



Published in final edited form as:

J Head Trauma Rehabil. 2023 ; 38(4): 329–335. doi:10.1097/HTR.0000000000000859.

Return to School After Traumatic Brain Injury: Description of Implementation Settings

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Abstract

Objective: Children who experience traumatic brain injury (TBI) of any severity may need accommodations when they return to school—the setting that manages academic achievement and learning. However, variations exist in current return to school (RTS) programs that address a

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The authors declare no conflicts of interests.

child's transition to school following TBI. This article describes some of these return to school (RTS) programs and how they vary by setting.

Design: This article provides insights from a modified evaluability assessment that examined RTS programs and their readiness for rigorous evaluation. A secondary analysis was conducted to better describe the types and location of programs examined.

Results: Differences exist in program structure, access, and how care for children is monitored over time. RTS programs that serve children following TBI are located in healthcare settings, schools, and state agencies and vary in models of care due to their location and organizational structure.

Conclusions: Children who experience TBI benefit from a healthcare assessment and follow-up upon RTS that includes parental involvement. Models of care for this process vary based on program location and organizational structure. Further research and program evaluation are needed to better understand effectiveness and how to optimally monitor and care for children returning to school after a concussion or TBI.

Keywords

return to school; traumatic brain injury

PEDIATRIC TRAUMATIC BRAIN INJURY (TBI) is an acquired injury that represents a significant public health burden in the United States.¹ Children can experience changes in their health and development that impact learning and behavior at school following this injury. Parents and children navigate 2 systems of care following a TBI: healthcare and school.² To reduce TBI-related learning deficits when a child returns to school (RTS), most children benefit from services that coordinate information between healthcare providers, school administrators, and family members. However, very little is known regarding the efficacy of the various methods of delivering RTS services to children and their families.

WHAT IS KNOWN ABOUT MEDICAL MANAGEMENT OF TBI IN THE HEALTHCARE SETTING?

Children currently receive healthcare in many different settings following a TBI, and diagnosis and delivery of discharge instructions are varied.¹⁻³ Children may be seen in primary care or outpatient clinic settings, admitted to the hospital for acute care, transferred to a pediatric trauma center, or may be admitted to an inpatient rehabilitation program after the initial hospitalization.^{1,4,5} Research has shown that only few hospitalized children (4%) are admitted to inpatient rehabilitation and even less receive medically based therapy following their initial care.⁵⁻⁸

After the initial TBI diagnosis, follow-up medical care and related services for children can also vary. These variations are often influenced by the child's symptoms, recovery trajectory, and accessibility to and funding for services.⁹⁻¹¹ Medical follow-up may include one or more visits with a physician or specialist (eg, physical therapist, occupational therapist, speech-language pathologist, neuropsychologist, and/or behavioral psychologist). Health insurance often has a cap on the number of visits and/or length of time that services

are offered, one of the barriers to healthcare access. Healthcare providers cite access and availability to services in the healthcare setting as a critical need.¹² Caregivers report barriers to medical follow-up such as lack of education and understanding of needs at the time of TBI diagnosis, schedule conflicts, and lack of resources (eg, insurance, transportation, and income) as reasons for not seeking follow-up care.^{9,11,13}

THE TRANSITION FROM HEALTHCARE TO SCHOOL SETTINGS

The RTS process and communication between family, medical providers, and school professionals varies.¹⁴ The inconsistent communication among medical providers, parents, and school personnel about the injury and need for educational accommodations contributes to difficulties in accessing services.^{1,2} Many parents leave the healthcare setting with limited understanding about the potential effects the injury may have on their child's ability to learn and participate in school.¹⁵ As a result, many families experience challenges with coordinating information between the systems of care and school-based services.^{2,3,16} This is especially true for families that have been economically/socially marginalized or those with lower levels of health literacy.¹⁷

Some programs in the healthcare setting have expanded services to include educator support for RTS.^{1,16} Study findings of such programs show that children who receive inpatient rehabilitation are more likely to have an RTS transition program, be identified for special education services, and to be provided with school supports.^{16,18,19} The transition for these children may include receiving appropriate accommodations at school immediately following the injury; however, it does not ensure that students who have delayed symptom onset (ie, symptoms not observed at the time of injury) will be identified.¹⁹

WHAT IS KNOWN ABOUT SCHOOL SERVICES AFTER TBI?

