaviors, how the child perceives the behavior, and what strategies would be most helpful. Neuropsychologists also oversee and can provide cognitive rehabilitation.

Cognitive rehabilitation focuses on the recovery of cognitive impairments and the development of compensatory strategies. Appropriate strategies can help a child feel positive and competent, gain a degree of independence, lessen frustration and perhaps decrease the probability of challenging behaviors. Younger children are more likely to accept strategies while middle school and high school age children often have a more difficult time because they are very aware of the nuances that make them appear different to their peers.

Addressing Behavioral Challenges at School
Within the public school setting there can be multiple levels of intervention to address behavioral challenges. The consequences of inappropriate behavior in school can be social, academic, and may even affect placement. If severe behavioral acting-out occurs in school, students may be suspended unless the behavior is related to the student’s disability. When a child is displaying behavioral issues in school the school may take different steps depending upon the situation. Initially, the school may reach out to the parent regarding the behaviors. The parent and teacher may discuss the behaviors and establish a plan for addressing the behaviors, or the teacher may involve the school psychologist to assist in addressing the behaviors.

However, if initial attempts to address the behavior do not work there are other options. For children without an Individualized Education Program (IEP) or Section 504 Plan in place, the school may refer to I&RS (Intervention & Referral Services) to determine accommodations and modifications, and reconvene if they are not working within 30 days. For children with an IEP or Section 504 in place a Functional Behavioral Assessment (FBA) may be the next step in addressing behavior. The FBA is typically conducted within the school by one of the child study team members. The school may also choose to bring in an outside professional to conduct the assessment, such as a Board Certified Behavior Analyst. The purpose of the FBA is to determine what triggers negative behavior. It is also used to determine what motivates the student to continue the undesirable behaviors. An FBA can only be conducted in the environment where the negative behavior occurs with the purpose of using strategies to resolve the behavioral issues. It is a process which records events over time, so the results of this assessment will not be available immediately upon the child’s
return to school. It may also take a little time to determine which behaviors will remain problematic, as some behaviors will resolve or go away on their own. For negative behaviors which seem resistant to self-correction or mild intervention from the teacher, an FBA may be necessary. Sample FBAs are provided in the Appendix.

An FBA will typically take from 4-8 hours of direct observation, and should be conducted across settings, including small and large settings (classroom, assembly), structured and unstructured settings (classroom, playground). The FBA considers conditions that may contribute to the onset of negative behaviors by looking at reports about when, where, and how often the behavior occurs. With this information, a plan is created to address the conditions in order to minimize the undesirable behavior and replace it with more appropriate behavior. In other words, identifying the “triggers”, or antecedents to a behavior is the key to changing the behavior. The FBA should also involve a team approach, including feedback from the treating neuropsychologist. While the FBA will identify triggers it may not identify behavior caused by the brain injury, which the neuropsychologist can provide input on.

If you know that your child is having behavioral issues at school, ask your school about conducting an FBA that can clearly track the behaviors and provide clear recommendations to address the behavior. Once an FBA is completed, set up a meeting with the school to go over the results. Request all members involved with your child attend the meeting to give their input, or put in writing, what role they will play in helping your child succeed. It is also important to have a contact person identified who you can communicate with any time. Typically, one of the Child Study Team members, if your child has an IEP, will serve as the case manager and will be assigned as your contact person but another staff member may be chosen, such as the school nurse, school social worker, a teacher, or counselor.

All recommendations need to be clear and concise. A time line and re-evaluation requirements should be included. In other words, you need to understand what the recommendations are and what will happen if the recommendations are not successful. It is also essential to include what you, the parent, can do at home to support the strategies being used in school. You may want a separate meeting to discuss home-based issues so the proper time can be devoted to helping you devise an appropriate plan for home use. By knowing these procedures ahead of time, you can better advocate for your child and share responsibilities for the plan’s success, with school personnel.

Behavioral Interventions

There are a number of psychological issues that can develop after a brain injury. These may include an inability to control anger, mood swings, depression, low motivation, low self-esteem, lack of self-awareness, lack of awareness of deficits, and anxiety. Therapies which may be helpful include cognitive-behavioral therapy, anger management, supportive counseling, play therapy, and support group activities focusing upon coping, mastery and resilience.

Mastery describes an individual’s perception of having competence and a sense of control in a situation or environment. Having a sense of mastery decreases feelings of distress and can increase appropriate actions or behaviors by a child or adolescent.

Coping refers to how a person may approach a stressful situation and what strategies may be used to manage that situation. Coping strategies can be positive, such as seeking information, asking for help or, they can be
negative like avoiding necessary tasks or acting-out. Teaching children additional positive coping skills after a brain injury can help both prevent and lessen the psychological impact of a brain injury.

*Resilience* is the ability to “bounce” back after a setback. It is the ability to rely on internal resources to buffer the negative impact of thoughts, feelings or events. Coping and mastery enhance resilience, and resilience promotes mastery.

Psychological support can come from different specialists. In the educational setting, it may be either a school social worker or school psychologist. Outside of school, it may be a neuropsychologist, clinical psychologist, licensed counselor, or clinical social worker. While it is not possible to solve future behavior problems before they start, children and teens with brain injury can be taught to problem-solve.

Resilience can be fostered. Past studies of children described as resilient found the following significant factors: children were able to seek help, they had stable resources to obtain support, and they had the opportunity to help others (sense of mastery). The concept of resilience emphasizes that each child or adolescent exists in a system of people important to them. Those in the circle of contacts can respond to help maintain the child’s behavior or to improve it. Interventions designed to help children and teens increase self-awareness of their needs, learn self-advocacy, develop problem-solving strategies, and build confidence in interacting with others can be incorporated into school, home and work settings. These strategies should be updated as the youngster with a brain injury grows and they must be continually taught and reinforced to become part of daily life. In this way, children and adolescents with a brain injury have a template for dealing with future challenges and a means for changing behavior positively.

**What to Expect From Your School**

If your child has an IEP you should expect to have someone in the school serve as your child’s case manager. This person is responsible for pulling together the findings of all the above mentioned evaluations into a coherent summary. The narrative may include the history surrounding the brain injury, a brief review of the conclusions and suggestions from each evaluation, prior course of interventions, and any other pertinent information. Keep in mind that evaluations performed outside of the school need to be included.

A summary and recommendations should be seen as a dynamic document, updated on a regular basis, and reflecting changes in the child’s improvement and types of interventions. Parents may enlist the help of outside specialists, including neuropsychologists, case managers, advocates, etc. Those outside specialists may be able to help put the information together, attend school meetings and make additional recommendations.

Therapeutic management at its most effective is proactive; it looks ahead. The assessment and rehabilitation phases are good times to anticipate what may at first be the most difficult adjustment issues for a child or adolescent after a brain injury. Routinely, if the child is school age, neurocognitive testing and child study team evaluations can pave the way to maximize success in school re-entry and help develop skills to handle challenges. However, not every possible scenario can be envisioned or anticipated in advance. In fact, we can overwhelm and exhaust students by trying to teach them too many strategies to compensate for a brain injury. Therapy fatigue may also lead to inappropriate behaviors as children and adolescents just want to be like their non-injured peers.

**Examples:** Andrew is a 10th grader with receptive language delays due to his brain injury during the summer prior to entering 10th grade. He has had a difficult time handing in classwork and homework on time. As a result, his grades have suffered and his frustration shows up as a meltdown at home. Andrew’s mother
contacted the teacher explaining that Andrew was having difficulty understanding the assignment’s instructions. The teacher was grateful for the call because he thought Andrew was simply acting out. Together the mom and teacher decided to meet with Andrew’s case manager and the speech therapist at school and brainstorm ways to support Andrew. Andrew’s evaluations were reviewed and strategies were developed to address the issue. They decided that instructions would be written down for Andrew in precise steps that would be easy for him to follow. The classwork and homework assignments would be given to Andrew in advance so he could prepare at home prior to class. The speech therapist would focus speech sessions on breaking directions into manageable parts with the goal of having Andrew learn to do this independently over time. This arrangement was meant to build Andrew’s confidence in class and minimize his frustration. Andrew, his case manager, teacher, speech therapist and mom scheduled a meeting in one month to determine if the new strategies were working. Had this situation not been addressed, Andrew’s frustration could have deepened, leading to withdrawal or more intense acting out.

**Addressing Behavioral Challenges At Home**

The daily routine and the formal structure of the school day usually are not found outside of school; therefore, difficult behaviors that parents see at home may not be observed in school. Managing household chores, self-care, and interaction with family members can be at least as difficult as the demands of school and usually are more emotionally charged. Expressions of frustration, anger, and grief can build up and ultimately release in loss of control for any family member. Fatigue can also be a factor as children with brain injury are often working so hard to navigate through the school day that they are too tired to maintain control at home. Home is not supposed to be like school. Managing behavioral challenges at home must focus on what can realistically be accomplished in the home environment with cooperation from the entire family.

Key components to managing challenging behaviors at home:

1. **Prioritize the behaviors**

   Prioritize the behaviors, focusing on the most challenging first. Each family member may have a different idea of what is the most challenging behavior. Sometimes it is best to have the whole family meet and discuss behavioral issues, depending on the age of siblings and family dynamics. Parents need to decide how to best determine which behavior to work on first. When there are multiple difficult behaviors, mom and dad may decide that they will be the only ones in the family to address certain behaviors and will instruct siblings on how to respond when they see these behaviors. It can be helpful for parents to meet with each sibling separately to get a clear understanding of what their concerns and struggles regarding any behaviors caused by the brain injury.

   **Example:** Each morning Max throws his clothes on the floor instead of getting dressed resulting in everyone being late for school and work. Inevitably Max’s mom helps him get dressed in order to get everyone to school and work on time. This routine causes anxiety for Max’s siblings and his mother. Breakfast is disturbed and interrupted when Max’s mom needs to help him get dressed. Max, his mom, and siblings all get to school or work feeling upset and frustrated. Max’s mom would like to have Max dress himself and join his brothers and sisters for breakfast.

   There can be multiple reasons for specific behaviors. In the example above, Max could be frustrated because of difficulty with fine motor skills which make buttoning and zipping hard. Max could be deliberately delaying dressing in order to miss the bus so that mom will drive him to school. Or Max could be angry because of difficulties in school. The target behavior in this example is Max throwing his clothes instead of getting dressed. The objective is to decrease throwing clothes with the ultimate goal of having Max dress himself and join his siblings for breakfast before school.
Max’s mom and dad discussed how to help Max become more independent in the morning by dressing himself. They decided that dad would pitch in by setting the table for breakfast before he left for work to minimize mom’s time in the kitchen in the morning. Max’s mom and dad knew Max dressed independently for bed so they thought there might be other contributing factors to his morning behavior. In reviewing his reports from rehabilitation, they recalled that Max has some issues with over stimulation and fine motor skills. They realized that there was a great deal of activity going on as everyone tried to prepare for the day and decided that instead of telling Max to get dressed, mom would help him before beginning breakfast. This way she could observe whether or not he had any difficulty with his clothing and also gather more information about the effects of the activity level in the house during this time.

2. Make the plan fit the abilities
It is important to develop a plan that fits the abilities of the youngster with a brain injury. Parents are most likely aware of the tasks their child can accomplish with relative ease and others that are more problematic. It is important to understand both the physical demands of a task and the cognitive demands.

Example: The first morning of the new plan, Max was dressed and at the breakfast table on time with his mother’s support and help. To accomplish this, Max’s mom asked him to brush his teeth before getting dressed, then she closed the door to his room to minimize distractions and gave cues when it seemed that Max needed them. She learned that although Max could button and zip his clothes, he struggled depending on which the article of clothing and asked for help with certain kinds of buttons. She also observed that he seemed to get confused about which articles of clothing to put on first.

After school that day, Max and his mom talked about how to make the morning easier for him. They decided that they would make a list of what Max needed to do before going to the breakfast table. By putting his clothes on in the same order each day, it minimized the cognitive attention needed and helped him routinely dress himself. Max’s mom stayed in his room at first to provide cues and then moved outside his door as Max needed less help. Max and his mom also went shopping to purchase the particular type of jeans that are easiest for him to button.

