

## REPORT TO CONGRESS

The Management of Traumatic  
Brain Injury in Children

# Executive Summary





## INTRODUCTION

Among all age groups, young children have one of the highest rates of Traumatic Brain Injury (TBI) related emergency department (ED) visits.<sup>1</sup>

TBI affects children differently than adults. An injury of any severity to the developing brain can disrupt a child's developmental trajectory and may result in restrictions in school and participation in activities (e.g., sports). As a result of TBI, children can experience changes in their health, thinking, and behavior that affect learning, self-regulation, and social participation, all of which are important in becoming productive adults. Although most children recover well physically, they often experience changes in behavior and cognition that are not recognized immediately. Some of these post-TBI health problems emerge over time and are associated with significant financial and social challenges for adults having

sustained a TBI as a child. Unlike other developmental health conditions in children that are diagnosed at birth, TBI is an acquired condition that can occur anytime during childhood with potential for a sudden alteration in development. The management of TBI in children is complex and depends upon multiple service delivery systems that frequently do not provide systematic or coordinated care to ensure an optimal recovery.<sup>2</sup> However, due to the lack of robust scientific evidence identifying optimal pathways to recovery, current management is too often based on clinical practice experience rather than research.

This report describes the public health burden of TBI in children and adolescents, including the range of outcomes that may be experienced following a TBI. In addition, the report lays out the current systems involved in the management of children with TBI, identifies gaps that exist, and outlines some practices that hold promise in addressing those gaps. Finally, opportunities for action are offered that suggest ways to improve TBI care in children, and how we might advance our understanding of TBI care in the future.



## PUBLIC HEALTH BURDEN

Traumatic brain injury in children represents a significant public health burden in the United States. A traumatic brain injury disrupts the normal function of the brain, and can be caused by a bump, blow, or jolt to the head, or a penetrating head injury.<sup>3</sup>

In 2013, there were approximately 640,000 TBI-related emergency department

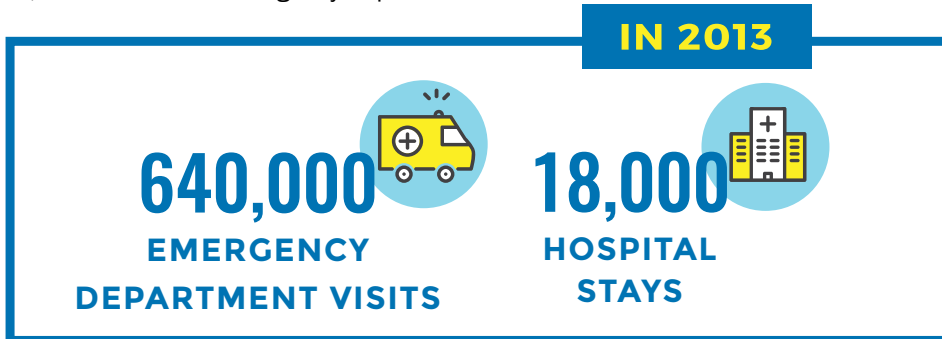
(ED) visits, 18,000 TBI-related hospitalizations, and 1,500 TBI-related deaths among children 14 years of age, and younger.<sup>1</sup> The leading causes of TBI-related ED visits, hospitalizations, and deaths for those 0-14 years of age were unintentional falls and being struck by or against an object, whereas for

those 15-24 years of age, the leading causes were motor vehicle crashes and falls.<sup>1</sup>

Another common cause of TBI is sports and recreational activities which accounted for an estimated 325,000 TBI-related ED visits among children and teens in 2012.<sup>4</sup>

TBI severity is typically separated into categories of mild, moderate, and severe based on a patient's initial clinical presentation. Mild TBI (mTBI) accounts for most (70-90%) TBI-related ED visits.<sup>5,6</sup> Although most TBIs are considered mild, TBI also accounts for a large portion of unintentional injuries that lead to severe disability and death in youth under age 19. Children with severe TBI are more likely to be hospitalized and have a lifelong disability compared to children who have a mild injury.

Although most people think of TBI as an acute condition, the effects of TBI can be chronic and disabling. It is unclear how many children currently live with a TBI-related disability, largely because childhood disability is not defined consistently. One study, which defined disability as the use of specialized medical and educational services, found that more than 62% of children with moderate-to-severe TBI experienced disability, compared to 14% of children with mTBI.<sup>7</sup>



# 61%

More than 61% of children with moderate-to-severe TBI experience a disability.