Many students who sustain a TBI will need postinjury supports at school, ranging from informal accommodations in the academic setting specific to their symptoms to longer-term efforts covered under educational laws and policies.¹ Existing school policies under the Individuals with Disabilities Act (IDEA) provide academic support for children returning to school with a new diagnosis such as concussion or TBI, which was added as a specific eligibility category under the IDEA in 1990. Medical documentation of the injury is required to qualify for services under this category along with an assessment on the impact of the injury on educational functioning, including a description of a student's educational performance to show the difference between pre- and postinjury functioning and the need for specially designed instruction.

Parents are most frequently the source of TBI notifications for school systems.² However, school personnel do not often have the training or experience to manage students with TBI and thus may not know how to respond when informed about one.^{3,16,20–23} Even children with more severe TBI are reported to have unmet or unrecognized needs by both healthcare providers and school staff upon their RTS⁷ and children with mild TBI (mTBI) may not receive healthcare provider recommendations when they return.²⁴

Few studies follow children enrolled in RTS programs from the point of medical diagnosis to symptom resolution or monitor children at school after accommodations have been offered to support symptom management. Understanding the landscape of RTS and how current programs and practices contribute to supporting student health and academic outcomes is important. The purpose of this article is to describe lessons learned from an evaluability assessment of existing RTS programs in spring 2016. RTS program models, location of services, and factors unique to each program will also be explained.

METHODS

The Centers for Disease Control and Prevention (CDC) initiated an evaluability assessment of existing RTS programs in spring 2016. Data collection, management, quality assurance, and analyses were determined to be public health evaluation activities by CDC human subjects oversight bodies and therefore did not require human subject review or institutional review board approval. Evaluability assessments are typically used to identify and assess programs' readiness to engage in a rigorous evaluation, an initial step needed to build the evidence base to justify more widespread adoption of a public health programs.²⁵ The project managers used the Systematic Screening and Assessment (SSA) evaluability assessment method to assess program readiness for evaluation and the plausibility for effectiveness, reach, feasibility, and generalizability.^{26,27} The SSA method integrates expert review with evaluability assessment methodology to identify promising practice-based strategies worthy of more rigorous evaluation studies.

The evaluability assessment methodology includes several steps. First, a request for promising RTS programs was made through an announcement to groups such as the Brain Injury Association of America, United States Brain Injury Alliance, National Association of State Head Injury Administrators, and other TBI-focused partners. The SSA process is used for initial review of the nominated programs to assess the following inclusion criteria: (1) reported collection or access to relevant data; (2) a specified link between healthcare and the school settings; (3) implementation for at least 6 months; and (4) no prior participation in a rigorous evaluation. The nominations were then reviewed by a panel of subject matter experts (SMEs) using a consensus process and scoring matrix to identify which were most suitable for more in-depth review via a site visit. These site visits were used to collect more information and to observe program staffing and data accessibility (ie, systems for data collection, and how data were used and collected). Site visit data were summarized and then reviewed in a second meeting of the expert panel using the same consensus process. Their deliberations focused on the relative strengths of each program to identify ones most ready for rigorous evaluation.

Program selection

Thirteen of the 15 programs submitting nominations were selected for further SME review. Two programs were removed due to incomplete applications. SMEs represented both federal and nonfederal agencies chosen to participate because of their expertise in TBI, education, medicine, school nursing, program evaluation, and evaluability assessments. The SMEs used standardized criteria to rate and select programs appropriate for the site visit using

an online rating form developed by a contractor with expertise in the SSA methodology. Four programs (2 based in a school setting and 2 in a healthcare setting) were selected for additional review via an in-person site visit to gather more detailed information on program processes. State-based programs were not included in the additional review phase because inclusion criteria for the collection of data related to the program were not met. Teams of 2, including 1 staff member from the CDC and 1 from ICF International, the contractor for this project, engaged with the selected organizations onsite. Interviews were conducted with parents, medical professionals, athletic trainers (ATs), school nurses, and program staff. Many lessons were learned from this assessment including the applications, evaluability process, and discussions with program leaders.

