Policy Recommendations for School Systems serving Students with Brain Injury

Did You Know?
Following traumatic brain injury (TBI), children experience persistent lower life satisfaction, reduced adaptive functioning and lower rates of participation in a variety of activities compared with children who have orthopedic injuries.¹ Those differences can persist throughout their formal schooling and across the lifespan.² More severe brain injuries carry a range of medical, health, cognitive, motor, emotional, and behavioral issues. Regardless of the severity of TBI, the significance of problems might not be realized until years after the injury when higher-level cognitive and behavioral functioning is required to meet typical developmental milestones, especially when the injury occurs at a very young age.³

Historically, TBI has been considered a low-incidence disability in public education; however, estimates indicate that nearly 145,000 children in the United States aged 0–19 are currently living with long-lasting, significant alterations in social, behavioral, physical, and cognitive functioning from a TBI. Yet, only 26,371 students nationwide are receiving special education services under the IDEA TBI eligibility category. A potential explanation may be that large numbers of students impacted by TBI are either not referred for special

education disability services or are misidentified and served under a different eligibility category of IDEA (e.g., SLD, OHI). This raises the possibility that many students are not identified and/or effectively served by educational practitioners in the public school system.

Using hospitalization data for moderate-severe TBI, a recent paper by the National Collaborative on Children’s Brain Injury (NCCBI) Public Policy Workgroup⁴ examined the discrepancy between the number of students expected to experience disability following hospitalization for TBI, compared with the number of students who receive special education services under the TBI eligibility category. With the exception of 6 states who expanded their state definition of TBI to include other forms of acquired brain injury, the number of students identified nationally under the Special Education TBI category is on average only 32% of the students who have moderate-severe TBI and who would be predicted to need special education services. Possible reasons for this discrepancy include lack of awareness about TBI as a disability, lack of communication between hospital and school, under-reporting of injuries by parents, and students with TBI receiving services under alternate disability categories.

**About NCCBI:** The National Collaborative on Children’s Brain Injury (NCCBI) is a collaborative of brain injury and school professionals working to improve services and supports for children with brain injury. NCCBI's current focus is on improving educational services for students with brain injury. Members of the NCCBI include:

- Family members of individuals with brain injury
- State Department of Education staff who provide statewide leadership and coordination of services for students with brain injury
- Special Education providers
- Administration for Community Living (ACL) TBI grant recipients who work closely with their state Departments of Education
- Representatives from both the ACL TBI Program and the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Representatives from the Center for Disease Control and Prevention (CDC)
- Pediatric brain injury researchers and clinicians
- National Association of State Head Injury Administrators (NASHIA) members
- Brain Injury Association of America (BIAA) members
- United States Brain Injury Alliance (USBIA) members

**Report to Congress on the Management of Traumatic Brain Injury in Children**

In 2018, the Centers for Disease Control and Prevention (CDC) created a Report to Congress entitled Report to Congress on the Management of Traumatic Brain Injury in Children: Opportunities for Action. The report describes the public health burden of TBI in children and adolescents, including the range of outcomes that may be experienced following a TBI.

The report stresses the importance of understanding gaps in care and developing approaches for optimal assessment, access to services, and service delivery to ensure that children with TBI have the best possible treatment and outcomes. In terms of Return to School, the Report points out that children and their families often experience difficulties accessing Return to School services, including longer-term formalized support, such as early intervention services, special education services, and support/accommodations through a Section 504 plan. Because of this, there is a critical need for follow-up care beyond the acute injury. The report includes the following Opportunities for Action:

**Opportunities for Action: Improving Children’s Return to School, Activity, and Independence After a TBI**

**Monitoring and service delivery**
- Educators and medical professionals within states can ensure that all children who return to school following a TBI are monitored and that needed services or accommodations are received.
- Educators and medical professionals should support the coordination of care across settings and providers that is centered on the comprehensive needs of children and their families.
- School personnel can prominently note identified TBI history in school records, and monitor children during critical transition periods, such as at transitions between elementary, middle school, high school, and then to adult roles.

