



NASHIA Tip of the Month!

Children and Youth with Traumatic Brain Injury

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Traumatic brain injury is a leading cause of death and lifelong disability among children and young adults in the United States. The estimated average number of TBIs that occur among children ages 0 to 14 is 511,257. In contrast the number of TBIs in adults aged 65 and older is 237,844. TBI- related emergency department visits accounted for a larger number of children (92.7) than in older adults (59.7%) (CDC 2002-2006 estimates).

The effects of TBI on children differ in several ways from the effects on an injured adult:

- Because the child's brain is still developing; injury may alter the course of development of the brain and its functions.
- After a brain injury, previously learned information, which provides important building blocks for subsequent learning, is retained and used. However, in very young children, these building blocks are relatively few, handicapping them as learners in comparison to similarly brain-injured older children or adults, who have larger foundations of intact information.
- The effects of the TBI on the child may not be seen directly after injury, but only become apparent in the child's life when, during the course of the child's development, affected skills are called upon. <http://icahn.mssm.edu/research/centers/brain-injury-research-center-of-mount-sinai/resources/faq/children>.

The effects of traumatic brain injury on children and their families are multi-faceted and can last for months and years post injury. Children's Rehabilitation Service (Alabama Title V Children with Special Health Care Needs) a Division of the Alabama Department of Rehabilitation Services in 2001 developed PASSAGES, a community-based family centered system of care to address the unique needs of this population. The centerpiece of PASSAGES is a care coordination model that assures access to comprehensive and coordinated services from hospital discharge to integration into home, school, and community settings. The following are lessons learned from the implementation of PASSAGES.

The outcomes for children are not only impacted by access to and quality of medical care and rehabilitation, but also by the availability of services and supports to their families and caregivers. For this reason, linking families to all potential resources in a timely manner is crucial. However, monitoring of these children and their families across the remainder of their development post injury can be key in maximizing potential outcomes for them.

For families of the newly injured child, easing the transition from hospital to home will mean something different for everyone. Individualized supports help ensure that families receive the information and resources that are specific to their needs and desires, and at a time when they can be most receptive to

the information. While there is a multitude of information that is deemed critical to learn in order to care for a child with a brain injury, families can only absorb so much information during the acute phase of injury and treatment. Providing a community support to reinforce and continue education and coordination of services beyond discharge can be invaluable to a caregiver who feels overwhelmed and underprepared to meet such challenges.

Families must often juggle multiple abrupt changes in their life aside from the injury of their child. There may be multiple children or family members injured and admitted to various facilities across various parts of a state. For those who may have limited social supports, it can be helpful to have assistance in prioritizing where to focus their time and energy until circumstances can stabilize.

Some families may experience the loss of loved ones and friends but yet have difficulty finding the time to address their needs to grieve. Specific resources for grief counseling or grief networks can remind family members of the importance to recognize the losses in their lives and develop healthy ways to work through the grief process over time.

Time from work to visit or care for children can jeopardize the employment of some families, and cause the loss of employment for others. Families often need financial resources to bridge the gaps of their own means of providing for their families. These resources may be provided by federal, state or local community based agencies. Families may need assistance in applying for these services and learning how to utilize them appropriately.

School aged children often need academic accommodations or supports not previously required before a brain injury. This can sometimes mean the need to transfer from a private school, where such services and supports may not be provided, to a public school, where various services are mandated. For those students who were already served in public school, these new needs can sometimes create a panic, which is driven by misconceptions or inaccurate information that they will suddenly become labeled, become separated from their peers, or even face ridicule because of their needs. Providing families with specific information on the process for providing their child with the necessary supports, as well as their rights and responsibilities in developing these supports can alleviate many unnecessary concerns. In the same vein, educators may also have misconceptions and unrealistic expectations about a child's behavioral and academic performance. Providing them with accurate medical information and supports for problem solving or voicing concerns is equally as important.

Lack of sophistication or experience with various systems can intimidate and even frighten some individuals into feeling that they cannot be an effective advocate for their child. It is helpful for individuals to gain some basic understanding of the various systems that they will encounter so as to clear up any misconceptions, gain an understanding of their rights and the rights of their children and to feel empowered as an advocate and provider for their child. This can be done on an individual basis, through formal support groups or even by linking individual parents together.

As children grow up with head injuries, their medical, cognitive and social functioning may change and require more or less supports and interventions. It is important for families and caregivers to have information about the spectrum of services that their community or state can offer as their children grow into adulthood. While adult services may not be assessable to children or teens, having information on the spectrum of services available when needed can alleviate a caregivers concerns over what may be available to their child as they age.

Additional information about the PASSAGES Community-Based, Family- Centered Model for Developing a System of Care for Children and Youth with Traumatic Brain Injury can be found at: www.rehab.alabama.gov/docs/traumatic.../passages-draft.pdf

For further information contact NASHIA at info@nashia.org.