RESULTS

Based on both the application and review process, we learned that programs were located in 3 settings: healthcare, educational systems, and state agencies. Table 1 provides a condensed description of how program features varied by setting.

Healthcare setting

The 2 healthcare settings typically focus on health and recovery, providing services that are medically necessary based on insurance approval. A child's care was typically overseen by a physician, although care may have been provided by a nurse practitioner or other specialists such as a neuropsychologist. Access to healthcare required insurance coverage or a co-pay for the visit, factors that can influence parents' decision to seek care in these settings. The length of time that children receive follow-up services and type of services received was based on medical necessity and could be impacted by health insurance therapy caps.

To address RTS, both medical programs (inpatient rehabilitation and concussion clinic) hired educators to serve as a liaison and advocate for school services. This was not a common practice across all healthcare settings such as emergency departments, pediatrician offices, and specialty clinics.^{1,2} Although services by medical professionals can be billed to insurance, educator services cannot and are covered by the overall program. A physician within the healthcare setting supported including this educator specialist as part of the interdisciplinary medical team that consisted of physicians, nurses, neuropsychologists, and rehabilitation therapists (physical, occupational, and speech-language pathologists). RTS programs who hired an educator primarily serviced patients in the community surrounding the facility and engaged in community outreach in this community to provide information to educational professionals about the impact of TBI at school. In both healthcare programs, the healthcare-based educators started the initial communication with the child's school system. This is a service provided with parent permission and a response to the perceived problem that parents do not often report a child's TBI or provide discharge recommendations to schools. Although healthcare educators monitor the children when they first return to school, medical follow-up is dependent on the parent returning for the child's clinical visit, which is often based on healthcare accessibility and understanding for continued care. Children enrolled in inpatient rehabilitation programs are more likely to have this educator support.

One program offered both inpatient and outpatient services to assist children younger than 18 years. Referrals were mostly from physicians and healthcare personnel. This program, led by physical medicine and rehabilitation specialists, has existed for close to 20 years and gradually was expanded from only working with moderate-to-severe TBI to include mild TBI/concussion in outpatient settings. The outpatient setting also has a concussion clinic run by orthopedic sports medicine specialists. The second program provided care for children experiencing mild TBI/concussion in an outpatient setting with a sports medicine/orthopedic physician. In addition to the interdisciplinary team members, this program included an AT. Most students seen were high school athletes.

School recommendations in these medically-based RTS programs come from various healthcare providers and specialties, as described earlier, creating variability by setting or discipline. The Health Insurance Portability and Accountability Act allows for information sharing in the medical setting. Healthcare providers can share information with educational staff outside of their systems and be involved with the transition to school with parent permission. Both programs in the medical setting are interested in understanding long-term outcomes for their patients; however, they can only follow those who return to the medical setting for care over time.

School setting

Two programs were visited in the school setting: one was run by the state and the other was administered by a local school system. In these programs, a TBI/concussion is typically identified by parent or student report to educational personnel, or by teachers or the school nurse if the injury occurs at school. In some cases, children are identified by CHILDFIND, a state-based program for identifying children at risk for disability and in need for enrollment in special education.^{1,28} Once the injury is reported, educators typically take time to assess its impact on school performance. A teacher, guidance counselor, AT, school psychologist, speech-language pathologist, and school nurse are often the personnel designated in a school setting to lead the team that acts on this report.

