

# Improving Educational Outcomes for Children and Youth with Traumatic Brain Injury (TBI)

National Association of State Head Injury Administrators in partnership with the National Collaborative on Children's Brain Injury

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# Introduction

The National Association of State Head Injury Administrators (NASHIA) has developed this paper to engage the U.S. Department of Education in collaboration with traumatic brain injury (TBI) stakeholders for purposes of improving academic outcomes for students with brain injury in juvenile justice/correctional systems, general education classroom settings, and for those receiving special education and related services. Although the current headline today is on sports-related concussions, students may incur a TBI as the result of a traffic crash, fall, playground injury, violence and child abuse. According to the Centers for Disease Control and Prevention (CDC):

- TBI is a leading cause of death and disability in children and youth in the United States.
- Forty percent of Americans diagnosed with mild TBI (mTBI) are children between the ages of 15-19 years old.
- From 2006-2010, more than half (55%) of TBIs reported among children 0 to 14 years were caused by falls.
- At least 75% of all TBIs reported are classified as mild/concussion (mTBI).

Since the late 1980's, state education departments have developed resources and training to help educators with assessment and teaching students with brain injury. In some states, the U.S. Department of Health and Human Services Federal TBI State Grant Program, authorized by the TBI Act of 1996, as amended, has provided the impetus to develop these resources in collaboration with state TBI programs, which may reside in state health, vocational rehabilitation, education, and social services agencies. In addition to these efforts:

- At least ten states' TBI programs are currently collaborating with their state juvenile justice and corrections systems to identify youth who are incarcerated who may have sustained a TBI affecting academic learning; behavior; and community integration once released. (AL, AK, CO, IA, IN, OH, NE, NY, PA, TX, and UT).
- As the result of a National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) grant, Glang et al. 2015 found approximately half of state Departments of Education have identified personnel focused on brain injury. The amount of time varies significantly from state to state. (The Center on Brain Injury Research & Training, University of Oregon.)
- Since 2009, when the state of Washington passed the first "return to play" law, all states have enacted similar legislation to manage sports-related concussions.
- Seven states have since enacted legislation with provisions that reference a "return-to-learn" policy after a concussion: Hawaii, Maryland, Massachusetts, Nebraska, New York, Vermont, and Virginia.
- The U.S. House Energy and Commerce's Subcommittee on Oversight and Investigations is holding a series of roundtable discussions on the impact of sports-related concussions, including youth sports, which was the topic of the May 2016 discussion.

• The National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC) is soliciting nominations for school re-entry programs designed to help children return to their learning environment after concussion and other TBI for purposes of on-site visits and assistance with program evaluation.

While these efforts are appreciated, they are few and specific in the states in which they have developed. As brain injury is a complex disability, it takes many partners to ensure children/youth with brain injury are properly identified and supported. To move forward, NASHIA asks that the U.S. Department of Education collaborate with NASHIA and other stakeholders by:

- Participating on Centers for Disease Control and Prevention (CDC), National Center in Injury Prevention and Control's quarterly TBI stakeholder calls, which focuses on the Injury Center's initiatives, including children's initiatives;
- Engaging with states involved in juvenile justice projects to develop best practice guidelines for identifying and supporting students with TBI in the juvenile justice settings, in keeping with ED's priority in juvenile justice;
- Working with NASHIA and other TBI stakeholders to develop guidelines for screening/identification, assessment and support of students with brain injury both in general and special education to ensure ED is meeting FAPE for these students;
- Designating brain injury as a priority as it relates to personnel preparation, both pre-service and in-service;
- Integrating technical assistance to states about brain injury through existing technical assistance priorities of OSEP;
- Integrating brain injury information and resources in materials produced by the department; and
- Engaging in stakeholder and Congressional discussions relating to "Return to Learn" after a concussion.

## **Educational Recommendations**

Recent work conducted by the National Collaborative on Children's Brain Injury (NCCBI) and projects supported by the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR) have indicated the need for better identification, assessment, and training of educators. As the U.S. Department of Education currently does not fund a national center on TBI to assist regular classroom educators and special education teachers and related personnel with identification, assessment, behavioral issues or teaching strategies, NASHIA recommends that ED consider establishing such a center. In absence of a designated center, then NASHIA recommends expanding the scope of existing centers, where pertinent, to help to address TBI-related disabilities, some of which are noted below.

The following are areas of concern we believe ED can help to address.

### **Juvenile Justice**

NASHIA applauds the Secretary's and ED priority of ensuring an appropriate education for youth involved in the juvenile justice system. The ED/Department of Justice's publication on "Guiding Principles for Providing High Quality Education in Juvenile Justice Secure Settings," notes the high number of youth in these settings with mental health and disabilities, however, the report does not address the disproportionate number of youth who are involved with the criminal justice system who have experienced brain injury. Literature indicates that there are between 26% and 50%. If these youth are not properly identified, the efforts of ED to ensure FAPE for those in the juvenile justice setting will fall short.

