REPORT TO CONGRESS

The Management of Traumatic Brain Injury in Children:

Opportunities for Action

SUBMITTED BY

Centers for Disease Control and Prevention

National Center for Injury Prevention and Control

Division of Unintentional Injury Prevention

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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.[1]

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.[2] 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.[3]
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.[1] 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.[1] 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.[4]

IN 2013

640,000
EMERGENCY DEPARTMENT VISITS

18,000
HOSPITAL STAYS

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.[5,6] 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.

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

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.[7]

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.[8-11] Symptoms of mTBI can include headaches and dizziness, as well as problems with thinking, memory, physical activities, emotions and moods, and sleep.[12-20] 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.[13,14,21-23]

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.[24-28] 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.[29] 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.[30-33] 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.[7]

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.[19,29,34-36] A growing body of research indicates that for many students with moderate-to-severe TBI, post-high school career outcomes are poor.[37-40] 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.[41] Students with TBI also showed lower rates of enrollment in postsecondary education and independent living than those with most other disabilities.[41] To date, there are no longer-term studies on children with milder injuries, or those who sustain multiple concussions across childhood.

We have limited understanding of how childhood TBI impacts attainment of adult milestones (e.g., high school graduation, employment, or enrollment in post-secondary 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.[42]

Socioeconomic status and family functioning also influence recovery.[43-47] 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.[48] Economic and social disadvantage are associated with poor cognitive and academic outcomes following a severe TBI.[45,49] 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.[50] 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.[20,45,51] The adverse effects on families can persist for many years following injury.[52,53]

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.[54]

This is especially relevant to rural areas where access to pediatric specialized physicians and facilities[55-5] as well as specialized TBI services[58] 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,[59] supports and accommodations through a Section 504 plan,[60] 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, 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.[2,61-63] 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.[61,64,65] 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.[66] There is substantial variation in care among the sites where children are seen for acute injury care. Not only are there inconsistences in TBI assessment, but also in the comprehensiveness of discharge recommendations for all severity levels of TBI.[2,67]

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.[68] 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.[68] 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.[69]

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.[70-72] 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.[73] 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[67,74,75] 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[2,76,77],
- The potential under-identification of students with TBI for special education services[61] and
- A lack of awareness of educators about the effects of TBI on learning.[73,78,79]

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.[81] 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.[81-84] 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.[85] 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[86] and continue to have some basic misconceptions and knowledge gaps about TBI and the effects of brain injury on students in their classrooms.[78] In general, educators need better training in methods that are effective with students with TBI.[61,87-89]

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.[90-94] Only a few rigorous, systematic clinical trials have been performed.[93] For mTBI, the most recent guidelines recommend pacing, or gradual return to cognitive and physical activities, as tolerated by symptoms.[95-97] 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.[98] Managing more prolonged symptoms has not been the focus of prior consensus statements or guidelines and is primarily based on consensus opinion.[99] 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

- 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

- 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

- 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

- 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

- 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

- 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

- 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

- 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,*[100] 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."[100] 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.

THE BACKGROUND

BACKGROUND

The Traumatic Brain Injury Act of 2008 (Pub. L. 110-206) (TBI Act) authorized research and public health activities related to TBI. It amended Part J of Title III of the Public Health Service Act (42 U.S.C. 280b et seq.) by, among other things, inserting section 393C-1 entitled *Study on Traumatic Brain Injury*. This section authorized the Secretary of Health and Human Services, acting through CDC, to conduct a study on traumatic brain injury. The Traumatic Brain Injury Reauthorization Act of 2014 (Pub. L. 113-196) directed CDC to compile a Report to Congress on the management of TBI in children, specifying that the "Director of CDC in consultation with the Director of NIH shall conduct a review of the scientific evidence related to brain injury management in children such as the restriction or prohibition of children from attending school or participating in athletic activities following a head injury, and identify ongoing and potential further opportunities for research."

SECTION I

The first section of this report describes the public health burden of TBI in children by providing information on incidence, disability prevalence, health disparities, and the economics of injury care for children.

SECTION II

Section II describes the range of impacts experienced by children who sustain a TBI.

SECTION III

Section III describes service delivery systems and the continuum of care in the healthcare and educational systems, availability and access of care for children, state-based services for children, and a description of the current state of care for all injury severities.

SECTION IV

Section IV identifies gaps in the care received by children who have sustained a TBI, and describes practices that may be a means to better ensure optimal care.

The final section offers opportunities for action that are aimed at addressing key gaps in the science and practice of caring for children who have sustained a TBI.

> The CDC developed a plan to address the legislative language within the TBI Act of 2014 that directed the CDC to produce a Report to Congress on the management of TBI in children.

In July 2015, the CDC convened a writing group consisting of internal TBI subject matter experts along with external experts that specialize in TBI medical and educational services. In August 2015, a report outline was presented to a group of external reviewers with diverse pediatric experience including physicians, educators, parents, state and federal agency representatives, and university researchers to provide feedback on the proposed report content. Incorporating reviewer feedback, the co-authors devised a first draft of the report by reviewing the scientific literature related to the topics of: TBI outcomes, brain development in children, management of TBI in children, policies related to the management of children with special healthcare needs, disabilities as a result of developmental conditions, and health disparities. Searches of databases including Medline, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsychInfo, and Education Resources Information Center (ERIC) were completed for TBI-related outcome and intervention studies. No date limit was applied in most of the search strategies. Searches were performed using keywords such as: brain injury, concussion, children, adolescent, pediatric, family, outcomes, intervention, management, effect, sequelae, prognosis, function, rehabilitation, cognitive, education, school, behavior, and social.

The authors conducted a broad-based review of the literature, including studies that might not have met the criteria used in systematic reviews, such as literature examining emerging and current "best practices" in children's TBI rehabilitation. The writing team also examined policy documents related to the provision of services for children with medical conditions and disabilities. CDC initiated a meeting with the Department of Health and Human Services stakeholders (i.e., National Institute of Health (NIH), Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institute of Neurologic Disorders and Stroke, (NIH/NINDS) and the Administration for Community Living (ACL), whose purview touches on the management of TBI in childre,n to discuss the report plan and release timeline.

TBI subject matter experts at the CDC, leadership in the CDC's Division of Unintentional Injury Prevention, and the external reviewer group reviewed the initial draft. The final draft incorporated feedback from these reviewers. Representatives from the National Center for Medical Rehabilitation Research (i.e., NICHD/NCMRR), ACL National Institute on Disability, Independent Living and Rehabilitation Research (ACL/ NIDLRR) and the Office of Head Start (Administration for Children and Families) have served as external reviewers of the report outline, initial draft, and final document.

THE BURDEN

THE PUBLIC HEALTH BURDEN OF TRAUMATIC BRAIN INJURY IN CHILDREN

INCIDENCE

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.[3]

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.[1] The leading cause 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.[1] Sports and recreation-related TBIs are a leading cause of TBI-related ED visits among children and teens with an estimated 325,000 occurring in 2012.[4]

Children with TBI can present to a number of clinical locations: the ED, urgent care clinics, primary care, concussion/sports medicine clinics, or other specialty clinics. In addition, some do not seek or receive medical care.[101] Recent research examining the point of entry in a large healthcare network found that among pediatric patients with mild TBI (mTBI), 82% initially visited primary care, 5% visited specialty care, and 12% visited an ED.[102] This information suggests that incidence estimates of pediatric TBI based solely on ED visit data are significant undercounts, likely missing those with mTBIs seen at lower levels of care, in addition to those with mTBIs who don't seek care at all.[101] Because of these gaps in TBI surveillance, researchers have found it difficult to accurately estimate the true incidence of pediatric TBI, a critical factor in understanding the public health burden it represents.[5,103,104]

Rates of TBI-related deaths and TBI-related hospitalizations among children have decreased in recent years (i.e. from 2007 to 2013).[1] However, TBI-related ED visits among children have significantly increased during the same time period.[1] More specifically, ED visits as a result of TBIs experienced during sports and recreational activities have increased.[4] The increase in ED visits may not be a true increase in incidence, but rather a response to increased public concern about concussion, resulting in a higher likelihood of seeking care, improved training of clinicians in concussion diagnosis, and the passage of legislation in all 50 states requiring healthcare provider clearance prior to a child returning to play.

INJURY SEVERITY

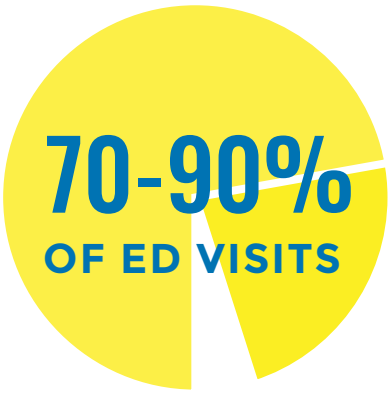
TBI severity is typically separated into categories of mild, moderate, and severe based on a patient's initial clinical presentation, and is measured by behavioral indicators, primarily the Glasgow Coma Scale (GSC),[105] and the pediatric coma scale.[106] As defined by the GSC, a score of 13-15 is labeled an mTBI, a score of 8-12 is labeled a moderate TBI, and a score less than 8 is labeled a severe TBI.[105] Complicated mild TBI is a designation given when a child has a mild GSC rating (13-15) with neuroimaging findings (e.g., skull fracture, intracranial bleeding) on the day of injury.[107-109] The presence of a visible abnormality on imaging suggests greater neuropathology in the child's brain at the time of injury, although the long-term effects of such documented changes on children's brain structure and outcomes are mixed.[108,110,111] The concept of mTBI is thus viewed as a continuum when imaging findings are included in the severity ratings.

Most TBIs are mild, and are commonly called concussions.[112] From this point forward, we will refer to concussions as mild TBI (or mTBI). Mild TBI accounts for 70-90% of TBI-related ED visits.[5,6] In a study of children seeking emergency medical care from hospitals for TBI (N=2940), 84.5% had mTBI, 13.2% had moderate TBI, and 2.3% had severe TBI.[113] Moderate-to-severe TBI occurs at a lower rate than mTBI in children, but is associated with worse outcomes. In addition, African American, Hispanic, and Native American children are more likely than white children to experience more severe TBI, and have higher mortality rates.[114-117]

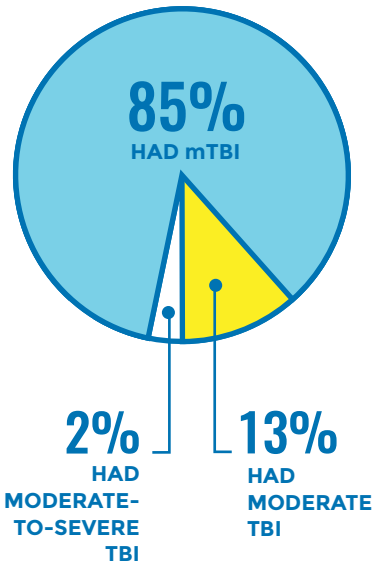
MECHANISM OF INJURY

The cause, or mechanism of TBI, is an important consideration in understanding its epidemiology because the mechanisms of injury suggest the types of events that need to be prevented. The leading mechanisms of TBI vary by age, but falls, motor-vehicle crashes, and sports and recreation-related injuries are the primary mechanisms of injury in children.

mTBI ACCOUNTS FOR



In a study of children seeking emergency medical care from hospitals for a TBI:



Falls are the leading cause of TBI-related ED visits in the youngest children (0-4 years), accounting for more than 70% of TBI-related ED visits in this age group in 2013.[1] Injuries caused by falls (35.1%) and being struck by, or against an object account for the majority of TBI-related ED visits among youth 5-14 years of age.[1] For persons in the 15-24 years age group, the proportions of TBI-related ED visits resulting from assaults, falls, and motor vehicle events are nearly equal.[1] African American, Hispanic, and Native American children are more likely than white children to experience a TBI caused by violence[114-117] or to be struck by a motor vehicle while walking or bicycling.[116]

In 2012, approximately 430,000 ED visits resulted from sports and recreation-related mTBI.[4] Nearly 70% of those ED visits (325,000) were among those 0-19 years of age.[4] From 2001 to 2012 the rate of sports and recreation-related ED visits increased significantly among males, particularly among those 10-14 years of age (139.9% increase) and those 15-19 years of age (119.3% increase). Among males, the largest number of ED visits for sports- and recreation-related mTBI occurred as a result of injuries while bicycling, or playing football or basketball. A similar increase was found for females, particularly among those 15-19 years of age (211.5% increase) and those 10-14 years of age (145.2% increase). Among females 0-19 years of age, the largest number of ED visits for sports and recreation-related mTBIs occurred as a result of injuries while bicycling, engaging in playground activities, or horseback riding.[4] In addition to sports-related injuries, the rate of ED visits for playground-related TBIs significantly increased from 2005 to 2013.[118]

> During 2001–2013, an annual average of 21,201 children 14 years of age and younger were seen in the ED for playground-related TBIs. The highest rates of playground-related TBIs were found among males and children 5-9 years of age.

Abusive head trauma (AHT) in children is a mechanism of injury most frequently experienced by young children, and it generally results in moderate or severe injury. Annual estimates of AHT ED visits and hospital admissions from 2001 to 2006 were 3,227 nationally; nearly two-thirds of those visits resulted in hospital admission, a reflection of the typical severity of AHT.[119]

THE EFFECTS OF TBI IN CHILDREN

Adults with moderate-to-severe TBI who receive inpatient rehabilitation typically experience significant changes in critical aspects of their daily life. These include higher rates of unemployment, disability, and even a reduced life expectancy.[120,121] However, children, who are in the midst of significant brain development, differ greatly from adolescents and adults in brain biomechanics, pathophysiology, and neurodevelopment.[122] Injuries of any severity to the developing brain can negatively impact children's behavior and cognitive skills as they grow, placing them at risk for significant changes to their developmental trajectory across multiple domains. An additional consideration is that children typically recover well in relation to the outward physical manifestations of the injury (e.g., physical skills), but may have sustained damage to their brain, affecting thinking and behavior that is often not visible. The "invisible" nature of a TBI may lead to unmet care needs and difficulties with meeting societal expectations, resulting in misattribution of an individual's behavior, and discrimination.[123]

To date, little research has examined long-term adult outcomes following a childhood TBI. In particular, it is unclear how changes in brain development and skill attainment caused by a TBI in childhood impacts achievement in adult metrics, such as educational attainment, employment, and adult health. The burden of TBI in children can be explained by examining disability, participation limitations, economic impact, and disparities in healthcare. In this section, we provide an overview of these issues with more details offered in subsequent sections.

PREVALENCE OF DISABILITY

It is unclear how many children currently live with a TBI-related disability, largely because childhood disability is not defined consistently. For example, some groups define disability by a child's limitations or eligibility for special education, whereas others use rehabilitation service utilization as a metric. A study published in 2008 estimated that 145,000 children were then living with a TBI-related disability nationally. However, that number was calculated by extrapolating national estimates from discharge dispositions in a single state.[124] Disability estimates based on the use of specialized medical and educational services indicate that more than 61.6% of children with moderate-to-severe TBI received new services, compared with 14.3% of children with mTBI, and 8.3% of children with arm injuries.[7] Although service utilization is highest among children with severe TBI, the higher incidence of mTBI disproportionally skews the number of children using services toward those with mTBI.

