

# STATE OF THE STATES:

Meeting the Educational Needs of  
Children with Traumatic Brain Injury



**Mount  
Sinai** *Brain Injury  
Research Center*



**BRAIN INJURY  
ASSOCIATION**  
OF AMERICA



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In this report we focus on the extent to which public schools across America are meeting the educational needs of children with traumatic brain injury (TBI). We first discuss why this issue is important, and then we provide an analysis of interviews conducted with state education agencies (SEAs) and brain injury consumer organizations (BICOs) in 49 states, describing their practices in identifying, classifying, assessing and teaching children who have experienced brain injuries. The final section focuses on policy implications of these findings.

"We" refers above to the Brain Injury Research Center of Mount Sinai (BIRC-MS), which was funded to undertake this study by the National Institute on Disability and Rehabilitation Research. The Brain Injury Association of America collaborated in all aspects of the study, including developing the questionnaire and preparing this report (including policy implications).

## **DEFINING THE ISSUE**

The education of children with TBI is at issue because, although the hard data indicate that TBI is a leading cause of disability in children<sup>1-3</sup>, this fact has not been adequately acknowledged in the educational practices of America's public schools. In contrast to the conclusion one might reach based on the small number of students with TBI who are currently receiving special education services, TBI is not an orphan disease affecting only 25,000 children<sup>4</sup>. In reality, nearly a half million children in the U.S. under the age of 15 visit emergency rooms *each year* reporting a brain injury, and an additional 35,000 are hospitalized<sup>5</sup>. A recent longitudinal study<sup>1,2</sup> found that about 17% of children tracked from birth experienced a brain injury requiring medical attention by age 15. ("Medical attention" included hospitalization and visits to an emergency room or to a doctor's office.) This figure suggests that currently up to seven million U.S. school children (age 5-15) may have experienced a brain injury. And, this is a conservative estimate, as the seven million does not include those with brain injuries who did not seek medical assistance and those who were older than 15 when they were injured.

Which of these children need to be receiving special education services? First, all of the 35,000 children hospitalized with (usually moderate-to-severe) TBI each year must become known to their schools and their needs for special education assessed upon return to school, since the vast majority will experience life-long challenges affecting learning. Second, an important point to be emphasized here is that most of the half-million childhood brain injuries seen in

ERs each year are relatively mild<sup>5</sup>. (This means that the person has experienced a blow to the head and a brief loss of consciousness or a period of being “dazed and confused” – this is a standard definition of mild brain injury<sup>6-8</sup>.) Studies suggest that only 15-22% of mild brain injuries result in symptoms that persist after the first few weeks or months<sup>9</sup>. Thus, approximately four out of five injuries cause few if any enduring problems, and most children with mild TBI will have no long-term challenges triggered by the injury. *But the one-in-five children who do have persisting symptoms after a mild brain injury translates to more than one million U.S. schoolchildren (age 5-15) who have experienced a medically treated TBI and are currently symptomatic* (again, a conservative estimate). Let us be clear that the “symptoms” these children are facing are typically major cognitive, emotional and behavioral challenges that are triggered by the injury.



The child with a mild TBI who may or may not evidence long-term post-injury symptomatology and the child with a moderate-to-severe TBI who, with few exceptions, will face life-long challenges, suggest that schools face a daunting set of challenges of their own: Finding the millions of children with relatively mild injuries that *may* or may not affect their educational progress and tracking them over time to see if symptoms abate or emerge later in the developmental process. With more severe injuries and for those with mild injuries who remain symptomatic, schools need to ensure that the child is identified as soon as educational challenges are evidenced. Identification must set in motion a timely assessment of functioning and

provision of services and accommodations that are responsive to the educational needs so identified.

In sum, the educational system’s “failure to identify” is of two types: (1) not identifying in the child’s school record every injury that has occurred and establishing procedures to track the child’s progress, and (2) not identifying when a child post TBI evidences problems triggered by injury and then responding appropriately.