**School transitions**
- Schools and state agencies can work with healthcare professionals to develop and evaluate healthcare-to-school transition processes for preschool children that better utilize state-level services to help with the identification and management of TBI when these children begin elementary school.
- Schools can monitor students as they transition between elementary to middle school and then from middle school to high school.
- Schools can consistently work with families to identify the optimal pathway to learning (and subsequent high school graduation) to enhance adult outcomes for children who have sustained a TBI.

**Opportunities for Action: Improving the Transition to Adulthood for Children with TBI**
- Evidence-based approaches supporting the transition to post-secondary education and employment for students with TBI need to be developed to ensure optimal adult outcomes and the effectiveness of these approaches in promoting healthy lifestyles for young adults needs to be evaluated.
- Partnerships between schools and state vocational rehabilitation agencies need to be developed to best utilize the federally mandated (WIOA) Pre-Employment Transition Services, between the ages of 13 and 21.

**Opportunities for Action: Improving Professional Training for Those Involved in the Management of TBI in Children**
• Enhanced training of educators in TBI management is needed within education curricula, as well as through the expanded use of in-service training models.

To support educators in aligning these opportunities for action with the Individuals with Disabilities Education Act (IDEA), specifically for students who have sustained a brain injury, NCCBI has created the following chart with information and recommendations. These recommendations focus on IDEA Part B, the federal law protecting students with TBI ages 3-21.

Many of the recommendations are also applicable to professionals working with very young children ages 0-3 receiving services through IDEA Part C. Part C is a family focused system that provides early interventions to infants and toddlers and their families to help them learn to work with their children and provide support to manage the cognitive, behavioral, communication, and other life changes associated with TBI. Recommendations in this paper should also be considered for children ages 0-3 including:

**Data Collection/Screening** tools that inquire about the child’s history of TBI

**Professional development** that addresses the long term and latent effects of TBI and takes into consideration that families and caregivers play a central role in their child’s recovery because they are responsible for making decisions about educational and long-term supports\(^5\)

**Monitoring of service delivery** especially during the transition from Part C to Part B (when the child turns 3 years old) to ensure continuity of services and continued family involvement in educational decision-making; and

**Ensure a smooth transition** from Part C to Part B by reinforcing regular collaboration among agencies serving young children with TBI and the school system so that all professionals serving children are knowledgeable about the needs of the child.

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| **Definition of TBI for ages 3 and above**<sup>1</sup> (20 U.S.C. Sec. 1401 [2004], 34 C.F.R. Sec. 300.8[c][12]) | The federal definition includes only traumatic brain injury (TBI) which are injuries caused by external force. As stated above, on average, the number of students identified nationally under the Special Education TBI category is only 32% of the students who have moderate-severe TBI, and who would be predicted to need Special Education services. This specific TBI definition can cause disparities in identification/services for students who have non-traumatic brain injuries (internal event) and who have similar educational needs. Some states have expanded their TBI definitions to include students who have sustained non-traumatic brain injury (injuries to the brain from an internal event, e.g., lack of oxygen or blood flow). States who have expanded their definitions have the potential for more alignment with strategies to meet the unique needs of students who have sustained any type of acquired brain injury (traumatic or non-traumatic). | **States can consider developing and implementing a screening, identification, and assessment protocol** containing three critical elements – staff education, screening and structured interview, and focused assessments. 6  
**Add screening questions about acquired brain injury to:**  
- Childhood Medical History/Developmental History forms used in the Child Find process  
- the students’ annual physical exam  
- every school’s kindergarten registration process.  
Based on the literature, there is support for providing similar academic supports for students with traumatic and non-traumatic brain injury.  
**States can examine the numbers of students in their TBI category, and whether they are identifying students who have sustained a TBI at the expected rates and are serving those students.** 7  
**States can examine whether students with non-traumatic brain injury are receiving the services/supports they need.** |