The primary focus at school for students who experience TBI is the injury's impact on learning. Schools offer a continuum of support services for students including accommodations in the general classroom setting, nurse health plans, 504 plans, and special education services. Ancillary therapy services such as physical, occupational, and speech-language therapy, social work, and counseling may also be offered at school to support the student in a classroom. Parents are not charged a fee for services in school programs. Students with a medical condition can receive a health plan written by a school nurse, an academic adjustment offered by the teacher or student support team, or, if available, a concussion management team in an RTS program. Schools can offer a 504 plan²⁹ for students who need more intensive support or specialized services through an Individualized Education Plan in Special Education under the Individuals with Disabilities Education Act.³⁰ TBI is a category for services under the IDEA.

The Family Educational Rights and Privacy Act, a federal law, governs school release of student information that protects the privacy of education records. The law applies to all schools that receive funds under the US Department of Education. When a student presents

with changes in behavior or academic performance at school or if staff in the school know of an event that could have resulted in a TBI, schools are still required to address the child's symptoms, even if they have not been seen by a healthcare provider and given an official medical diagnosis. The number and length of services is based on the student's symptoms and academic performance.

Both school programs initially started when the IDEA deemed TBI as a condition and were federally funded through their state Department of Education for several years to serve children ages 5 to 18 years with moderate-to-severe TBI. Since 2007, they have expanded to include mild TBI/concussion due to numerous students presenting at school. Based on our review, local school systems can volunteer to develop a concussion management team. Both programs follow children who sustain a TBI through high school graduation using an online tracking system and have extensive partnerships within their state that include rehabilitation facilities, pediatric hospital systems, state-based Brain Injury Associations and injury centers, and the state department of health. Both programs offer professional training to educators and community outreach to schools.

One program is housed within an individual school district. Using electronic school records, the program identifies participants through attendance officers who screen for TBI whenever a child is absent from school due to an injury. In this system, students are tracked through injury recovery and followed through graduation. In contrast, the other school-based program is housed within the state's regional center for special education. Students with mTBI/concussion are followed by a concussion management team located in the local school system until their symptoms resolve. However, they are referred to the regional center if TBI symptoms persist after 4 weeks. Students continue to receive accommodations from the regional center and are tracked through high school graduation via a data reporting system.

State agency setting

Two state-based programs were nominated but did not meet program eligibility criteria for a site visit due to lack of available data to better understand outcomes. Despite this, we did learn from the application review that these programs offer case management services to children, which warrants further description. Case management services for persons with brain injuries have been initiated largely because of advocacy from states' affiliate groups. These groups assist state agencies in promoting partnerships that build systems to support persons with brain injury and their families. Each state has a lead agency for TBI, which also supports state-based programs. States also have home and community services waivers for those with TBI and existing services for other types of pediatric health conditions that assist with the care of children with TBI. Eligibility for state services is determined by medical documentation of the TBI and patient needs without a service charge to families. Patients can be referred to this system by family members, healthcare or education professionals, and state agencies. Case management systems work with both medical and educational settings to help children and their families find services and coordinate services and support communication between parents and healthcare providers. A state agency employs a coordinator of services who communicates directly with healthcare and

education professionals to understand needed services and to facilitate RTS requirements. State-based programs have developed resources for parents to support healthcare and school communities. They can refer high school graduates to adult service networks if the child and their family still need assistance.

DISCUSSION

The evaluability assessment identified programs that offer RTS services for children after a TBI in 3 different settings: healthcare, schools, and state agencies. Models varied by setting according to their focus and organizational structure. The healthcare settings prioritized medical necessity, recovery, and insurance coverage to serve children. The public school-based programs served all students reported to have a concussion/TBI and addressed the impact of health conditions on academic progress. The state-based programs were linked to state agencies and offered case management through staff who work with both healthcare and school services. While this evaluability assessment provided qualitative information about the various RTS programs, no systematic evaluation of the effectiveness of programs on student health and academic performance has been done to date.