## OUTCOMES OF TBI IN CHILDREN

A TBI of any severity experienced by a child can result in changes that affect a child's daily life.<sup>8-11</sup> Symptoms of mTBI can include headaches and dizziness, as well as problems with thinking, memory, physical activities, emotions and moods, and sleep.<sup>12-20</sup> Longitudinal studies suggest that most children with mTBI recover from the initial symptoms within 6 weeks after injury, with approximately 60% having persistent symptoms at one month post-injury, 10% at three months post-injury, and less than 5% at one year post-injury.<sup>13,14,21-23</sup>

More severe brain injuries carry a range of medical, health, cognitive, motor, emotional, and behavioral issues. 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.<sup>24-28</sup> Because of this, there is a critical need for follow-up care beyond the acute injury.

### School and post-school outcomes

A child's daily life centers on school, social participation, and extracurricular activities. A TBI of any severity can negatively affect a child's future ability to learn and perform in school.<sup>29</sup> Children with moderate-to-severe TBI earn worse grades, show higher rates of grade retention, and receive more special education services than their uninjured peers.<sup>30-33</sup> Students with mild injury typically recover within a few weeks, and most of them return to their pre-injury classrooms. However, in a large study following children younger than 18 years of age, 14% of children who experienced an mTBI needed educational support services at school 12 months later.<sup>7</sup>

We know very little about the long-term adult outcomes of TBI in children. Most longitudinal studies of children with moderate-to-severe TBI have examined outcomes in children for intervals that are too short to understand how TBI impacts adult outcomes.<sup>19,29,34-36</sup> A growing body of research indicates that for many students with moderate-to-severe TBI, post-high school career outcomes are poor.<sup>37-40</sup> One study found that fewer than half of students with TBI who had been out of school a year or more had a paying job outside the home.<sup>41</sup> Students with

TBI also showed lower rates of enrollment in postsecondary education and independent living than those with most other disabilities.<sup>41</sup> To date, there are no longer-term studies on children with milder injuries, or those who sustain multiple concussions across childhood.

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**i** We have limited understanding of how childhood TBI impacts attainment of adult milestones (e.g., high school graduation, employment, or enrollment in postsecondary education). Studies of adults who sustained a childhood brain injury suggest common pathways to social difficulties, such as lower educational attainment and incarceration.

## FACTORS INFLUENCING OUTCOMES

In addition to injury severity and the type of care a patient receives following injury, many factors can influence recovery from childhood TBI. Individual patient characteristics, such as age and pre-injury functioning, can play a big role in a child's recovery. Co-occurring health and developmental conditions, such as a mental health diagnosis and Attention-Deficit/Hyperactivity Disorder (ADHD), can influence a child's outcomes after TBI; however, there is limited evidence connecting medical conditions to achievement of longer-term milestones in children who have sustained a TBI.<sup>42</sup>

Socioeconomic status and family functioning also influence recovery.<sup>43-47</sup> In any family environment, a TBI is an unexpected event that can create significant changes in family economic status and structure. Family-level factors are critical social-environmental influences on outcomes in children following a TBI.<sup>48</sup> Economic and social disadvantage are associated with poor cognitive and academic outcomes following a severe TBI.<sup>45,49</sup> Regardless of injury severity, many parents recognize differences in their child compared to their pre-injury status, which creates worry and concern for their future, especially as they approach adulthood.<sup>50</sup> Parent/caregiver burden and family dysfunction are a particularly important consideration because they are a strong determinant of a child's recovery, with children from well-functioning families demonstrating better psychosocial functioning.<sup>20,45,51</sup> The adverse effects on families can persist for many years following injury.<sup>52,53</sup>

## CURRENT SERVICE DELIVERY SYSTEMS

The management of TBI in children is complex and dependent upon multiple service delivery systems that often are neither systematic, nor coordinated to provide care across the child's lifespan. In particular, there is large variation in what constitutes follow-up care and service delivery in critical areas, such as insurance coverage, utilization of pediatric trauma centers, service delivery in the schools, early intervention services, support for transition to adulthood, and family support. The goal of initial management for all types of brain injury is to determine injury severity, and to safely triage individuals to the most appropriate level of care. At this time, a wide range of treatments are prescribed post-injury. Management may include recommendations for graduated return to activities (school and physical activities), medication, and a range of therapies and other treatments.