## THE PROBLEM OF IDENTIFICATION

### **How can it be that every year schools fail to identify TBI and/or its sequelae in the hundreds of thousands of children who yearly sustain brain injuries?**

We will first consider those children with brain injuries who are relatively easy to identify. These are students who sustain a moderate-to-severe TBI and, consequently, are out of school for a significant period while hospitalized. In the best scenario, an assigned member of the hospital staff is in contact with the school to ensure planning for an appropriate transition back into the classroom. In this case, schools not only are told about the injury and are prepared for transitioning the child back to school, but they also receive medical documentation of the TBI, which is required in many states before a child can receive special education services. However, as our interviews of SEAs and BICOs revealed (see below), even these potentially easy “finds” are not uniformly identified upon return to school (or they may be identified, but do not necessarily get appropriate services).

It is children with so-called mild injuries who are by far those most difficult to “find” within schools. This is the case for two reasons: schools aren’t told of the injury and the injury’s sequelae may not be obvious to educators who are in contact with the injured child. Mild TBI is often an invisible injury.

First, why aren’t schools told? Typically after a mild injury such as a concussion sustained outside of

school, children are taken to an emergency room and are discharged with only a brief warning to the parents about the possibility of headaches, dizziness or similar symptoms; the family typically leaves with the expectation that their child will be “just fine”. Further, many children who sustain a mild TBI do not receive any medical attention at all, such as a child who is abused or one who is injured without an adult present. In cases such as these, it is highly unlikely that schools will be notified of the injury. *These unreported injuries might get identified if schools systematically screened for TBI as part of required yearly medical checkups, but most schools have not implemented this type of procedure.*

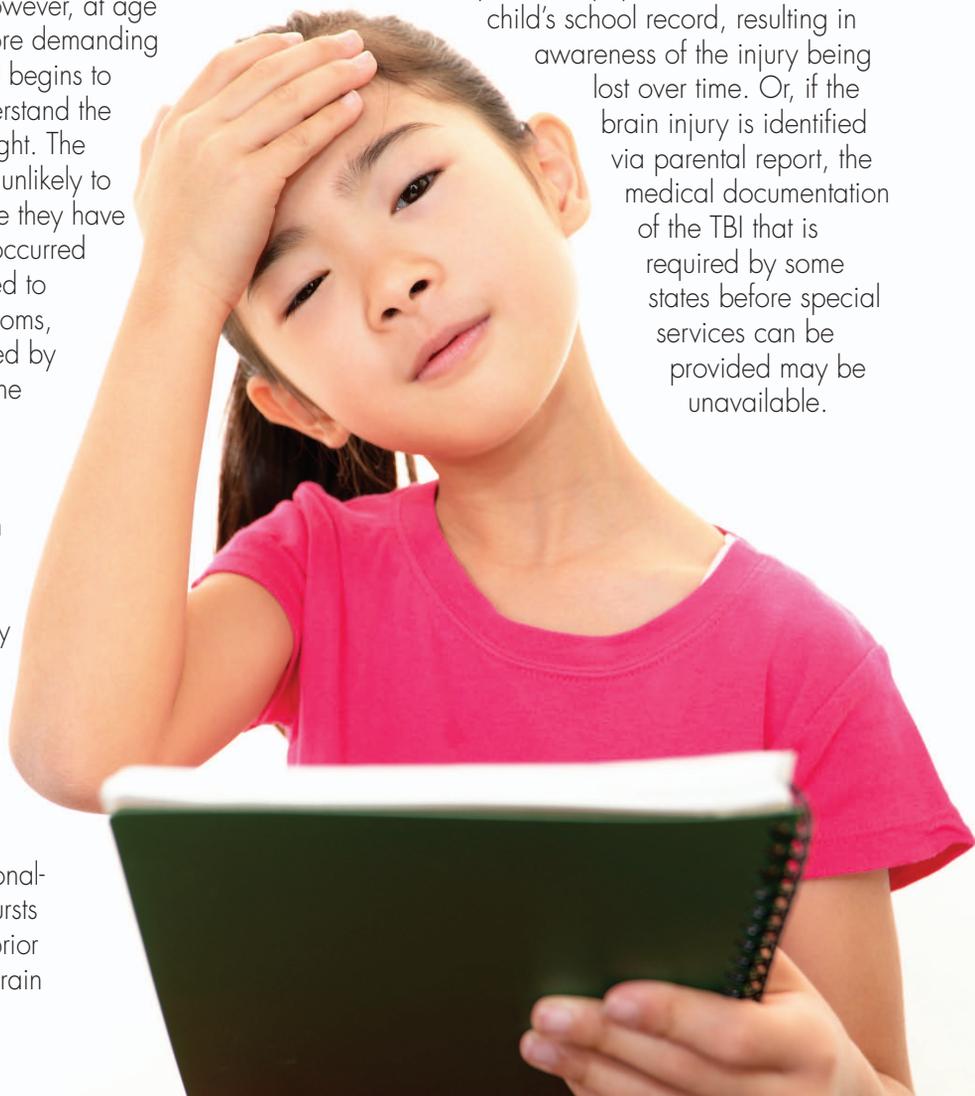
Why is it that challenges triggered by a child’s TBI may be invisible to educators? One reason is that due to the child’s developing brain he/she may seem okay in the short term but then “grows into” the injury. For example, a 7-year-old who is concussed may experience symptoms immediately that resolve after a few days or weeks. However, at age 11, when school becomes more demanding on cognitive abilities, the child begins to flounder, being unable to understand the math that 11-year-olds are taught. The child’s parents and school are unlikely to respond appropriately because they have forgotten the brain injury that occurred four years ago that had seemed to “heal” with no long-term symptoms, and educators are not reminded by the child’s school records, as the injury was never noted.

