

# Service Delivery in the Healthcare and Educational Systems for Children Following Traumatic Brain Injury: Gaps in Care

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**Objective:** To provide a review of evidence and consensus-based description of healthcare and educational service delivery and related recommendations for children with traumatic brain injury. **Methods:** Literature review and group discussion of best practices in management of children with traumatic brain injury (TBI) was performed to facilitate consensus-based recommendations from the American Congress on Rehabilitation Medicine's Pediatric and Adolescent Task Force on Brain Injury. This group represented pediatric researchers in public health, medicine, psychology, rehabilitation, and education. **Results:** Care for children with TBI in healthcare and educational systems is not well coordinated or integrated, resulting in increased risk for poor outcomes. Potential solutions include identifying at-risk children following TBI, evaluating their need for rehabilitation and transitional services, and improving utilization of educational services that support children across the lifespan. **Conclusion:** Children with TBI are at risk for long-term consequences requiring management as well as monitoring following the injury. Current systems of care have challenges and inconsistencies leading to gaps in service delivery. Further efforts to improve knowledge of the long-term TBI effects in children, child and family needs, and identify best practices in pathways of care are essential for optimal care of children following TBI. **Key words:** *children, education, healthcare, rehabilitation, traumatic brain injury*

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PEDIATRIC TRAUMATIC BRAIN INJURY (TBI) is a chronic health condition with effects that can extend beyond the time of initial medical care and impact neurobehavioral development and overall health.<sup>1-7</sup> Child development is complex, encompassing physical, psychosocial, and cognitive aspects coupled with increased environmental expectations for more sophisticated behavior. Neurologic injury secondary to trauma in childhood can affect these key phases of development with resulting long-term effects requiring specialized, acute, and long-term management. Therefore, addressing the needs of pediatric TBI survivors requires dedicated efforts across both healthcare and educational systems; however, the provision and coordination of these services are complicated.<sup>8,9</sup> Current services are insufficient because there is often a discrepancy between the need for pediatric rehabilitation and school services, receipt of those services, and an inadequate understanding among parents about the need for therapy and educational support following discharge from acute medical care.<sup>10-12</sup>

Pediatric TBI is a leading cause of morbidity and mortality in the United States costing \$1 billion per year.<sup>7,13</sup> Children 14 years and younger account for

half-a-million emergency department (ED) visits for TBI annually.<sup>14</sup> Rates of TBI-related ED visits increased for all age groups from 2001–2002 through 2009–2010, rising most for youth 4 years of age and younger, by more than 50% between 2007–2008 and 2009–2010, from 1374.0 to 2193.8 per 100 000.<sup>15</sup>

Compared with adults, children and youth have the greatest risk for long-term consequences from a TBI. Their vulnerability for changes in brain development and neuropsychological impairment that impacts academic and social outcomes supports a critical need for follow-up care beyond the acute injury. In particular, there is an essential need to optimize coordination between healthcare and educational systems of care. To better understand children's issues related to healthcare and school services, a workgroup from the Pediatric-Adolescent Task Force of the American Congress of Rehabilitation Medicine (ACRM) convened to examine management practices for children following TBI. By reviewing children's outcomes related to development, health, and school performance as well as care practices, we describe issues in pediatric TBI service delivery and provide recommendations to maximize children's care and long-term management over their lifespan.

## METHODS

The ACRM Brain Injury Interdisciplinary Special Interest Group (BI-ISAG) established the Pediatric-Adolescent Task Force (PATF) composed of pediatric rehabilitation physicians, neuropsychologists, educators, speech-language pathologists, occupational therapists, and physical therapists to provide leadership in the area of pediatric brain injury rehabilitation. The group's aim is to bring a multidisciplinary, pediatric research focus to projects and conferences in the ACRM and facilitate member collaboration. Within the PATF, a workgroup formed to examine the continuum of care of children with TBI at the time of the injury and formulate recommendations with the following objectives:

1. Review epidemiology, injury characterization, and outcomes in pediatric TBI related to service needs in the healthcare and educational systems.
2. Outline practices of care for pediatric TBI across the continuum from acute injury through chronic management.
3. Describe issues in pediatric TBI management and service delivery that create barriers to optimal care for children with TBI in healthcare and school settings.
4. Offer recommendations to improve TBI service delivery.