ECONOMIC IMPACT

Estimates of the economic impact of a TBI vary depending on how costs are considered. Using data from a nationally-representative sample, Brenner, Harman, Kelleher, and Yeates[125] estimated that healthcare expenditures for mild-to-moderate TBI-related services in children averaged $77.9 million per year, with an average per capita expenditure of $1,044 ($166 for TBI-specific services and $878 for general healthcare). The estimates produced by that study did not account for the costs associated with a severe TBI, so they represent an underestimate of the total cost of TBI. Another study calculated that pediatric TBI inpatient charges accrued to more than one billion dollars per year for TBI-associated hospitalizations.[126] A study of the direct medical costs of AHT, which tends to result in more severe TBI in children compared to other causes, estimated the annual cost to be $69.6 million nationally.[119]

THE OUTCOMES

OUTCOMES AND CONSEQUENCES OF TBI IN CHILDREN

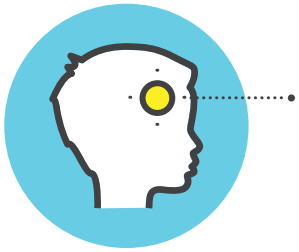
> A TBI of any severity experienced by a child can contribute to health difficulties, physical impairments, cognitive difficulties, and deficits in behavior, socialization, adaptive functioning, and participation.[8-11]

Studies comparing children who sustained a moderate-to-severe TBI and an injured control group (e.g., children who sustained an orthopedic injury) have found that the children recovering from a TBI generally have lower life satisfaction, reduced adaptive functioning, and lower rates of participation in activities, and those changes persist over time.[7,10,127] Although most children will have a good recovery after mTBI,[13,14] some children with mTBI are at risk for disability and long-term effects that alter their participation in school and the community.[127]

The effects of brain injury in children are additionally complex because the injury impacts a brain that is still developing. A child's course of recovery is superimposed on normal developmental processes, potentially affecting not only previously-learned skills, but also the development of future skills. Thus, problems can manifest years after the injury, as the complexity of skills required to meet future developmental milestones increases. Potential problems include later academic failure, chronic behavior problems, social isolation, difficulty with employment and relationships, and in some cases, involvement in illegal activities.[128-131] The effects of a TBI are frequently described as "heterogeneous" and "diverse" because each injury and course of recovery is unique. In addition to the developmental processes described above, children may experience other health and learning difficulties or social and familial challenges, and any of these can complicate the recovery process.

THE EFFECTS OF TBI ON THE DEVELOPING BRAIN

Children's brains differ from their adult counterparts in both structure and function. As children mature, the systems that control brain function build over time and are influenced by a person's genetics and life experiences.[132-136] For example, the frontal area of the brain, which plays an important role in behavioral regulation, begins to develop in early childhood and continues into adulthood. Thus, a variety of behavioral abilities, such as the development of social skills and impulse control, are not fully attained until late adolescence or adulthood. Attainment of these complicated skills can be harmed when children sustain a TBI in childhood, before these systems have fully developed.[137] Although it is known that children's brain development is vulnerable following a TBI, there are many unanswered questions about the timing, resiliency, or mechanisms by which brain systems develop throughout childhood. Consequently, little is known about how a TBI interacts with this process.

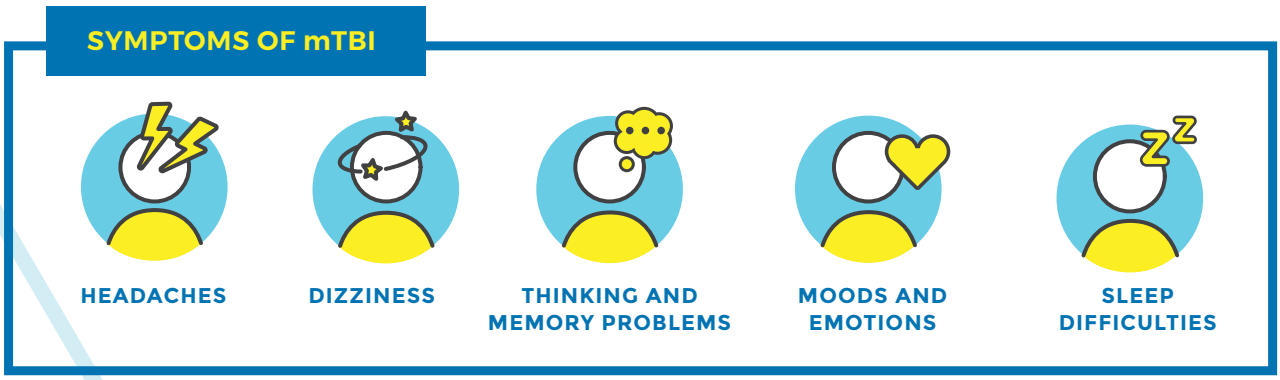


The frontal area of the brain, which plays an important role in behavioral regulation, begins to develop in early childhood and continues into adulthood.

Recent brain imaging studies found reduced brain size and structural changes in certain areas of the brain among children who experienced a TBI with imaging findings, especially at a young age,[138-140] supporting the notion that disruptions in brain systems during childhood could underlie observed behavioral and neurocognitive changes, and academic problems years later.[139,141] Although the exact effects of a childhood TBI on brain development require more study, emerging physiological and imaging findings of anatomic changes suggest the importance of protecting children from sustaining TBIs. Recent research supports the notion of a TBI as a chronic condition in adults because of the number of health, cognitive, behavioral, and social effects that can persist or progress over an individual's lifespan.[142] Similar long-term chronic effects almost certainly impact children in similar ways, except potentially for a longer period of time. More studies are needed that follow children into adulthood to understand these relationships.

MEDICAL AND HEALTH OUTCOMES

Medical and health outcomes in children are complicated by the fact that children can have other developmental conditions, such as Attention-Deficit/Hyperactivity Disorder, which may contribute to experiencing a TBI, or compound the effects of a TBI.



Mild TBI

Common symptoms of mTBI include headaches, dizziness, and problems with thinking/memory, changes in moods/emotions, and sleep difficulties (Table 1).[12-20] Symptoms usually develop immediately, but they can also develop over a few days after injury. Longitudinal studies suggest that most children with mTBI recover from the initial symptoms within 6 weeks after injury, with 30-60% having persistent symptoms at one month post-injury, 10% at three months post-injury, and less than 5% at one year post-injury.[13,14,21-23] Although children can recover quickly from the initial symptoms, little information is available about the long-term outcomes of single or multiple mTBIs in children, particularly among those who experience an mTBI at a young age. In addition to changes in thinking and memory, children can also experience changes in their motor systems, such as balance[143] and postural instability,[144] and these can affect the motor performance that is critical for a return to physical activities.[145]

30-60%
of children with mTBI have persistent symptoms one month post-injury.

Cumulative effects of mTBIs

Some children experience more than one mTBI, and there is limited and conflicting information about how multiple injuries can affect outcomes.[146] One recent study found that a previous mTBI was associated with longer time-to-symptom resolution.[147] Symptom duration was influenced by the number of prior mTBIs and the time elapsed since the most recent injury.[147] There have also been incidents in which a combination of subclinical blows to the head and mTBIs are thought to have led to severe TBI, resulting in diffuse brain swelling and death.[148,149] These incidents highlight the importance of immediately removing children from sports and recreational activities when an injury is suspected. There is also growing concern that cumulative head trauma over a lifespan can lead to cognitive and behavioral decline later in life, and that early exposure to head trauma, even if subclinical, could be a contributing factor to these impairments many years later.[150-154] In general, however, studies are mixed regarding the effects of multiple mTBIs in relation to cumulative problems,[146] and documentation of more than one mTBI is inconsistent and infrequent in medical records.

TABLE 1

Common symptoms after mild TBI

(Adapted from the fact sheet, *CDC HEADS UP for Healthcare Providers*)

THINKING AND MEMORY	PHYSICAL	MOODS AND EMOTIONS	SLEEP
• Has difficulty thinking clearly • Feels slowed down • Has poor concentration and poor memory • Forgets instructions • Answers questions slowly • Feels sluggish, hazy, foggy, or groggy	• Dazed or stunned appearance • Clumsy movements • Headache • Fuzzy or blurry vision • Nausea or vomiting • Dizziness • Balance problems • Double or blurry vision • Sensitivity to noise or light • Fatigue • Poor energy	• Mood, behavior, or personality changes • Irritability • Sadness • More emotionality • Nervousness or anxiety • Just not "feeling right" or "feeling down"	• Sleeping more than usual • Sleeping less than usual • Trouble falling asleep

Moderate-to-severe TBI

More severe injuries can cause a range of medical, health, cognitive, motor, emotional, and behavioral issues that can present early and later after injury, and the severity of issues can change over time. 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.[24-28] Medical issues that occur after a TBI can affect multiple body systems (Table 2). For children who survive severe injuries, long-term morbidity is a significant risk.[42] Acute injury factors associated with increased morbidity and disability include: the presence of abnormal eye reflexes; abnormal muscle tone and posturing; a GCS score below 7; age of injury less than 2 years; low blood pressure; elevated blood sugar; low blood oxygen levels; poor brain blood flow; development of post-traumatic amnesia; and physical abuse as the mechanism of injury.[155-164] GCS scores at 72 hours and oxygen levels during emergency evaluation are factors highly predictive of the risk for long-term global disability after TBI in children.[165] Children with more severe TBI can experience a greater number of motor control symptoms than those with mTBI (Table 2). Even children who recover well physically following moderate-to-severe TBI are likely to have decreased balance and gait speed, and increased step variability while walking, all of which can limit participation in sports and other activities.[166] Overall, children with more severe injuries are at greater risk for developing complex medical conditions, such as seizures, and are more likely to require support for eating via feeding tubes, requiring considerably more comprehensive medical services and management by caregivers.

TABLE 2

Summary of possible medical issues after a traumatic brain injury

MEDICAL ISSUE	DESCRIPTION
Autonomic dysfunction	Autonomic dysfunction after a TBI is characterized by increased heart rate, breathing rate, temperature, blood pressure, sweating, and muscle activity.[167] Autonomic dysfunction is more common in moderate-to-severe TBI, but little is known about this area in mTBI.
Disorders of consciousness (e.g., decreased levels of arousal)	Disorders of consciousness that typically occur after a severe TBI include: coma, vegetative state, minimally conscious state, and post-traumatic confusional state.[168] Children with disorders of consciousness after a TBI often survive longer than similarly affected adults, and they are more likely to regain consciousness.[162,163]
Post-traumatic headaches	Post-traumatic headaches occur after a head injury, and are one of the most common problems encountered after a pediatric TBI.[169] In mTBI, headaches are very common initially, but resolve or return to baseline over time. A smaller percentage of children develop persistent headaches long-term after an injury.
Swelling or increased fluid in the brain	A TBI can result in a state of increased fluid or swelling in the brain in all severity levels. Clinical signs of increased fluid or swelling can include irritability, or depressed mental status, seizures, increased muscle tone, and functional decline. Treatment for post-traumatic hydrocephalus can require placement of a drain.[170,171]
Problems with hormone production and regulation	Problems with hormone production and regulation can occur after a TBI. Monitoring for such problems after pediatric TBI is especially important because growth, including physical and brain development, can be significantly altered by hormone abnormalities.[172-180] Regular screening for brain-related endocrine problems is recommended after moderate-to-severe pediatric TBI because endocrine problems can develop months or years after an injury.[181] Timely management of endocrine dysfunction after a pediatric TBI helps to facilitate normal growth and development.[173]
Gastrointestinal/ nutritional problems	Injuries to the abdominal area or problems with the gastrointestinal (GI) system are common after a TBI.[165] Even without an associated GI injury, children with a severe TBI are at risk for GI problems, including upper GI bleeding, reflux, constipation, and other bowel problems.[182] Early identification of GI problems is crucial, so appropriate treatments can be started. Children might require a feeding tube to support nutritional and energy needs.[183]

Urinary system problems	Problems with the urinary system are common after severe brain injuries.[184] Many of those urinary problems resolve over time after an injury.[185]
Motor dysfunctions	Tight or spastic muscles, poor coordination, tremors, weakness, and deficits in balance are common motor abnormalities seen after all severities of pediatric TBI.[186-197] The location of injury in the brain determines the type of motor dysfunction that follows pediatric TBI. Problems associated with motor impairments can lead to problems in developmentally and age-appropriate function, including walking and self-care skills, along with the ability to participate in higher-level sports and recreational activities.
Respiratory problems	Children can experience breathing problems that require intubation at the time of injury and, if the condition persists, tracheostomy placement.[198] Practices for airway management are followed more often in severe TBI. The incidence of tracheotomy placement in children is 2.9% for those requiring craniectomy.[199] Long periods of unconsciousness and mechanical ventilation are associated with respiratory complications beyond injury care.[200]
Unexpected bone growth	The incidence of bone growth in unexpected areas after severe pediatric TBI is 10-23%.[201-203] This typically occurs about four months post-trauma.[201] The hip, knee, shoulder, and elbow are the most commonly-involved sites.[202]
Blood clotting disorders	Blood clotting disorders can occur after mostly moderate-to-severe TBI, leading to complications.[204]
Sensory issues	Vision and hearing can be affected after a TBI of all severities. Double vision can result from injury to nerves in the brain or head and facial areas.[205] An injury affecting the vision tracts in the brain can cause loss of vision in certain areas. A TBI that leads to severe brain swelling in a child can result in blindness; some or complete recovery can occur. In mTBI, visual and eye movement problems are also common.[206] Hearing loss after a TBI commonly results from a fracture of the temporal bone, and is usually one-sided.[207,208] However, even mild hearing loss puts a child at risk for impaired development of skills, such as speech development. Problems in smell or taste resulting from injuries to certain nerves in the brain or head and face are often associated with decreases in appetite, which lead to feeding problems. An inability to appreciate body odor and maintain appropriate hygiene can lead to social challenges for teens with deficits in smell after a TBI.
Seizures	Most seizures occur immediately (<24 hours) after a pediatric TBI.[209-212] The incidence of seizures after pediatric TBI ranges from 9.6-68% for early (< 7days) seizures[209-213] to 1-20% for late (>7 days) seizures.[211,213,214] Children less than 3 years of age with a severe brain injury, brain swelling, or a displaced skull fracture have a higher risk of early post-traumatic seizures.[215] Children with a severe TBI are also at increased risk of developing seizures longer after injury (>10-15 years) than adults.[216,217]

COGNITIVE, BEHAVIORAL, AND SOCIAL EFFECTS OF A TBI

> Cognitive problems after a brain injury affect not only learning, but also how children interact with their environment.