Also, the “what to look for” in symptoms persisting after brain injury varies from child to child. For some children, the manifestations of the injury may be primarily cognitive – she has more trouble learning, is slower to respond, has trouble with memory or can’t stay focused. For other children, the problems may be more along the emotional-behavioral axis – he has outbursts of temper that were not seen prior to injury. Other children with brain

injuries may experience a broad range of cognitive, emotional and/or behavioral challenges that involve multiple domains of function. *The complexity of post-TBI symptomatology and the relative lack of knowledge about TBI amongst educators lead to misclassification of children with TBI, for example as “Learning Disabled” or “ADD/ADHD”.*

In sum, failure to identify, track and take appropriate educational action for children with brain injuries can occur in several ways:

1. A hospital-based transition program either is lacking or its message fails to be received and interpreted appropriately by the child’s school.
2. No one notifies the school that an injury has occurred and/or systematic screening is not part of the school’s policies and procedures.
3. The school is notified, but this information is not translated into an appropriate response. For example, the injury is not recorded in the child’s school record, resulting in awareness of the injury being lost over time. Or, if the brain injury is identified via parental report, the medical documentation of the TBI that is required by some states before special services can be provided may be unavailable.



Alternatively, problems that are affecting learning are recognized, but schools do not implement appropriate assessment and programming because of misdiagnosis/misclassification or for a variety of other reasons.

## THE PROBLEM OF WHAT TO DO

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### **What can be done to better identify children with brain injuries and then assist them to learn optimally in the classroom?**

Before we review suggestions based on our interviews of SEA and BICO informants, we summarize the conclusions that are to be published in a White Paper<sup>10</sup> that is an outcome of the Children's Brain Injury Summit on the "essential components of a state-wide educational structure to support students with TBI across the spectrum of injury severity":

- Under-identification can be minimized through:
  - Education of staff in charge of screening and assessment
  - Use of a structured screening interview
  - Use of psycho-educational evaluations to determine the functional impact of brain injury
  - Systematic communications between medical and educational systems
- Educators need to be well-trained to address the needs of children with TBI:
  - Use of evidence-based practices to improve outcomes
  - Hands-on training of educators
  - In-classroom consultation by experts
  - Ongoing educational support
- Progress of children with TBI needs to be carefully documented with meaningful outcome measures, e.g., grades, attendance, satisfaction of parent and child, dropout rates, graduation rates, and the like.