### Literature search strategy and review process

The literature search process was conducted by the smaller work group within the PATF and was composed

of 3 pediatric rehabilitation medicine physicians, a neuropsychologist, a school psychologist, a health scientist, and a speech-language pathologist. The methodology used to construct group discussion about TBI care in children was based on suggestions provided by the Institute of Medicine (2011). To begin, the literature search was divided into 2 main periods postinjury: (1) acute care including acute rehabilitation for pediatric TBI (injury–3 months postinjury) and (2) post-acute care, outpatient care, and school transition for pediatric TBI (4 months postinjury with no upper limit for time postinjury).

Utilized databases were selected for systematic evidence search to ensure that multidisciplinary representation would be evident in the results. In addition, ancestral searches of relevant citations were included. Table 1 provides the keywords used, point of care terms and inclusion/exclusion criteria, and databases accessed.

For the acute period articles, the initial search resulted in 1665 articles. Duplicate articles and ones that did not meet inclusion criteria were removed from consideration (1630). A total of 35 articles were retained after the initial screening procedure.

For the outpatient/transition articles, the initial search resulted in 67 489 articles. Duplicate articles and ones that did not meet inclusion criteria were removed from consideration (67 395). A total of 94 articles were retained after the initial screening procedure.

All of the search results and articles that met criteria were available to the group members via a shared Google document. The members of the PATF work group reviewed initial literature search results individually and circulated feedback via e-mail. Work group members provided additional citations not captured in the initial literature review. During 2 in-person meetings, the shared Google document was reviewed and group members agreed via consensus about themes for final inclusion. A manuscript outline was developed followed by a draft manuscript created from sections written by individual group members and compiled by the lead author. Following review and revision by the coauthors, interested group members from the larger PATF provided feedback on the draft.

## IMPACT OF TBI ON CHILD DEVELOPMENT

TBI results in a common set of cognitive/behavioral weaknesses, which affect daily function, including school achievement. However, TBI outcomes in children are extremely variable even when TBI severity is considered. Neurocognitive developmental functioning for children requires ongoing learning and the acquisition of new skills. Care after TBI requires attention to both the recovery of previously learned skills lost to injury, and to ongoing development of new cognitive skills. Even subtle cognitive deficits and slowed

**TABLE 1** *Keyword, points of care, inclusion/exclusion criteria, and databases accessed*

Keyword search	Child AND head injuries, closed; or Pediatric head injury; or Pediatric head trauma; or Pediatric AND brain injuries; or Acquired AND brain injuries; or Acquired brain injury AND children; Acquired brain injury in children.
Points of care	(1) Acute Care/Rehab–inpatient, “acute care”; treatment, instruction, rehabilitation (type, diversity, intensity; acute inpatient rehabilitation, and inpatient rehabilitation); 2) Outpatient/Transition–outcome, impact, deficit, school, “school performance”, friendship*, family, “family life”, access to services, and advocacy.
Inclusion criteria	Overall inclusion criteria for committee-reviewed articles included those focused on pediatric traumatic brain injury (peri-natal period through 21 years of age), including expert opinion, book chapters, and review articles and original research. Additional inclusion criteria for different points of care included: Acute care/rehabilitation (treatment provided during the acute hospitalization or rehabilitation period) and outpatient/transition (treatment provided during the longer term rehabilitation period, outpatient care period, or during school transition after injury).
Exclusion criteria	Articles were not included for consideration if adults (those 21 y of age) were included in the sample/discussion and it could not be determined the specific handling of those 18–21 y of age, if a distinction could not be made between those in the sample/discussion that had experienced TBI vs ABI, or if the article discussed other medical complications that can be associated with TBI (eg, orthopedic injury and cardiac injury).
Databases utilized	PubMed, CINAHL, ProQuest Nursing and Allied Health Source, PsycINFO, The Cochrane Collaboration, Academic Search Complete and Web of Science.