## Call to Action:

NASHIA recommends that ED partner with the states that have current initiatives in the juvenile justice settings to identify the best practices and resources for screening and identification of brain injury among this population and to better understand best practices for supporting youth with brain injury in the juvenile justice setting. ED is in a position to scale these efforts up and promote these practices across states by sending communications to state education agencies and youth services programs.

### General Education

1. Concussion (Mild TBI) and Moderate TBI

Students with mild to moderate TBI are usually integrated into regular education classrooms, sometimes with adaptations and modifications. Often, however, students who are injured at a younger age may return to the regular classroom, but the injury is not noted in school records as the student progresses from grade to grade. Then, when the long-term consequences of a TBI emerge affecting behavior and cognition, educators may fail to recognize the causation of the problems and attribute the problems to lack of interest, puberty or other reasons.

Concussions (mild TBI) has recently been identified as an emerging issue with an alarming rate of children/youth who have been identified as sustaining concussion annually. According to the Centers for Disease Control and Prevention (CDC) pediatric TBI accounts for 3,000 deaths, 29,000 hospitalizations, and 473,947 emergency departments (ED) visits in the US annually among children less than 15 years of age. At least 75% of all TBIs reported in the United States are classified as mild/concussion (mTBI). Forty percent of patients diagnosed with mTBI are children between the ages of 15-19 years old.

Nationally, concussion in youth is being recognized in the sports arena. "Return to Play" state laws are providing much public awareness with regard to the impact of sports-related concussions and whether athletes should continue to play once injured. Educators, physicians and families should also be aware of potential impact on educational learning – short-term and long-term. In addition, not all mTBIs are caused by a sports-related concussion and not all TBIs are mild. Public awareness and educational materials need to be developed nationwide to inform parents and health care providers as to the need to report children and youth who have sustained a TBI to their school districts and to understand and to look for TBI-disability symptoms which will impact academic learning. Thankfully the majority of children/youth with uncomplicated mild brain injury will resolve within 4-6 weeks with proper management and support by the families, schools and medical settings. The National Collaborative on Children's Brain Injury and the CDC are two entities working on developing consensus on best practices as it relates to return to learn.

## Call to Action:

ED should assist school districts in promoting awareness and educational materials to inform parents and health care providers as to the need to notify school districts when children and youth have sustained a TBI and how to look for TBI-disability symptoms which will impact academic learning.

ED is key in ensuring Return to Learn guidelines are distributed to states with technical assistance provided to states in setting up infrastructure within their schools to address the needs of children/youth in the general education setting who have sustained concussions.

ED should provide resources and materials to regular classroom teachers to understand TBI-related symptoms, regardless of cause and severity, and the impact on academic learning.

### **IDEA/Special Education**

#### 2. Identification and Reporting

Students with severe TBI who are hospitalized will generally be referred for special education and related services. However, this does not always happen particularly with regard to students who are injured during the summer months. Students with a mTBI may receive treatment in an emergency room or did not seek medical treatment at all. For whatever reason, determining appropriate methods, including screening tools, for identifying students with TBI-related disabilities needs to be addressed.

The extent of moderate to severe TBI among children and youth is well documented by the Centers for Disease Control and Prevention (CDC), as well as states through their emergency room, trauma registry, hospital discharge, and other health related data systems. While these current data systems have limitations in terms of identifying <u>all</u> Americans who sustain a TBI, it is concerning that the numbers reported through these systems do not correlate with the number of students with TBI as reported by states in accordance with the Individuals with Disabilities Education Act (IDEA) Child Find requirement, thus many believing that there is a significant under reporting of students with TBI. Approximately 145,000 children live with a TBI related disability, but the number of students enrolled in the TBI category of special education is 24,878.

### Call to Action:

With input from NASHIA and TBI stakeholders, ED can provide guidance on evidenced based practices for screening that can be implemented both by Child Find and through the pre-assessment process when determining eligibility for IDEA.

## 3. Improve Cognitive and Behavioral Assessments and Interventions

Once identified, assessment should include assessment of cognitive deficits in memory, attention, information processing, organization, speed, /learning and problem solving. Often, students will remember old learning, but not be able to learn new information. While symptoms may not be readily apparent, students may have problems with executive functioning which impact their ability to plan, organize, analyze tasks, remember things, prioritize, pay attention and get started on tasks – all necessary skills for students to engage in academic learning successfully. Educators and families may notice personality changes after TBI. Students with TBI can become over-stimulated easily (i.e. extraneous noise, too much information too quickly), which may lead to difficulty thinking and emotional distress. Physical activities, cognitive activities and fatigue can contribute to outbursts and inappropriate behavior. Understanding and assessing the student's environment to determine what may trigger behavioral problems will help to curb the behavior. And, understanding how to address depression and other mental health issues associated with TBI is imperative.