The CDC is working to develop the first-ever evidence-based clinical guideline on the diagnosis and management of mild TBI among children and adolescents. This Guideline will be based on recommendations from a federal advisory committee, informed by a Pediatric Mild Traumatic Brain Injury Guideline Workgroup composed of leading experts in the field. Although the Pediatric Mild Traumatic Brain Injury Guideline workgroup acknowledged research gaps in both diagnosis and treatment of pediatric mild TBI, the Guideline – based on the current best available evidence and informed by expert opinion – will represent an important step forward in providing consistent care for children with mild TBI. There is also a need for stronger evidence to inform standards of care for the treatment of moderate and severe TBI. In the absence of evidence, individualized symptom management is the most common recommendation. There is evidence to suggest that care from pediatric specialists results in better outcomes for pediatric TBI patients. For example, children who receive inpatient rehabilitation at pediatric hospitals typically have more efficient functional improvement than children receiving inpatient rehabilitation at other hospitals.<sup>54</sup>

This is especially relevant to rural areas where access to pediatric specialized physicians and facilities<sup>55-5</sup> as well as specialized TBI services<sup>58</sup> are more limited.

When children are ready to return to preschool or school, a range of supports and services are available, including early intervention services, special education under the Individuals with Disabilities Education Act,<sup>59</sup> supports and accommodations through a Section 504 plan,<sup>60</sup> and informal supports provided by a classroom teacher. Younger children (0 to 3 years) can be referred to early intervention services via Child Find, which requires school systems to identify, locate, and evaluate children from birth to 21 years of age with disabilities or suspected disabilities. School nurses and comprehensive healthcare clinics at schools provide an important system of health and mental health services for children with TBI. However, it is unclear to what extent nursing or special education services are utilized for TBI across the country, especially in private or charter schools.

Families of children with a TBI can take advantage of resources available to parents of all children with disabilities (e.g., PACER Family-to-Family Health Information Centers, Parent Training and Information Centers). Some states offer support groups specifically for parents and families ([www.biausa.org](http://www.biausa.org), [www.usbia.org](http://www.usbia.org)). Furthermore, some state services provide case management for families to assist navigation between medical and school services.



**Each state and U.S. territory has a lead agency and coordinator for TBI services. States also rely on the Federal TBI grant program in the Administration for Community Living, Department of Health and Human Services, to meet the needs of underserved populations, including children and youth with a TBI. Twenty-three states have TBI trust funds designated by legislation to support services for individuals of all ages with a TBI.**

# IDENTIFYING GAPS AND IMPROVING THE MANAGEMENT OF TBI IN CHILDREN

There is frequently an incomplete understanding about the effects of TBI beyond the initial injury among parents, healthcare professionals, and educators.<sup>2,61-63</sup> This often creates barriers to optimizing outcomes for children across their lifespan, including achievement of high school graduation, employment, and engagement in a healthy lifestyle. It is widely recognized that children with brain injury are under-identified for health and educational services and under-served by existing supports, placing them at risk for poor health and educational outcomes.<sup>61,64,65</sup> Understanding the gaps in care and developing approaches for optimal assessment, access to services, and service delivery is critical to ensuring that children with TBI have the best possible treatment and outcomes.

## Access to comprehensive care at the time of injury

Access to specialized care in a pediatric trauma center at the time of the injury is especially important for children because early injury care can influence long-term outcomes.<sup>66</sup> There is substantial variation in care among the sites where children are seen for acute injury care. Not only are there inconsistencies in TBI assessment, but also in the comprehensiveness of discharge recommendations for all severity levels of TBI.<sup>2,67</sup>

## Long-term management

Currently, there are no formal systems to monitor the health of children with a TBI over time. Most children with a TBI are discharged home following initial injury care at the ED.<sup>68</sup> For children who are hospitalized, whether a child receives long-term medical rehabilitation services often hinges on health insurance status; only 1.5% of uninsured children move directly from the hospital to inpatient rehabilitation, compared to 4% of children with private insurance.<sup>68</sup> Frequently, children who need pediatric rehabilitation services do not receive them. In the first year after injury, a substantial portion of children with moderate-to-severe TBI have unmet or unrecognized healthcare needs.<sup>69</sup>

## Family support and training

The suddenness of a TBI forces parents into multiple roles, including advocacy for their child in the healthcare and school settings.<sup>70-72</sup> Few parents understand the potential for a TBI of any severity level to become a chronic medical condition, nor are they aware of the pathways to care beyond initial medical services. When children return to school, parents often encounter a lack of understanding about the effects of the injury and find that school services are not suitable for a student who has experienced a TBI in the midst of their development.<sup>73</sup> In the long-term, parents and caregivers may experience impairment to their own functioning due to the stress experienced when caring for their child.