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7 Contact NCCBI for your state’s identified TBI statistics relative to the projected TBI prevalence rates - [drew.nagele.psyd@gmail.com](mailto:drew.nagele.psyd@gmail.com).
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<td>Evaluation Sec. 300.15</td>
<td>We have learned, since the early 90’s when the IDEA TBI category was first developed, that brain injury in students would prompt a different type of evaluation. It is more than just a blow to the head, now thought of as a chronic health condition or a chronic disease. The evaluation regulations do not specify evaluation tools for brain injury or the implications that brain injury may have on gaining accurate and complete assessment data. There is potential for better outcomes if appropriate training and tools are used for evaluation. Training for educators must include: • the long-term effects of TBI on learning and behavior and the impact of childhood TBI on the family, • practice with evidence-based interventions, and continued mentoring, feedback, and consultation in the school setting. Program development models that incorporate brain injury consultation in the school setting can help teachers feel more prepared and knowledgeable in working with students with TBI. Many states do not require secondary disability identification nor collect this data. Being able to track brain injury eligibility across multiple disability categories would afford knowing whether students with brain injury are getting services to meet their unique needs.</td>
<td>Adopt a neuropsychological or a neuro-educational framework which can provide valuable information about brain processes (e.g., executive functioning) issues common after TBI. Examples of such frameworks are: 1) The Colorado Building Blocks of Brain Development© Framework, developed as a general guideline and beginning “reference point” for professionals working with students where a brain injury is suspected or known to be present. The framework offers a wide range of suggested assessment tools and intervention strategies for students with brain injury. 2) North Carolina model of construct approach – school psychologists are trained and provide assessment of children with TBI. States can elect to track, collect, and analyze, secondary disability identification to provide training for special education providers on a neuro-educational framework, referenced above.</td>
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8 Glang, A., Todis, Sublette, Eagan Brown, & Vaccaro, 2010
9 Myers RK; Eagan Brown BL; Conway AT; Nagele DA; Vaccaro MJ; Kendi S; Zonfrillo MR. Examining a statewide educational consulting program for pediatric brain injury. *Clinical Pediatrics* 2017 1(11): 9922817732146
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Re-Evaluation Sec. 300.303 | IDEA requires periodic re-evaluation of eligibility, at least once every three years. Students with brain injury may need more frequent re-evaluation as they recover. IDEA allows this per IEP team decision, but many IEP teams are not aware of this need. | More frequent re-evaluation would be indicated for students in the recovery stage since students will be changing rapidly during the first couple of years after a brain injury - also for transitions between grades/schools.

Development, review, or revision of the IEP Sec. 300.324 | Students with brain injury need frequent IEP review as they recover. Goals may need to be modified or changed more frequently than annually. IDEA allows this per IEP team decision, but guidance to IEP Teams on this might lead to better services/outcomes. As learning/cognitive demands get higher in middle and high school, this can be harder for students with gaps in their executive function and they may need new supports to achieve transition successfully. | More frequent review and revision of the IEP for the purpose of tracking students’ developmental needs, throughout their education, and their transition to adult roles. The latter would occur starting at age 14 and consistent with the Workforce Innovation Opportunity Act (WIOA).