3. Use professional support
Parents may need help determining the triggers for behaviors or thinking of strategies to address certain behavioral issues. They may have tried a variety of ways to address a specific behavior with little or no progress. Clinical and academic reports may be helpful; however, it may be necessary to consult a professional for assistance and support. Consultation with the school’s case manager can help identify resources. In cases where a child has had extensive rehabilitation, clinicians who worked with the child usually can provide some feedback and suggestions. These professionals are often open to a phone call to answer questions or provide suggestions. Family counseling may also be helpful as the entire family copes with changing roles and routines.

Max: Max’s mom had contacted the school’s case manager and requested a meeting with the Child Study Team. She learned that the speech therapist has been working with Max on sequencing his academic tasks which could also work with his dressing challenges. She also requested that the school psychologist see Max to provide some extra support during school.

Bringing a Therapeutic Team Home
Within school or rehabilitation settings, teams of professionals knowledgeable about age-appropriate interventions for behavioral challenges are routinely in place. This is not the case at home, so parents or caregivers must assemble their own teams when behavioral problems are so intense that the family is unable to manage them. Some behavior management plans used effectively in school may not be transferrable to home given the differences in routines and family responsibilities. Home needs to feel like home for all family members, so interventions need to fit the family setting.

Outpatient therapies to address behavioral problems can be obtained from brain injury rehabilitation
programs or from licensed therapists such as neuropsychologists, neuropsychiatrists, behavioral neurologists, psychologists, social workers, and licensed professional counselors. Some brain injury rehabilitation programs offer in-home services that include multiple types of therapies to address the numerous factors that may contribute to behavioral challenges at home. For some children with severe behavioral problems, in-home services can be effective and help the child and family members learn to use interventions where and when they occur.

When children with brain injury engage in high-risk or destructive behaviors that could imperil their ability to remain at home, parents or school personnel may find outside services specifically designed for these times.

Medications for Challenging Behaviors

Medications can sometimes be used or recommended to help manage behaviors following a brain injury. It is critical for families to be aware of the potential side effects of medications, as well as interactions with other medications they may be taking. It is a good idea to also share this information with key school personnel, such as the teachers and school nurse. While there is a stigma associated with medications, particularly with children and adolescents, behavior that is unmanageable, even with interventions, may become manageable with medication. Don’t be afraid to talk to your child’s doctor about medications.

Monitoring for High Risk or Suicidal Behaviors

As children move into adolescence and young adulthood in general, the possibility that they will engage in suicidal thoughts or actions increases. During this period, the brain’s executive functioning system is still developing and the adolescent’s emotions can be intense. The ability to imagine the future, understand consequences of one’s actions, and to spontaneously problem-solve also develop during this time. Peer influence takes precedence over that of parents, which can lead an adolescent to feel isolated from those peers whose executive functioning abilities are not impaired and who have experience surviving the stresses of youth. Add the cognitive impairments and psychological impact of a brain injury to these factors and the concern for both suicide and potentially harmful high-risk behaviors is intensified.

A brain injury can affect a child or adolescent and the family throughout the life, as the individual grows and faces new challenges. While much that is positive can occur, a teen or young adult can also be frustrated by the increasing demands for independence and expanded social roles. At the same time, the teen is trying to build an identity and self image as a competent person. Some of the suicide risk factors consistent with brain injury are: medical issues, mental health problems, impulsivity, poor self-control, hopelessness, and recent losses. Some of the stresses that are especially relevant for adolescents and young adults with brain injury are: emotional stress, loss of support systems, change of roles within the family, and decreased ability to function within social relationships.

Behaviors that are described as “high-risk” are not necessarily actively suicidal behaviors, but still can result in injury or death. High-risk behaviors include substance abuse, impulsivity, lack of caution, defiance, self-destructive and destructive acts, and the perception of invincibility that leads to potentially self-destructive behaviors. Teens and young adults may abuse substances for multiple reasons such as needing to fit in with peers, self-medicating depression or anxiety, or avoidance of situations that they feel they cannot manage. These behaviors are not limited to individuals with brain injury, but as with suicidal risk factors, they can coincide with other behaviors.

It is imperative that an adolescent who has had a brain injury and shows signs of suicidal or high-risk behaviors be referred for an appropriate assessment by a mental health professional as soon as possible. Waiting can be dangerous, particularly if someone is impulsive or is acting out. If the adolescent or young adult already has a psychotherapist, this person can either perform the assessment or make a referral to a mental health facility or emergency services. If behaviors arise in school that indicate suicidal thoughts or risks, the school psychologist,
social worker, or counselor can initiate a referral for assessment by a certified screener. This can be done either by contacting the mobile crisis unit or contacting emergency services and having the student transported to the nearest hospital emergency department.

Even if the assessment finds that the individual is not at immediate risk to harm self or others, the assessment can be helpful by recommending additional psychological support services for the child or youth, family, and school personnel.
Chapter 6
When Crises Happen—Getting Help

Previous sections of this booklet reviewed how to plan ahead to help your child and family; however, sometimes crises occur. This section helps you recognize a behavioral crisis and find resources in the mental health system and community.

Preparing for a Crisis

A crisis can happen unexpectedly or it can be the result of stress slowly building up in your child’s life. For example, a child’s transition from high school to college or from school to employment is often stressful and can lead to a crisis sooner or later. Sometimes it may not be evident to others just how much stress the child is dealing with as “putting up a good front” is often an attempt to hide feelings of depression, anxiety, or anger to others.

Breaking down, wanting to give up, and even acting up are common reactions among any of us when we are under repeated and seemingly uncontrollable stress. But the stress can feel overwhelming or impossible to a child or adolescent with a brain injury who is already struggling with physical, emotional, behavioral and cognitive changes.

By taking steps in advance, you and your family can be better prepared if there is a crisis. In other words, “Hope for the best, but prepare for the worst.” These steps are similar to how you would prepare for any emergency but in this case, you are preparing for a behavioral emergency which may need special resources.

Step 1. Keep records of your child’s medical and behavioral health history. These records should include information on allergies, medications, doctors and specialists. If the brain injury has affected your child’s behavior, it is helpful to keep any medical records which state this. Never give up your copy but make extra copies in case they are needed.

Step 2. Have a list of doctors, neuropsychologists, and other therapists to contact during a crisis. Keep their contact information handy as they are valuable resources. You may want to give their contact information to other physicians and therapists involved in your child’s care.

Step 3. Prepare a Family Emergency Plan. The end of this chapter describes how to create a Family Emergency Plan. Like an Advance Directive in the event of a medical crisis, it will serve as a touchstone for treatment planning during a crisis. Make sure this includes legal documentation, such as any guardianship or trusteeship, or advance directives (medical or psychiatric).

By following these steps, you will have a tool kit to share with treatment providers in the event of a crisis.

Family Members Coping Together with Behavioral Crises

A crisis affects the entire family. The family may initially lose control over the situation. Family members also may feel a range of emotions including fear, anger, and guilt. In the midst of a crisis, families may feel so shocked and confused with self-doubts about what to do that they feel unable to make decisions or take action. Family members may not immediately reach out for help during a behavioral crisis; however, when the usual strategies are not working, changes and new strategies may be needed.

These new strategies will naturally vary, based on the child’s special needs, specific dangerous behaviors during crisis episodes, and existing support systems. Families can rely on past experiences to identify which strategies to use to maintain control and avoid further escalation of inappropriate behavior.

Keep in mind that it is best to discuss and agree on these plans when the household atmosphere is calm, well
before the onset of a behavior crisis. These strategies can always be revised after being put to the test.

Consider the following as your family moves forward to develop strategies to help your child when in crisis:

• Work together in your family to build a solid foundation of trust and mutual understanding.
• Explore new opportunities together to empower all family members and develop needed supports.
• Reassure all members of the family they are not alone in dealing with the child’s challenges.
• Find solutions through a family effort and become even stronger as coping skills improve.
• Seek appropriate professional advice and support as an important step in addressing the special needs of your child.
• Begin by obtaining referrals from brain injury rehabilitation providers, trusted physicians, service providers, families, and/or friends in order to identify qualified professional resources.
• Use a collaborative therapeutic treatment approach involving professionals and family members.
• Seek help from people outside your family. Sometimes neighbors, fellow congregants at your regular place of worship, or friends can help provide another perspective or support.
• Help siblings by sharing information and support about what your family is facing during crisis situations. Parents and/or guardians sometimes believe they should protect younger children by isolating them from severe behavioral episodes, but this may not always be possible. However, if younger children are in danger of physical harm during a behavioral crisis, they should be isolated from the event.
• “Track behaviors” in a journal as this is a great tool for evaluating medications (are they working or not?) and identifying trends, triggers or antecedents to problem behaviors.

Creating a Family Emergency Plan

It is important for any family who has a child with behavioral issues to develop a Family Emergency Plan. The ultimate goal is to prevent a crisis. By developing an individualized practical plan for safety in an emergency, and by implementing the strategies outlined in the plan when a crisis arises, families can lessen the negative impact of these events for their children as well as for everyone present.

The child who is affected MUST be involved in the planning process as much as is age-appropriate, especially for older teens. People may have their own preferences regarding emergency services.

Emergency plans do involve and reflect a level of “risk tolerance.” Some people/households have a high degree of fear and push for crisis response and hospitalization with relatively mild causes. Others have experienced economic setbacks, unnecessary hospitalizations, etc., from such an approach, and choose to handle the crisis themselves.

It is helpful to record your plan in a notebook or folder that is both easily reachable and portable. Following are some suggestions to include in your Family Emergency Plan notebook or folder:

• A contact list of people willing to come to your aid at the onset of a crisis, such as friends, relatives, and/or neighbors
• A contact list of all individuals involved in the care of your child; for example, doctors, therapists, teachers, social workers, case managers, the provider agency management team, and/or direct care staff
• All telephone and address information for the people listed above
• A list of any outreach support services that might be needed during an emergency situation
• Up-to-date medical information about your child, including current daily medications, the reasons they were prescribed, the doctor(s) who prescribed them, dosages, special medical needs, allergy information, etc.
• A one-page summary about your child and any special needs. Include current program information, prior hospitalizations, and any important details that would help familiarize someone with your child’s likes, dislikes or fears. Include all information that you think you might need in an emergency.

Additional Points about the Emergency Plan

• Make copies of the Family Emergency Plan notebook or folder so that it can be with you and your immediate family members at all times.
• Consider giving copies of your Family Emergency Plan to other family members and/or close friends who are willing to support you in a time of crisis.
• Ask that the details of the emergency plan be included in the individual’s IEP.
If your child no longer lives in the family home, it is still advisable to establish an individualized emergency plan for his or her full-time residence. It is advisable to be prepared, because a crisis can take place anywhere, at any time.

Remember to update your emergency plan as necessary, particularly as new and successful behavior management strategies are discovered, or as new or different medications are prescribed.

Include the following information in your emergency plan: a) triggers to behavioral outbursts, b) de-escalation techniques that have been successful, c) preferred activities, favorite topics of conversation, interests.

Attach any information or copies of official documents that you might require in an emergency pertaining to medical insurance, Medicaid coverage, Certificate of Guardianship, etc.

**Dealing with Crisis “In the Moment”**

This section considers how to deal with a behavioral crisis “in the moment,” including agencies that can help at home and provide treatment as an alternative to hospitalization. It also describes what may take place in a psychiatric crisis center if this is needed.

The first step is to recognize the severity of the situation and to determine whether outside resources are needed. You can start with assessing the level of danger to your child and others. Ask yourself the following questions:

1. Has my child lost control?
2. Is my child unable to follow instructions to calm down?
3. Is there a strong possibility that someone could be hurt physically?
4. Is someone in immediate danger because of my child’s out-of-control behavior?

**Services through Child Behavioral Health Services**

If the answers to the above questions are “No” and there is no immediate risk to the life or health of your child or others, you can contact Mobile Response and Stabilization Services (MRSS). This service is offered by contracted case management agencies of the NJ State Department of Children & Families’ Children’s Behavioral Health Service System of Care.