Potential cognitive, academic, and social effects are summarized in Table 3. Common cognitive effects observed after injury include impairments in attention, memory, processing speed, and executive functions (cognitive flexibility or the ability to switch thinking about topics quickly, working memory, self-monitoring, self-regulation, planning, organization, and decision-making).[42] These thinking and behavioral controls underlie a child's behavior and interaction with other people and the environment. The subsequent behavioral and social effects of childhood TBI across the spectrum of severity can greatly affect quality of life for children and their families. In a study examining social participation, parents reported a reduction and limitations in peer interactions and community activities for children discharged from inpatient rehabilitation.[10] In addition, the long-term effects of such injuries — achievement of adult milestones, such as high school graduation, enrollment in post-secondary education, healthy lifestyles, and employment — remain unknown.

mTBI

Although initial recovery for most children with mild injury is relatively quick (typically 1-6 weeks),[13,14,218,219] even an mTBI can have academic, social, and quality-of-life implications for children and their families.[16,220-222] Studies have noted increased hyperactivity and reading impairments in some children following mTBI, among other problems; however, development of long-term cognitive and behavioral deficits is unlikely following a single mTBI.[12,18-20,223-226] Up to a third of children with mTBI develop behavioral or psychological symptoms that persist beyond the initial injury recovery period, such as poor conduct and problems with empathy and peer relationships.[14,20,227,228] More recent research examining social behavior in children after mTBI found difficulties in social outcomes, including problems with emotional perception, social skills, social problem-solving, and social language use.[9,137,229] It is unclear why persistent, long-term issues emerge for some children who experience mTBI. Emerging evidence suggests that pre-injury health conditions and a history of more than a single mTBI contribute to longer recovery and persistent symptoms.[147,230]

Moderate-to-severe TBI

Changes in cognition following moderate-to-severe TBI can directly affect a child's daily life at school and home for years. In particular, executive function deficits were reported 5-10 years post injury in children with severe injuries.[231,232] Changes in executive functioning and other aspects of cognition contribute to deficits in behavioral and social interactions after a TBI. Many children experience personality changes, and exhibit a range of maladaptive behaviors as a result of a brain injury and its related cognitive changes.[42] More than two-thirds of children with a severe TBI develop psychiatric disorders following an injury.[233] Social functioning, defined as the way an individual uses their social skills to interact with others,[234] is often significantly affected by a childhood TBI.[137] Children with an early brain injury (before 2 years of age) are especially vulnerable to significant social impairment.[235] During the transition from childhood to adolescence, when expectations for the use of appropriate social skills increase, social-emotional challenges can become increasingly apparent among children injured when they were much younger.[236-238] Difficulties can include disruptive behavior, emotional distress, poor conduct, and problems with empathy, moral reasoning, and peer relationships.[239] Addressing potential social-behavioral deficits can be even more critical to successful school functioning than addressing academic and cognitive deficits.[9,240,241]

Changes in cognition and behavior as a result of a TBI can affect children's healthy lifestyle choices, and contribute to negative outcomes, such as placement in restrictive environments (i.e., incarceration), substance abuse, harm to self and others, and reduced life expectancy.[42]

TABLE 3

Potential cognitive, academic and social-behavioral effects of a TBI [137,241]

CATEGORY	DESCRIPTION
Cognitive	Self-regulation, executive function, attention, information processing, memory problems
Academic	Inconsistent learning, knowledge gaps, lower educational attainment
Social-behavioral	Deficits in social information processing, peer relationships, social adjustment skills, language use, and participation

School outcomes

A child's daily life is centered 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.[29] Children with a moderate-to-severe TBI earn worse grades, show higher rates of grade retention, and receive more special education services than their uninjured peers.[30-33] Students with a 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 twelve months later.[7] Furthermore, educational needs can emerge over time as school demands increase, especially among children injured at a young age. In a cross-sectional study, children with complicated mild and moderate TBI needed more school supports 6 years post-injury than they did 2 years post-injury.[111] Recent studies examining adults with a history of mTBI also report an increased risk for lower educational attainment, particularly among those who sustain multiple mTBIs.[242]

14%

of children who experienced an mTBI needed educational support services at school twelve months later.[7]

Transition to adulthood

Young adults with a TBI experience cognitive and neuropsychological consequences that can significantly influence their educational and vocational outcomes after high school.[243,244]

Moving from childhood to adulthood

A growing body of research indicates that for many children with a TBI, exposure during childhood is associated with risks of impaired adult functioning,[245] and career outcomes are poor after high school.[37-40] One study[41] examining students with moderate-to-severe TBI found that fewer than half of these students who had been out of school a year or more had a paying job outside the home. Students with a TBI who qualified for special education (severity not specified) had lower rates of enrollment in post-secondary education than students with:

- **Hearing impairments**
- **Visual impairments**
- **Orthopedic impairments**
- **Speech or language impairments**
- **Autism**
- **Learning disabilities**
- **Other health impairments**

Students with a TBI also showed lower rates of independent living than those with most other disabilities. Post-secondary outcomes following childhood TBI suggest that students with a TBI who enrolled in post-secondary education or training were more likely to emerge unprepared for employment.[39] At age 25, most individuals who sustained a moderate-to-severe childhood TBI still worked at entry-level or low-skilled jobs, whereas their nondisabled peers had higher-paid skilled and professional positions.[246] Even young adults injured late in high school might not experience the full effects of changes in their cognition until they start college.

The transition to adult healthcare can also be a challenge for children who sustain a TBI. A recent integrative review of healthcare for children with developmental health conditions reports the current process of transition to adult healthcare for children is deficient in providing consistent and sufficient transfer from pediatric to adult healthcare.[247] Currently, unlike other chronic healthcare conditions in children, children with a TBI may not be consistently seeing a specialty care provider. In many cases, there may not be a particular healthcare provider who follows the child across development into adulthood who can manage the transition to an adult provider. A contributing factor is that a child's primary healthcare provider may not be informed about the TBI experienced or a child's TBI history. As knowledge about TBI-related health effects in adulthood emerges, the critical importance of managing that transition becomes more evident.

FACTORS THAT INFLUENCE OUTCOMES

Many factors, including injury severity, age, individual patient characteristics, social-environmental factors, and access to healthcare can influence recovery from childhood TBI.

Age at injury

TBI at younger ages is associated with worse outcomes than an injury sustained later in development.[26,40,248] TBIs occurring at ages that coincide with critical periods of brain and cognitive development can result in more pronounced difficulties.[249] As children with a history of TBI develop, behavioral and cognitive problems can continue to emerge as task demands increase over time.[236,250] For example, children who sustain a moderate-to-severe TBI before the age of 7 years have substantially worse outcomes than children who suffer a similar injury at an older age.[251-256] Young children with more severe injuries have more pronounced problems with cognitive and school-readiness skills, including memory, spatial reasoning, and executive function.[8,257-259] Sustaining a severe TBI at an early age is also associated with poor employment outcomes. After leaving school, those youth are more likely than youth injured later in childhood to hold entry-level or low-skilled jobs with low pay, and they work fewer hours per week.[40,248]

> Children who sustain a moderate-to-severe TBI before the age of 7 years have substantially worse outcomes than children who suffer a similar injury at an older age.

Severity of injury

More severe injury is associated with long-term effects on cognitive and school readiness skills, including memory, spatial reasoning, and executive functioning. [8,257-260] However, it appears that the influence of injury severity wanes over time as one study found that injury severity was less predictive of outcomes compared to other factors one year post-injury.[261] A severe injury at a young age has been associated with the poorest long-term outcomes, including lower cognitive skill recovery.[40,262,263] However, emerging studies have demonstrated risks for behavior and social difficulties following even mTBI in children.[264-266]

Compared to children with TBI caused by unintentional injuries, children who sustain AHT experience a more severe form of injury and have worse outcomes on average. Factors contributing to poor outcomes for this mechanism of injury include younger age of injury,[159,267-269] more severe initial injuries,[268-272] and higher rates of secondary brain injuries from poor oxygenation of the brain.[268,271,273] These types of injuries frequently call for more comprehensive medical management, requiring some parents to care for a child with a tracheostomy, feeding tube, or other medical interventions. Children who experience AHT are often removed from their homes due to ongoing concern for their safety and are placed in foster care. Thus, not only are some children forced to deal with changes in their medical condition, but they must also adapt to a different family environment, an important contributor to TBI recovery.

Individual characteristics and pre-injury functioning

Individual characteristics, such as gender, genetics, pre-injury cognitive ability, learning disabilities, coping styles, and health conditions, such as ADHD, anxiety, depression, mood disorders, and migraines are potentially important determinants of outcomes following TBI.[22,47,91,274-284] Recent research reports a high prevalence of TBI in adolescent athletes with a history of ADHD or diagnosed learning difficulties.[285] Mental health conditions, such as depression and anxiety, poor problem-solving skills, and considerations aligned with suicide risk[286] are also associated with TBI in children.[233,287] Emotional symptoms in adolescents after a sports-related mTBI can contribute to the development of new psychiatric disorders, isolated suicidal ideation, and worsening symptoms of a pre-existing psychiatric disorder.[288] Although limited research has been done on co-occurring conditions in children, the context of other health and learning conditions in a child's life can affect their outcomes following a TBI.[2,289,290] Particularly in young children, it is difficult to determine whether a health or learning condition was present before the injury or if the condition was a result of or exacerbated by the TBI. Pre-injury functioning is also correlated with various cognitive and behavioral outcomes. Persons with higher levels of pre-injury cognitive functioning often preserve more functional capacity after a TBI than those with lower pre-injury function.[291] This hypothesis suggests that a person might be able to use cognitive resources post-injury to support their recovery and functioning. Younger children have less cognitive reserve than older children because of their short life experience and developmental stage. For example, a child who has a TBI at age 4 has not yet learned to read, whereas a child who experiences a TBI at age 14 has not only learned to read but is reading complex material. Finally, growing evidence for the role of genetic influence on outcomes suggests that some alleles, or gene variants, might confer neuro-protection to some and vulnerability to others post-TBI.[292]

Family and environmental factors

Socioeconomic status and family functioning also influence recovery trajectory.[43-47] Family-level factors are critical social-environmental influences on outcomes in children following a TBI,[48] including caregiver distress or depression and deteriorating family functioning.[293,294] Aspects of the home environment, such as parental responsiveness, negativity, and discipline practices are linked to a child's behavioral recovery.[295,296] Economic and social disadvantage are associated with poor cognitive and academic outcomes following severe TBI.[45,49] Negative social outcomes from TBI are further exacerbated post-injury when family environments include low socioeconomic status, limited resources, and poor family functioning.[241] Limited resources may be tied to where the family lives. Access to pediatric specialized physicians and facilities is more limited in rural areas[55-57] due to availability of transportation, distance from home to healthcare, as well as specialized TBI service availability.[58] Family socioeconomic disadvantage combined with severe injury lead to the poorest long-term outcomes.[297]

In any family environment, a TBI is an unexpected event that can create significant changes in family structure. Parents often have to take time off from work to care for children. Depending on the length of hospitalization and child care requirements, parents sometimes need to leave their employment, which changes a family's financial status. Furthermore, parents sometimes change their

parenting practices after the injury because of their worry and concern, and that further affects the child's outcomes.[298] 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.[50]

Several studies have demonstrated that a childhood TBI can have persistent adverse effects on caregiver and family well-being. The stress on parents from caring for the injured child often leads to increased marital conflicts[299] and high levels of psychological symptoms and distress in family members.[52,300,301] Factors, such as greater injury severity,[52,301,302] high levels of chronic family stress, coupled with deficient resources,[303] maladaptive coping strategies,[35,303,304] and unmet healthcare needs[293] appear to place caregivers at elevated risk for psychological distress. Parent/caregiver burden and family dysfunction are a particularly important consideration because they are a strong determinant of a child's psychosocial recovery, with children from well-functioning families demonstrating better psychosocial functioning.[45,49,51] The adverse effects on families can persist for many years following injury.[52,53]

A TBI during childhood is associated with offending behavior and incarceration in adolescents.[131,305-307] In a longitudinal birth cohort study, TBI status was associated with criminal behavior, regardless of age at injury and injury severity.[307] Factors that contribute to risk for incarceration after a TBI include substance abuse,[131,307] experiencing multiple TBIs,[131,305] untreated TBI,[306] mental health diagnosis,[131,305] and family disadvantage (low socioeconomic status and parental education).[307] Of concern is that the incarceration can occur during adolescence, a time when the transition to adulthood is just starting, making it even more difficult to achieve successful educational and vocational milestones.[308]

THE CARE

MODELS OF SERVICE DELIVERY, AVAILABILITY, AND ACCESS FOR CHILDREN: CURRENT STATE OF CARE

Assessment and management of TBI in children often starts in the healthcare system, frequently in the ED or primary care physician's office.

After initial injury care, children generally return to their schools and communities for continued management of the effects of the TBI. Children receive care from two separate service delivery systems in the healthcare and educational settings, and these two settings are often not well-coordinated or integrated.[2] In addition, there is large variation in the services available at the state and community level. This section describes ongoing medical management, school services, and community-based care children receive following brain injury. Very little evidence supports any of the currently used models of service delivery; where it is available, however, we include the evidence of efficacy.

MEDICAL MANAGEMENT

Mild TBI

Many children with an mTBI visit an ED for initial care, although those who are older than 5 years of age and have private health insurance typically see their pediatrician.[102] Regardless of the treatment location, the goal of initial management for all types of brain injury is to determine injury acuity, and safely triage individuals to the most appropriate level of care. Across all severities of brain injury, it is important to assess immediately for the possibility of more severe injury or other potential injuries (e.g., injury to the spinal cord) that would require immediate evaluation. It is important to assess airway, breathing, and circulation, as per the emergency care guidelines, to make sure the individual is medically stable.[91] When more severe or immediately life-threatening problems have been ruled out, the focus can turn to assessing and managing signs and symptoms of mTBI. Currently, the highest level evidence is for patient and family education. Table 4 provides a summary of current pediatric mTBI management evidence.