## Return to school

Many students who sustain a TBI will need post-injury support at school, ranging from informal academic support specific to their symptoms<sup>67,74,75</sup> to longer-term formalized support (e.g., early intervention services, special education services, support and accommodations through a Section 504 plan). However, children and their families often experience difficulties accessing these services.

### The causes of an inability to access available educational services include:

- A lack of communication between healthcare and educational institutions about a child's injury<sup>2,76,77</sup>,
- The potential under-identification of students with TBI for special education services<sup>61</sup> and
- A lack of awareness of educators about the effects of TBI on learning.<sup>73,78,79</sup>

Further study is needed to understand the type and availability of school-based services and qualified staff to serve students with TBI in rural areas.





## Return to activity

Although return-to-play guidelines for sports have been devised for mTBI, similar consensus guidelines have not been developed for return to other recreational and physical activities outside of organized sports.

Following TBI, children are at risk for increased social isolation and reduced participation in activities outside of the school setting, and this can have harmful effects on their well-being.

While there may be awareness of these risks among those who care for children, there is a lack of guidance as to how to minimize these risks. Additionally, neither consensus nor evidence-based guidelines for return to activities after moderate and severe TBI exist.

## Transition to adulthood for children with TBI

As children reach adulthood, the transition from pediatric to adult medical care providers is a particular area of clinical concern.<sup>81</sup> Research has demonstrated that access to (and use of) healthcare services declines significantly as adolescents transition to adult care, resulting in worse health outcomes in adolescents with identified health conditions.<sup>81-84</sup> In the public school system, only children enrolled in special education when they enter high school

receive transition planning for post high school graduation as part of their educational program under IDEA. Private schools that do not accept federal funds are not required to provide specialized educational services for transition plans for students with a TBI.

## Professional training

Effective medical and educational management practices implemented by trained professionals can contribute to successful outcomes for children with TBI. However, many medical, educational, and other professionals who provide care and support for children after TBI received limited training specific to TBI recognition or management. Further, there is a significant lack of healthcare providers with pediatric-specific TBI training.<sup>85</sup> Lack of adequately trained healthcare providers leads to inconsistent and variable clinical assessments, inconsistent diagnoses, variable guidance about expected recovery course, and variability in management decisions early and later after injury. In the school setting, teachers lack training in their academic programs<sup>86</sup> and continue to have some basic misconceptions and knowledge gaps about TBI and the effects of brain injury on students in their classrooms.<sup>78</sup> In general, educators need better training in methods that are effective with students with TBI.<sup>61,87-89</sup>

## Research

We currently know very little about long-term outcomes for children with TBI. At present, most management of TBI is based on consensus guidelines and expert opinion.<sup>90-94</sup> Only a few rigorous, systematic clinical trials have been performed.<sup>93</sup> For mTBI, the most recent guidelines recommend pacing, or gradual return to cognitive and physical activities, as tolerated by symptoms.<sup>95-97</sup> Implementation of those pacing recommendations, as the cornerstone of management in this population, is variable. High-quality studies are necessary to determine the ideal duration and intensity of rest, and the ideal time

to introduce both cognitive and physical activity. There is wide variation in the use of medications after mTBI, with no high-level evidence for the use of any medication.<sup>98</sup> Managing more prolonged symptoms has not been the focus of prior consensus statements or guidelines and is primarily based on consensus opinion.<sup>99</sup> A wide range of medical, behavioral, physical, and other therapies are used in the management of mTBI, but definitive, high-level evidence-based guidelines do not currently exist. CDC is currently developing the first evidence-based guideline for the management of mTBI in children, based on a systematic review of the available evidence conducted by a panel of pediatric mTBI experts. This guideline will include clinical recommendations based on the systematic review and is expected to be released in 2018.

More research is needed to understand children's long-term outcomes and effective management approaches that support children achieving adult milestones, such as high school graduation and employment.

Further, we need to better understand how management and intervention across a child's lifespan relate to everyday improvements for children and their families. Overall, there is a critical need to reduce variability and inconsistency in care delivered at the time of injury, and over the long-term after mild and more severe pediatric TBIs. Standardization of care is critically needed; however, a better evidence base is required to inform management practices.





## Opportunities for Action: Enhancing Healthcare Services to Improve the Management of TBI in Children

### At the time of the injury visit

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- Healthcare providers assessing TBI can consistently inquire about the child’s medical history and family circumstances, and consider these factors in treatment planning. Providers can advise parents to maintain a record of their child’s TBI history to complement data in a child’s medical record.
- Healthcare providers can offer guidance and written information to caregivers about the types of healthcare, state, and school services that are available for their children after a TBI. Healthcare providers should encourage caregivers of children with a TBI to remain with a “medical home,” or consistent primary care provider, across the child’s lifespan to facilitate care that is more comprehensive.