## Call to Action:

ED should expand the role of the Positive Behavioral Intervention and Supports (PBIS) to include appropriate behavioral assessments, interventions and supports for students with TBI-related behavioral problems.

## 4. Teaching Strategies

There are specific strategies that are useful in teaching students with TBI, including accommodations to assist with memory, organization, reducing distractions, and so forth. Impaired memory associated with TBI will prevent someone from being able to learn through rote learning, often used to help students to recall information. While the majority of students with mTBI may not need special education and related services, they may benefit from accommodations which may be delineated through 504 Plans and from trained educators who understand how to provide educational instruction that takes into account cognitive and behavioral problems, which often emerge long after the injury took place.

### Call to Action:

ED should expand its TA capacities to include issues pertaining teaching strategies for TBI.

### 5. Transition Services

Research related to transition planning for students with TBI is limited. Often, students are injured in their teens and as a result, their plans for the future are altered, as well as their concept of who they are since the injury. Many will graduate, but will find they cannot continue on to college as previously planned, or even complete a job application or handle multiple tasks required of vocational training, higher education or employment. In many schools the school guidance counselor at the secondary school level assumes the role of helping students with career choices. In some schools, their roles have often spilled over to mental health and substance use issues, but not TBI-related disabilities. Recognizing TBI-related issues and helping the student to plan accordingly after secondary education is critical – whether the student is receiving special education and related services or not. Identifying community resources and supports may assist in this effort.

## Call to Action:

Develop methods and procedures to identify, document, and widely disseminate research-based information on best practices in dropout prevention and intervention for students with TBI, particularly those who are injured in their teens.

ED should help develop guidelines for school guidance counselors with regard to assisting students with TBI with transitioning to vocational training, higher education or job planning.

# 6. Teacher Preparation

Educators need to be well-trained to address the needs of children with TBI, as no two injuries are alike and the symptoms vary considerably among those who sustain a TBI. Training, consultative services and resources will help educators to better identify, assess and educate children with TBI-related disabilities.

#### Call to Action:

ED, specifically OSEP, can be instrumental in supporting the existing Technical Assistance Centers to be well versed in brain injury in order to be able to provide TA to states regarding these issues.

### 7. Promote Promising Practices:

Several states have implemented an educational model developed by the Kansas Department of Education and the University of Kansas Medical Center to provide training, consultation, and technical assistance to educators serving students with brain injuries and their families. The Tennessee Project BRAIN, a partnership between the Tennessee Disability Coalition and the Department of Health's TBI Program, was created with a federal TBI State Grant to (1) partner with Tennessee hospitals to promote effective communication between healthcare professionals, families and educators; (2) reach out to families & students to share helpful tools and resources; (3) provide training and ongoing support to schools, families and healthcare providers in the early identification of children with TBI; and (4) connect all school faculty and staff to topical resources, information, and classroom supports. Similarly, the Pennsylvania BrainSTEPS School Re-Entry Consulting Program consults with school teams and families in the development and delivery of educational services for students with ABI. Additional states with similar efforts are: OR, CO, NE, and AZ.

## Call to Action:

Partner with these states to develop promising practices guidelines for all states. Ensure dissemination of these guidelines/practices.

### 8. Prepare and Inform Families

Parents, particularly parents with older teens who are injured, may not know their rights under IDEA or 504 or what to expect from the school. While state Parent Training and Information Centers are funded to assist parents with children and youth with disabilities, parents of students with TBI often do not know about these centers and/or these centers do not know how a TBI affects a student's learning to know how to help parents navigate through the educational process.

#### Call to Action:

State Parent Training and Information Centers should be equipped to help parents of children with TBI and provide outreach to ensure that parents have information needed.

### About the National Collaborative on Children's Brain Injury (NCCBI)

NCCBI was formed to develop recommendations for building statewide capacity to support students with brain injury. Although *there* are significant gaps across all service domains for children/youth with brain injury, NCCBI focuses first on community, family, and rehabilitation issues in relation to school services.

#### About the National Association of State Head Injury Administrators (NASHIA)

NASHIA's mission is to assist state governments in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. NASHIA has engaged in a variety of initiatives that relate to children/youth with brain injury. For further information about NASHIA contact Lorraine Wargo, RN, Executive Director, at <u>execdirector@nashia.org</u> or phone: 802-498-3349. Learn more about NASHIA at <u>www.nashia.org</u>. For more information about public policy contact Susan L. Vaughn, MEd, Director of Public Policy at publicpolicy@nashia.org.

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