TABLE 4

Summary of the evidence base for mTBI management [93]

MANAGEMENT ISSUE	EVIDENCE LEVEL
Pre-activity or injury	
Baseline neuro-cognitive testing if child/adolescent plays high-risk sports	B
Initial presentation after injury	
Assess and treat any physical, cognitive, and neurologic deficits	A/B
Determine need for CT imaging	A
Consider admission or prolonged observation if child/adolescent shows red flag symptoms (e.g., severely worsening headaches, repeated vomiting, change in state of consciousness)	B
Treat acute headaches	C
Prescribe physical and cognitive rest	B/C
Discharge after initial presentation	
Provide verbal information and written handouts to child/adolescent and parents/caregivers	A/B
Educate on expected course of recovery and return to learn/play	B
Advise on risks and complications of re-injury, especially persistent symptoms	B
Advise on managing sleep proactively	C
Advise on managing headaches	B
Advise on coping with fatigue	B
Advise on maintaining social networks and interactions	B
Advise on avoiding alcohol and other recreational drugs	B
Advise on not driving during recovery	B
Advise on general monitoring; promote regular follow-up with primary care or sports medicine physician until symptoms disappear; refer to specialized care if symptoms persist after one month	B/C
Interim assessment – When can the child/adolescent return to learn and play?	
Recommend a stepwise return-to-learn plan	B/C
Implement return-to-learn plan after acute symptoms have improved	B/C
Recommend additional assessment and accommodations if symptoms worsen or fail to improve	B/C
Implement return-to-play plan only after return-to-learn program has started	B
Refer to an expert in mTBI for help with return-to-play decisions or retirement from contact sports	B
Provide verbal information and written handouts to individual and parents/caregivers	A/B
Re-assessment after one month – What to do if symptoms persist?	
Assess any modifiers (e.g., pre-injury history of TBI, learning disabilities, depressive disorder, or migraine disorder) that might delay recovery	B
Eliminate medications that might mask or modify symptoms	B

Assess, document, and manage significant, prolonged complaints based on specific symptoms, etiology, and time since injury	B
Assess and treat any physical, cognitive, and neurologic deficits	B
Place every child on a sleep hygiene program	C
Screen for factors that can influence sleep/wake cycle	B
Consider non-pharmacologic treatments to improve sleep	C
Consider prescribing medications on short-term basis if sleep has not improved	C
Refer to pediatric sleep specialist if sleep not improving	C
Take detailed headache history	B
Establish the degree and duration of the disability caused by the headaches	C
Perform neurologic exam and a head/neck exam	C
Consider non-pharmacological, complementary, or alternative medicine therapies for headache	C
Consider treating migraine headaches with prescription medication	B
Assess for persistent cognitive difficulties	B
Manage any cognitive impairments	B
Assess for balance and vestibular impairments	B
Assess for benign positional vertigo	B
Refer for further assessment and treatment if balance or vestibular system is dysfunctional	B
Assess ongoing vision dysfunction	B
If visual disturbance is present, refer to vision specialist	B
Assess/manage persistent fatigue symptoms	B
Assess for existing and new mental health symptoms and disorders	B
Obtain report of mood and feelings from child/adolescent and parents/caregivers	B
Treat any mental health problems	B
Consider referral to pediatric mental health specialist	B
Recommend rehabilitation therapy to improve symptoms and mobility, as needed	B
Consider broad differential diagnosis	C
Consider need for specialist therapy if symptoms persist	B
Work with primary care professional and school/employer on accommodations to tasks or schedules	B
Provide verbal information and written handouts to child/adolescent and parents/caregivers	A/B

Grading system

A= Consistent, good-quality, patient-oriented evidence (examples: at least one large randomized control trial, meta-analysis, systematic review with homogeneity, or large, high-quality, multi-center cohort study)

B= Inconsistent or limited-quality patient-oriented evidence (examples: smaller cohort studies, case studies, and control trials with limitations)

C= Consensus, usual practice, opinion, or weaker-level evidence

Source: (www.essentialevidenceplus.com/product/ebm_loe.cfm?show=sort. Accessed May 8, 2014)[309]

Recognizing the lack of evidence-based pediatric mTBI guidelines, the CDC's National Center for Injury Prevention and Control's (NCIPC) Board of Scientific Counselors (BSC) created the Pediatric Mild Traumatic Brain Injury Guideline Workgroup to inform the development of a guideline. This workgroup conducted a review of the existing literature, and developed recommendations for healthcare providers who care for children after an mTBI. The workgroup, composed of leading experts in the field, submitted a report titled, *Systematic Review and Clinical Recommendations for Healthcare Providers on the Diagnosis and Management of Mild Traumatic Brain Injury in Children* to the NCIPC BSC in August 2016.[315] The report presents evidence-informed recommendations based on a rigorous review of the literature on mTBI care for children. Recommendations were made in the areas of diagnosis, prognosis, and management/treatment. The report, informed by public comment and approved by the NCIPC BSC, will be used to advise the development of the first evidence-based guideline on the diagnosis and management of pediatric mTBI in the United States.

A variety of medications are used to treat the symptoms of an mTBI;[310-313] however, there are no definitive, evidence-based recommendations.[98] The most common medications used in mTBI symptom management in children are headache-related medications.[311] Other medications are also used to manage the variety of symptoms that occur after an mTBI, including cognitive, behavioral, mood, emotional, sleep, fatigue, and concentration/attention problems.[310] Currently, there is no known medication that will speed recovery, and most medication use for mTBI is off-label. It is also common for children with a range of persistent symptoms to be referred for speech, occupational, behavioral/psychological, physical, vestibular, vision, and other types of therapy to manage cognitive, behavioral/emotional, and physical problems following an mTBI.[314] At this time, a wide range of treatments are prescribed post-injury; however, the field lacks the strong evidence-base needed to definitively inform standard of care recommendations. Individualized symptom management is the most common recommendation. To date, most evidence available for the management of pediatric mTBI is level B (inconsistent or limited-quality patient-oriented evidence [examples: small cohort studies, case studies, and control trials with limitations]) or C (consensus, usual practice, opinion, or weaker-level evidence).[93]

MODERATE-TO-SEVERE TBI

> With more severe TBI, aggressive medical management is often needed, and rapid transfer to a pediatric trauma center is recommended.

Computed tomography (CT) scans typically assess for structural problems, such as skull fractures, brain swelling or bleeding, and pressure on the brain. Due to concerns that radiation associated with CT scan use in children can lead to an increased risk of brain cancer later in life, clinical decision rules have been developed for when CT scans should be considered to identify clinically significant brain injuries.[317] The use of those rules is generally reported to be favorable.[318,319]

After initial stabilization, management of children with more severe injuries depends on the presenting signs and symptoms. Acute medical management guidelines have been published, but the acute medical care provided for moderate-to-severe brain injuries continues to vary.[320] Treatment at a certified pediatric trauma center is generally associated with better outcomes than treatment in other facilities.[66] A variety of critical care interventions is used to manage the various acute medical issues that present after injury, including increased pressure in the skull or brain (i.e., increased intracranial pressure), blood pressure variability, glucose abnormalities, temperature variability, nutritional deficits, respiratory problems, seizures, and blood clotting disorders.[160,320-335] Evidence is mixed, and there is variable implementation of management strategies; however, adherence to acute and critical care TBI guidelines is associated with improved outcomes.[160,320,324-329,332-337]

Although much acute medical management focuses on survival and minimizing acute medical problems, it is important to pursue the ultimate goal of returning the child to optimal function and quality of life. Delaying the transition from an intensive care unit (ICU) to acute rehabilitation results in fewer functional benefits than early transition. Earlier initiation of a formalized inpatient brain injury rehabilitation program is associated overall with shorter hospital stays and improved outcomes.[338,339] Transfer to rehabilitation is recommended as soon as the child is medically stable.[340] Inpatient rehabilitation involves a multidisciplinary, specialized team typically led by a physician who specializes in rehabilitation medicine and guides the management of the physical, cognitive, and social issues encountered by children and their familes after TBI.[341] Critical management domains for acute rehabilitation after pediatric TBI include ongoing medical management; family-centered care; cognitive, communication, speech, language, and swallowing impairments; gross and fine motor skill impairments; neuropsychological, social, and behavioral impairments; school reentry; and community integration.[314] The portion of hospitalized children discharged to inpatient rehabilitation is estimated to be 3.7%, but this number varies widely among states.[68] According to the authors, inpatient mortality of pediatric hospitalized patients and being uninsured contribute to this estimate. Availability of specialized TBI rehabilitation programs, especially in rural areas, insurance coverage for rehabilitation services, and eligibility for inpatient rehabilitation services, all contribute to the low use of rehabilitation care.[55-57,342,343] Insurance coverage is identified as an important factor in children's access to specialty care, such as rehabilitation. Although children with public insurance (Medicaid and CHIP) may have better access to specialty care than children without insurance, they are less likely to have access to specialty care than children with private insurance.[344]

As with mTBI, various medications are used to manage the chronic sequelae of moderate-to-severe TBI.[345] However, the evidence for specific medication usage after brain injury is poor, and use in pediatric TBI is generally off-label.[345,346] Medications are used to manage a range of medical, cognitive, behavioral, psychological, pain,

and other issues that occur after pediatric brain injury; however, a definitive evidence base and guidelines for use of medications are lacking.[345,347-349] The extrapolation of medications used in adult TBI to children should be done carefully because a child's response can differ from an adult's. Because there is a paucity of strong evidence for the use of medications in the management of pediatric TBI sequelae, more research is needed.

HEALTH DISPARITIES IN TBI CARE

Disparities in care for children who have experienced a TBI have been documented in relation to race/ethnicity, disability status, sex, income, geography, and insurance status.[115,350-356]

> In a national study of children with special healthcare needs, a higher prevalence of special healthcare needs was reported among older children, African Americans, males, and children from low-income or single-parent households.[357]

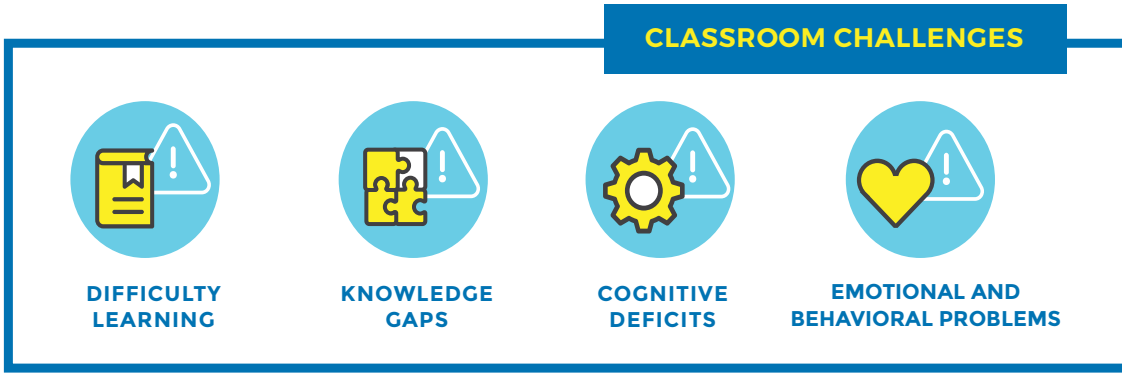
Those patterns align with studies reporting disparities in care received and outcomes among African American[350,351,353] and Hispanic children,[355,358] relative to non-Hispanic white children. In addition, several factors are associated with a lower likelihood of being hospitalized for pediatric TBI, including younger age, non-white race, being uninsured, and being treated at a community hospital (versus a trauma center).[354] Primary care physicians are more likely to be the single source of care for persons with TBI-related disability in rural areas, and they are unlikely to have received advanced training in the management of a TBI.[55]

There is evidence to suggest that care from pediatric specialists, relative to care from adult healthcare providers, results in better outcomes for pediatric TBI patients. Children who receive inpatient rehabilitation at children's hospitals typically have more efficient functional improvement than children receiving inpatient rehabilitation at other hospitals.[54] Overall, pediatric-focused inpatient rehabilitation units meet a larger total number of inpatient rehabilitation quality indicators than other facilities.[359] Facilities with therapists specially trained in pediatrics had the best adherence to motor, neuropsychological, and community integration quality indicators.[314] Inpatient rehabilitation units that admit only children also did better than other units in the cognitive, neuropsychological, and school re-entry domains, with Commission on Accreditation of Rehabilitation Facilities certification associated with better adherence in the school re-entry domain.[314] However, it is important to note that in the continuum of care following a moderate-to-severe TBI, acute medical care lasts only weeks to months, whereas the management and recovery that occur in outpatient medical settings and at home and school lasts for many years. One of the best predictors of receipt of outpatient rehabilitation is receipt of inpatient therapies or consultation with a rehabilitation physician during acute care.[360]

Children with abusive head trauma (AHT) are more often diagnosed at pediatric hospitals than in non-children's hospitals or referred for hospital admission from pediatrician offices and outpatient settings.[361] They typically have worse outcomes post-injury compared to those who experience unintentional injury, in part because their family environment is frequently altered as a result of the intentional nature of the injury. Keenan and colleagues report that one year later, almost 50% of the children with AHT continue to be in some type of foster care.[362] AHT is considered a more severe form of injury in children younger than age 2, and children with AHT are 8 times more likely to have a long duration of hospital stay.[361,362] Most likely, children in foster care have public insurance.[362]

SCHOOL MANAGEMENT: RETURN TO LEARN

Children with all levels of TBI severity experience cognitive and behavioral problems that can adversely affect school performance.[29,363,364] Children with a TBI have more daily performance variability, difficulty learning new information (despite maintaining pre-injury skills), and knowledge gaps, as well as cognitive deficits, including attention, concentration, and processing speed difficulties. These difficulties can make academic work more challenging following a TBI. Furthermore, behavioral problems, such as poor conduct, and problems with empathy and peer relationships can negatively affect the school experience.[14,20,227] A range of supports and services are available for children ages 0-22, including early intervention services, special education under the Individuals with Disabilities Education Act (IDEA, 2004), supports and accommodations through a Section 504 plan,[60] and informal supports provided by a classroom teacher.



The vast majority of brain injuries in children are mTBIs,[6,365] with symptoms typically lasting 1-6 weeks.[65] When students who experience mTBI return to school, most will respond positively to a well-orchestrated, short-term plan of physical rest, simple classroom adjustments (e.g., extra time on tests, reduced homework load), and slight environmental changes (e.g., fatigue breaks).[75] Many schools use a Response to Intervention (RTI) model in general education whereby students with learning difficulties are provided with supports and tailored interventions at varying levels of intensity depending on their needs (RTI Network; www.rtinetwork.org). However, there is variation in RTI implementation among states.[366]

Students who have ongoing symptoms following a TBI can receive formalized supports and accommodations through a Section 504 plan[60] to ensure they have full access to the academic curriculum. A 504 plan might include physical accommodations (e.g., automatic door openers), assistive technology (e.g., keyboard for taking notes), or a modified class schedule.

> Most children will respond positively to a well-orchestrated, short-term plan of physical rest, simple classroom adjustments, and slight environmental changes.

This plan could also include accommodations to compensate for limitations that could prevent the student from fully taking part in classroom learning or demonstrating what s/he has learned, such as being allowed to use a tape recorder rather than taking notes in class, being granted extra time to take a test, or having a quiet place designated for study or test-taking. Other accommodations frequently recommended for students as part of a 504 plan following a TBI include a shortened school day, help with organization, memory aids, and rest breaks.

Special education

Students with a TBI who have significant learning or behavioral challenges might be eligible for special education services in public schools. Categories for eligibility under IDEA were originally designated to represent developmental conditions, such as learning disabilities, while acquired medical conditions, such as TBI, were grouped under the other health-impaired (OHI) category. TBI was added as a specific eligibility category under IDEA in 1991. To qualify for services under the TBI eligibility category, most states require medical documentation of an event (of any severity) likely to have caused a TBI. Assessments must show a difference between the student's pre- and post-injury performance, and the student must demonstrate a need for specially designed instruction to benefit from the educational environment. For students deemed eligible for special education after a TBI, a team, typically composed of parents, the student (if older than age 14), a special education teacher, a regular education teacher, and a district representative, create an individualized education plan (IEP) that details how the student's education will be specially designed. It can include services, such as speech-language therapy, physical therapy, occupational therapy, or special classes to help the student benefit from educational services. It can include intensive academic and social-behavioral intervention by a special education teacher and must include specific, annual academic goals. IDEA contains several protections for students on IEPs and their parents, including an annual review of the student's progress that can be used to update IEP goals for the coming year. IDEA is mandated for all public schools in the U.S.