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| **Evaluation procedures**  
Sec. 300.304 | IDEA requires that evaluation be conducted in a way that is not discriminatory and in a way that is most likely to yield accurate information, including assessment of children with impaired sensory, manual, or speaking skills.  
Students with brain injury may need more accommodations in testing due to decreased stamina, alertness, processing speed, memory, communication status, etc. Also, it is not uncommon for skills/processing to come back after an injury, in a splintered or uneven manner - which can skew assessment data. | Ensure that the evaluation be done in a cognitively accessible fashion and must incorporate environmental learning observations.  
Ensure the use of appropriate accommodations in the testing process (example visual field cuts - oculomotor assessment, auditory processing, and acuity, etc.). |
| **Additional evaluation procedures**  
Sec. 300.500 | IDEA allows for the review of existing data in both evaluation and re-evaluation procedures. Students with TBI often have rich sources of data outside of the school setting (hospital records, rehabilitation records, records of private providers) that may be essential for the IEP team to use in identification and planning.  
Often, the IEP team does not think about outside data that can be critical to good identification and planning. Guidelines that remind IEP teams about possible outside sources of data to look for can be helpful in ensuring better outcomes for students with brain injury.  
Schools can better coordinate information about a brain injury known by some agents of the school with others (such as a school absence, sports or recreation injury, a car accident, an illness) so that proper and timely health evaluation may occur. | Regularly evaluate students’ absenteeism, outside health records for the existence of a health condition that can qualify a student for specially designed instruction.  
Educate teachers/school personnel about brain injury, as a health condition, and how a brain injury can manifest in different ways over time.  
States can consider partnering with their Departments of Health to provide specialized healthcare services for children with special healthcare needs (Title V Maternal and Child Health Services) that are not able to be met by the regular healthcare system. |
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**IEP Team**<br>Sec. 300.321<br>IDEA requires an individual who can interpret the instructional implications of evaluation results be part of the IEP team.<br>Outside evaluations conducted in clinic environments without the benefit of classroom/school observation may not reflect an accurate picture of a student’s functioning in the school environment and may be difficult to apply to the student’s school program.<br>Because students with brain injury have cognitive impairments that affect their ability to learn, they may require specialized evaluation (such as a neuro-educational evaluation). To meet this need, the team needs to develop the capacity internally or may need to find someone outside of their district to conduct and interpret a specialized evaluation.<br>Locate training opportunities for school district personnel who can administer neuro-educational evaluation, interpret the results, and align interventions and services.<br>**States can develop a brain injury program** that have team members who have brain injury specific training.\(^\text{12}\)<br>**Independent Educational Evaluation**<br>Sec. 300.502<br>IDEA provides parents with the right to an IEE when they disagree with an evaluation conducted by the school district.<br>Parents have the right to obtain an outside neuropsychological evaluation (or other specialized evaluations) in the IEE process.<br>Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) are in the US and Territories. These Centers perform a variety of services for children and youth with disabilities, families, professionals, and other organizations that support them. To find the PTI or CPRC that serves your community, go to: [www.parentcenterhub.org/find-your-center](http://www.parentcenterhub.org/find-your-center)<br>Ensure IEE’s are completed by a team who has training and experience in the identification of brain injury. Evaluations need to include classroom observations, and the identification of the needs of the student within the school setting.<br>Locate professionals who can administer neuro-educational evaluation, interpret the results, and align interventions and services.<br>**Child Find**<br>Sec. 300.111; Sec. 303.115; Sec. 303.302<br>Child Find requires all school districts to identify, locate and requiring medical documentation of TBI for students to be eligible for special education services can be a barrier to effective identification and service delivery. Students may lack documentation because they never sought medical attention, may not have access to medical documentation (e.g., foster/adopt, migrant families).<br>States can consider developing and implementing a screening, identification, and assessment protocol containing three critical elements – staff education, screening and structured interview, and focused assessments.\(^\text{13}\)<br>---\(^\text{12}\) Pennsylvania and Colorado have the statewide BrainSTEPS model - [www.brainsteps.net](http://www.brainsteps.net)<br>\(^\text{13}\) Dettmer, J., Ettel, D., Glang, A., & McAvoy, K. (2014). Building statewide infrastructure for effective educational services for students with TBI: Promising practices and recommendations. The Journal of Head Trauma Rehabilitation, 29(3), 224–232. doi:10.1097/HTR.0b013e3182a1cd68
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| evaluate all children (birth-21yrs) with disabilities, regardless of the severity of their disabilities. | Typically questions about brain injury are not included on annual screening/medical history forms. Research shows that multiple questions, asked in different ways, are necessary for parents to recall and identify an incident that could have resulted in a brain injury. Screening for TBI involves asking an informant (usually the parent/care giver, older children may be able to answer for themselves) a series of questions designed to determine whether a child has ever received a blow to the head that might have caused a brain injury. These screening questions should be asked at least annually. Questions such as, “has your child ever been involved in a motor vehicle crash?” or “has your child ever had a concussion, been knocked out, or lost consciousness?” then trigger follow-up questions or assessments to determine whether the child should be evaluated for a TBI. If screening is not done annually, a brain injury may be missed especially if it occurs over the summer months. Or if there have been multiple mild brain injuries that have occurred over time that may have cumulative effects or may cause learning differences. | Add screening questions about acquired brain injury to:  - Childhood Medical History/Developmental History forms used in the Child Find process  - the students’ annual physical exam  - every school’s kindergarten registration process.  
Adopt a TBI screening tool to be used annually. Several screening tools have been developed for schools to better identify and serve students with TBI.  
- Colorado BrainCheck Survey  
- SAFE Child  
- HELPS Brain Injury Screening Tool  
- OSU TBI-ID |