Mobile Response and Stabilization Services are available 24 hours a day, 7 days a week. They provide face-to-face crisis response within one hour of notification. The services are designed to defuse an immediate crisis, keep children and their families safe, and keep children at home or in a current living situation (such as a foster home, treatment home, or group home) in the community.

**You can access Mobile Response and Stabilization Services by calling 1-877-652-7624.**

**Crisis Services**

If the answer to any of the crisis questions listed above is “Yes,” then your child may be having a serious behavioral crisis. The next step is to figure out what resources can help.

First, it is important for you to decide whether it is safe to manage your child yourself, especially if your child is self-destructive, damaging property, or behaving in a way that is a danger to self or others. In those situations, the safest alternative is to call for emergency assistance.

Tell the emergency worker that your child is in crisis and has a brain injury. While waiting for these workers to arrive, try to make your surroundings as safe as possible by removing dangerous objects. Others who do not need to be there should leave.

Your child may calm down either before the emergency workers arrive or when they arrive. However, it is also possible that your child may become even more distressed or agitated at the sight of first responders. The emergency workers will assess the situation. If they believe your child does not present a danger to self or
other child, they may not transport your child to a hospital.

If your child needs emergency medical services, they may recommend going to a hospital emergency department by ambulance or with police assistance.

**What to Expect in the Emergency Room**

You will be asked to sign a consent form giving permission for your child to be treated. You will also be asked to complete a general information form. This part will be easier if you have your Family Emergency Plan with you. If you are the legal guardian for a child over the age of 18, you should have a copy of the official court document.

You will be asked for information on your child’s health insurance or Medicaid. If your child is uninsured, the hospital social worker can help you apply for Charity Care or the New Jersey Hospital Payment Assistance Program, and for Medicaid. The hospital social worker can also tell you about the income requirements for Medicaid eligibility before you fill out an application. If your child’s hospital is not covered by any of these, your family can apply to the Catastrophic Illness in Children Relief Fund (CICRF) to cover a portion of the bills and can be reached at 1-800-335-FUND (3863).

The emergency physician will conduct a routine physical exam to rule out major medical problems that might be a contributing to your child’s behavioral crisis. If there have been any recent changes in your child’s medical condition, be sure to give this information. The emergency department physician will inquire about your child’s diagnosis and medical history. It is important to tell everyone who will be working with your child about the brain injury. Having contact information for your child’s professional support team including doctors, therapists, and staff at community provider organizations can be a great help. Be sure to include professionals who are familiar with the emotional and behavioral consequences of your child’s brain injury, such as a neuropsychologist or neuropsychiatrist.

The emergency department physician will ask you about the circumstances that led to your child’s visit. It will be helpful if you can share pertinent information about any recent changes in your child’s life. This may include information about recent medical problems or changes in medications, or any significant events at school or at home.

**Why Must You Wait in the Emergency Room?**

Unfortunately, just about everyone waits in the emergency department. Depending on what else is going on, it can easily be several hours until your child is seen and medically cleared. However, receiving medical clearance does not mean that your child has been accepted for inpatient psychiatric care or has been admitted to the hospital. Medical clearance is approval from a healthcare professional to do a certain activity or undergo a medical procedure. Once cleared, your child may be seen by a screener and a psychiatrist. This may involve moving to a separate area for psychiatric screening. This may take several hours.

**What to Expect if Your Child Needs Psychiatric Care**

Some hospitals have medical and psychiatric emergency screening services on-site, while others have them in separate locations so your child may be moved. A screening clinician usually conducts an intake interview and a psychiatrist may meet with you and your child.

The possibility of psychiatric care can be frightening for both a child and parents. It is important to know that children cannot be involuntarily admitted to psychiatric hospitalization. Only individuals 18 and older are subject to current laws. The criteria used to determine the need for psychiatric hospitalization are based on whether or not individuals present a danger to themselves, to others, or to property. If emergency staff believe your child presents such a danger, they may need to use any or all of the following:

*Medication to help manage the crisis*

Your child may be given a short-acting psychiatric medication often referred to as a “PRN.” This is medication
that is given on an as-needed basis to help calm and lessen agitation while in the emergency department. As the PRN’s sedating effects wear off, your child may feel confused and disoriented and become agitated again. If your child has previously had negative effects from PRNs, you may want to make sure that the Psychiatric Advance directive indicates what medications, if any, are acceptable, and the reasons for any refusal of specific medications.

**What if Your Child Needs to be Hospitalized?**

This information does not apply to children under 5 years of age because they will not be admitted to a psychiatric hospital or a psychiatric unit in a hospital. Children under 5 will be discharged home after they are stable. The team planning your child’s discharge will make sure that you are connected to in-home services offered by case management agencies under contract with the NJ State Department of Children & Families’ Children’s Behavioral Health Service System of Care.

Otherwise, depending on the severity of psychiatric symptoms, the crisis center psychiatrist might recommend that your child be committed voluntarily or, if 18 years or older, involuntarily to inpatient treatment. Such inpatient psychiatric services for children are offered at specialized units that are separated from adult patients. The hospital crisis center may house these services, or these services may be offered through a nearby or attached facility.

Inpatient psychiatric care provides a safe structured environment where behavioral crises can be stabilized using medication management and intensive therapy. Staff members include a psychiatrist, clinical psychologists, and advanced practice nurses. They may also include therapists and social workers. Your primary contact will likely be with the psychiatrist assigned to your child’s care as well as the social worker. As with all professionals you encounter throughout this process, you should make them aware of your child’s brain injury and provide information such as medical history, medications, allergies, and so on.

Prior to discharge, the psychiatrist should contact you with a treatment plan. This may include outpatient counseling services and a medication plan. At this time, you may wish to involve your child’s neuropsychologist, neuropsychiatrist, and primary care physician to coordinate services and treatment, so there can be a smooth transition upon your child’s discharge.

**Steps to Take Following a Crisis**

Share information with everyone involved in your child’s care. This is ultimately the family’s responsibility. It will help give your child more consistent quality-based care and services.

**ALWAYS FOLLOW INSTRUCTIONS REGARDING PRESCRIBED MEDICATIONS FOLLOWING A CRISIS!**

Notes regarding medications:

a. If your child is not already being seen by a neuropsychiatrist or behavioral neurologist, contact one for an appointment. A neuropsychiatrist is dual certified in neurology and psychiatry and can make better-informed decisions for medication management. Some psychiatric medications have adverse effects after a brain injury; this is especially the case if multiple drugs are prescribed.

b. Work closely with your child’s prescribing doctor. Sometimes changes are needed because the medication no longer seems effective, or the child appears to need a change for some other reason such as difficult side effects.

c. New medication can be sedating initially. This does not necessarily mean that your child is over-sedated. Medications can take time to reach optimal effectiveness.

d. There occasionally may be problems caused by the interaction of multiple drugs. By keeping a log of what appear to be the side effects from medications and sharing this information with the provider who prescribed the medication, you can provide important information.
Chapter 7
Transition to Adult Life

Transition to Adult Life

Through the completion of high school, students with brain injury who have behavioral challenges can access support services and educationally-based therapies within the public school systems via IDEA Child Study Teams in the schools. State services such as the New Jersey Department of Children & Families Children’s System of Care or Special Child Health Services can provide case management to help families maximize access to resources and coordinate needed services.

Once a student graduates from high school, IDEA no longer applies. Child health and mental health services serve youths up to ages between 18 and 21 years. When a young adult with behavioral challenges ages out of the pediatric system, the next transition is into the adult behavioral healthcare services. Compared to the coordinated services and legal mandates of IDEA, adult behavioral healthcare can be fragmented and harder to access.

Adult services take a different approach to the delivery of behavioral or mental health services. Whereas in school, parents are routinely involved in service planning, adult services consider the young adult as the primary client. Parents and other family members can only receive information if the young adult provides written consent for them to receive personal or medical information unless guardianship has been attained.

A young adult with a brain injury now moves to post-secondary educational settings, employment, or supported work programs that usually do not have in-house behavioral supports. They also expect a level of independence consistent with the young adult’s age. Reasonable accommodations through 504 continue to exist in adult settings, but therapeutic services are not mandated or funded under 504. That means that behavioral and other neurorehabilitation therapies for the needs of a young adult with brain injury must be obtained on an outpatient basis. This is often delivered on a piecemeal basis depending on the availability of services within the area and funding sources.

In addition to the loss of mandated education services, the transition from the routinized environment of high school to the less structured unfamiliar settings of work or college can be stressful. This can trigger new behavioral problems or a resurgence of previously managed behavioral issues. Grief may arise again in the face of new academic and social demands combined with separation from high school social supports. Young adults may be able to continue with their pediatric neuropsychologist for some period of time, but based on the level of training of the professional, may need to transfer care to another neuropsychologist and/or neuropsychiatrist trained in treating adults with brain injury.

It is imperative that a determination be made during the last year of high school of what behavioral healthcare and rehabilitation therapies will have to transfer to adult services. A plan should be in place prior to graduation for the transfer of care so that there is no gap in support services after graduation. Given the specific needs of a person with a brain injury and behavioral challenges, consistency of support is vital to preventing deterioration in functioning. At a minimum, a basic behavioral care transition plan should include: neuropsychological services, 504 plans that may lessen or avoid stressors that trigger acting out behaviors, psychotherapist or life coach trained in working with people with brain injury, and identified family members or caregivers to help obtain services and receive information for proper care. The choice by a young adult with brain injury of another adult who can receive confidential health or behavioral health information can be achieved by signing a release of information with specific providers.

However, if there is concern that the young adult with brain injury will need ongoing assistance in handling personal and financial affairs, a power of attorney can be designated through a legal document signed by the individual with the injury. Guardianship of the person or finances, or full guardianship of a young adult with brain injury, should be considered when a competency assessment indicates that the young adult does not have the cognitive abilities to make decisions for him or herself. Further information on power of attorney and
guardianship can be obtained from the Brain Injury Alliance of New Jersey and the New Jersey Department of Human Services Division of Disability Services.

Adults’ needs go beyond education and employment. There are a range of issues to be considered including legal; recreational/leisure activities and appropriate behaviors; transportation-driving or public; medical; independent living; financial and personal/family needs.

There are several issues to begin to consider prior to graduation...

- **Legal** – Can they be their own guardian? Handle their own finances?
- **Recreational/leisure activities and appropriate behaviors** – How involved are they in their community? Do their behaviors interfere with this?
- **Transportation-driving or public** – How will they get around independently?
- **Medical** – If they are seeing pediatric specialists who will oversee their medical care into adulthood?
- **Independent living** – Can they live alone? With supports?
- **Financial and personal/family needs** – How will they pay for rent, food, etc.?

Transition planning through school can and should begin at age 14. If behavioral issues are a problem they should be considered as part of the transition plan. As part of your child’s transition plan ask the above questions and work to find solutions prior to graduation. If you can’t find answers to the questions through your school contact the Brain Injury Alliance of New Jersey’s Helpline at 1-800-669-4323 or info@bianj.org.

Speak with your child’s healthcare team also as early as age 14 to learn more about brain injury specific resources for adults, including referrals for adults physiatrists (rehabilitation physicians), neuropsychologists, neuropsychiatrists, behavioral neurologists, neurologists and any other healthcare providers you may need for your child as they transition to adulthood. Ask your healthcare provider or the healthcare provider they are referring you to how familiar they are working with individuals with brain injury who sustained their injury during childhood. It is important to know, as early as possible, who can assist with behavioral issues into adulthood. Also remember that you are never alone. The Brain Injury Alliance of New Jersey is always available to help you and your family down your path.