SHORT-TERM PLAN

Accommodations may include:

PHYSICAL REST

EXTRA TIME ON TESTS

REDUCED HOMEWORK LOAD

MORE FREQUENT BREAKS

SPECIFIC HELP AT SCHOOL

IDEA is designed to improve educational opportunities and performance for all children with disabilities, regardless of their enrollment in public schools or parent-placed private schools.

As authorized by the 2004 Amendment to IDEA,[367] public schools are required to engage with private school representatives and parents of these children, and use the Child Find process to identify students who may be eligible for special education.[367] According to a recent report, 43% of private schools have students receiving IDEA services. This percentage is larger than utilization by private schools of any other federal education program. Speech therapy and special education instruction are the most common services utilized by students in private schools.[368] Private schools vary regarding provision of special education and rehabilitation services, by state and individual school practices.

Special case: Children injured before age 5

Students injured before starting formal schooling (younger than age 5) do not have a single point of entry for services outside of a hospital.[77] One source of follow-up care is with the child's pediatrician or family physician. Children from birth to 3 years can be referred to early intervention services funded by the state and federal government to minimize the effects of a disability or developmental delay. Infants and toddlers who are delayed in development, or have a diagnosed medical condition with a high likelihood of affecting their development, can also be referred to state-based programs by their parents, physicians, hospitals, schools, state agencies, child care providers, or social service providers.

States are required to coordinate payment for early intervention services from federal, state, local, and private sources, including public and private health insurance. All states and territories receive funds for a statewide system of multidisciplinary coordinated care through Part C of the Grants for Infants and Families program of IDEA (Office of Special Education Programs). Once a referral is made, the family provides permission for an initial assessment, which is done in a natural environment for the child (i.e., the home.) For children deemed service-eligible, an individualized family service plan (IFSP) is devised to include all services (e.g., medical treatment; nursing; physical, occupational, and speech therapy; social services; and counseling) the child will be receiving, the type of environment where the services will be delivered, and the schedule for progress review. Coverage for services under Part C extends past age 3 years at which time there are requirements to include education in addition to other medically-based services contained in the plan. For children with existing IFSPs, a plan is developed to transition to other services upon reaching 3 years of age.

Young children are more likely to be in day care and preschool prior to school entry. In 2011, 61% percent of children between the ages of 3-6 were enrolled in center-based care (day care, nursery school, preschool or Head Start).[369] Head Start programs, in particular, provide or obtain evidence-based vision and hearing screenings as well as a screening to identify concerns regarding a child's developmental, behavioral, motor, language, social, cognitive, and emotional skills. In addition, and in consultation with parents, Head Start programs determine whether each child has ongoing sources of continuous, accessible health care provided by a health care professional that maintains the child's ongoing health record, and ensures that children with identified health conditions receive follow-up care (§ 1302 Subpart D – Health Program Services).

Transition-age youth

For children and adolescents with TBI, the transition to adulthood is a period of vulnerability.[39,40] Successful transition to post-secondary education and career opportunities is more likely to occur when students receive transition services and access to resources that can help them identify realistic post high school goals and provide connections to vocational rehabilitation.[40] Like younger students, transition-age youth identified as eligible for special education due to the effects of a TBI can receive a range of services (e.g., specialized instruction, augmentative therapies) under IDEA. In addition, beginning no later than age 16, all students who have IEPs must receive services designed to help them successfully transition from high school to adulthood.[370]

Private, charter, and homeschool services

Very little is known about how children with a brain injury are supported in private and charter schools. Children in private schools and homeschools are entitled to services under IDEA, and can receive ancillary (occupational, physical, and speech therapy) services under an IEP; however, private schools are not mandated to provide the same educational services as public schools.

RETURN TO PLAY AND RECREATIONAL ACTIVITY

Return to play and participation in recreational activities is another important consideration for children. Managing the return to these activities involves understanding the child's symptom resolution, including response to increased exertion, and the characteristics of the activity. The primary concerns are ensuring that children do not have additional mTBIs, a more severe TBI, or adverse health effects because they have returned to the activity too soon. Most of the work in this area has focused on sports-related mTBIs, and experts have developed protocols and guidelines for a graduated return-to-play protocol.

The Sideline Concussion Assessment Tool (SCAT)[371-373] and the Acute Concussion Evaluation (ACE)[374,375] are often used on sidelines and in EDs to screen for the signs and symptoms of mTBI. The SCAT is on its third version, and has been adopted by several sports organizations. Both SCAT and ACE require special training for their scores to be valid or useful, and individuals with the necessary training and expertise are not always present at youth sporting activities. The SCAT3 is used in some outpatient clinic settings to assess and guide management of mTBIs. The CDC's *HEADS UP* program for parents, coaches, and children/adolescents has several online training modules that describe how to recognize an mTBI and appropriately remove an individual from activities to prevent further injury.[376] *HEADS UP* also includes information for healthcare providers on assessing and managing a return to activities, along with materials providers can offer patients and their families in clinic.[376]

> The use of neurocognitive and neuropsychological assessments has been a significant part of mTBI-related research and clinical practice for more than 25 years.[377-379]

The use of computerized assessments for the evaluation of mTBI has increased exponentially in community and clinical care settings recently.[378] There are several tests available for use.[379,380] Computerized assessments are intended to be part of a multifactorial assessment and not a standalone evaluation.[378,380] Although neurocognitive and neuropsychological assessments generally have a relatively strong empirical foundation, evidence to definitively guide their use in assessing and managing mTBI is insufficient. There is also insufficient evidence to decide whether traditional or computerized assessments are superior.[377,381] Likewise, although having an accurate measure of baseline cognitive functioning, especially for individuals with above- or below-average cognitive functioning pre-injury, is believed to be helpful,[379] the evidence is insufficient to recommend preseason baseline testing as time- and cost-effective or even as superior to not testing.[377] Additionally, there are concerns about the reliability and validity of computerized screening.[377,379] Sophisticated psychometric methods can help researchers interpret test results to identify cognitive problems and monitor recovery after injury,[377] but continued refinement is needed. Incorporating a clinical neuropsychologist into the management team to assist with test interpretation is important[380] but often not possible.

Guidelines for return to non-sports physical activities (e.g., bike riding, playground activities) are currently lacking. In organized sports, once an mTBI is identified, all states require that children be assessed by an appropriate healthcare provider to determine a safe return-to-play protocol.[382] Recent consensus guidelines[90-92] describe an incremental return to activities (both academic and athletic) as the cornerstone of mTBI management (Table 5). A period of complete rest is recommended immediately after the injury; however, the optimal duration for that rest is unclear. Recent research indicates that a shorter rest period might be better than longer rest.[383] Furthermore, recent work also indicates that the introduction of activity might help speed recovery, especially in individuals with prolonged symptoms.[384-390] More research is needed to better understand the role of rest and activity in managing mTBI.

General return-to-play guidelines[92,391] and sport-specific guidelines[96] have been developed; however, there is variability in the scope and implementation of RTP guidelines. In a study of college-level athletic trainers, use of multifaceted assessment batteries at baseline was rare, but multifaceted assessments during acute assessment and return-to-participation time points were more common.[392] There was good agreement on the use of graded return-to-exercise protocols for return to participation; however, there was variation in how those protocols were implemented. A barrier to use of multifaceted baseline assessments was lack of staffing or funding for assessments.[392]

Additionally, most current consensus guidelines are based primarily on adult information, and more conservative return-to-activity protocols are likely needed for youth.[393] More evidence is needed to characterize optimal return-to-play guidelines.[95] Finally, while this has not been established scientifically, the same general return-to-play principles applied to organized sports are thought to be applicable to the recovery from non-sports TBI.

Unlike mTBI, no clear return-to-play or other recreational activity guidelines are available for moderate-to-severe TBI.[394] Furthermore, activity recommendations for children who experience a severe brain injury at a very young age are lacking. Children with moderate-to-severe TBI often experience motor system effects that can compromise their speed and agility in sports and recreational activities. In general, physicians are concerned that a child's reduced cognitive and motor functioning after a moderate or severe TBI creates increased injury risk, and that another injury could result in a more severe TBI than expected and prolong their recovery from the initial injury. Available evidence supports that children with an initial TBI are experiencing additional head injuries at a higher rate following initial injury care.[395,396]

TABLE 5

Graduated return to play guidelines[92,391]

Return to sport guidelines have also been individualized for specific sports.[96]

REHABILITATION STAGE	FUNCTIONAL EXERCISE AT EACH STAGE OF REHABILITATION	OBJECTIVE AT EACH STAGE
No activity	Complete physical and cognitive rest.	Recovery
Light aerobic exercise	Walking, swimming, or stationary cycling, keeping intensity <70% maximum predicted heart rate. No resistance training.	Increase heart rate
Sport-specific exercise	Skating drills in hockey, running drills in soccer. No head impact activities.	Add movement
Non-contact training drills	Progression to more complex training drills (e.g., passing drills in football and ice hockey). May start progressive resistance training.	Exercise, coordination, and cognitive load
Full contact practice	Following medical clearance, may participate in normal training activities.	Restore confidence and allow coaching staff to assess functional skills
Return to play	Normal game play.	

STATE-BASED SERVICES AVAILABLE TO CHILDREN WITH A TBI

> In addition to school, there are federal, state and local programs available for children that can be utilized to help children with a TBI.

For example, some states use the existing Intellectual/ Developmental Disabilities Systems to provide services such as rehabilitation services and in-home supports for children. At least 10 state TBI programs are currently collaborating with juvenile justice and correctional systems within their state to identify incarcerated youth with a TBI, and devise community integration plans once released.[397] However, there is limited information on the reach and effectiveness of these programs for children with TBI. Each state and U.S. territory has a lead agency and coordinator for TBI services, all of whom are members of the National Association of State Head Injury Administrators (NASHIA). The types of state agencies designated as the lead agency varies, but can include Departments of Public/Community Health, Vocational Rehabilitation, Social Work, Mental Health and Addiction Services, Division of Aging, and advisory boards on TBI. State support of services beyond hospital care for TBI started in the 1980s, and was expanded by authorization of the TBI Act of 1996.[397] Since then states have addressed the needs of TBI survivors and their families by legislation or executive orders to develop a service infrastructure that can include an advisory board, brain injury registry, designation of a state agency, and funding for services.[397] Twenty-three states have TBI trust funds, designated by legislation, to support services for individuals of all ages with TBI. States also rely on the Administration for Community

Living (ACL/HHS) Federal TBI grant program to expand and improve services for individuals with a TBI using allocated funds to meet the needs of underserved populations, including children and youth with TBI. In addition to efforts to build infrastructure for TBI, states have worked to expand existing disability, health, and children's programs to meet the needs of children with a TBI, including educator training.[397] Despite wide variability between states in terms of service infrastructure and funding support for services, state programs have not been systematically evaluated to determine best practices and effectiveness.

Preschool grants for children with disabilities

This program (U.S. Department of Education, Law and Guidance, YEAR) provides grants to states and territories for special education and related services (i.e., speech, occupational, and physical therapies). Each state can determine which children with developmental disabilities or medical conditions to include. States must include school readiness and pre-literacy skills as part of each child's educational program under these grants. At 5 years of age, children enrolled in preschool special education receive a transition plan to school. Children who sustain a TBI prior to entering school are eligible for these programs that can offer a developmental evaluation, school services, and monitoring of development until kindergarten. Parents and healthcare professionals can contact the child's neighborhood school to inquire about a referral to preschool services in their county.

Child Find

This program, mandated by IDEA and implemented by states, requires school systems and early intervention programs to identify, locate, and evaluate children from birth to 21 years of age with disabilities or suspected disabilities.[398]

Components of Child Find include defining the target population (as determined by each state), screening and identifying children, tracking children through the referral process, parent and teacher training, and interagency coordination. Child Find provides a mechanism for identifying children with a TBI who might have developmental delays or disabilities. Healthcare providers can contact the Child Find program in their state to inquire about the referral processes. This system offers a method for children injured prior to school entry to receive an evaluation for potential services.

Family supports

Parents and caregivers are the de facto case managers for childhood TBI survivors across the lifespan. Families critically influence the management process, particularly because a significant portion of recovery occurs following hospitalization. Parents also play a pivotal role in supporting their child's educational program.[399,400] Families of children with a TBI can take advantage of the same resources available to parents of children with other types of 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, such as a peer-visiting program offered by the Brain Injury Association of Georgia. As part of this program, parents whose children have experienced a TBI volunteer to visit parents of children with a recent TBI while their children are still in the hospital. The Brain Injury Association of America offers support groups for parents through their state affiliates (www.biausa.org). Brainline offers online information for families (www.brainline.org/caregivers). Some state services provide case management for families to assist the navigation between medical and school services. The effectiveness of many of these programs is unknown. For example, it is unclear the extent to which these programs benefit the broad range of families who experience TBI (across race, ethnicity, geography, and income levels), and at what point in the recovery process family support interventions are most beneficial.

Health Services in Schools

In addition to educational services, schools sometimes provide health services for a student who has had a TBI. School nurses and comprehensive healthcare clinics at schools provide an important system of health service delivery for children with a TBI. A previous survey estimated that 81.5% of schools had a school health services coordinator, and 86.3% of responding schools had a part-time or full-time nurse.[401] In 2012, more than three fourths of school districts reported having policies that provide for administration of medications, case management for disabilities, CPR, first aid, identification for school-based management of disabilities and chronic health conditions, and violence prevention.[402]

Students with a TBI are eligible for school health services from both a chronic health and disability perspective. For such children, a school nurse can facilitate benefits access and case management, identify mental health issues, refer students to appropriate services, and administer medication at school. School health clinics can provide other services for children who are Medicaid eligible. Children with a TBI can be supported for medical services through state Medicaid funding implemented under IDEA, or through school-based or linked health clinics. Health-related services covered under an IEP or Individual Family Service Plan (IFSP) are subject to Medicaid requirements for coverage, including medical necessity, inclusion in an existing service category (i.e., physical speech and occupational therapy), adherence to all state and federal regulations, and being included in the relevant state's Medicaid plan (Centers for Medicare and Medicaid Services).

Medicaid reimbursement is not available for educational services and there is no Medicaid benefit entitled "School Health Services" or "School-Based Services." Children under the age of 21, however, are entitled to the screening and treatment services pursuant to the mandatory federal benefit known as the "Early and Periodic Screening, Diagnosis and Treatment" (EPSDT) benefit. Services under this mandate include a comprehensive array of screening services, including a mental and physical developmental history, physical examination, appropriate immunizations according to the schedule for pediatric vaccines established by the Advisory Committee on Immunization Practices, laboratory testing, health education, and anticipatory guidance for both the child and caregiver.

Children with a TBI might be eligible to receive Medicaid treatment services in schools if several Medicaid conditions are met. It is no longer the case that children are only able to access Medicaid coverable services if those services are included in an IEP/IFSP. (CMS issued guidance in the form of a State Medicaid Director [SMD] Letter, #14-006, http://www.medicaid.gov/federal-policy-guidance/downloads/smd-medicaid-payment-for-services-provided-without-charge-free-care.pdf, which clarified Medicaid payment is allowed for Medicaid-covered services for Medicaid-eligible beneficiaries when delivered by Medicaid-qualified providers.)