- Four key elements of infrastructure are recommended:
  - Leadership on TBI initiatives within the state's department of education
  - Identified processes for referral and collaboration between medical, rehabilitation and school systems
  - Policies in place that allow for identification and eligibility for educational supports in the absence of medical documentation
  - Funding and administrative support for personnel training.

In the next section of this report, we review the responses of 43 SEAs and 45 BICOs (representing 49 states) as to how well schools are addressing the recommendations outlined above. Structured interviews of representatives of SEAs and BICOs were conducted by telephone by staff of the BIRC-MS in 2012.

## THE CURRENT STATE OF THE SCHOOLS: SURVEY RESULTS

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### **Identification of Children with TBI**

Identification, as a first step in meeting the educational needs of children with brain injuries, requires three elements: identifying that the child has a brain injury, transmitting the information to the child's school and then ensuring that the information is appropriately recorded in the child's school records, so that school personnel can consistently remain aware of brain injury as a potentially education-relevant event in the child's history.

Policies supporting these elements have not been generated at the state level. When they exist at all, they are locally defined. No state has implemented a statewide systematic means of identifying children with mild or moderate-to-severe injuries, and only two-thirds of SEAs and half of BICOs report having any identification mechanisms for TBI in their states. None of them screen systematically for history of brain injury, including the report of current symptoms. Some are considering changes to better address these failures to identify, but they have not yet implemented these new procedures.



In terms of the two meanings of identification we defined in an earlier section, it is necessary for documentation of the injury to become part of the school record, whether a child is currently symptomatic or not. However, for most states documentation of an injury in the child's record only occurs if the child meets eligibility criteria for special education. This comprises a primary barrier to identification, tracking and appropriate service provision of children with brain injuries.

We discussed with respondents five means for identification/tracking: (1) hospital transition programs, (2) Child Find\*, (3) concussion legislation, (4) screening and (5) trauma registries.

### **HOSPITAL TRANSITION PROGRAMS:**

In about half the states (reported by 29 BICOs and 22 SEAs), one or more programs housed in hospitals engage in outreach to schools and provide transition services for children with TBI. These are not statewide programs, but exist primarily in pediatric hospitals and elsewhere on an institution-by-institution basis. Respondents viewed the effectiveness of these services as varying widely based on the degree to which: (1) communication between hospital, school and parents was clear and systematic, and (2) the programs were integrated with education and advocacy networks.

**CHILD FIND:** Half the states (25) referenced Child Find as their primary mechanism for identification. However, as noted in the introduction, only about 25,000 children with

TBI are currently "found" across the U.S. The number of children reported within each state ranged from 37 to 1,469. It is possible that many children with TBI, especially those with milder injuries, are served via 504 Accommodations\* because they do not meet special education requirements. However, only one of the SEA respondents knew the number of children being served under this provision of the law, and only 14 knew who could be asked in their state to provide the information. Furthermore, several respondents noted that 504 mechanisms in their states do not use defined disability/impairment categories, so only the total number of children receiving 504 services could be determined, not the number with TBI.

**CONCUSSION GUIDELINES:** Although many states (29)\*\* reported some form of concussion management law or guidelines, very few (2 SEA, 1 BICO) include any type of tracking, recording or reporting mechanisms. Further, the laws/guidelines often apply only to children injured in school-sponsored sports activities. They do not address children injured in other contexts (e.g., summer injuries, playground injuries, younger children); and they rarely cover private schools (9 SEA, 6 BICO) or recreational sports leagues (6 SEA, 3 BICO). *Some respondents pointed out that concussion guidelines comprise a good starting point for raising awareness among families, coaches and*

\* See Glossary, p. 10.

\*\*We realize this is an under-estimate of the number of states with concussion guidelines/laws, as additional states have taken action since the BIRC-MS interview was conducted.

*school staff.* Thus, while concussion laws/guidelines support appropriate responses by educators in terms of return-to-play and return-to-school, they do not contribute substantially to the tracking of children with brain injuries in a way that supports the provision of appropriate educational services over the long term.