The Brain Injury Alliance of New Jersey provides a free booklet, *Preparing for Life After High School: The Next Steps*, to help families better understand how to prepare for the transition to adult services following a brain injury. You can request a free copy of this booklet at info@bianj.org or download a copy at www.bianj.org.
Chapter 8

Conclusion: Making the Journey to Wellness Together

This booklet was intended to present an overview of the behavioral issues you may face after a child or adolescent has sustained a brain injury. It was not meant to be comprehensive, nor does it cover all the issues. For more in-depth information, you are directed to the Brain Injury Alliance of New Jersey, your family member’s rehabilitation professionals or other professional sources available for further information and assistance if you are facing behavioral issues.

When your family member’s life changed in the split second it took for the injury to occur, your life changed too. You have been handed one of life’s greatest challenges. How you deal with it is as individual as the circumstances that surrounded your family member’s injury. Your actions now may very well determine the path you follow for the rest of your life.

You need to be comfortable with the choices made in regard to treatment, medications, behavior management, long-term care, financial and legal issues, and the like because you have to manage those choices. Assume as much strength and power as you need to make things happen for your family member.

As you ride the rollercoaster of brain injury rehabilitation, remember that even as you dip down to the base, the rollercoaster will rise again. It may be a slow uphill climb, but there will be improvement and adjustment.

There may be times during your family member’s rehabilitation process when you feel you just cannot meet the challenge any longer. When this happens, listen to yourself and take some respite. You may only need a part-time respite, or perhaps a longer period of relief. Whatever the case, do not look at it as a personal failure if you need to explore the possibility of placing your family member somewhere rather than your home for either a short or long-term period.

You have to know when you have reached your limit. If you do not, you will be unable to meet the challenges of managing your family member’s rehabilitation program. You are your family member’s rehabilitation program. You are your family member’s greatest resource at this time, so protect and take care of yourself.
APPENDIX A:

Functional Behavioral Assessment Sample: Parent & Student Interviews

Functional Behavioral Assessment Behavior Support Plan (F-BSP) Protocol

Functional Behavioral Assessment Interview – Teachers/Staff

Student Name _________________________________    Age:____    Grade:____    Date:____________

Person (s) interviewed:__________________________________________________________________

Interviewer ___________________________________________________________________________

Student Profile: What is the student good at or what are some strengths that the student brings to school?
_____________________________________________________________________________________
_____________________________________________________________________________________

STEP 1: INTERVIEW TEACHER/STAFF/PARENT

Description of the Behavior

What does the problem behavior(s) look like?

How often does the problem behavior(s) occur?

How long does the problem behavior(s) last when it does occur?

How disruptive or dangerous is the problem behavior(s)?

Description of the Antecedent

When, where, and with whom are problem behaviors most likely?

<table>
<thead>
<tr>
<th>Schedule (Times)</th>
<th>Activity</th>
<th>Specific Problem Behavior</th>
<th>Likelihood of Problem Behavior</th>
<th>With Whom does Problem Occur</th>
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</table>
Summarize Antecedent (and Setting Events)

**What situations seem to set off the problem behavior?** (difficult tasks, transitions, structured activities, small group settings, teacher’s request, particular individuals, etc.)

**When is the problem behavior most likely to occur?** (times of day and days of week)

Description of the Consequence

What usually happens after the behavior occurs? (what is the teacher’s reaction, how do other student’s react, is the student sent to the office, does the student get out of doing work, does the student get in a power struggle, etc.)

--- End of Interview ---

**STEP 2: PROPOSE A TESTABLE EXPLANATION**

<table>
<thead>
<tr>
<th>Setting Event</th>
<th>Antecedent</th>
<th>Behavior</th>
<th>Consequence</th>
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</thead>
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</table>

**Function of the Behavior**

For each ABC sequence listed above, why do you think the behavior is occurring? (to get teacher attention, to get peer attention, gets desired object/activity, escapes undesirable activity, escapes demand, escapes particular people, etc.)

1. ____________________________________________________________________________

2. ____________________________________________________________________________

How confident are you that your testable explanation is accurate?

<table>
<thead>
<tr>
<th>Very sure</th>
<th>6</th>
<th>So-So</th>
<th>3</th>
<th>Not at all</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Functional Behavioral Assessment Interview – Students

Student Name _____________________    Age:____    Grade:____    Date:_________________
Interviewer ______________________________________________________________________

Student Profile: What are the things that you like to do, or do well, while at school? (E.g. activities, classes, helping others, etc.)________________________________________________________
_________________________________________________________________________________

STEP 1: INTERVIEW STUDENT

Description of the Behavior
What are some things you do that get you in trouble or that are a problem at school? (e.g. talking out, not getting work done, fighting, etc.)

How often do you _______________ ? ( Insert the behavior listed by the student)

How long does _______________ usually last each time it happens?

How serious is _________________? (Do you or another student end up getting hurt? Are other students distracted?)

Description of the Antecedent

Where, when and with whom are problem behaviors most likely?

<table>
<thead>
<tr>
<th>Schedule (Times)</th>
<th>Activity</th>
<th>With Whom does Problem Occur</th>
<th>Likelihood/Intensity of Problem Behavior</th>
<th>Specific Problem Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Low 1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High</td>
<td></td>
</tr>
</tbody>
</table>

35
Summarize Antecedent (and Setting Events)

What kind of things make it more likely that you will have this problem? (difficult tasks, transitions, structured activities, small group settings, teacher’s request, particular individuals, etc.)

When and where is the problem most likely to happen? (days of week, specific classes, hallways, bathrooms)

When is the problem behavior least likely to occur? (days of week, specific classes, hallways, bathrooms)

Setting Events: Is there anything that happens before or after school or in-between classes that make it more likely that you’ll have a problem? (missed medication, history of academic failure, conflict at home, missed meals, lack of sleep, history or problems with peers, etc.)

Description of the Consequence

What usually happens after the problem occurs? (what is the teacher’s reaction, how do other student’s react, is the student sent to the office, does the student get out of doing work, does the student get in a power struggle, etc.)
Sample Functional Behavior Assessment Reports for a Student with Brain Injury
(Two sample Functional Behavior Assessments are shown, as Functional Behavior Assessment reports can vary from school to school and district to district.)

**Sample 1**

**Name:** Joe_
**Date of Birth:** 11/0/02
**Age:** 10yrs 11mo
**Date of Evaluation:** 9/24/13

**FUNCTIONAL BEHAVIOR ASSESSMENT**

**Background Information**
Joe_ was referred for a functional behavior assessment to evaluate academic, behavioral, and social needs. He is 6th grade at the (School name). Joe_’s classroom is comprised of eight students, one classroom teacher, Ms. Smith and three classroom assistants, Ms. Jones, Mr. Michaels, and Ms. Kelly.

Mrs. Smith’ classroom utilizes a behavior management strategy known as “Rate and Evaluate”. The Rate and Evaluate system requires both students and classroom staff to track behavior and award points. Students have the opportunity to “cash” in points three times during the day for access to a preferred activity. Earn 1 requires 40 points, earn 2 requires 46 points, and earn three requires 20 points. If a student does not have enough points to cash in for a preferred activity he/she is still offered a break with access to a reinforcing but less preferred activity. Points are awarded for respectful, responsible, and safe behavior. These behaviors include raising hand, using an inside voice, using respectful language, allowing one person to speak at a time, beginning and completing work on time, using materials appropriately, staying in one’s seat, maintaining personal space, keeping one’s work area clean, and keeping one’s self safe. Bonus points are also awarded throughout the day for other pro-social behaviors. Rate and Evaluate sheets are completed consistently every 20 minutes throughout the school day.

The observation on September 23rd took place during “Fun Week”. A morning activity in the form of creating a rainbow in the school field to take pictures and interact with the Medford Fire Department took place mid-morning for approximately twenty minutes.

**Operational Definitions:**
*Non-compliance:* Refusal, not following directions when delivered a minimum of 2x

*Disruptive Behavior:* Yelling, crying, throwing items, banging items, inappropriate verbalizations (i.e.: “I hate you”)

**Assessment Methods**
Direct Observation (School)
Data Collection (Partial Interval, ABC, On-Task)
Records Review (2013/2014 IEP)

**Direct Observation**
**9:10a (Arrival/Morning Routine):** Students entered the classroom and utilized cubbies to unpack. Morning activities included announcements over the intercom and the Pledge of Allegiance. Joe_ participated appropriately.

**9:20a (Spelling):** The students were given directions to attend specific learning/work areas of the classroom either independently or with a small group. Joe_ was assigned to the spelling center to work one on one with one with Ms. Kelly whom administered a spelling test. Ms. Kelly read the words aloud and Joe_ completed their spelling on paper. Joe_ demonstrated compliance.

**9:25a (Computer):** Joe_ transitioned from the spelling test to spelling activities on one of the classroom computers. Disruptive behavior in the form of yelling and banging on the computer keyboard was demonstrated in response to the computer and mouse being defined as “slow” on Joe_’s behalf. Joe_ was provided with reminders and support for the remainder of the computer activity.
9:35 (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied. Mr. Michaels provided Joe_ with verbal praise for following directions well. He was asked to work on refraining from yelling.

9:41a (Writing): The class transitioned between work areas. Joe_ was given directions to join Ms. Smith and one additional peer at the writing center. Mr. Michaels transitioned with Joe_ and provided direct support as needed throughout the activity. Ms. Smith informed the group today’s session would focus on peer edits and self-edits with respect to a story the students have been working on. Students were asked to read their story aloud and make edits based on peer feedback. Joe_ responded to these directions by stating, “This is why I hate writing”. The statement was ignored and Joe_ was asked to read his story aloud. He complied. He accepted peer feedback well when offered, stating, “I can do that”. Joe_ then listened to the peer read her story aloud and offered appropriate feedback.

The writing center was then given directions to transition to the computers to make edits to their stories. Joe_ complied. Disruptive behavior in the form of indicating the computer was “too slow” as it was loading. Joe_ was reminded to be patient and began to work once the computer loaded within in a few seconds.

9:55a (Shirt Change): Ms. Smith asked Joe_ to go into the bathroom and change into his Fun Week Shirt, as the class would be called shortly to participate. Joe_ complied.

10:00a (Rate and Evaluate): Joe_ returned to the classroom. Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied and then followed directions to complete his story edits on the computer.

10:10a (Fun Week Activity): Ms. Smith’s class was called over the intercom to attend the Fun Week Activity outside. Mrs. Smith gave the class directions to sit in their homeroom seats and demonstrate “work readiness”. Joe_ complied and was provided with verbal praise for following directions. As Ms. Smith called students to line up each was praised for demonstrating “work readiness” behavior. Joe_ transitioned outside with his class and other Kirby’s Mill School classes appropriately.

10:19a: Joe_ requested to leave the group. He expressed fear of a bee flying around, as well as, fears of being stung as he is allergic. Ms. Smith complied with Joe_’s request and moved away from the bee and the group, but remained outside among the activity.

10:21a (Snack and Break): The class transitioned back into the classroom from the Fun Week activity for snack and break. Joe_ was praised for transitioning into the building and the classroom appropriately. Ms. Smith informed the class recess and snack/break would be switched today. Joe_ and peers complied without concern regarding the unexpected schedule change.

Ms. Smith called students demonstrating “work readiness” to get their snacks. Joe_ brought in microwavable popcorn that was prepared in the classroom. Joe_ conversed with peers appropriately and transitioned to the computer for his preferred break time where he conversed with peers and played games. He was not observed to indicate the computer being slow when engaged in preferred computer activities, as he did previously when required to complete work assignments.

10:54a (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied.

10:55a (Recess/Outside): The class transitioned from snack/break to recess outside. Joe_ walked in line with peers and interacted appropriately when outside. Joe_ and peers utilized the swings, jungle gym, and played tag. At times Mr. Michaels also joined in the play.

11:10a (Current Events): The class transitioned back to the classroom from recess. Once in the classroom and seated Joe_ demonstrated disruptive behavior in the form of yelling and demanding an additional ten minutes of break time. The additional break time being requested had been scheduled for the second earned break of the day. Ms. Smith began reading the designated article on Australia and brush fires. Joe_ continued to verbally demand ten minutes of break time. He was offered the opportunity to go to a separate area in the classroom to calm down and regroup. He chose to stay in his seat.
When demonstrating calm behavior (absence of yelling, calm body), Ms. Smith called on Joe_ to read a paragraph aloud. Joe_ responded by saying, “I don’t want to read”. The behavior was ignored and within three seconds Joe_ began to read. When finished reading, Ms. Smith praised Joe_ for his participation.