The conditions in the SMD Letter include: the individual is a Medicaid beneficiary; the service is a covered Medicaid service provided in accordance with the approved state plan methodologies, including coverage under the EPSDT benefit; the provider is a Medicaid-participating provider and meets all federal and/or state provider qualification requirements; the state plan contains a payment methodology for determining rates that are consistent with efficiency, economy and quality of care; third party liability requirements are met; Medicaid payment does not duplicate other specific payments for the same services; the state and provider maintain auditable documentation to support claims for federal financial participation; the state conducts appropriate financial oversight.

THE GAPS

ADDRESSING THE GAPS: OPPORTUNITIES FOR ACTION TO IMPROVE THE CARE OF CHILDREN WITH A TBI

> It is widely recognized that children with a brain injury are under-identified for health and educational services[61,64,65] and under-served by existing supports, placing them at risk for poor health and educational outcomes.

Children's risk for adverse outcomes following a TBI supports the need for further investigation aimed at understanding the gaps in care and the development of approaches for optimal assessment, access to services, service delivery, and transition to adulthood. Approaches should include parent and caregiver support as they have been shown to have a critical role in a child's recovery. This work is critical to ensure that children with a TBI of any severity have the best possible opportunity to maximize their recovery.

In this section, we provide an overview of critical gaps in the field of pediatric TBI management and offer recommendations to address these gaps.

ACUTE MEDICAL MANAGEMENT

There is significant variability in the quality of acute care received, and a lack of true evidence-based standards for children.

Access to comprehensive care at the time of the injury is especially important for children because the type and quality of care delivered can influence long-term outcomes;[66] however, there is substantial variation in care provided. Brain Trauma Foundation Guidelines have been developed for comprehensive management of TBI in Level I and Level II trauma settings. Healthcare providers in trauma centers are more likely than those in other facilities to adhere to those guidelines, and adherence is associated with a reduction in the lifelong effects of TBI, including disability.[403,404] In addition, children with TBI are twice as likely as adults to arrive at a hospital via private transport by parents or family members instead of by ambulance.[405] Private transportation loses the benefit of EMS services and the application of Field Triage Guidelines that can facilitate a pathway to a trauma center for care where more comprehensive care guidelines apply.[405] There are inconsistences in TBI assessment and in the comprehensiveness of discharge recommendations for all severity levels of TBI. Children treated at pediatric trauma centers have significantly better outcomes than those treated at adult trauma centers.[66] However, children are more frequently (34.9%) not treated initially at a trauma center, relative to other age groups,[405] suggesting that they may be less likely to receive timely and optimal acute care soon after injury.

35%

About 35% of children treated for TBI aren't treated initially at a trauma center.

Follow-up after emergency department care is inconsistent.

Most children with TBI are discharged to home following initial injury care at the ED,[68] with rates of hospitalization decreasing in recent years.[1] Some studies show that the rate of follow-up visits in the year after TBI, particularly to children's primary healthcare providers (e.g., pediatricians), is low (37-40%), suggesting a lack of coordinated follow-up care.[69,406] Currently, there are no formal systems by which the health of children with TBI can be monitored over time. Further, there has been little research describing the typical course of long-term medical management of children with mild or moderate TBIs who are seen in pediatrician offices or specialty clinics. Due to the range of injury severity and the complex nature of TBI in children, individualized care is needed, but uniform standards of providing optimal care are not practiced in all healthcare locations.

Access to healthcare after TBI is inconsistent.

There is significant variability in healthcare coverage for services after initial injury treatment for children, and the type of insurance coverage contributes to the level of available care.[342,343] Some states also have brain injury waivers or trust funds that offer additional resources for children. In addition, school-based health clinics and Medicaid practices for covering children in the schools can address some of the coverage discrepancies, especially for children in rural areas. Telemedicine is a promising practice that can potentially address the management of health and behavioral issues after the injury diagnosis.[407,408] In 2010, the Patient Protection and Affordable Care Act (ACA) included provisions to extend dependent healthcare coverage for children on their parents' plans until the age of 26, extending benefits into an age group that had a relatively low level of coverage.[409] This is a key period of transition for those with a TBI from pediatric to adult healthcare.[409,410]

Clinical decision support tools are used inconsistently.

Within electronic health record (EHR) systems, clinical decision support tools can be made readily available to aid clinicians in diagnosing and managing TBI.[411] For example, these EHR modules can provide clinicians with a consistent set of TBI diagnostic questions, and provide clinically-validated discharge instructions.[411] Despite the promise of these tools in increasing the consistency of care, their availability is inconsistent, and the content is variable. Further evaluation is needed to better understand the usefulness of these tools.

LONG-TERM MEDICAL MANAGEMENT

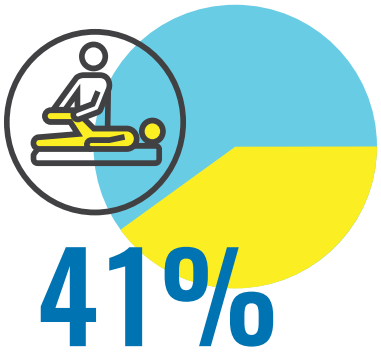
There is a lack of consideration of TBI as a chronic disease in children.

Recognition of moderate and severe TBI as a chronic disease is a recent development in adults,[142] but that recognition has not extended to the ways children with a TBI are managed over time. Although TBI meets the criteria for the Children with Special Healthcare Needs (CSHCN) program,[357] and aligns with criteria for a chronic health condition in childhood,[412] research studies have not identified the most effective long-term medical management strategies for children, regardless of TBI severity. Care standards that identify the optimal care continuum are limited, and those that are available are not used in all healthcare settings across the country. Research on the effectiveness of existing standards is sparse. Specifically, there is a poor understanding about the contribution of healthcare and school services to children's long-term outcomes.[2]

Rehabilitation services are not consistently available, and there is variability in service quality.

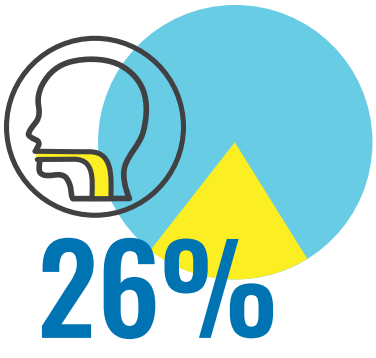
Frequently, children who need pediatric rehabilitation services do not receive them. For children who are hospitalized, there is significant variation between hospitals in the proportion of children referred to rehabilitation services during the course of the hospital admission.[413]

In a cohort of hospitalized children with a TBI who were admitted to the ICU and survived until hospital discharge, only 41% received a physical or occupational therapy evaluation during the acute phase of care (median time 5 days post-admission), and only 26% received a speech or swallowing evaluation (median time 7 days post-admission).[413]



41%

RECEIVED PHYSICIAL THERAPY EVALUATION



26%

RECEIVED A SPEECH OR SWALLOWING EVALUATION

> The length of time to referral for additional services in these studies indicates that children who are hospitalized for only 1-2 days are unlikely to receive an assessment for additional services during their hospital stay.

Another important factor is the degree to which parents recognize the need for therapy and educational services after their child is discharged from acute medical care.[62,69,414] Since parents are often the conduit to the receipt of care for their children, this lack of recognition can result in needed care not being received. Finally, whether a child receives long-term medical rehabilitation services often hinges on the availability of financial resources, particularly insurance coverage, to pay for care. Similarly, admission to inpatient rehabilitation is also influenced by health insurance status; only 1.5% of uninsured children are discharged from the hospital to inpatient rehabilitation, compared to 4% of children with private insurance.[68]

Another hindrance to optimal care is the significant variability in the services provided during inpatient rehabilitation, even among those who are admitted. For example, in a national sample of children's rehabilitation facilities, Rivara et al.[415] found substantial variation in the degree to which patients received recommended care. Using a measurement tool[314] that assesses how well a children's rehabilitation facility provides care across seven domains (e.g., general management, family-centered care, cognition and communication, motor skills, neuropsychological assessment and social skills, school re-entry, and community integration), they found that only 5 of 9 institutions scored greater than 50% on implementing recommended care indicators across key management domains in their programs, and only one institution scored above 70%.[314] This variability could result in part from a lack of agreement about key elements of recommended care, and could also reflect a lack of standardization of care across personnel.[314]

The Commission on Accreditation of Rehabilitation Facilities (CARF) is an independent, nonprofit accreditor of rehabilitation programs. Programs that seek CARF accreditation receive assistance and monitoring in offering high quality services based on recognized organizational and program standards (www.carf.org). CARF-certified inpatient rehabilitation units that admit only children did better than other facilities in the cognitive, neuropsychological, and school reentry domains.[314] CARF certification thus offers a mechanism for monitoring the quality indicators of children's inpatient rehabilitation, especially during the transition from the healthcare system to school. However, CARF or rehabilitation certification is not required; more consistent certification of facilities could help reduce the variation in quality.

There are frequently unmet needs after hospital discharge.

In the first year after an injury, a substantial portion of children with a moderate-to-severe TBI have unmet or unrecognized healthcare needs.[69] The unmet healthcare need most frequently reported by parents is cognitive services for their child. Parents most frequently reported an unmet need at 12 months post-injury because of a lack of physician recommendation, lack of provision by the school, or expenses.[69] Although outpatient follow-up for children with TBI can occur in a variety of settings depending on local resources, Slomine et al.[69] found that many children did not visit a healthcare provider in the year following their injury.

The medical home concept is not implemented consistently in TBI care.

> The utilization of a medical home, a place for routine medical care that also takes into account families' input, needs, and situation (i.e., family-centered care), is critical for children with special healthcare needs.

Patients with chronic health conditions who have a medical home are more likely than those who do not to have consistent medical care and family support, resulting in fewer unmet needs and a planned transition to adult healthcare.[416,417]

Many states have a lead agency for TBI[397] that can cover services, support advocacy efforts, and in some cases, administer a trust fund for expenses related to the TBI. Similar to medical home services, a small number of states also offer state-based case management services for individuals with a TBI. As an example, the state of Alabama's Department of Rehabilitation Services provides coordinators specifically trained to work with families enrolled in their Passages Program (www.rehab.alabama.gov/individuals-and-families/vocational-rehabilitation-service-general/traumatic-brain-injury-program/children-youth-and-traumatic-brain-injury), a model for long-term care that offers individualized, family-centered care coordination between hospitals and schools, as well as connections to community resources. However, programs similar to these are not consistently available within states, further contributing to the variation across states in the availability of services.

FAMILY SUPPORT AND TRAINING

Families experience significant stress after an injury.

The effects of a TBI often give rise to severe familial stress.[301] Unlike parents of children with developmental health conditions who experience their child's symptoms and disability from birth or infancy, parents of children with a TBI may face a sudden, unexpected alteration in their child's health, development, and behavior, as well as their family routine. After the TBI, families must come to terms with the changes in their child's functioning and, in the case of more severe injuries, the need to provide increased levels of care due to the child's physical and cognitive disabilities.[418]

Because so much of the recovery process happens after the child leaves the medical setting, families play a critical role in rehabilitation. A significant body of research has documented that the relationship between caregiver and child functioning is reciprocal: parental distress and depression, maladaptive parenting strategies, and critical and directive parent–child interactions contribute to poor child outcomes,[20,45,419] and child behavior problems contribute to caregiver burden and distress.[259,293,420]

These findings provide strong evidence for the value of targeting supports to family members to promote positive child outcomes. A variety of promising practices in the area of family support and training have been tested in small studies; however, these practices are not widely implemented.

Few parents understand the potential for a TBI of any severity level to become a chronic condition, nor are they aware of the pathways to care beyond initial medical services. Most studies to-date have examined parent response following moderate-to-severe TBI. Findings from those reports indicate that a parent's experience with the healthcare system at the time of injury can significantly impact their adjustment and understanding of what to expect from their child.[70,72] At the time of injury, parents may report initial relief that their child survived the injury, but they are unclear about what to expect in terms of recovery and need for services.[72] During initial care, healthcare providers often use terms and language that parents do not understand. One study of the parents of children with severe TBI found that parents did not perceive their child's healthcare providers were managing the TBI in the context of the broader health and function of the child and the family.[72] The suddenness of a TBI forces parents into multiple roles, including the role of advocate for their child in the healthcare and school settings. However, many parents are not given the information they need to understand the long-term trajectory of recovery or the options available to get systematic support in dealing with their new reality.[70-72] Caring for their child at the time of injury can require a leave of absence from work, and disruption in income. When children return to their communities, the need for support and information grows as parents become increasingly aware of their child's difficulties, and how that impacts the entire family.[72] Parents of children with mTBI might also experience a disruption in their lives through additional healthcare appointments to manage the effects of the injury. All parents of children with a TBI face additional stressors when their child returns to school. At school, they 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 development.[73] Finally, more research is needed to better understand the role of family stress, as well as family resilience, on long term outcomes for children with a TBI.

Education provided to families after a TBI is insufficient.

> Providing parents with information about TBI can alleviate parental stress.[421,422] Most children who experience mTBI will recover fully within several weeks, and will need only short-term supports at school.

However, especially for high school students, the symptoms associated with mTBI, even if they only last several weeks, can have a significant effect on school performance.

Some cognitive, behavioral, and social issues emerge over time following a TBI, and parents report a lack of information about what to monitor.[423] Current evidence suggests that for many students with a TBI across the injury severity spectrum, the lack of connection between the healthcare and educational systems leads to poor tracking of child educational needs.[2,111,414] At the time of injury and intermittently throughout care pathways, it is important for parents to receive information about: 1) keeping a personal health record with information about the child's injury, medical visits, and care recommendations; 2) being watchful for signs and symptoms of brain injury that can emerge over time; 3) communicating with their child's school about the injury and the need for monitoring in the school setting; and 4) tracking the number of brain injuries across the child's lifespan. A variety of web and text-based materials have been developed specifically for parents of children with a TBI. CDC's *HEADS UP* initiative (www.cdc.gov/headsup/youthsports) offers educational resources geared toward parents of children with mTBI,[424] including a list of the signs and symptoms of mTBI, and information about how to manage a suspected mTBI in coordination with medical and educational professionals. Brain injury advocacy groups (e.g., Brain Injury Association of America, United States Brain Injury Alliance) also offer current information for families, and a variety of web-based materials that are tailored to parents of children with a TBI (e.g., Brainline Kids). However, the impact of these education programs has not been evaluated thoroughly, and they are not implemented widely or consistently.

Parental support and training is lacking.

There is limited research on how best to support parents whose child experiences a TBI. Parents who participate in parent training find it helpful,[425] with skills-based training in stress management resulting in reductions in parental depression and anxiety.[426] Support groups and peer mentoring can also provide support.[427] In the school context, findings from a preliminary study with parents of children with a TBI suggest that parent advocacy training can lead to improved communication skills, which can then positively contribute to parent–teacher interactions.[428]

Research based on individual-level data suggests that paid family leave, which allows new mothers to delay their return to the workforce, is associated with positive parental and child outcomes and reduces family stress by improving family income.[429] Studies are needed to determine if extending those benefits to families with a TBI can reduce their stress and burden following the injury.