**SCREENING IN SCHOOLS:** Three states have a question regarding TBI on the health screening cards students must complete at the beginning of each school year. (Although this is a step forward, BIRC-MS research suggests that such general questions lead to substantial underreporting, and that asking several specific questions is a much better approach to jogging memory for injury events<sup>11</sup>.) A few states (2 SEA, 3 BICO) are considering adding such a question and also are piloting programs for screening in some schools/counties.

**TRAUMA REGISTRIES:** Although many respondents (22 BICO and 23 SEA) reported a trauma registry in their state that includes TBI, they did not view registries as a means for identifying brain injuries in children in a way that is currently useful to schools, as registries only provide information to schools if the parents initiate a request. Registries are funded to address epidemiological goals (to “count” trauma cases). Additionally, some registries only include people who were admitted to the hospital, excluding those who were solely seen in the emergency room. *While some respondents suggested parents be given the option while in the hospital to sign a release so that relevant information about their child’s injury could be conveyed to schools, some parents are likely to withhold such permission for fear of their child being labeled as “brain injured,” with the perceived stigma that is attached. Thus in addition to all the barriers to identification already discussed, “stigma” is one that has received little attention.*

## Classification of Children with TBI

Once a child has been identified as having been injured or as having current learning challenges, the next step educational systems take is to classify the child’s disability. Most states use the TBI category under special education (as TBI is one of the 14 disability

categories identified in the IDEA\*), and children with moderate-to-severe injuries usually receive this classification. Children with mild injuries may not be classified under the TBI category because documentation of their injury may be absent or inadequate. However, if these children are exhibiting challenges, they may be assigned another label. Specifically, 36 SEA and 33 BICO respondents noted that children with TBI often receive services under disability categories other than TBI. The most common of these are: Other Health Impaired (20 SEA, 13 BICO) and Specific Learning Disability (19 SEA, 11 BICO), but other categories were frequently mentioned: Behavioral Disorder (10 SEA, 7 BICO), ADD/ADHD (0 SEA, 11 BICO) and Emotional Disorder (19 SEA, 7 BICO). *As one respondent stated, “There are 12 or 13 special education classifications, and I’m willing to bet that, if we went into those, we would find children with brain injuries in every one of them.”*

Not all states use secondary classifications, so if a child’s physical injury is deemed primary, his/her TBI may be ignored. Speech and Language Impairment (10 SEA, 3 BICO), Visual Impairment (6 SEA, 1 BICO), Orthopedic Impairment (6 SEA, 3 BICO), and Multiple Disabilities (10 SEA, 2 BICO) were all cited as categories that might get primary status over TBI.

Misclassification occurs for a variety of reasons, including lack of awareness of TBI, not associating a child’s struggles and problems in learning with a known TBI and greater funding attached to disability categories other than TBI.



## Assessment of Children with TBI

Assessment should be focused on defining the child's educational needs – identifying both his/her strengths and weaknesses as they relate to learning. As is the case with identification, assessment varies widely within states, from one school district to the next. Most often assessment is not TBI-specific, with neuropsychological testing rare (only 4 SEAs and 9 BICOs mentioned it) because of scarcity of funding and/or of trained staff/consultants. In most states, assessment is undertaken for children with moderate-to-severe injuries as a matter of policy, but for those with mild injuries, parents typically must serve as advocates to get their child assessed (9 SEA, 20 BICO). According to our respondents, parental advocacy plays a critical role in catalyzing the assessment/accommodation process, especially when the child's struggles may not be obviously tied to the injury. Thus, most states operate on a principle of not providing assessment until a child is struggling and clearly on the road to school failure. In some states, a medical record of injury is required before an assessment can be done. This presents a major roadblock for children who did not receive medical attention or for migrant parents who have poor access to medical records.

## Educational Services

TBI-specific approaches to address the educational needs of children with brain injuries have not been adopted in any of the states. While SEAs recommend evidence-based practices to local districts for educating all children, respondents did not know of any specific practices that meet this criterion in teaching children with TBI. A few states are exploring the provision of evidence-based training workshops for their school personnel. In sum, best practices for teaching children with TBI have not been successfully disseminated nor adopted by school districts across the U.S.