### Opportunities for post-injury services

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- Systematic examination of healthcare-to-school transition programs and practices is necessary by educators and healthcare providers to inform the field about best practices.
- Hospital systems and healthcare providers can work to optimize and streamline delivery of post-acute care, rehabilitation, and community services for children with a TBI, and their families. Adoption of quality care standards (e.g., The Commission on Accreditation of Rehabilitation Facilities, an independent nonprofit accreditor of health and human services) can facilitate improvement of service delivery. Existing networks, such as Child Find, a state-based reporting system for locating and assessing children suspected of needing specialized school services, can be utilized to address potential needs across the continuum of care.

### Systems opportunities for clinical decision-making tools

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- Clinical decision support tools are promising, but need wider use and evaluation to demonstrate their utility and effectiveness.



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

### Models of care

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- Policies that expand support for school-based health clinics and telemedicine can be considered as a means to improve follow-up care after a TBI, especially in rural communities.
- Guidelines for return to sports after mTBI can continue to be refined and informed based on new evidence. Processes devised for return to sports can be amended to cover return to all children’s recreational activities, and also serve as a point of reference for return to sports and recreational activities after a more severe TBI.

### Monitoring and service delivery

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- 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 the move from elementary to middle and high school.

### School transitions

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- Schools and state agencies can more frequently 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 from elementary to middle and then 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

- Models of care for children with a history of a TBI who transition from pediatric to adult healthcare systems need to be developed and supported within the healthcare system.
- 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.



## Opportunities for Action: Improving Professional Training for Those Involved in the Management of TBI in Children

- Healthcare professionals who care for children after a TBI would benefit from more formalized training related to TBI diagnosis and management, both as part of their medical and nursing school programs and through continuing education.
- Enhanced training of educators in TBI management is needed within education curricula, as well as through the expanded use of in-service training models.



## Opportunities for Action: Filling Knowledge Gaps

More research is needed in the following areas in order to improve the care of TBI in children:

### Foundational science is needed

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- Produce comprehensive estimates on the incidence and underlying causes of pediatric TBI, as well as on the use of healthcare and rehabilitation services following a TBI. CDC's pilot National Concussion Surveillance System can provide initial data, but long-term surveillance is needed to track trends to inform prevention efforts.
- Investigate the effects of a TBI experienced during particular periods of brain development on subsequent physical, cognitive, behavioral, and social growth and development.
- Disentangle how non-TBI-related issues, such as the child's family environment and co-occurring health conditions, impact recovery. Identify modifiable risk and protective factors associated with short- and long-term outcomes of a TBI.
- Determine the feasibility of developing a pediatric version of the TBI Model Systems database as a means to better understand long-term outcomes after pediatric TBI.
- Collect natural history data that will describe differential recovery trajectories across both age and severity that could be used for the development of and presentation of personalized medical treatment.

### Science is needed to advance acute and long-term management of pediatric TBI

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- Evaluate existing healthcare-to-school transition models (i.e., return-to-learn processes).
- Evaluate the efficacy of guidelines and management protocols across domains of care, including CDC's forthcoming pediatric mTBI guideline.
- Support clinical trials, rigorous quasi-experimental, and evaluation studies that examine effectiveness of healthcare, rehabilitation, and technology-assisted interventions across multiple settings, including, inpatient, outpatient, and at school.



## CONCLUSION

In 1985, the first textbook on pediatric TBI management by Mark Ylvisaker, *Head Injury Rehabilitation: Children and Adolescents*,<sup>100</sup> was published. This work was the first comprehensive documentation of the impact of a TBI on a developing child, and the need for improved management of TBI in children. Many of the opportunities for action in this report were noted in the original text, and continue as unmet needs after all this time. Over the past 30 years, we have seen a proliferation of research that better describes children's brain development, outcomes from a TBI, and service needs. Unfortunately, services to support TBI management in children after initial injury care have declined in availability, length of time, and consistency within the United States.

The information provided in this report represents a call-to-action to improve the care children receive after a TBI so they can maximize their potential for recovery.

Moving forward, this effort will require increased coordination and collaboration among the many stakeholders focused on the burden of TBI in children. A quote from the Mark Ylvisaker book still resonates: "Long-term care extends beyond the four walls of our rehabilitation facility and touches all aspects of a child's life."<sup>100</sup> All involved with the care of children can use this report and the opportunities for action within as a guide to improve care for children who sustain a TBI.



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