Family-focused therapy programs are under-utilized.

One of the few evidence-based models of comprehensive support for families of children with a TBI is problem-solving therapy (PST). Over a series of sessions, families receive training in cognitive reframing and staying positive, step-by-step problem solving, and family communication skills, coupled with education about the common cognitive and behavioral consequences of brain injury and strategies for responding to them. A series of randomized clinical trials has demonstrated the efficacy of both face-to-face and online family PST, providing compelling support for its feasibility and efficacy as an approach for improving both caregiver and child outcomes following a TBI.[430-432] Interventions focusing exclusively on training parents in positive parenting skills have also demonstrated improved child behavior.[433-436]

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

At the time of the injury visit

- 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 the 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 and monitoring.

Opportunities for post-injury services

- Systematic examination of healthcare-to-school transition programs and practices is needed 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, (CARF), 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 services across the continuum of care.

Systems opportunities for clinical decision making tools

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

RETURN TO SCHOOL

> Prior to injury, most students are enrolled in regular education.[437] Many students who sustain a TBI will need post-injury support at school.

Students with mTBI generally need informal support specific to their symptoms during recovery.[67,74,75] Students with mTBI with significant symptoms, and students with more significant injuries, often need formalized support (i.e., section 504, IEP).

There is frequently poor coordination of services at the school level.[61] Best practice guidelines suggest that each school or local education region should have a TBI Management Team that can create and implement an appropriate education plan to support students with a TBI.[75] The TBI Management Team, with a designated leader, can assist with the medical–educational transition, oversee implementation of academic supports, and provide ongoing monitoring of student progress. The school nurse is the recognized healthcare provider at school, and can assist with this process. While there are a number of local efforts aimed at addressing this issue, state-wide TBI Management Teams are in place in only two states. In Pennsylvania, school-based Concussion Management Teams support both student athletes and non-athletes who are returning to the demands of school while recovering from TBI. These teams partner with regional consultants, who are available to schools as an additional layer of more intensive student mTBI support, consultation, and training as needed.[437] In Oregon, regional consultants often provide this type of support to any district serving a student with a TBI.

There is often a lack of communication between healthcare and educational systems.

Many students return to school following an injury without any communication between the medical and educational systems. In a study examining the return to school experiences of children who had been hospitalized overnight for a TBI, there was no communication between the hospital and school for approximately half of the children.[2,76] Preschoolers typically leave medical care without any connection to post-injury services because they are not yet enrolled in school.[77] The disconnect between healthcare and educational systems can influence whether children receive any behavioral, academic, or cognitive services in school.[73,438] Although parents can assist with the transition from hospital to school, they might not fully understand the academic and behavioral challenges their child experiences at school, and they often have an overly optimistic view of the student's recovery that influences their decision-making and the amount of information they provide to educators.[62]

Students who receive inpatient rehabilitation services often have a team of professionals to support them and their families through the transition back to school. However, one study in 2014 found that only approximately 4% of children who are hospitalized for TBI receive inpatient rehabilitation.[314] Moreover, substantial variation exists among pediatric rehabilitation programs in the preparation for return to school.[439] Students with mTBI often do not receive any school accommodations despite recommendations that accommodations be made available for several weeks or months post-injury.[440] As a consequence, both parents and school personnel can become frustrated and discouraged by children's continuing difficulties and the disruption to their normative development.[441]

4%

Only about 4% of children who are hospitalized for a TBI receive inpatient rehabilitation.

School nurses can play a key role in the hospital-to-school transition and can serve as a liaison between school and a child's medical home. However, school nurse-to-student ratios vary drastically from state to state. Only 17 states have ratios that fall within the national recommendation of 1 nurse per 750 students.[442]

Several hospital-to-school transition models exist for students with mTBI[67,443,444] and those with more significant brain injuries.[89,445] In Oregon and Pennsylvania, regional TBI consultants provide a linkage from the hospital to the school setting. In those states, a medical professional can contact either the state coordinator or a local consultant to facilitate the return to school process. To date, there has been no systematic evaluation of any return to school models. CDC is currently examining a range of promising programs that provide a healthcare-to-school linkage to better understand the processes that are optimal in ensuring children with a TBI are monitored after they return to school and receive appropriate accommodations and/or services.

Injuries may be forgotten over time.

Because cognitive, behavioral, and mental health challenges related to a childhood TBI can emerge over subsequent stages of brain development,[34,255] students with a TBI should be monitored over time.[88,446] After the first year post-injury, educators are unlikely to connect an old TBI to current academic difficulties, and initiate appropriate educational support services.[414] Typically, a student's current teacher might not even be aware that the TBI occurred. Students who are identified and qualify for special education will be monitored as part of their IEP. For students with TBI who do not receive special education services immediately post-injury, ongoing monitoring is

critical.[88,446] For example, students with a TBI might need additional supports when they transition to middle school, even if they had previously adapted well to elementary classrooms where demands for self-management and independent study are minimal. A simple red flag system can be implemented in any school to ensure that students with mild–moderate injuries are carefully monitored.[447] Using the red flag system, a designated member of the school's brain injury management team communicates regularly with the student's teacher(s) to ask about medical, academic, and behavioral concerns. However, this type of system has not been formally evaluated, and is not widely implemented.

Early intervention and special education services are frequently not accessed for young children with a TBI.

Preschool children who experience a TBI are eligible for an assessment through state-run early intervention and preschool services in every state. Informing parents about these resources at the time of initial care establishes a follow-up pathway for health and developmental monitoring, which is especially important for children with a TBI, whose needs may change over time.

Not all children with significant post-TBI needs receive special education services.

The most recent special education census data indicate a continued, significant discrepancy between the incidence of TBI and the identification of children with a TBI for special education services. One estimate suggests that approximately 145,000 school-age children live with persistent disability following a TBI.[124] However, in 2008, according to the U.S. Department of Education, the total number of students receiving special education services under the TBI category was 24,857,[367] suggesting that fewer than 20% of students who likely need services are actually receiving them. Rates of identification for special education are higher among students with severe TBI, problem behavior, poor academic performance, and socioeconomic disadvantage.[31,32]

Another challenge is that special education identification rarely occurs after the first year post-injury; children who are not referred for special education at the time of the hospital–school transition are unlikely to be identified.[414] It is possible that some children with a TBI receive services under different disability labels (e.g., "other health impaired"); however, it is unclear whether such services address the unique cognitive and behavioral needs of students with a TBI. In a recent survey, a majority of state special education directors reported that students with a TBI are not appropriately identified.[448] State directors reported only 40% of students with a TBI were classified under the TBI category; students with a TBI were more often identified under the categories of Specific Learning Disability, Other Health Impairment, Emotional Disturbance, and Others.[448]

The potential for under-identification is particularly significant for children injured at a young age. The total number of children served in the Early Childhood Special Education program during the years 2014-2015 was 753,697, with only 1,106 children in the TBI category.[449] The reason for the low number of children in educational services compared to those seen for care in the healthcare system is not well understood. It is possible that, like older students, these children are identified for services under a different eligibility category, or parents and healthcare providers may not understand the need for specialized support services for young children who experience a TBI and therefore do not make referrals at the time of injury care.

The factors contributing to identification for special education warrant further investigation.[39] It could be that some children do not require intensive services, that their families want to avoid the stigma of special education, or that there is limited parental understanding about the supports and services available at school.[448] The under-identification of children affected by a TBI for special education services is one indicator reflecting the difficulties parents face in navigating the continuum of services after their child sustains a TBI.

Traditional educational assessment and instructional approaches may be ineffective.

Traditional assessment protocols may need to be altered to effectively assess the unique and changing needs of students with a TBI. Assessment should be ongoing with built-in progress monitoring so that TBI-related services can be appropriately modified as a student's needs change.[61,64] Further, standardized office-bound assessments might not provide an accurate picture of a student's capabilities after a TBI.[88,450] A valid and useful evaluation of these students should use ecologically valid assessments, such as parent and teacher behavior scales that measure a student's performance in the classroom setting. Unfortunately, most schools do not implement these recommended assessment approaches with students with a TBI.

The enormous variability within the population of students with a TBI (e.g., varying pre-injury profiles of ability, variable educational needs related to the nature of the brain injury, and post-injury medical care) calls for highly individualized approaches to instructional and behavioral supports in the classroom. Although the intent of special education law is to provide an individualized plan for each student with disabilities, in many schools, special education services are organized around existing programs.[39] Particularly at the secondary level, special education is likely to be organized by severity of disability, with students labeled "severely disabled" receiving training in skills for daily living, social skills, and vocational skills, and students labeled "mildly disabled" receiving remedial instruction in basic skills, simplified curricula, or assistance in study skills to meet graduation requirements. Students with a TBI rarely fit into either track, which can lead to an educational program that does not meet the student's unique needs.[451] Moreover, students who perform academically at or near grade level following a TBI might not be eligible for special education services because they do not demonstrate a need for specially designed instruction. The inability to obtain services can be particularly frustrating when a high-performing student struggles to earn average grades after a TBI. One potential solution is the broader use of evidence-based teaching and management strategies that were developed for students with other types of disabilities. These have been shown to be effective with minor modifications for students with a TBI.[450]

RETURN TO ACTIVITY AND INDEPENDENCE

Return to play guidelines and legislation are primarily focused on organized sports.

Consensus guidelines developed for return to sports after mTBI represent a promising practice that can be evaluated and expanded to include recreational and physical fitness activities following a TBI of all severities. Since 2009, mTBI legislation addressing concerns about health risks for young athletes has been passed in all states. Common elements in the legislation include coach education, removing athletes with mTBI symptoms from play, and requiring healthcare professional approval for return to play. These policies provide a base of support for further management of a TBI and return to physical activity and sports. However, similar consensus guidelines have not been developed for the return to other recreational and physical activities outside of organized sports. Additionally, no guidelines have been developed for return to sports and other recreational and physical activities after a moderate-to-severe TBI in children. Further research focused on testing and optimizing these guidelines is needed.

Effective driving assessment and training after TBI in children and teens are limited.

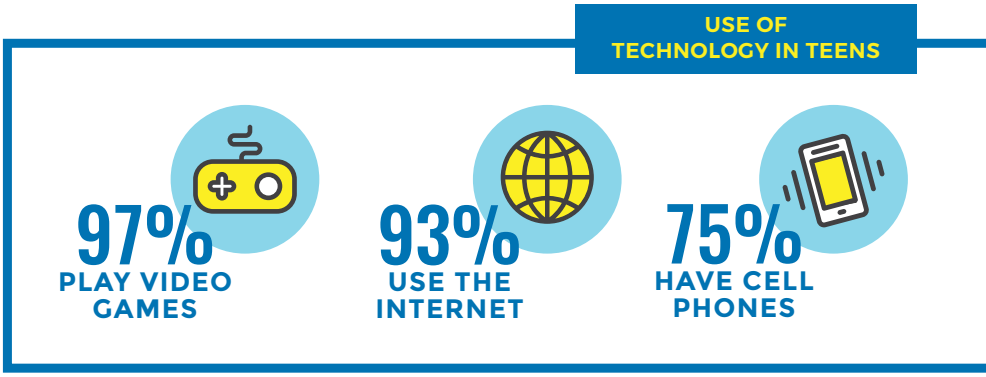
Driver assessment and training are important aspects of rehabilitation following a pediatric TBI.[452,453] A TBI can result in changes in cognition and reaction time, which can influence driving skills. Research examining driving after a TBI indicates that individuals who resume driving are less likely to wear seatbelts, are more likely to crash at night, and are at greater risk for multiple crashes than the general population.[453,454] Age of injury is associated with multiple crashes, with those who experience a TBI at a younger age more likely

to be involved in multiple crashes post-TBI.[454] It is unknown how many teens with a history of a TBI routinely receive driver assessment/training, or how teens and parents are advised in this area. Greater standardization of care and establishment of evidence in this area are needed. In addition to programs for teen driving, such as CDC's Parents Are the Key program (www.cdc.gov/parentsarethekey/index.html), and discussions about driver safety in pediatrician offices, a rehabilitation driving program that includes a detailed assessment with a driving simulator and on-road driver training might be warranted for children and teens with a history of TBI. Some rehabilitation programs offer this service to newly licensed drivers as well as to adults who are returning to driving after a TBI.

There is a critical need to optimize community engagement and participation for children after a TBI.

Research indicates that children with a TBI are at risk for increased isolation and reduced social participation,[10,80] as well as potential for incarceration and involvement with the justice system.[42,131,305-307] Although the risk for children experiencing social isolation has been identified, little is known about interventions that can positively impact the trajectory for optimizing healthy lifestyles for children with a TBI, particularly those who are injured at a young age. A better understanding about long-term management of this population will inform this area.

Greater use of technology holds promise in helping children after a TBI.



Computer-based technology, electronic aides, cell phones, and apps are part of many rehabilitation and school programs for children. A recent study by the PEW Research Center Internet & American Life Project reports that 97% of teens play video or computer games, 93% use the internet, and 75% have cellphones. One example of a promising use of technology in TBI management is an app-based intervention called Social Participation and Navigation (SPAN), which was designed to promote social participation in teenagers with a TBI through the combination of a smartphone app and weekly peer coaching with college students via Skype.[455] The SPAN app provides a framework for developing and implementing social participation goals, provides reminders for implementing steps and following through, and includes a range of informational tips and topics to support goal achievement. Although technology shows great promise for children with a TBI, few studies have evaluated the program effectiveness of SPAN and other technology-based tools.

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

Models of care

- 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

- 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

- 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 a 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 sustain a TBI.

TBI CARE DURING THE TRANSITION TO ADULTHOOD

> The transition to adult healthcare providers and to post-high school educational programs and employment is a particularly critical time for teens with a TBI. At this time, there is increased risk of a gap, or discontinuance of healthcare and career services.

Support for the transition to the adult healthcare system is inadequate.

Children and youth who experience a TBI at any point in their development can experience delayed effects and are particularly vulnerable to health challenges, poor post-school outcomes, and challenging career transitions as they move into adulthood. Researchers' and clinicians' growing understanding of the long-term health effects of TBI supports the notion that children with a TBI need support transitioning from pediatric to adult healthcare providers. This transition requires both teens and their healthcare providers to remain cognizant of the teen's history of childhood TBI, and the need for ongoing monitoring of the potential effects.