The services that are provided vary widely, according to respondents, depending on access to TBI expertise, which is provided largely by consultants who typically are part-time. Respondents in 25 of the states reported having a point person or agency that deals with children with TBI; their sole focus is not always on TBI, but rather on a range of disabilities. In some states (12 SEA,



4 BICO), a centralized registry of children with TBI and other disabilities is maintained, but it is used largely for data and reporting purposes, not for outreach or tracking.

In terms of school-to-work or school-to-college programs, most respondents (40 SEA, 38 BICO) referenced their state-federal vocational rehabilitation agencies as being available to all students needing transition services. Respondents in a few states (6 SEA, 9 BICO) report TBI-specific programs. Again, the quality and effectiveness of both general and TBI-specific programs were seen as varying widely, depending on resources, including staff with TBI expertise (13 SEA, 14 BICO), other programs that the transition organizations are networked with (9 SEA, 8 BICO) and funding (9 SEA, 6 BICO).

In conclusion, problems in educating children who are identified and classified by their schools as having a TBI can best be summarized in terms of a lack of standardized approaches incorporating best practices for teaching children with brain injuries. This results in a wide variability in responding to children with TBI.

The degree to which the education of these children is congruent with their TBI-related needs depends largely on the degree of advocacy by parents, the expertise at hand within the school district and the resources and services available (in reality rather than in theory). Respondents expressed frustration in terms of low awareness of TBI amongst educators and boards of education as well as inadequate funding of services that would better serve the needs of children with TBI.

# WHAT NEEDS TO BE DONE: POLICY IMPLICATIONS

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What is clear in listening to those who responded to our interview is the sound of frustration. These are people who want to do their best for and/or are advocates for children with TBI. They see (or hear about) children doing well and children floundering. They want to know how to better identify children with TBI and then meet their educational needs.

When respondents were asked what specific changes they would like to see to better address the educational needs of children with TBI, four issues echoed those outlined in the White Paper summarized earlier in this report:

- Better identification of TBI, including more and better hospital-to-school mechanisms
- More awareness of TBI
- Increased training for school staff
- More funding and educational resources

We have outlined the policy implications below that we (the BIRC-MS, in conjunction with BIAA) believe respond best to these findings, and are in concert with the data about unidentified TBI (especially mild TBI) and with the recommendations in the White Paper developed as an outcome of the Children's Brain Injury Summit<sup>10</sup>.

The recommendations we have made are based on the following principles:

- No recommendations should be promulgated as an unfunded mandate.
- For the sake of children whose lives may forever be altered because of TBI, all of those involved – hospitals, physicians, school systems, educators, parents, policy makers and advocates – must acknowledge the problem and commit to working collaboratively to enact solutions.
- The unmet educational needs of children with mild TBI and persisting challenges need to be as fully addressed as the needs of children with more severe injuries.

## SPECIFIC RECOMMENDATIONS

### Better identification of and research on TBI

- Establish federal and state policies that take into account the unique aspects of brain injury. Specifically, record every known TBI of whatever severity in a child's educational record, regardless of current eligibility for special education services. Establish procedures to track this information prior to the start of each the school year, so that each teacher new to the child is aware that one or more brain injuries may account for newly emerging problems in learning.
- Amend Section 300.8(c)(12) of IDEA regulations, pertaining to the definition of TBI, by adding: "States may require medical documentation to determine traumatic brain injury, or in the absence of medical documentation, the state shall develop guidelines for establishing a probable diagnosis based on clinical interview of a child/parent self-reporting a brain injury and evidence that such injury has resulted in functional impairment that adversely affects the student's educational performance."
- Change federal and state policies that address the issue of TBI as a secondary classification or diagnosis. A child with an orthopedic impairment and a brain injury still has a brain injury despite its being "secondary." In other words, the brain injury, within the educational context, cannot "disappear" because it is a secondary classification, as it generates its own strong demands for specific accommodations and educational practices suitable for children with TBI.