11:20a (Nurse): Joe_ left the classroom for a scheduled nurse’s visit in order for daily medication to be administered.

11:25a (Returned to Classroom): Upon returning to the classroom Joe_ was given directions to complete the “Who, What, Where” worksheet related to the article read earlier. Joe_ responded by verbally expressing, “I want ten minutes”. Mr. Michaels modified the worksheet for Joe_ by having him answer the last question of the article only. Joe_ complied with the modified work request.

11:30a (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied.

11:33a (Math): Mrs. Smith announced Math directions would be given when everyone was demonstrating “work readiness”. Within ten seconds, directions were delivered. Joe_ was paired with one additional peer and given directions to transition to Ms. Jones’s math station. Ms. Jones stated the two items in need of being completed including a fractions review and a worksheet with twelve problems. Following these two work items, computer time would be provided. Joe_ demonstrated verbal protest, demanding access to the computer. Ms. Jones offered to modify the assignment by having Joe_ and his peer answer three questions about fractions instead of engaging in an entire review. The three questions were followed by the completion of a worksheet. Throughout the lesson Joe_ demonstrated verbal protest and non-compliance. Direct support was required to complete the activities.

11:50a (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ demonstrated disruptive behavior in the form of crying and yelling indicating he wanted computer time. Mr. Michaels reminded Joe_ when he finished working he would have computer time. Joe_ complied.

12:00p (Computer): Joe_ accessed the computer. He demonstrated appropriate behavior while on computer until his score was not where he preferred it to be or he lost the game. When low scores and losing occurred, Joe_ engaged in disruptive behavior in the form of yelling. He was offered the choice of an alternative game but chose not to take it.

12:15p (Science/iPad): Ms. Smith directed the class to transition to science and iPad activities. Joe_ responded by yelling “I want ten minutes! I should be having extra break!”. The behavior was ignored and Joe_ transitioned within three minutes. During the science lesson/iPad Joe_ expressed verbal frustration with typing on the iPad and yelled, “I don’t want to do this! I want ten minutes!”. He was offered help by Ms. Kelly, which was accepted. Yelling and disruptive comments were observed for the duration of the lesson.

12:35p (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied.

12:36p (Science/iPad): Joe_ to work on the science activity with support from Ms. Kelly. He intermittently demonstrated disruptive behavior in the form of yelling and crying, “This is too hard for me!” Disruptive behavior was ignored and waited out. Within one to two minutes Joe_ consistently returned to work; verbal protest continued.

12:40p (Lunch Heat Up): Joe_ continued to work with Ms. Kelly demonstrating both compliance and crying behavior intermittently throughout activity. Ms. Jones, asked Joe_ for permission to prepare his lunch. Joe_ gave permission.

Ms. Smith reminded the class they had five minutes left of science prior to lunch. She also reminded the class they were working toward their second break.

12:45p: Joe_ continued to cry and verbally protest the science assignment. Ms. Kelly reminded him notes could be printed out for him to utilize so he would not have to scroll back and forth on the iPad. Joe_ continued to cry, verbally protest, and intermittently work.

12:50p (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied.
and simultaneously stated, “I hate my life.”

12:51 (Lunch): Ms. Jones shared with the students she was looking for “work readiness” in order to call individuals to line up for lunch. Joe_ walked through the hallway and transitioned to lunch without concern. Once in the cafeteria Joe_ ate his lunch and conversed with peers appropriately. Ms. Smith, Ms. Jones, Ms. Kelly, and Mr. Michaels eat lunch with the students.

1:17p (Return to classroom / Rate and Evaluate): The class transitioned from the cafeteria back to the classroom without concern. Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied. The class was then given their second break of the day. Joe_ chose to play on the computer, as did two other peers.

1:27p: Ms. Smith provided the class with a five minute reminder prior to transitioning to social skills activities.

1:32p (Transition): Ms. Smith provided the class with directions to join their social skills clubs (acting club or games club). Joe_ and one other peer were reminded they had earned ten extra minutes of computer time. Joe_ remained on the computer. Ms. Smith offered both boys the choice of a quiet activity on the computer or an activity with sound he was willing to wear headphones. Joe_ chose an activity with sound and headphones.

1:42p: Ms. Smith provided those with an extra ten minutes of choice time a one minute reminder.

1:43p: A timer went off signaling transition from computer to social club. Joe_ transitioned without concern to acting club. He worked cooperatively and complied with directions. He was observed to assist another peer in the group who was demonstrating social difficulties.

1:45p (Rate and Evaluate): Students were given directions to fill out their Rate and Evaluate sheets. Joe_ complied.

2:10p: Observation ended.

Data Collection
Data was taken in three forms:
1. Partial Interval: Data taken in 10-minute intervals to acquire an estimate on how often target behaviors occur throughout the day.

2. ABC (Antecedent, Behavior, Consequence): Data taken each time aggression and angry fingers occurred to determine potential antecedents and functions of behavior.

3. On Task: Data taken to determine how often student is on task (completing work, attending to lecture, making transitions, etc.) compared to peers. Data is taken in whole interval format.

Partial Interval Data
Partial interval data (Graph 1, Graph 2) indicate Joe_ engages in non-compliant and disruptive behavior during academic portions of the school day. On the day of this observation, behaviors occurred most often during the mid-morning and early afternoon hours. Activities during this time where behavior was most prevalent included Writing, Math, and Science.
ABC Data

ABC data examines the potential causes of behavior, the consequences for behavior both positive and negative, and Joe’s response to those consequences. Joe’s behavior is likely a function of escape/avoidance of demands (33%) and access to desired items/activities (60%).

Graph 2. ABC Data
Table 1. ABC Data Scenarios

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Antecedent</th>
<th>Behavior</th>
<th>Consequence</th>
<th>Response</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:26a</td>
<td>Spelling game on computer</td>
<td>Computer booting up</td>
<td>“Come on!, I hate this computer!”</td>
<td>Offered a choice to use a different computer</td>
<td>Chose to use a different computer</td>
<td>Access to desired activity/speed</td>
</tr>
<tr>
<td>9:30a</td>
<td>Spelling game on computer</td>
<td>Believed computer to be slow</td>
<td>Banging on keyboard</td>
<td>Asked to stop</td>
<td>Yelling</td>
<td>Access to desired activity/speed</td>
</tr>
<tr>
<td>9:30a</td>
<td>Spelling game on computer</td>
<td>Asked to lower volume on game or wear headphones</td>
<td>“Curse you!”</td>
<td>Offered choices of lowering volume or headphones</td>
<td>“Stop going so slow!”</td>
<td>Access to desired volume and speed</td>
</tr>
<tr>
<td>9:32a</td>
<td>Spelling game on computer</td>
<td>Believed mouse to be slow</td>
<td>“Stupid mouse!”</td>
<td>Offered a different activity not requiring mouse</td>
<td>“Oh my God why is it so slow!”</td>
<td>Access to desired speed</td>
</tr>
<tr>
<td>9:34a</td>
<td>Spelling game on computer</td>
<td>Believed computer to be slow</td>
<td>Yelling unintelligible sounds</td>
<td>Peer attempted to help</td>
<td>“Why do you tell me things I already know?!”</td>
<td>Access to desired speed</td>
</tr>
<tr>
<td>9:35a</td>
<td>Spelling game on computer</td>
<td>Hit wrong button on computer</td>
<td>“Stupid glitch, I didn’t want that button!”</td>
<td>Ignored</td>
<td>Continued to play game</td>
<td>Access to desired outcome</td>
</tr>
<tr>
<td>9:50a</td>
<td>Writing/Editing story</td>
<td>Computer booting up</td>
<td>“Come on, so slow!”</td>
<td>Reminded to be patient and give the computer a minute</td>
<td>Accepted feedback and calmed</td>
<td>Access to desired speed</td>
</tr>
<tr>
<td>11:10a</td>
<td>Current events</td>
<td>Transition inside from recess</td>
<td>“I want 10 extra minutes!”</td>
<td>Reminded 10 minutes of extra break would be given during the second break</td>
<td>“I want 10 extra minutes! I want 10 extra minutes!”</td>
<td>Access to 10 extra break minutes</td>
</tr>
<tr>
<td>11:19a</td>
<td>Current events</td>
<td>Asked to read a paragraph aloud</td>
<td>“I don’t want to read!”</td>
<td>Ignored and paused 5 seconds</td>
<td>Began to read</td>
<td>Escape/Avoidance</td>
</tr>
<tr>
<td>11:25a</td>
<td>Current events</td>
<td>Asked to complete worksheet</td>
<td>“I want 10 minutes!”</td>
<td>Directed to complete last question only</td>
<td>“I don’t want to write this!”</td>
<td>Escape/Avoidance</td>
</tr>
<tr>
<td>11:30a</td>
<td>Complete Rate and Evaluate</td>
<td>Asked to completed Rate and Evaluate</td>
<td>Yelling across the room to a peer</td>
<td>Redirected to complete Rate and Evaluate</td>
<td>Complied</td>
<td>Attention from peer</td>
</tr>
<tr>
<td>11:36a</td>
<td>Math</td>
<td>Fractions review</td>
<td>“I want to go on the computer! I don’t like worksheets!“</td>
<td>First work then you have computer time</td>
<td>“I don’t want to do this!”</td>
<td>Escape/Avoidance</td>
</tr>
<tr>
<td>11:36a</td>
<td>Math</td>
<td>Worksheet</td>
<td>“I hate my life!”</td>
<td>Ignored</td>
<td>Placed head on desk</td>
<td>Escape/Avoidance</td>
</tr>
<tr>
<td>11:50a</td>
<td>Math</td>
<td>Worksheet</td>
<td>Banging head on table</td>
<td>Given help</td>
<td>“I should be on the computer!”</td>
<td>Escape/Avoidance</td>
</tr>
<tr>
<td>12:15p</td>
<td>Computer</td>
<td>Used all available lives in game</td>
<td>Yelling</td>
<td>Offered suggestions and choices of other games</td>
<td>“I know!”</td>
<td>Access to additional lives</td>
</tr>
</tbody>
</table>
**On Task Data**

Data indicate Joe is on task on average 55% of the school day as compared to peers who are on task on average 75% of the school day. It should be noted Joe was observed to engage in maladaptive behaviors when presented with academic tasks and required prompting from support staff to stay on task across academic activities.

**Graph 3. On Task Behavior**

<table>
<thead>
<tr>
<th>Subject</th>
<th>Percent of Time on Task During Subject</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spelling Test</td>
<td>100%</td>
</tr>
<tr>
<td>Computer</td>
<td>100%</td>
</tr>
<tr>
<td>Writing</td>
<td>60%</td>
</tr>
<tr>
<td>Current Events</td>
<td>80%</td>
</tr>
<tr>
<td>Math</td>
<td>50%</td>
</tr>
<tr>
<td>Science</td>
<td>90%</td>
</tr>
<tr>
<td>Social Skills Club</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Records Review**

**IEP 2013/2014:** Core items from Joe’s current IEP related to behavioral and academic success are summarized below.

**Related Services:**

- **Speech:** 30 minutes/wk integrated in a group of 5 or less students
- **Personal Aide:** Full day 5x/wk
- **Social Skills:** 30 minutes 3x/wk integrated in a group of 5 or less students

**Academics**

- **Reading:** Difficulty with word recognition. On grade level with respect to comprehension activities. Does well with literal questions but struggles with inferences. Reading activities may elicit challenging behaviors.
- **Written Expression:** Difficulty with developing independent ideas and maintain organization. Will accept writing on ideas presented by others.
- **Math:** On 4th grade level. To begin 5th grade math book by mid year. Described as “enjoyed” by Joe. Most productive when working 1:1 with teacher. Goals include multiplication, division, time, fractions, and geometry concepts.