The transition from pediatric to adult medical care providers is a growing area of clinical concern among children with chronic health conditions.[81] 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.[81-84] The pediatric literature recommends a balance between adolescent healthcare responsibility and parental involvement during the transition process in which teens take increasing amounts of responsibility, and parents become less involved over time.[417,456,457] Provisions for the transition to adult healthcare services are core outcomes for the Children with Special Healthcare Needs (CSHCN) program. This program provides a mechanism to improve the healthcare transition, and to promote greater equality of services for those children with a TBI who are identified.[458] Children with ongoing medical needs can access services, such as specialized medical and nursing care, therapy, family support, care coordination, equipment, early intervention, special education, and transportation. The National Alliance to Advance Adolescent Health has created a *Got Transition Center* for health care transition improvement through a cooperative agreement with the Maternal and Child Health Bureau. The center serves as a clearinghouse for current transition information, tools, and resources (www.gottransition.org). Further, it serves as a resource for clinicians, youth with TBI, and their families to improve transition practices from pediatric to adult health care. Youth with TBI rarely undergo a systematic transition process, in part because of parents/families' and healthcare providers' limited understanding of the potential for the chronic health effects of TBI, as well as limited access to CSHCN model programs.

Youth with a TBI frequently do not access available programs focused on career transition after high school graduation.

Under IDEA, transition services are mandated for all students with disabilities enrolled in special education, beginning at age 16 (www.idea.ed.gov); however, states mandate these services at age 14. These services include a comprehensive written plan to provide goals for post-graduation that include education, employment, and support services for students' individual needs. Because many students with a TBI are not identified for special education, very few students with a TBI actually receive transition services.[40] Students injured during high school are often allowed by their families and school systems to graduate with their class, rather than stay in school longer to take advantage of services that could advance

their long-term career development after high school.[77] This contributes to a lack of preparation for many aspects of transition, such as career development, healthcare, linkage with community-based supports, and training in independent living skills such as personal finance and using public transportation.

Very little research has examined effective approaches to improving the post-secondary transition of students with a TBI. However, there is emerging literature that has identified promising practices for transitioning youth with other disabilities. The National Secondary Transition Technical Assistance Center has identified 33 practices that show evidence of improving student transition outcomes in youth with disabilities. These are categorized into 5 areas: student-focused planning, student development, family involvement, program structure, and interagency collaboration[459]

The Workforce Investment Opportunity Act aims to address the transition of youth with a TBI from high school. This Act requires coordination between and among agencies so workers and job seekers have more seamless access to high-quality career services, education, and training. The Act also requires that state vocational rehabilitation agencies allocate a portion of their budgets to assist youth with disabilities, including those with a TBI.[460]

The state-federal Vocational Rehabilitation (VR) program also provides services to individuals with actual or potential work disabilities.[461] A recent study found that only one-third of individuals with a TBI know about these services, and only 5-6% receive state VR services.[462] Intensive provision of more VR services that are tailored to individual needs has been associated with increased levels of competitive employment in transition-aged youth (16-25 years) with a TBI.[463] VR services that best predicted successful employment outcomes included job placement, job support, job search, vocational training, and informational/referral services.[463] Further, programs in place at the college level, such as Project Career at Kent State University, which utilize career services, technology interventions, and peer support are promising practices for supporting college graduation in students with a TBI.[464]

OPPORTUNITIES FOR ACTION

Opportunities for Action: Improving the Transition to Adulthood for Children with a 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.

PROFESSIONAL TRAINING FOR TBI IN CHILDREN

TBI education is lacking for pediatric healthcare providers.

> Effective medical and educational management practices implemented by trained professionals can contribute to successful outcomes for children with a TBI. However, many healthcare providers and educators receive little or no training in childhood TBI recognition or management.

Lack of training for healthcare providers leads to inconsistent and variable clinical assessments, inconsistent diagnoses, variable anticipatory guidance about expected recovery course, and variability in management decisions early and later after injury. Parents and children who leave the healthcare setting without proper instructions from trained providers will not have the information they need to manage injury effects across developmental stages if persistent symptoms occur, and that lack of information contributes to worse outcomes for children. Training for primary care and emergency care providers is of the utmost importance because they are often the initial contact for patients and their families and are often the only contact in rural communities.[465] Currently, a paucity of formal medical training is available for all of the healthcare providers who typically evaluate and manage children and adolescents after a TBI.

The approach to brain injury education is not standardized, and much of the available education focuses on mTBIs. Furthermore, medical students typically have limited exposure to and experience with mTBI management techniques.[466] Training is typically integrated into clinical and didactic educational programs for many specialties, but variation across programs' curricula is large. There are varying levels of training and varying practices across specialties that care for children with mTBI.[85] Furthermore, development of a standardized and evidence-based curriculum is difficult because of the lack of robust evidence for treating this population. There is currently wide variation in the care provided, and the use of current consensus guidelines.[467] Internet-based education has been effective across a broad spectrum of medical content areas [468-470] and shows promise for healthcare provider education in childhood TBI. The CDC's HEADS UP (www.cdc.gov/headsup/index.html) program is one example of an online training program for healthcare providers.[471] Additionally, a wide variety of organizations and institutions offer educational seminars and short courses to local healthcare providers. The effectiveness of these education and training programs has not been formally evaluated.

Wide variability also exists in the training provided for moderate-to-severe pediatric TBI. Acute management training for severe TBI is integrated into emergency care, trauma surgery, critical care, and other acute care specialty training programs; however, there is variability in the educational material provided and the resources available for training.

THE GAPS

There are only:

278 CERTIFIED BRAIN INJURY SPECIALISTS IN THE U.S.

and most primarily serve adults.

Training in the sub-acute and chronic care management of moderate-to-severe pediatric TBI also varies. In 2013, the Accreditation Council for Graduate Medical Education, in collaboration with the American Boards of Physical Medicine and Rehabilitation, Psychiatry, and Neurology, approved a competency-based accreditation program in brain injury medicine[472] to promote the training of residents and fellows. The American Congress of Rehabilitation Medicine offers a brain injury specialist certificate through the Academy of Certified Brain Injury Specialists. The Commission on Accreditation of Rehabilitation Facilities (CARF) also provides certification for clinical programs that meet defined criteria for a brain injury specialty program.[473] Broadly, accredited brain injury programs deliver services that focus on the medical, physical, cognitive, communication, psychosocial, behavioral, vocational, educational, accessibility, and leisure/recreational needs unique to individuals with an acquired brain injury.[473] Currently, there are approximately 278 certified brain injury medicine specialists in the US, and most of them primarily serve adults.[474] There is a paucity of healthcare providers with pediatric-specific training. For example, currently, there are approximately 224 board-certified pediatric rehabilitation medicine specialists nationwide.[474] In rural areas, transportation and availability of pediatricians may be barriers to pediatric care.

Educators typically have limited TBI-specific education.

Educators currently working in schools are frequently unprepared to work with students with a TBI.[73] Surveys of speech/language pathologists,[79] school psychologists,[475] and educators[78] reveal a limited understanding of TBI, suggesting inadequate preparation across professions. A recent survey of undergraduate general and special education teacher training programs in public and private universities across the United States revealed that TBI-specific training is minimal; most faculty in teacher preparation programs do not include information about TBI in the courses they teach.[86] State directors of special education perceive a continued, pervasive lack of educator awareness about TBI as a chronic disability (e.g., educators who do not understand the long-term consequences of TBI, and parents who are unfamiliar with the characteristics of students with brain injury, the definitions used by schools, or the effects of TBI on school performance).[448]

Teachers, especially those in general education, have some basic misconceptions and knowledge gaps about TBI, and the effects of brain injury on students in their classrooms.[78] All educators, both those preparing to become teachers and those currently teaching students, need effective training in methods that have been validated with students with a TBI, and in adapting strategies validated with students with other disabilities to students with a TBI.[61,87-89] Because educators receive little training in brain injury in teacher preparation programs,[78,86,475] several states have developed in-service training models to ensure that educators understand how best to support students with a TBI in the classroom. One such approach is the TBI Consulting Team model.[89,445] Originally developed in Kansas and implemented there from 1989 to 2010, the goal of the model is to make a group of trained school-based consultants available to schools statewide to provide in-service training and ongoing consultation to educators of children with a TBI.

Currently, several graduate programs offer coursework and certification in TBI focused on school psychology and special education (e.g., the TBI Transitional Special Education Certificate Training Program, University of Colorado TBI certificate, Hamline University TBI Certificate, and the TBI Master's Program at George Washington University). A variety of existing online in-service training modules could also be used to supplement coursework in undergraduate teacher preparation programs (e.g., University of North Carolina TBI Online Curriculum, Brain Injury Alliance of New Jersey, and Rutgers Continuous Education). These programs are accessed by a very small minority of today's educators.

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.

BUILDING RESEARCH TO GUIDE TBI MANAGEMENT IN CHILDREN

The evidence base for TBI management is very limited.

Currently, most management of TBI is based on consensus guidelines and expert opinion.[90-94] Only a few rigorous, systematic clinical trials have been performed.[93] For mTBI, the most recent guidelines recommend pacing or gradual return to cognitive and physical activities as tolerated by symptoms. Implementation of those pacing recommendations, as the cornerstone of management in this population, is variable. High-quality studies are needed to determine the ideal duration and intensity of rest and the ideal time at which 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.[98] Managing more prolonged symptoms has not been the focus of prior consensus statements or guidelines and is primarily based on consensus opinion.[99] A wide range of medical, behavioral, physical, and other therapies is used in the management of mTBI, but definitive, high-level evidence-based guidelines do not currently exist. CDC is currently developing a 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.

For more severe TBI, a second edition of the guidelines for acute medical management has been developed.[320] Those guidelines focus primarily on management strategies in the ICU for infants, children, and adolescents. Standardizing ICU treatments based on best practice guidelines is associated with improved outcomes at discharge from the ICU.[336] Overall, variability remains in the implementation of guidelines, and research is ongoing to understand which management strategies are most effective. Currently, a National Institute of Neurological Disorders and Stroke (NINDS)-funded international, multi-site study, Approaches and Decisions in Acute Pediatric TBI Trials (ADAPT), is in progress to evaluate the effects of acute care interventions on outcomes among children with severe TBI (www.adapttrial.org). Further research is needed to critically evaluate the guidelines, to further refine recommendations, and to ultimately improve care.

We know little about long-term outcomes following childhood brain injury.

Currently, studies following children from the time of injury until early and later adulthood are significantly limited.

> It is important to better understand how a TBI affects and interacts with brain development and the child's environment in the short and long-term to allow for a better prediction of children's outcomes after the injury.

Investigation of the impact of a TBI on development should include an examination of the effects of co-occurring childhood health conditions, TBI history, and the child's family and social environment to best understand and identify modifiable risk and protective factors.

One promising practice is the Traumatic Brain Injury Model Systems (TBIMS) program for adults; however, a similar pediatric program does not exist. This program started in 1987 and continues with support from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDLRR/ACL/HHS). TBIMS' primary mission is to provide state of the art care to improve outcomes among individuals with TBI aged 16 years and older who have received inpatient rehabilitation. Each of the 16 centers, as well as previously-funded centers, contribute follow-up data to the TBIMS National Database, a longitudinal database begun in 1988 that includes information on more than 15,000 individuals who were admitted for acute TBI inpatient rehabilitation. The TBIMS National Database for adults includes longitudinal information on demographic characteristics, pre-injury history, cause of injury, and level of disability, as well as long-term medical, social, community living, daily living, and employment outcomes. A similar database for children with a TBI does not yet exist, despite the compelling need for a better understanding of the long-term outcomes of children with mild, moderate, and severe TBI. Because very few children are admitted for rehabilitation, entry into the pediatric database would need to include multiple entry locations (e.g., EDs, primary care providers, specialty care providers, urgent care centers, and schools). On the positive side, schools already produce annual progress reports for children that include their grades and support services received, which provides an opportunity to collect data on an annual basis in order to follow children over time.

In the past few years, several initiatives have been proposed to standardize data collection and increase data sharing (e.g., Federal Interagency TBI Research [FITBIR] Database) for research focused on children with TBI. In 2012, a TBI workgroup of experts specializing in pediatric brain injury was formed as part of a National Institutes of Health (NIH) interagency effort to standardize data elements for children.[476-478] Using a group consensus process, the group established a set of pediatric common data elements (CDEs) by identifying critical domains (e.g., demographics, laboratory, biomarkers, assessment/treatment, academics, family/environmental, outcomes), measures (e.g., imaging, behavioral, and parent report), and structures (e.g., core, supplemental, and emerging elements). A challenge for this workgroup was the selection of measures that covered age and development across a child's lifespan, with limitations in instruments assessing infants and toddlers. The ADAPT trial is currently validating some of these pediatric TBI CDEs. In 2016, NINDS led the development of a complimentary set of standardized data elements for use in studies focused on sports-related TBI (commondataelements.ninds.nih.gov/SRC.aspx#tab=Data_Standards). The establishment of common data elements for research is a critical step in understanding children's long-term outcomes. By encouraging the collection of common data elements, the ability to combine data sets and increase the effective sample size of studies is enhanced. Further assessment of these measures is indicated.

Incidence estimates of TBI in children significantly underestimate the scope of the problem.

Public health surveillance can identify how many people are affected by a particular health problem, whether it is increasing or decreasing in scale, and who should be targeted for intervention. Current pediatric TBI incidence estimates are significant underestimates as they are based on healthcare received in an emergency department. One study suggested that this may miss the 80-90% of pediatric TBIs treated in primary care, urgent care, and specialty care, as well as those that go untreated.[102] At present, CDC is piloting a National Concussion Surveillance System as a means to fill these gaps and provide a better estimate of the TBI burden. Pilot implementation of this system will begin in 2018. If taken to scale following the pilot study, this system has the capacity to better estimate the incidence of TBI in children across the lifespan and at a national level. In addition, this system has the potential to improve our understanding of the full range of circumstances leading to pediatric TBI and track healthcare utilization and services received after a TBI.

More research is needed to optimize service delivery and functioning after an injury.

Evaluation of current promising practices is needed to identify novel treatments or approaches to care, and determine the best approaches to care that maximize children's outcomes. Previous studies have identified unmet needs, but little research has been done that provides evidence-based guidance about how to better meet those needs. Contributing to the complexity of intervention studies is the fact that the majority of children do not receive long-term follow-up care in the healthcare system, and few are identified at school after initial injury care. Although some promising practices for interventions have been identified in small cohorts of children, a larger scale effort is needed. TBI is unique in children because it disrupts a period of typical development, rather than affecting the child from birth. We need to better understand how management following an injury can best address children's and parents' needs to promote child development and positive, long-term adult outcomes. Furthermore, we need to better understand how approaches used in research and other isolated settings relate to everyday improvements in the lives of children and their families. In October 2016, NIH convened TBI researchers, experts on brain development, clinicians who treat youth concussion, and patient advocates to discuss pediatric concussion. The deliberations addressed the state of knowledge, the adequacy of current diagnostic tools and treatments, ongoing research supported by the NIH and others, and feasible study designs to address major gaps in knowledge.

CONCLUSION

As a result of a 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 a productive adult. 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.[2,61,64,65] This report describes the public health burden of TBI in children and youth, details the current systems involved in the management of children with TBI, and identifies gaps that exist and some practices that hold promise in addressing those gaps. The report's opportunities for action suggest tangible ways to improve TBI care in children in the near-term, and outlines a research agenda that can advance our understanding of TBI care in the future.

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

- 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 a pediatric TBI.
- Collect national history data that will describe differential recovery trajectories across both age and severity that could be used for the development of personalized medical treatment.

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

- 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.

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APPENDIX

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