Abbreviations: ABI, acquired brain injury; TBI, traumatic brain injury.

information processing following TBI can have adverse effects on academic achievement and learning.<sup>16</sup> In addition, postinjury cognitive deficits can hamper social and behavioral development.<sup>17–21</sup> Although there is limited research on the chronic effects of childhood TBI across the lifespan, existing evidence supports that disruptions to cognitive development may further impact development in other functional domains such as behavioral and social functioning, which in turn can greatly affect a quality of life, including participation in school, social, and extracurricular activities.<sup>22,23</sup>

A primary cognitive domain impacted by TBI is executive functioning (EF). At the root of many academic, social emotional, and behavioral issues that can follow a TBI are problems with a subset of EF–self-regulation, the internal control functions that direct and organize all nonreflexive or non-automatic behavior, including social, cognitive, and linguistic behavior.<sup>24</sup> Difficulty with self-regulation can have broad impact on academic achievement, affecting many of the cognitive-behavioral skills required for successful learning. Cognitive processing speed may also be reduced dramatically after a TBI,<sup>25</sup> resulting in a child’s slow response to a teacher’s question or instructions, or needing more time for task completion. Memory problems, another cognitive area impacted following TBI (sensory, working, and/or long-term memory; retrograde and anterograde amnesia), can limit the ability to learn new content or skills such as reading comprehension, math problem-solving, or multistep tasks.<sup>26–28</sup> Perceptual or sensorimotor deficits can cause increased sensitivity to light and sound, dimin-

ished ability to screen out background sounds, or create a lack of the visual-motor coordination needed to function at school.<sup>29,30</sup>

Because TBI is a chronic health condition with potentially long-term presentation of deficits, overall health and wellness can be impacted.<sup>2,4</sup> Fatigue is a common consequence,<sup>31</sup> especially early in the postacute recovery phase. The child’s physical stamina may be compromised, or the child might have other physical injuries that adversely affect school performance (eg, arm or hand paresis that can impact writing). The complexity of TBI sequelae on school performance underscores the importance of communication and collaboration between health care providers, educators, and families in children’s return to school following TBI.

## FACTORS INFLUENCING CHILDREN’S OUTCOMES

TBI at younger ages is associated with worse outcomes than injury sustained later in development.<sup>32–34</sup> This suggests “critical windows” of age ranges coinciding with critical periods of brain and cognitive development during which time TBI may result in more pronounced sequelae.<sup>35</sup> Over time, behavioral and cognitive problems not evident at younger ages can continue to emerge and may intensify as task demands increase.<sup>36,37</sup>

TBI severity also predicts cognitive and school readiness skills, including memory, spatial reasoning, and EF. Negative outcomes increase with the severity of TBI.<sup>38–42</sup> A severe injury at a younger age has been

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associated with the poorest long-term outcomes, including lower cognitive skill recovery and delayed development.<sup>34,43,44</sup> Emerging studies on mild TBI indicate risk for behavior<sup>45</sup> and social problems<sup>23,46</sup> following even a less severe injury in children.

Family environmental characteristics, such as socioeconomic status, overall family functioning, and parenting practices, may affect a child's educational performance as well as social (participation and interaction) and behavioral outcomes post-TBI.<sup>20,22,47-51</sup> Children live within the context of the family environment that affects not only parenting skills and practices, but also medical follow-up and communication with schools, which, in turn, impacts management. In general, strong family social support and cohesion is predictive of children's adaptive functioning, social competence, and global functioning postinjury.<sup>47,49,52,53</sup>

Medical conditions such as neurologic disorders (eg, motor difficulties and epilepsy), attention-deficit hyperactivity disorder, mental health conditions, and sleep disturbances are linked to TBI<sup>54</sup>; although the impact of co-occurring conditions on children's outcomes from TBI has not been well studied. Children with prior psychiatric disorders and/or those with dysfunctional families are more likely to experience negative psychosocial effects after TBI.<sup>40,44,55-58</sup>

Although many studies link injury severity to eventual outcomes, other factors (eg, age, family structure, and other co-occurring medical conditions) also contribute to children's progress and development after a TBI of any severity. The complexity of factors involved with children's outcomes and identified risk for changes in cognition that influence development supports the critical need for management and follow-up after the initial injury care.