- Research is needed on best practices for [systematic screening](#) for TBI in school children. How detailed should questions be to obtain valid and reliable reportage? What approaches can be used to encourage valid reports, acknowledging that parents/children may be loath to report on brain injury for a variety of reasons? This could be accomplished through a Child Find Demonstration Project or a Patient-Centered Outcomes Research Institute study.
- [Expand and improve Child Find requirements](#) through IDEA reauthorization. IDEA requires all states to have a “comprehensive Child Find system” to assure that all children who are in need of early intervention or special education services are located, identified and referred. To identify young children with developmental delays, the federal law specifies that states must have a lead agency and coordinating council comprised of federal agencies, including Title V of the Social Security Act (Maternal and Child Health); Early and Periodic Screening, Diagnosis and Treatment program (EPSDT); Title XIX of the Social Security Act (Medicaid); Head Start; and the Developmental Disabilities and Bill of Rights Act. The purpose is to ensure coordinated efforts across state programs responsible for health, education and social services programs. This requirement should be expanded to include representation on the coordinating council of TBI Act-funded programs (CDC surveillance and HHS state grants). Further, the mission should be expanded to include coordinated efforts to identify children of any age with TBI through screening, assessment and procedures for referrals from hospitals, primary care physicians, and other health care providers (similar to efforts undertaken for infants and toddlers.)
- [Develop and disseminate guidelines](#) for school districts, charter schools and private schools with regard to identifying (via observation) TBI-related disabilities, screening for TBI, and assessment tools to help in identifying TBI-related deficits.
- [Fund the expansion of data linkage projects](#) whereby children and youth identified through registry data reporting systems are provided information and referral services upon hospital/ER discharge, to help transition children to school and to other resources. CDC has funded several small pilot projects to explore the potential for using personal identifiers obtained in TBI surveillance data systems to link people with TBI to information about services. Building on “lessons learned” from these projects, additional projects should be funded specifically for children and youth with TBI.

## **Expanded awareness of TBI**

- Fund, develop and distribute [public awareness announcements and educational materials](#) on TBI to state education departments and school districts 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.
- Assist states that have enacted legislation on sports-related concussions and return-to-play guidelines in developing [guidelines pertaining to return to school/class](#) after sports-related concussion.

## **Increased training for school staff and development of appropriate programming**

- [Develop and disseminate guidelines to schools](#) focused on appropriate educational interventions and accommodations, as well as behavioral and educational strategies. Such guidelines should be based on evidence generated via research and, where research has not been done, based on clinical experience.
- Through reauthorization of ESEA (Elementary and Secondary Education Act, or No Child Left Behind) and IDEA, coordinate resources to [train educators, including special educators](#), in identifying TBI-related disabilities and behaviors that impede educational success, and in instituting educational practices to ensure good academic outcomes.
- Support Race to the Top, Investing in Innovation and other federal programs that support teacher quality to [prioritize the preparation of general educators to be effective in improving outcomes for diverse students](#), including students with TBI.

- Make readily available [on-line training and resources](#) to assist educators, both regular and special educators, to assist them as situations arise. Develop multi-media approaches (e.g., live chat, apps) in keeping with the technology with which younger educators are familiar.

## Strengthen parents as advocates

Because parents can be the strongest advocates for their child's education, they need to be empowered to know their rights under IDEA and Section 504 and to exercise their responsibilities. They need to better understand the implications of TBI on educational outcomes. Many of the current efforts to assist parents, such as IDEA-funded Parent Information Centers, focus primarily on parents who have children with intellectual or developmental disabilities. These Centers and other parental resources should expand their capacity to provide assistance to parents of children and youth with TBI.



### GLOSSARY

**IDEA:** The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to eligible infants, toddlers, children and youth with disabilities. Young children with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Older children and youth (ages 3-21) receive special education and related services under IDEA Part B.

**Child Find:** Child Find refers to the legal duty imposed by the IDEA on public school districts to proactively identify/find children who may have a disability and be in need of special education services.

**504 Accommodations:** This term refers to Section 504 of the Rehabilitation Act of 1973, which makes the granting of accommodations for a child's disability by schools a matter of the child's civil rights. IDEA differs in that its focus is on educational activities, while Section 504's focus is on requiring due process and prohibition of discrimination based on disability.

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