**Social Competency**

- Described as demonstrating “highs” and “lows”. Has demonstrated socially appropriate behavior by welcoming new students and attempting to make others feel comfortable in the classroom. Described as always willing to help fellow students in need.
- Difficulty controlling emotions and behaviors as demonstrated by lying on the floor, screaming, making verbal threats, and attempts to physically re-organize the environment. Noted data indicates highs and lows are correlated with medication changes. Data is said to indicate Joe as being able to manage more academics and social interactions when medication is stable. Actual data was not noted in the IEP.
Joe_ is said to respond well to frequent movement breaks throughout the day. Having him participate in errands and giving him time to run around in places like the gym are noted to be helpful.

Environmental modifications, as needed, such as work modifications and number of students present are noted as helping Joe_ be successful.

Joe_ is said to respond well to accessing the iPad for reinforcement. Described as enjoying sharing the iPad with peers, engaging in conversation about activities and games.

**Instructional Planning Needs**

- **Environment:** Allows for at least 4 hours of direct instruction, small class size, strategically placed furniture and materials, positive self management strategies, student centered and peer related campus activities, hands on learning, and access to electronics and media equipment.

- **Teacher and Support Staff:** Will receive training, coaching, and consultation to respond to changing needs, receive in class support from clinicians and related services staff.

- **Daily Program:** Match task difficulty to functionally determined levels and self-regulatory abilities, capitalize on interests, and respond to quickly to changes in intensity, energy, and mood. Built in generalization, social skills in small group and natural situation, opportunities to develop coping skills, utilization of positive behavioral supports, access to the internet and technology, utilized principles based on Applied Behavior Analysis, and frequent choice opportunities.

- **Psychologist:** Consults with teachers 1x/month, consults with teachers 1x/week, observes student 3x/wk, and reviews student data weekly.

- **Data Collection:** Daily data collection across settings, cumulative weekly graphs.

**Behavior Intervention Plan**

- Strategies target behaviors will be defined and objective measures prior to intervention will be maintained.

- Strategies should include reinforcement, antecedent strategies, and response cost if warranted.

- Data collection may include frequency count, time sampling, interval recording, percentage/assessment of permanent products.

- Parents will receive correspondence detailing data.

**Modifications**

- **Classwork/Materials:** Additional time to complete work, assistance in staying organized, prompting, repetition, daily schedule, study guides, simplify direction, state expectations clearly.

- **Appropriate Behavior:** Activities that require movement, avoid confrontational techniques, “cooling off” location, accept responsibility for behavior, maintain integrity of student, recognize signs of frustration, provide alternatives, frequent reinforcement, implement behavior intervention plan.

- **Tests:** Allow to type, allow to make corrections for credit, adjust font accordingly, allow re-take opportunities.

- **Environment:** Keep work area free of unnecessary materials, provide opportunities for movement and activity change, seat in area with minimal distractions.

**Summary and Recommendations**

Joe_ was observed at the (School name) School on Thursday 9/24/13 from 9:10 to 2:10p. Joe_ was observed across settings and activities. Data indicated behaviors in the form of non-compliance and disruptive behavior to occur regularly throughout the school day in response to academic demands. Joe_ has access to a behavior self-management system, as do his peers, as well as access to shared support that was observed to be individualized as needed. The following recommendations are suggested:

1. Continue with the current behavior self-management system of Rate and Evaluate. The systems allows access to frequent reinforcement throughout the course of the school day and offers the students and staff an opportunity to check in with one another every twenty minutes. This assists in creating student accountability and responsibility and allows staff to be aware of the student’s needs regularly.

2. Utilize visual supports throughout the school day in addition to the Rate and Evaluate system. Joe_ may benefit from utilizing a written checklist during each subject. The checklist should clearly and simply state the expectations of that subject and work area, as well as any reinforcement that may follow. The schedule may be written in list form and should be easy to change throughout the day (i.e.: Dry erase marker and board). The schedule move with Joe_ to each work area. This will aide him in understanding the expectations of each work
area and allow him to concretely see when he will have access to preferred activities such as the computer.

3. Utilize behavioral momentum by presenting Joe_ with a series of “easy” tasks and/or modified work activities followed by tasks that are viewed by Joe_ as more difficult. The goal is to have Joe_ respond to easier requests/tasks more frequently in order to increase the likelihood he will independently respond to more difficult requests/tasks in the future.

4. Daily data collection in the form of partial interval data and ABC data. Data of this nature will allow Joe_’s team to see how often and when behaviors are occurring. In addition, the ABC data will provide insight into function, as well as, what consequences may be maintaining maladaptive behavior. Data should be graphed and analyzed monthly by a Board Certified Behavior Analyst. The BCBA should then provide classroom staff with appropriate feedback and make modifications if needed to behavior plans and strategies.

5. Joe_ would benefit from on-going behavior consultation with a Board Certified Behavior Analyst onsite in school on a monthly basis. Consultation is suggested to include observation, data collection/analysis, and the development of a behavior intervention plan (BIP) to be incorporated in Joe_’s IEP. The current behavior intervention plan located in the IEP does not indicate specific target behaviors, operational definitions, or antecedent and consequence strategies. The plan and IEP should be revised to do so.

6. Joe_ currently attends Music with the regular education 7th grade students. Given the frequency and intensity of Joe_’s disruptive and non-compliant behavior, as indicated by behavior data, when presented with academic demands and transitions away from preferred activities, his current classroom placement is appropriate at this time.

7. By report, maladaptive behavior in music is significantly lower than in the academic classroom (data supporting this statement was not available for review at this time). This is likely due to the nature of the activities and the decrease of academic demands placed on Joe_ during music.

In order to assess whether Joe_ can be successful in the regular education academic setting at this time, it is suggested consideration be given to Joe_ participating with access to direct support in one regular education academic subject such as social studies in addition to music. Data should be collected across both settings by the assigned direct support staff each time Joe_ participates. The trial should take place over the course of one month. Data will provide further insight as to Joe_’s needs and ability to be successful in the regular education setting at this time. Data should be analyzed monthly by a Board Certified Behavior Analyst. It is also suggested the Behavior Analyst observe Joe_ across each setting monthly.

Consideration should be given to having Joe_ participate regularly in counseling sessions to develop coping skills and self-regulation skills regarding frustration, anger management, social situations, thoughts and feelings that may act as a catalyst with respect to emotional challenges and meltdowns.

8. On-going consultation with Joe_’s consulting neurology team to discuss and manage medication regimens that may benefit overall functioning. This should be done in conjunction with intensive counseling services to develop coping skills and self-regulation skills regarding social situations, thoughts and feelings that may act as a catalyst with respect to disruptive behavior and social challenges.

9. Continue to utilize DRO (differential reinforcement of other behavior) procedures to “catch Joe_ being good”. The goal of differential reinforcement is to increase the frequency of appropriate behaviors while simultaneously decreasing the frequency of maladaptive behaviors such as disruptive behavior and non-compliance. For example, offer Joe_ verbal praise on a rich schedule of reinforcement when he is engaging in behavior other than the target behaviors of disruption and non-compliance (i.e.: following directions, working appropriately, talking in a calm voice, etc.). Offer praise on a schedule of every 10 minutes for 1 week. Increase the praise interval by 5-minutes each week.

Thank you for the opportunity to participate in Joe’s care. If you have questions or concerns, please feel free to contact me (email address and phone).
**Sample 2**

**Student:** CHILD  
**School:** Elementary  
**Date of Birth:** 2006  
**Grade:** 1st  
**Date of Report:** 2014

**Reason for Referral**
A functional behavior assessment (FBA) was requested to determine appropriate recommendations for the following skills deficits and interfering behaviors exhibited at school.

**Interfering Behaviors:**
- **Non-Compliance:** not initiating a response for following staff directions within 5 seconds of the given direction.
- **Leaving the Area:** any instance of leaving the area without staff permission.
- **Aggression:** any instance of pushing or hitting peers.

**Skill Deficits:**
- Following whole group routine-based instructions throughout the day
- Transitioning from a high preferred activity to a low preferred activity
- Appropriate play skills
  - Cooperative play
  - Appropriate play themes
- Social Skills
  - Greeting peers/adults
  - Initiating comments with peers
  - Proximity to peers
  - Gaining attention

**Assessment Methods**
Functional Assessment Interview  
Direct Observation

**Functional Assessment Interview**
An interview was conducted with Anika’s classroom aide, Ms. Millman. Ms. Millman described the skills deficits and interfering behaviors which are problematic in her classroom and are impacting Anika’s ability to access the school curriculum.

**Interfering Behaviors**

*Non-Compliance:* Non-Compliance includes not initiating a response for following staff directions within 5 seconds of the direction. This behavior is exhibited quite frequently and can occur several times in a 45 minute lesson. Ms. Millman reports these behaviors typically occur during work times or during transitions suggesting a possible function of escape or avoidance.

*Leaving the area:* Leaving the area is any instance where Anika is outside her expected area without staff permission. Ms Millman reports Anika can display this behavior when she is in area when there are no instructional activities (i.e., cafeteria and playground) and when the subsequent activity will be work/demand related. This behavior in the past used to occur at a frequency of one time per day and more recently occurs at a frequency of two times per month. Possible functions for this behavior could be avoidance or attention motivated.

*Aggression:* Aggression occurs when she engages in pushing or hitting of peers. Ms. Millman reports this occurs at a moderate frequency of about two times per week. It is likely the function of this behavior is peer attention because it is exhibited when she is located in proximity to her peers and usually ends with her peers verbally interacting with her.
Skill Deficits
In addition to the interfering behaviors, Ms. Millman indicates there are a range of skill deficits that are impacting Anika’s ability to access the school curriculum as well as engage in appropriate social interactions with peers.

Transitions: Ms. Millman reports that Anika requires verbal and sometimes physical guidance to comply with typical daily routines throughout the day. She at times needs additional verbal incentives, bribes or discussions with adults to have her transition from one activity to the next. There is no formal incentive system used by teachers.

Play Skills: During less structured or transition time, Anika demonstrates inappropriate peer interactions including aggressive interaction with her peers such as rough play and pushing. She exhibits minimal interactions with peers, and rather depends on them for interaction. The goal is for Anika to appropriately interact with peers by initiating and responding to comments and/or questions and engaging in cooperative play with a variety of play materials and types of play.

Other Information
When asked regarding Anika’s school schedule, Ms. Millman reported that Anika has little behavioral difficulty during small group instruction (between 9 and 11am). At 11am, she begins to have more difficulty being that she returns to the large group regular education class and engages in a special or classroom work/center time. These times usually involve paper/pencil tasks if she is does not have a special (i.e., Music or Gym). She has difficulty about one time per week coming back in from recess which occurs around 11:55. Her behavior can be improved with transition warnings and incentives (i.e., game between Anika and her two friends to see who is the last one to line up). At 12:15, Anika has lunch. Although her behavior is considered appropriate for the majority of the week, she can be aggressive with peers a few times per week. After lunch (around 12:40), during DEAR time she has difficulty picking too many books and wants to read them all, which can cause difficulty transitioning back to the next activity. Her next activity is Calendar which occurs around 1:05. After Calendar, Anika has math in a small group setting. In this setting, her behavior tends to be better.

Direct Observations
Observations were completed in both large group and small group settings, as well as the playground on two separate occasions to gather additional data on target behaviors, rates of occurrence, and to identify antecedents and consequences associated with the target behaviors. During the classroom observations, the following activities were observed: Whole group Gym time, snack, transitions, and small group instruction.

Engagement
The following table displays Anika’s and her peers behavior during small group instruction when there was one staff with two students. Her behavior was very appropriate and at similar rates to her peers. Her off-task behaviors included playing with items (e.g., chapstick and shoes) and occurred at low levels. She was able to spend the majority of the time engaged in the lesson.
The next observation of engagement occurred during a small group instructional setting where the staff to student ratio was two teachers to seven students. As the graph indicates, Anika was very appropriate and able to engage well during the lesson, as did her peers. Her only instance of off-task behavior was calling out.