## PRACTICES OF CARE

Children receive care for TBI in a variety of settings depending on the level of acuity and time points after their initial injury. Settings can include EDs, intensive care units, inpatient rehabilitation programs, primary care offices, outpatient rehabilitation services, and the educational system. It is important to note that in the continuum of care, acute medical care (from the trauma center to inpatient rehabilitation) occurs in a relatively short timeframe measured in months compared with the years of recovery managed in home and school environments. Table 2 lists the types of services available in each system of care.

### Healthcare system

Medically, TBI is diagnosed based on the history of a bump, blow, or jolt to the head or a penetrating head injury that may or may not be associated with loss of consciousness and is associated with symptoms that are categorized into physical, cognitive, emotional, and sleep domains.<sup>14,59</sup> The ED is often the place of initial injury care and source of data for TBI estimates.

Most TBIs are mild in severity and are commonly called concussions (CDC, 2003). Children with mild head injuries may present to clinical locations other than the ED, such as pediatricians' offices,<sup>60</sup> or may not seek care at all, making it difficult to accurately estimate the true incidence of injury, which in turn complicates the understanding of overall outcomes.<sup>61-63</sup> More severe TBI requires comprehensive medical management that can include assessment for structural problems such as brain swelling, bleeding or pressure on the brain, brain imaging, and/or transfer to a pediatric trauma center.<sup>64,65</sup>

**TABLE 2** *Current practices of care*

Medical care	Educational care
Acute injury care	General education
Emergency department	Student Support team monitoring
Urgent care	Title 5 tutoring services
Pediatrician office	504 Plan
Specialty care office (neurology, concussion clinic)	Guidance counseling
Hospitalization	Special education
Rehabilitation	Self-contained classroom
Inpatient rehabilitation	Team taught classroom
Day rehabilitation	Related/ancillary services
Outpatient rehabilitation	Speech pathology
Physical medicine and rehabilitation clinics	Physical therapy
Outpatient follow-up	Occupational therapy
Pediatrician	Psychological services
Specialty care (neurology, rehabilitation clinic)	Social work
Neuropsychology	Therapeutic recreation
Other specialists	Counseling
	Audiology

Injury severity, location of initial injury care (trauma center vs community hospital), presence of comorbidities or other injuries, and age are factors associated with hospital admission among children with TBI.<sup>66</sup> For children with severe TBI, more aggressive acute care and specialized protocols have been associated with better outcomes.<sup>67,68</sup> Even when children are hospitalized after TBI, there can be a wide degree of variability in rehabilitation efforts during the hospitalization.<sup>69</sup> A small number of children with TBI (~4%) are admitted to inpatient rehabilitation<sup>70</sup> and a minority of children receive ongoing therapy services following initial care.<sup>3,11,71</sup> In a recent study of Medicaid-insured children hospitalized after TBI, only 29% received any type of outpatient services regardless of TBI severity.<sup>72</sup> Furthermore, a study of Medicaid service availability in the state of Washington found that less than 20% of all rehabilitation providers in the statewide database accepted Medicaid.<sup>73</sup>

Quality of care indicators were recently established for inpatient rehabilitation for children with TBI.<sup>74</sup> Rivara et al<sup>74</sup> indicators included the following domains: (1) general management, (2) family-centered care, (3) cognitive-communication, (4) speech, language, and swallowing impairment, (5) gross and fine motor skills impairment, (6) neuropsychological, social, and behavioral impairments, (7) school reentry, and (8) community integration. These indicators provide specific recommendations for assessment and management; however, they are based on expert consensus without evidence to verify their validity and clinical feasibility.

Transition from healthcare to school services is also characterized by substantial variability.<sup>75</sup> The majority of research has described the transition process from hospital to school for hospitalized children. It has been shown that the return to school process is critical to children's outcome and that successful return to school requires integration between entities, specifically the hospital and the school.<sup>76,77</sup> Children who receive systematic transition services as part of their medical care are more likely to be identified for specialized support services at school, such as speech therapy.<sup>76</sup>

Neuropsychological evaluations are often included in pediatric hospital care. Although empirical research on the utility of neuropsychological evaluations on the outcome is sparse, recent reports provide evidence that neuropsychological consultation is associated with a reduction in symptoms in children with persisting post-concussive symptoms<sup>78,79</sup> and high parent satisfaction rates.<sup>80</sup>