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Related services, including school health services and school nurse services. (20 U.S.C. Sec. 1401 [26] [2004], C.F.R. Sec. 300.34 [c][13]) | Students who have sustained a brain injury may have health conditions (e.g., seizures, medications) that need care in the school setting. School health/nurse service can be critical to support the health needs of students with TBI. Regular communication between schools, families and medical providers can lead to better utilization of school health/nurse services and coordination of care. This coordination and communication are key elements in supporting students with TBI in their return to learn and ongoing school success. | Adopt a process for communicating with parents and healthcare providers to better identify and support the individual needs of the student via the IHP and/or IEP. Utilize Individualized Healthcare Plans (IHPs) in conjunction with IEPs to help the school team provide appropriate healthcare supports in an educational setting.

**Supporting Data by Section:**

**Definition of TBI for ages 3 and above (20 U.S.C. Sec. 1401 [2004], 34 C.F.R. Sec. 300.8[c][12])**

**Evaluation (Sec. 300.15)**

**Re-Evaluation (Sec. 300.303)**

**Articles of interaction of recovery with developmental process:**
Development, review, or revision of the IEP (Sec. 300.324)

Brain maturation over time:

Articles about students with disabilities needing different approaches to vocational rehabilitation:

Articles about lack of follow-up and students not having their cognitive and educational needs met

Evaluation procedures (Sec. 300.304)
  https://issuu.com/braininjuryprofessional/docs/bip_november_2017?e=1121786/58553366
• CO Building Blocks of Brain Development© is a framework for multidisciplinary school teams to utilize for neuro-educational assessment and services. https://cokidswithbraininjury.com/educators-and-professionals/brain-injury-matrix-guide

Additional evaluation procedures (Sec. 300.500)

IEP Team (Sec. 300.321)

Independent Educational Evaluation (Sec. 300.502)
• Best Practices consulting models for students with brain injury are available at the sites below.
  ○ www.brainsteps.net
  ○ http://www.cde.state.co.us/cdesped/brainsteps
  ○ www.cbirt.org
  ○ https://youthbraininjury.obaverse.net/2/view/view.php?id=41

Child Find (Sec. 300.111; Sec. 303.115; Sec. 303.302)
Screening tools:
• Colorado BrainCheck Survey - https://www.chhs.colostate.edu/ot/research/life-outcomes-after-brain-injury-research-program/
Related services, including school health services and school nurse services. (20 U.S.C. Sec. 1401 [26] [2004], C.F.R. Sec. 300.34 [c][13])

- Tennessee Traumatic Brain Injury Toolkit for providers:
  - [https://www.tndisability.org/toolkit-healthcare-providers](https://www.tndisability.org/toolkit-healthcare-providers)
  - [https://www.tndisability.org/toolkit-school-nurses](https://www.tndisability.org/toolkit-school-nurses)

For more information on brain injury in children and youth, or the National Collaborative on Children’s Brain Injury (NCCBI) - please contact:

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