![Graph showing percent of observed time on-task and off-task for Ellen and Peer.]

**Compliance**

The following graph displays the compliance data collected across the two days of observations. The data was collected each time a direction was given to Anika from a staff member. The data investigates the percentage in which Anika followed directions, but also aspects of the directions given. Each of these aspects of giving directions is described below the graph.

![Bar graph showing compliance data.]

The first bar on the left indicates the frequency of individual directions. It appears that most directions given to Anika are individual ones. This is important because if she was having difficulty following large group directions then we may need to teach her attending skills. However, in this instance attending skills are not an issue, but rather her preference in following the direction.
The second bar indicates her rate of compliance. She was 52% compliant to these directions. We would expect a compliance rate of 85% or better for most students.

The third bar represents the frequency at which the direction was repeated if it was not followed the first time given. Research indicates that when noncompliance occurs, effective directions are repeated. It is best that this percentage is above 90% or more. If Anika knows that staff will not follow up on a direction then she will be less likely to follow it.

The fourth bar is the frequency of directions stated as a direction (i.e., open the door) versus a question (i.e., Can you close the door please?). Effective directions are stated as a directive. During these observations, staff demonstrated this aspect well.

The fifth bar indicates the frequency with which eye contact is provided to Anika when giving a direction. Providing eye contact to students when a direction is given is found to increase compliance. It would be best to have this bar about 80% or greater.

The sixth bar relates frequency of reinforcement. Providing reinforcement at a level of 1 out of 4 times that she complies (about 23%) is considered effective for a classroom that has little to no problems with compliance. However, for students who have difficulty complying it is best to have at least a 1:1 ratio of reinforcement to compliance until the rate of compliance reaches 80%.

The last bar, or the bar the furthest to the right, indicates the frequency with which Anika followed through when a direction was repeated. This occurred about 29% of the time when a direction was repeated. It is best to have an additional procedure in place to have consistency when Anika does not follow a direction when repeated a second time.

**Aggression**

Small and large group activities were observed during each of the observations (3/29/06, 4/5/06). During these observations Anika demonstrated aggressive behavior 3 times and there were 34 instances of non-compliance.

<table>
<thead>
<tr>
<th>Antecedent</th>
<th>Behavior</th>
<th>Consequence</th>
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</thead>
<tbody>
<tr>
<td>Proximity to Peer (100%)</td>
<td>Aggression</td>
<td>Peer interaction mediated by Teacher (100%)</td>
</tr>
<tr>
<td>Academic Direction (100%)</td>
<td>Non-Compliance</td>
<td>Ignored (46%)</td>
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<td></td>
<td></td>
<td>Teacher Attention (54%)</td>
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</tbody>
</table>

During the instances of aggression, Anika was next to a peer and she would physically grab a peer or hit a peer. A verbal interaction with the peer would follow, as well as support from her aide. Each of the aggressive behaviors occurred during a time when there were less structured activities in place.
**Antecedents:**
- Move from High Preferred to Low Preferred Activity
- Academic Direction

**Desired Behavior:**
Follow teacher direction

**Consequence:**
- Complete work and gain teacher attention

**Current Behavior:**
Non-compliance

**Consequence:**
- Escape demand
- Teacher Attention

**Alternate Behavior:**
- Asking for a break
- Asking for help

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**Antecedents:**
- Peers in Proximity

**Desired Behavior:**
- Appropriately interact with peers

**Consequence:**
- Positive Peer attention

**Current Behavior:**
- Aggression to Peers

**Consequence:**
- Attention from peers

**Alternate Behavior:**
- Teach peer interaction skills; requests for peers to play with her
Functional Assessment Summary Statements

Recommendations

Anika has been having difficulty with following teacher directions as well as interacting with her peers. Her teacher’s concerns are regarding her interfering behaviors as well as her skills deficits and the impact they are having on accessing the curriculum and developing functional interactions with her peers. Interviews and observations have helped to identify the needs and future direction of Anika’s programming. Based on the information gathered, the following recommendations can be made:

1. Anika would benefit from small group social skills instruction to develop appropriate social interactions with peers in a controlled supported environment. It is recommended these groups start with 1-2 peers. Facilitation from a staff member familiar with the principles of Applied Behavior Analysis for these small group interactions would be beneficial. Staff should utilize these principles to demonstrate and model appropriate interactions, follow through with reinforcement strategies, and apply appropriate corrective procedures when necessary.

Her aggressive behavior with peers does not appear to be an attempt to gain a tangible or to prevent access to an item from a peer. Rather she appears to use this behavior to interact with her peers. She would greatly benefit from learning to interact during semi-structured interactions and moving slowly to independent social play activities.

2. A Behavior Support Plan (BSP) should be developed based on the above displayed functional assessment summary statements for compliance as well as appropriate interactions with her peers. The BSP should be employed throughout environments to reduce interfering behaviors and reinforce following directions.

If Anika does not want to follow a direction, if it is not intrinsically important to her, then external reinforcement is necessary to provide her with motivation to follow through with the expected activity. As such, it is recommended that the behavior support plan include a positive consequence procedure whereby she is reinforced frequently for following directions. She had a previous program which reinforced her following directions. It is recommended that her team review this program and determine if this would be appropriate for Anika or whether she may need something more intensive. Her level of non-compliance should inform the level of her program. In essence, more frequent non-compliance should lead to more frequent periods of reinforcement for her being compliant (i.e., at least a 1:1 and ideally a higher ratio of reinforcement to compliance).

Her BSP should include a section targeting appropriate interactions with peers. Currently, she has limited skills in verbally engaging with peers, and this behavior needs to be taught quickly. However, prior to her being independent in demonstrating this skill with her peers, staff should assist by intervening, modeling the appropriate interaction, and following through with corrective feedback with Anika.

3. Behaviors should be assessed frequently through the analysis of daily data collection throughout environments. Data should be collected on the following behaviors: following directions (partial interval or occurrence during activity), appropriate interactions with peers (partial interval or occurrence during activity). Changes in expectations and goals for Anika should be based on this data. It is recommended that these goals be consistent with IEP programming, if her IEP includes behavioral goals.

Thank you for the opportunity to contribute to Anika’s program. It was a pleasure to observe and interact with her and her staff. If you have any questions or comments about these recommendations please contact me at (XXX) XXX-XXXX or via email at XXXX.

_________________________
Board Certified Behavior Analyst
As you read this book, you may think of questions like “How can I better understand how my child's brain injury may affect their behavior?” or “What resources can help me educate my child's school district about the effects of brain injury?” The purpose of this resource index is to point towards answers to your questions.

The resource index is organized by chapter. Each chapter may bring up questions related to the content. There are questions for each chapter and beneath each question, a listing of possible resources. Some resources can come directly from the Brain Injury Alliance of New Jersey's programs, while others can be found on the Internet or by calling another agency, such as the Statewide Parent Advocacy Network. We hope this resource index will help you help your child.

**Chapter 2: Brain Injury and Behavior**

What resources can help me learn how my child’s brain injury may affect their behavior?

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
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<tr>
<td><strong>Brain Injury Alliance of New Jersey Helpline and Borrow-and-Borrow Library</strong>&lt;br&gt;<a href="http://bianj.org/helpline">http://bianj.org/helpline</a>&lt;br&gt;<a href="http://bianj.org/publications">http://bianj.org/publications</a>&lt;br&gt;800-669-4323&lt;br&gt;<a href="mailto:info@bianj.org">info@bianj.org</a></td>
<td>Our Helpline Specialists can answer questions about pediatric brain injury and guide you to professionals like pediatric neuropsychologists.&lt;br&gt;Our Browse-and-Borrow Library has many books and videos on behavior and brain injury; you can borrow these materials free of charge.</td>
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<tr>
<td><strong>Brain Injury Alliance of New Jersey: Brain Injury Basics, Adjustment to Brain Injury</strong>&lt;br&gt;<a href="http://bianj.org/brain-injury-basics">http://bianj.org/brain-injury-basics</a>&lt;br&gt;<a href="http://bianj.org/adjustment-brain-injury">http://bianj.org/adjustment-brain-injury</a>&lt;br&gt;800-669-4323&lt;br&gt;<a href="mailto:info@bianj.org">info@bianj.org</a></td>
<td>Brain Injury Basics and Adjustment to Brain Injury are free information sessions offered around the state. Each session provides useful information on the effects of brain injury and the process of family adjustment and coping. You can register online or by calling BIANJ.</td>
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<tr>
<td><strong>Brainline</strong>&lt;br&gt;<a href="http://www.brainline.org/">http://www.brainline.org/</a></td>
<td>Brainline is a good informational website, with articles such as “Understanding Your Child’s Behavior after Severe Brain Injury” and videos such as “Is Your Child the Class Troublemaker or Does He Have Traumatic Brain Injury”.</td>
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What types of interventions are appropriate for behavioral challenges after brain injury?

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<td>Our Helpline Specialists can discuss possible interventions for behavioral challenges, help you understanding funding options such as insurance and help you find a professional.&lt;br&gt;Our Browse-and-Borrow Library has some books that discuss specific interventions and others that offer a general overview of them.</td>
</tr>
<tr>
<td><strong>Information on Pediatric Neuropsychology</strong></td>
<td>Pediatric Neuropsychologists provide evaluation and treatment for children with brain injury, and can help parents come up with treatment plans for their children with behavioral problems. The websites listed here offer introductory information on pediatric neuropsychology. You can call the BIANJ Helpline if you are looking for a neuropsychologist in your area.</td>
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<tr>
<td><strong>Information on Functional Behavior Analysis</strong></td>
<td>Functional Behavior Analysis is an evaluation of behavior patterns in the classroom or home that provides families with information on how to manage behaviors in all environments. The websites listed here offer introductory information on Functional Behavior Analysis. You can call the BIANJ Helpline if you are looking for Functional Behavior Analysts in your area.</td>
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<td><strong><a href="http://www.behavioradvisor.com/FBA.html">http://www.behavioradvisor.com/FBA.html</a></strong></td>
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<td><strong><a href="http://www.ped.state.nm.us/RtI/behavior/4.fba.11.28.pdf">http://www.ped.state.nm.us/RtI/behavior/4.fba.11.28.pdf</a></strong></td>
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<td><strong><a href="http://www.bridges4kids.org/IEP/fba.pdf">http://www.bridges4kids.org/IEP/fba.pdf</a></strong></td>
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<td><strong>Brainline</strong></td>
<td>Brainline is a good informational website, with articles such as “Understanding Your Child’s Behavior after Brain Injury”, “Handling Behavior”, and videos like “Learning to Minimize Risky Behavior for Teens with TBI”.</td>
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<td><strong><a href="http://www.brainline.org/">http://www.brainline.org/</a></strong></td>
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<tr>
<td><strong>Chapter 3: Brain Injury and Families</strong></td>
<td>How can we learn family communication strategies related to the prevention and management of behavioral challenges?</td>
</tr>
<tr>
<td><strong>Brain Injury Alliance of New Jersey Helpline and Borrow-and-Borrow Library</strong></td>
<td>Our Helpline Specialists help you think through problems related to communication between family members and provide resources, including supports and the help of professionals including family therapists. Our Browse-and-Borrow Library offers books and videos that discuss family communication, and offer helpful strategies and suggestions.</td>
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<td><strong><a href="http://bianj.org/helpline">http://bianj.org/helpline</a></strong></td>
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<td><a href="mailto:info@bianj.org">info@bianj.org</a></td>
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<td><strong>Brain Injury Alliance of New Jersey Children and Adolescent Support Groups</strong></td>
<td>BIANJ offers two support groups for children and adolescents affected by brain injury and their parents: one at Children’s Specialized Hospital in New Brunswick, and the other at Weisman Children’s Hospital in Marlton. The groups’ contact information is on our website.</td>
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<tr>
<td><strong>Family Support Organizations</strong></td>
<td>Every county in New Jersey has a Family Support Organization (FSO) to assist families whose children face behavioral challenges. FSOs offer a variety of services including peer support, support groups for parents, and more.</td>
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<tr>
<td><strong><a href="http://www.state.nj.us/dcf/families/support/support/">http://www.state.nj.us/dcf/families/support/support/</a></strong></td>
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**The Family Support Center of New Jersey**  
(800) 372-6510  

The Family Support Center is an information resource for families of special needs children. Services include a Helpline and “Training Calendar” that lists education opportunities by professionals who focus on helping families affected by their disabled children’s behaviors.