### **Educational system**

In the school system, TBI is identified by parents' notification of medical conditions and accommodation needs. Many parents leave the hospital with limited un-

derstanding of a need to change their child's school program as a result of a TBI<sup>10</sup> and experience difficulties coordinating healthcare and school-based rehabilitation services.<sup>72</sup> School personnel often do not have training on identification and management of students with TBI.<sup>76,77</sup>

Although a category in Special Education for TBI has existed since 1990 (IDEA Federal Special Education Law 1990 revision of PL94-142), the census in this category is low compared with the injury rate in children and also with the estimated number of children living with a TBI-related disability.<sup>76</sup> Most states require medical documentation of the TBI and reports of a change in academic performance from preinjury status. Few children are identified for TBI-related special educational services because there may be limited hospital to school transition services<sup>77</sup> and because of a lack of educator awareness of the effects of TBI on student performance.<sup>81</sup> Many students with TBI are misidentified as having other disabilities—learning disabilities, emotional disturbance, or intellectual disabilities—that may not be attributed to the TBI.<sup>81</sup> Children who do not qualify for special educational services can receive support through Section 504 plans (Rehabilitation Act of 1973); however, there is limited guidance and data for this type of accommodation that is only accounted for at the local school level.<sup>76</sup> Academic support can also be offered via child support teams at local schools, but documentation of this type of support is nonexistent outside school records. Schools offer rehabilitation services, such as physical, occupational, and speech therapy, that are allocated based on learning needs rather than medical needs. These services are referred to as “ancillary” or “related” services in IDEA law. Utilization of these services is only documented within a child's Individualized Educational Plan (IEP). Both identification for services and service utilization for TBI-related issues are limited in an educational setting.

### **PROBLEMS WITH CURRENT SYSTEMS OF CARE**

Current literature on children's outcomes indicates changes from the TBI that support service needs. However, there is limited research on the effectiveness of the care continuum that children and their families navigate for postacute injury care or scientific examination of components in the healthcare or educational system on children's outcomes. There are problems with the current systems of care that lead to gaps in optimal care for children with TBI:

1. *Identifying at-risk children at the time of injury.* There is significant variability in how the child's medical history, school performance, and family circumstances are considered in the initial injury assessment and care

planning. There are also considerable inconsistencies in communication of medical information between healthcare and educational settings. Some healthcare facilities provide recommendations for school modifications or a liaison from medical to school transition, particularly if the healthcare system has an inpatient rehabilitation unit that serves children.<sup>77</sup> However, children who do not receive rehabilitation may not have a formal return to school process. In addition, there is a segment of the pediatric population who is not seen for medical care at the time of the injury and, therefore, may not be identified in the healthcare or school setting.

2. *Failure to receive follow-up services.* Most children with TBI are discharged to home following initial injury care at the ED<sup>65</sup> and only a small percentage receive outpatient services.<sup>72</sup> Currently, there are no systems or guidelines in place for determining service eligibility or procedures for monitoring of children's progress after a TBI.

Reports of unmet healthcare needs and underidentification of children affected by TBI in schools are partly related to the difficulties parents face in navigating the continuum of services following TBI. Access to care is influenced by family functioning and insurance status, indicating that children with cohesive families and with commercial insurance coverage were more likely to receive services and report satisfaction with their care.<sup>3,11</sup> In addition, students who sustain less severe injuries, such as mild TBIs, often fail to receive school accommodations even if healthcare providers make recommendations for accommodations.<sup>82</sup>

3. *Lack of transitional services, intervention planning, and follow-up.* Transition from healthcare to school services is also characterized by substantial variability.<sup>75</sup> In the first year after the injury, a substantial portion of children with moderate or severe TBI have *unmet* (~20%) or *unrecognized* (~10%) healthcare needs, with cognitive services being the most frequent among these.<sup>11</sup> Reasons for unmet needs include lack of physician recommendation or referral, services not provided in school settings, failure of parent follow-up, and cost.<sup>11</sup> Although outpatient follow-up for children with TBI might occur in a variety of settings depending on local resources, Slomine et al<sup>11</sup> found that many children did not even visit a healthcare provider in the year following their injury. Some studies show that the rate of visits to the children's primary healthcare provider (eg, pediatrician) in the year after the injury was also low (37%–40%), indicating a lack of coordinated follow-up care from the child's medical home base.<sup>3,11</sup>