Reliable communication between healthcare and school systems is a critical part of the RTS transition.³¹ Parental consent is required for the healthcare system to contact the school about the injury, which explains why schools may not receive a report about the TBI. Communication from the school to the healthcare provider can be challenging due to the diversity of providers who see children with TBI.³¹ In addition, it may be difficult for schools to coordinate with a child's healthcare provider if parents do not offer appropriate contact information. When an injury occurs at school, the student may not receive medical care for varied reasons such as lack of or insufficient insurance or parents' decision not to seek care.³¹ In school-based programs, school nurses can support parents in seeking care when their child is injured and communicate to the healthcare community when authorized by parents.³² Because schools typically establish policies at a local level, much variation exists on how RTS and attending to injuries at school can be addressed.

Monitoring children over time is an important issue. Professionals in healthcare settings indicated that they can only monitor children over time if families schedule and return for follow-up visits, an option only available with continued access to medical care. In contrast, school programs can monitor children over time until high school graduation, particularly if they use electronic school records. However, gaps exist in the ability to monitor and reassess children long-term after injury, especially at critical transition points such as middle to high school. Although public schools are federally funded to serve all children when an injury is reported, children enrolled in private schools or home schooled may not receive the same type of identification and support services. Children served by state agency-based programs may be monitored for many years. However, these programs are not universal, and the number of children served is unknown, as is the impact of case management on enrollment in services and the effect on health and academic outcomes.

Limitations exist in this evaluability assessment of current RTS programs. First, information gleaned through this process was potentially limited in scope because nominating was done

through TBI stakeholder groups and each program considered was required to have access to relevant data, a link between healthcare and school settings, had been implemented for 6 or more months, and had no prior rigorous evaluation on record. Other programs likely exist and may operate differently than the programs examined. Second, only 4 RTS programs were assessed in depth based on site visits. We only learned about other programs such as state-based programs, through the application process. A more in-depth examination of these nominated programs might have shown alternative findings.

CONCLUSIONS

RTS programs that participated in the evaluability assessment were identified in 3 different settings (healthcare, educational, and state agencies). Each setting varied in meaningful ways, but all offered processes for facilitating a child's RTS after a TBI. Healthcare, school, and state agency assistance is commendable; however, which type of program best serves students of all ages and etiologies of TBI upon RTS is unclear, as is whether one type of program is more effective in serving students' level of injury severity. Further research is needed to determine whether these programs are effective and to better understand processes by which they monitor and care for children in the transition to school after a TBI and their progress over time.

Acknowledgments

Research reported in this publication was supported by the Centers for Disease Control and Prevention, National Center for Injury Prevention and Control's Contract #HHSD2002013M53944B. The findings and conclusions in this publication are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. The collection of information was approved under OMB Control Number 0920-1009.

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TABLE 1

Typical features of return to school program models evaluated

Role/aspect	Healthcare settings <i>n</i> = 2	Educational <i>n</i> = 2	State agency <i>n</i> = 2
Leader	Physician	Teacher or educational team	TBI state lead agency; TBI advocacy group
Purpose	Health and recovery	Learning and academic achievement	Case management and coordination of services
Funding	Fee for service based on health insurance coverage	Teacher salaries and stipend from federal, state, or local system funds	State agency grants; federal grants (HRSA, ACL), TBI trust funds
Information sharing requirements	HIPPA	FERPA	HIPPA and FERPA
Service guidance	Medical necessity	Maintaining a student in an educational program	Case management (intermediary)
Services	Physician support; therapies PT, OT, SLP vision services, psychology, neuropsychology, educational liaison (in some settings)	Therapies PT, OT, SLP school psychology, school counselor, school social worker, school nurse	Resources for services
Qualification for services	Medically necessary/insurance approval	TBI event and symptoms; verified as eligible for special education	TBI documentation (medical documentation or self-report)
Length of services	Based on therapy caps from insurance and insurance status	Determined by how health condition affects learning and school performance	Determined by need and available resources

Abbreviations: ACL, Administration for Community Living; FERPA, Family Educational and Privacy Rights Act; HIPPA, Healthcare Insurance Portability and Accountability Act of 1996; HRSA, Health Resources and Services Administration; OT, occupational therapy; PT, physical therapy; SLP, speech-language therapy; TBI, traumatic brain injury.