**TBI Express Partner Training**  

This is a training program offered by the University of Sydney that focuses on communication strategies after brain injury, providing video examples of successful communication strategies between family members and the person with the brain injury.

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### How can we help siblings and other family members adjust?

**Brain Injury Alliance of New Jersey Helpline and Borrow-and-Borrow Library**  
[http://bianj.org/helpline](http://bianj.org/helpline)  
[http://bianj.org/publications](http://bianj.org/publications)  
800-669-4323  
info@bianj.org

Our Helpline Specialists can talk to you about issues that child siblings of children with brain injury face, and discuss professionals who can help them learn about brain injury and how to cope with the effects of a sibling’s brain injury.

Our Browse-and-Borrow Library has several books and videos concerning how to explain brain injury to children, which can be resources in helping young siblings learn and cope.

**Brain Injury Alliance of New Jersey Children and Adolescent Support Groups**  
[http://bianj.org/support-groups](http://bianj.org/support-groups)  
800-669-4323  
info@bianj.org

BIANJ offers two support groups for children and adolescents affected by brain injury and their parents: one at Children’s Specialized Hospital in New Brunswick, and the other at Weisman Children’s Hospital in Marlton. The contact information for the support groups is available on our website at the link to the left.

**The Sibling Support Project**  
[https://www.siblingsupport.org/about-sibshops/find-a-sibshop-near-you](https://www.siblingsupport.org/about-sibshops/find-a-sibshop-near-you)

The nationwide Sibling Support Project offers a program, Sib Shops, that “provides brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting”. There are several Sib Shop programs in New Jersey, which you can find using the website directory to the left.

**Brainline**  
[http://www.brainline.org/](http://www.brainline.org/)

Brainline is a good informational website, with articles such as “My Child’s Brain Injury: Family Matters”, “Siblings of Children with TBI: What About Them” as well as videos like “Giving Support to Parents and Siblings of a Child with Traumatic Brain Injury”.

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How can families learn stress management and coping skills?

**BIANJ Helpline, Library**  
Helpline and Borrow-and-Borrow Library  
http://bianj.org/helpline  
http://bianj.org/publications  
800-669-4323  
info@bianj.org

Our Helpline Specialists can talk to you about stressors arising from a child’s behavior issues after brain injury, and point towards resources.  

Our Browse-and-Borrow Library has several books and videos concerning stress and coping in the context of pediatric brain injury, as well as resources specific to coping with behavioral problems that result from brain injury.

**BIANJ Adjustment to Brain Injury**  
http://bianj.org/adjustment-brain-injury  
800-669-4323  
info@bianj.org

Our Adjustment to Brain Injury information sessions are free sessions that discuss family emotional distress, adjustment, and coping after brain injury. You will have the chance to ask questions and learn about resources.

**BIANJ Support Groups**  
http://bianj.org/support-groups  
800-669-4323  
info@bianj.org

BIANJ’s support groups are a great resource for parents and other family members who are seeking to cope with the difficult impact of brain injury. We have support groups around the state, some of which are specific to family members, others of which are attended by family members and persons with brain injury.

**Family Support Organizations**  
http://www.state.nj.us/dcf/families/support/support/  

Every county in New Jersey has a Family Support Organization (FSO) to assist families whose children face behavioral challenges. FSOs can help families develop coping skills through involvement in their support groups, peer to peer support, and information about helpful local resources like family therapists.

**Brainline**  
http://www.brainline.org/  

Brainline is a good informational website, with articles such as “Coping with Loss and Change”, and “Managing Stress Effectively After TBI” as well as videos like “How Therapy After Brain Injury Can Help Identify the Elephant in the Room”.

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**Chapter 4: What You Should Know After the Injury**

Is there help to get through the process of transitioning from my child’s inpatient hospital or rehabilitation stay to home and school?

**BIANJ Helpline, Library**  
Helpline and Borrow-and-Borrow Library  
http://bianj.org/helpline  
http://bianj.org/publications  
800-669-4323  
info@bianj.org

Our Helpline Specialists can talk to you about the transition process, and help you understand what steps to take to set up appropriate services in the school and in the community.  

Our Browse-and-Borrow Library has several books and videos about pediatric brain injury, the role of the school system after discharge from an inpatient setting, and how to set up the home to ensure a child’s safety after discharge.
### BIANJ Support Groups

**http://bianj.org/support-groups**
800-669-4323  
info@bianj.org

BIANJ’s support groups are a great resource for parents and other family members going through the transition process from an inpatient setting to home and school. Parents and other family members can share their experiences with you and help you cope and prepare.

### BIANJ Family Support

800-669-4323  
info@bianj.org

Our Family Support Specialists are advocates and professionals with extensive experience with brain injury, who can help you understand the process of transitioning from hospital/rehab back to the community, work with the school team to set up special services, and work with other community agencies to set up supports. You can ask about the Family Support program by calling BIANJ’s Helpline or emailing us.

### Statewide Parent Advocacy Network

**http://www.spanadvocacy.org/**  
(800) 654-7726

The Statewide Parent Advocacy Network (SPAN) can answer questions about transition from hospital / rehab to home, with their focus on the provision of special education services once a child has returned from hospital / rehab to the school and is in need of special services.

### Chapter 5: Managing Behavior at School & Home

What resources are available for advocating on behalf of a child’s needs with the school district?

### BIANJ Helpline, Library

**Helpline and Borrow-and-Borrow Library**  
**http://bianj.org/helpline**  
**http://bianj.org/publications**

800-669-4323  
info@bianj.org

Our Helpline Specialists can talk to you about advocating with the school district on a child’s behalf, including the procedures involving in requesting 504 and IEP meetings, and what to do if the school is not being cooperative.

Our Browse-and-Borrow Library has several books and videos about children with brain injury in the educational setting, that includes several resources on family-school advocacy.

### BIANJ Family Support

800-669-4323  
info@bianj.org

Our Family Support Specialists are advocates and professionals with extensive experience with brain injury, who can advocate for your child with the school district and other entities. You can ask about the Family Support program by calling BIANJ’s Helpline or emailing us.

### Statewide Parent Advocacy Network

**http://www.spanadvocacy.org/**  
(800) 654-7726

The Statewide Parent Advocacy Network (SPAN) is a non-profit “one-stop resource” for parents of special needs. Help from SPAN might include technical information about 504 and IEP implementation, referrals to advocates and free information sessions that address many aspects of the special education system.

### Disability Rights NJ

**http://www.drnj.org/**  
(800) 922-7233

Disability Rights New Jersey is the state’s designated protection and advocacy agency for people with disabilities. One of the services they offer is attorney and advocate programs for special education, especially when special education conflicts have entered into legal stages of mediation, due process and beyond.
**Chapter 6: When Crises Happen—Getting Help**

What resources are available to help my family prevent and prepare for behavioral crises?

<table>
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<tr>
<th>Resource</th>
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<tr>
<td><strong>BIANJ Helpline, Library</strong>&lt;br&gt;Helpline and Borrow-and-Borrow Library</td>
<td>Our Helpline Specialists can talk to you about resources you can access in the event of a behavioral crisis, and provide you with the appropriate professional references for help in a crisis as well as crisis prevention planning. Our Browse-and-Borrow Library has several books and videos about severe behavior after brain injury and ways to cope with a crisis.</td>
</tr>
<tr>
<td><a href="http://bianj.org/helpline">http://bianj.org/helpline</a></td>
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<tr>
<td><a href="http://bianj.org/publications">http://bianj.org/publications</a></td>
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<tr>
<td>800-669-4323</td>
<td><a href="mailto:info@bianj.org">info@bianj.org</a></td>
</tr>
<tr>
<td><strong>BIANJ Family Support</strong></td>
<td>Our Family Support Specialists can work with your family, to figure out what supports to access in order to prevent crises or receive support if a crisis does occur. You can ask about the Family Support program by calling BIANJ's Helpline or emailing us.</td>
</tr>
<tr>
<td>800-669-4323</td>
<td><a href="mailto:info@bianj.org">info@bianj.org</a></td>
</tr>
<tr>
<td><strong>Mobile Response to Behavior Crises</strong></td>
<td>If a behavior crisis does occur, you can quickly access help through the Mobile Response and Stabilization Services (MRSS) offered by service providers in each New Jersey county. MRSS defuse immediate crises, keep families safe, and provide additional follow-up services to maintain children safely in their own home.</td>
</tr>
<tr>
<td><a href="http://www.state.nj.us/dcf/families/csc/mobile/">http://www.state.nj.us/dcf/families/csc/mobile/</a></td>
<td>1-877-652-7624</td>
</tr>
<tr>
<td><strong>Family Support Organizations</strong></td>
<td>The Family Support Organizations are a good resource to help families prevent behavior crises by linking them to peer support, support groups and other resources that help families pro-actively prevent a behavioral crisis.</td>
</tr>
<tr>
<td><a href="http://www.state.nj.us/dcf/families/support/support/">http://www.state.nj.us/dcf/families/support/support/</a></td>
<td></td>
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<tr>
<td><strong>Family Crisis Handbook</strong></td>
<td>The “Family Crisis Handbook” is a great, free resource that discusses various aspects of behavior crisis, including prevention, resources when a crisis does occur, and family coping.</td>
</tr>
</tbody>
</table>

Are there resources to help families develop support networks of friends, extended family members, and community members?

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BIANJ Helpline, Library</strong>&lt;br&gt;Helpline and Borrow-and-Borrow Library</td>
<td>Our Helpline Specialists can talk to you about developing a support network, sharing stories and suggestions on this topic and articles that have helped families expand their supports. Our Browse-and-Borrow Library has many books on the topic of locating and expanding community resources and support networks for families of children affected by brain injury.</td>
</tr>
<tr>
<td><a href="http://bianj.org/helpline">http://bianj.org/helpline</a></td>
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<td><a href="mailto:info@bianj.org">info@bianj.org</a></td>
</tr>
<tr>
<td><strong>BIANJ Support Groups</strong></td>
<td>BIANJ's support groups are a great resource for parents and other family members who are seeking to develop a support network. The individuals who attend these groups can give you advice and support and share with you the resources they access in their own community.</td>
</tr>
<tr>
<td><a href="http://bianj.org/support-groups">http://bianj.org/support-groups</a></td>
<td></td>
</tr>
<tr>
<td>800-669-4323</td>
<td><a href="mailto:info@bianj.org">info@bianj.org</a></td>
</tr>
<tr>
<td>Family Support Organizations</td>
<td>Every county in New Jersey has a Family Support Organization (FSO) to assist families whose children face behavioral challenges. FSOs can help families develop coping skills through involvement in their support groups, peer to peer support, and information about helpful local resources like family therapists.</td>
</tr>
<tr>
<td><a href="http://www.state.nj.us/dcf/families/support/support/">http://www.state.nj.us/dcf/families/support/support/</a></td>
<td></td>
</tr>
<tr>
<td>CaringBridge</td>
<td>CaringBridge is a free website that helps families plan supports, coordinate care, and receive help from those who choose to join their support network; it also allows the family to keep people informed and share messages of hope in a protected, respectful space.</td>
</tr>
<tr>
<td><a href="http://www.caringbridge.org/">http://www.caringbridge.org/</a></td>
<td></td>
</tr>
<tr>
<td>Brainline</td>
<td>Brainline is a good informational website, with articles such as “Making Connections After Brain Injury” and “The Power and Potency of Social Capital”, and videos like “Finding the Right Caregiver after a Brain Injury”.</td>
</tr>
<tr>
<td><a href="http://www.brainline.org/">http://www.brainline.org/</a></td>
<td></td>
</tr>
</tbody>
</table>