The majority of research to date has identified the return to school process as critical to outcome

and that successful return to school requires integration between entities, specifically the hospital and the school.<sup>71,72</sup> Although a neuropsychological evaluation can provide targeted recommendations to facilitate optimal school reintegration, research findings indicate these evaluations are rarely conducted (0.1%).<sup>3</sup>

4. *Failure to identify and utilize TBI-related educational services.* Identification for services and service utilization for TBI-related issues is limited in an educational setting. Beyond the initial transition from healthcare to school services, successful academic achievement can become progressively more arduous as a child ages. Increased difficulties in academic achievement as the child ages and advances to higher grade levels are related to combination of factors including long-term cognitive deficits (eg, executive functioning) paired with increases in environmental expectations that place greater demands on cognitive skills like organization and problem solving, as well as ineffective communication between parents and schools about the injury. Furthermore, if the school is not aware of the TBI and the student is not identified as needing support services at the time of injury, educational issues emerging later are unlikely to be attributed to the TBI, and consequently, may be inappropriately managed or supported. Few children are identified for TBI-related special educational services, in part because there are limited hospital to school transition services<sup>83</sup> and because of a lack of educator awareness of the effects of TBI on student performance.<sup>81</sup>

## Proposed Solutions

1. Identifying at-risk children at the time of injury
  - Education for healthcare providers, parents, and educators about the importance of seeking medical care at the time of the injury and considering the child's health history.
  - Improve identification and documentation practices for children at risk for TBI-related disability. Children with severe injuries have the greatest risk for disability. Measures used at the time of injury care, such as Glasgow Coma Scale scores, duration of coma/loss of consciousness, posttraumatic amnesia, and time to follow commands, can inform healthcare providers about this risk.
  - Establish a clinical point of contact, such as a social worker or nurse coordinator, who can identify children at risk, facilitate interdisciplinary communication between various service systems, refer for assessment to rehabilitation services, refer for neuropsychological evaluation, and connect families with outpatient services and school services.

2. Evaluating, monitoring, and follow-up services
  - Educational materials provided at the time of injury should stress the importance of informing their primary healthcare provider and school about the injury and monitoring children's behavior and school progress.
  - A standard of care should be that all children who sustain a moderate to severe TBI are evaluated for rehabilitation services. During this time, evaluation for need for and level of rehabilitation services (eg, inpatient program, outpatient PT/OT/SLT consultation) can occur.
  - Children with mild TBI who are experiencing prolonged symptoms will benefit from a specialty evaluation to determine service needs. These children can be referred to outpatient services, neuropsychologists, and schools for follow-up.
3. Establishing standards or guidelines for systematic transition services
  - Algorithms for transitional services should be developed for children at all levels of TBI severity (ie, from concussion to severe TBI), and at various points of service entry. These algorithms should include disposition to appropriate medical follow-up and should always include the child's pediatrician as well as any specialty care services, such as neurology, outpatient occupational therapy, or mental health services.
  - Children who are hospitalized after TBI should work with a school liaison within the healthcare setting who will obtain consent from parents to initiate contact with the child's school and provide education about the child's condition to the educational team. The school liaison may be a dedicated staff member assigned as a hospital school liaison, but since most hospitals do not have such individuals on staff, this role can be filled by a point of contact (eg, social worker, rehabilitation therapist, or nurse) described earlier.
  - Neuropsychological evaluation is an important, but underutilized service for children and adolescents experiencing TBI. A neuropsychologist helps characterize the nature of the child's cognitive and behavioral changes within the context of his/her injury, explains how the child's TBI will affect his/her real-world functioning, educates the child and family about what challenges they may face as the child recovers, and provides recommendations for treatment planning.
  - Upon hospital discharge, parents should be given clear documentation of the child's medical diagnoses and recommendations from healthcare providers, including TBI-associated compli-

cations and what to monitor when their child returns to home and school.

4. Improving access to TBI-related educational services
  - Healthcare professionals can provide written documentation of the injury, complications, and recommendations to the parents with instructions to provide the report to their child's teacher, school principal, or guidance counselor at school.
  - Educational best practices for children with TBI include (a) appropriate, systematic identification, (b) educator training on TBI and interventions to address the effects of the TBI in school, and (c) systematic state support for educators working with students with TBI.<sup>76,81</sup> School systems can improve service delivery for children with TBI by incorporating these practices into educational programs.
  - If a neuropsychological evaluation or consultation has been conducted, parents can be apprised of the need to include this assessment in their school reporting. Most neuropsychological reports provide recommendations and documentation needed for initiating special education services, including what level of support may be needed (eg, homebound, 504, and IEP), the disability category (eg, TBI, other health impaired, and specific learning disability), and specific educational supports needed.

## DISCUSSION

Children who experience a TBI are at risk for effects that negatively impact their development, health, and school performance. Most children with mild TBI typically recover more quickly from their injury symptoms. Although for some children, TBI is a chronic condition that requires ongoing management,<sup>54</sup> the heterogeneity in outcomes supports postinjury care that is individualized. The care children receive following TBI crosses 2 distinct service delivery systems that are not well coordinated or integrated. Significant advances in acute medical care for children have resulted in increased survival and reduction in secondary injury complications. However, there is evidence of low utilization of long-term healthcare services delivery including services that can support injury recovery and transition to school services. Furthermore, the setting where children spend the majority of time across development, namely school, does not have a systematic coordinated method of identifying children and providing for support and services over time. Children are at risk for a chronic health condition because of the TBI without systematically identified pathways to help them do their job at school.

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Parents play a key role in the management of children's health, but have limited understanding of the potential for TBI to be a chronic medical condition and lack accessibility to systems of care beyond initial healthcare services. The current models of service delivery have different definitions of TBI diagnosis and identification as well as diverse methods for providing coordinated care to create a continuous care pathway. At the time of the injury, current evidence of best practices supports a model of care that provides parent education, regardless of point of entry into the healthcare system, and offers hospital to school transition services. Efforts to link both systems of care, supporting family and child involvement in the continuum of care, informing educators about the effects of a TBI on school performance, advising families about the range of school services offered for learning support, and long-term monitoring of children's school performance are practices that will facilitate solutions to current gaps in service delivery. Specific rehabilitation disciplines, such as physical, occupational, and speech therapy, offer services in both healthcare and school settings, which can also help to bridge the gap. Improved continuity of services from the healthcare to educational system will facilitate optimal outcomes for children following traumatic brain injury.

## LIMITATIONS

The primary focus of this article was to describe the overall healthcare and school service delivery systems related to what we know about the needs for care following traumatic brain injury as a starting point for further research and action for service delivery improvement. As evidence becomes available, a more rigorous approach to evaluating service delivery systems can occur. We recognize that all issues related to the management of TBI were not addressed in the scope of this article. Child participation and functional outcomes, environmental factors (policies and attitudes, resources), and other types of service delivery systems (community services, state-based services) contribute to the care of TBI in children.

Other types of transitions (eg, transition within school settings and from high school to adulthood) are critical points for long-term management that require further examination. The variability in service delivery by state and local systems provides challenges for providing concrete methods for meeting the recommendations. It is our hope that this report on the overarching issues of service delivery within and between healthcare and school settings sparks further research to better understand the needs and services available to children after TBI and ways to improve services.

## CONCLUSION

Establishment of collaborations to address gaps in knowledge and service delivery for children with TBI among healthcare service providers, educators, and families will facilitate improvement in delivery of care for TBI.<sup>18</sup> Future recommendations for research include a better understanding of (a) factors impacting the long-term effects and service needs for children with all TBI severity levels, including services outside the school setting, (b) environmental barriers to recovery and development, such as family resources and education, (c) systems of communication/collaboration between healthcare providers, educators, and families of children with TBI that best facilitate good health and well-being outcomes for children, and (d) screening needed for history of TBI at the time educational problems are identified at school. This article is a first step in describing the healthcare and school service delivery systems that parents navigate following TBI in children. It adds to the existing literature on healthcare and school-based services by identifying gaps between and within the systems and offering potential solutions for improving care. Given the potential for children with TBI to have long-term consequences and the limited amount of research on children's attainment of adult milestones, continued attention should be paid to long-term monitoring to fully understand the impact of TBI on development and service needs.

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