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Examining a Statewide Educational Consulting Program for Pediatric Brain Injury

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Abstract

This study describes characteristics of students with acquired brain injury enrolled in a statewide educational consultation program and the program's support activities. Utilizing de-identified data from a statewide brain injury school consultation program, descriptive analyses of demographic and injury characteristics, including medical diagnosis (concussion/mild traumatic brain injury (TBI), moderate-severe TBI, and non-TBI), referral characteristics, educational placement, and the types of program activities were undertaken. 70% of students were referred for concussions/mild TBI and students were infrequently referred by medical professionals. Most students with concussion/mild TBI experienced recreational injuries (59%), while students with moderate/severe TBI commonly experienced road traffic injuries (48%). The greatest proportion of program team members' time was spent in consultation with school personnel (24%), communication with families (20%), and communication with school personnel (16%). Results suggest that the program addresses important communication and coordination needs among families, medical professionals, and educators and identifies opportunities to enhance program utilization.

Keywords

traumatic brain injury; concussion; education; postacute care; pediatric

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CONFLICTS OF INTEREST

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INTRODUCTION

In recent years, acquired brain injury (ABI), comprised of both traumatic and non-traumatic injuries, has received increased attention as both a leading cause of death and disability in children and young adults.^{1, 2} While a recent decrease in deaths due to traumatic brain injury (TBI) has been observed,¹ increasing numbers of children and adolescents require medical care and on-going support in returning to activities following TBI.² School-aged children and adolescents have the highest rates of ABI¹ and national data suggest an increasing incidence of concussion, particularly among adolescents.³ This highlights an urgent need for novel policies, practices, and programs to support injured youth, especially related to academic support and school re-entry. ABI contributes to impairments, including cognitive, speech-language communication, memory, attention/concentration, reasoning, abstract thinking, physical functioning, psychosocial behavior, and information processing.⁴⁻⁸ Among children and adolescents with ABI, these impairments may contribute to significant challenges in educational attainment.^{9, 10} Many youth with ABI earn lower grades, are more likely to experience grade retention, and require more special education services than their non-injured peers.^{11, 12} Frequently, school personnel are called upon to understand ABI and ensure that the academic needs of affected students are adequately met,¹³ despite limited knowledge of or training that is ABI-specific to support students.^{14, 15}

BrainSTEPS (Strategies Teaching Educators, Parents, and Students), an innovative collaboration between state agencies and local school districts, seeks to improve educational outcomes for youth with ABI. In 2007, the Pennsylvania Department of Health established BrainSTEPS to provide educational consultation and training to schools to improve the quality of education for students with ABI. BrainSTEPS, implemented by the Brain Injury Association of Pennsylvania (BIAPA), supports statewide programming for children and adolescents with ABI. The 31 BrainSTEPS teams, led by one statewide program coordinator, are comprised of nearly 300 educators, medical rehabilitation professionals, and parents, who are trained in understanding the educational needs of students following ABI. Employers provide team members time to engage in program activities. Teams provide consultation and education to school personnel regarding educational plans, accommodations, and modifications with the purpose of supporting students' return to the classroom and improving educational outcomes. Team members participate in the development of Individualized Education Programs (IEPs) for special education needs, 504 Plans for educational accommodations, interdisciplinary collaboration between families and medical, rehabilitation, and school personnel, and support classroom teachers in adjusting curricula and teaching strategies. BrainSTEPS addresses a critical need by providing school personnel, families, and students with the information and resources necessary to understand the effects of ABI on educational performance.¹⁵

The BrainSTEPS infrastructure affords the opportunity to examine educational needs of youth with ABI, both acutely and longitudinally. Importantly, BrainSTEPS provides a continuous source of programmatic data regarding educational modifications intended to facilitate success for students with ABI. The present study established the processes and procedures by which limited BrainSTEPS data could be shared for research purposes, and identified strengths and limitations of the data to facilitate research efforts. This study

described the characteristics of students with acquired brain injury receiving BrainSTEPS services since 2008 and the educational support activities provided by the program for students with ABI in Pennsylvania. Results from this study may inform potential efforts to improve the timely referral of youth to services by medical and rehabilitation professionals.

PARTICIPANTS AND METHODS

This retrospective study utilized data from the BrainSTEPS online data collection system. Programmatic, de-identified student-level data were extracted and shared with investigators at The Children's Hospital of Philadelphia (CHOP). This study was deemed exempt by CHOP's Institutional Review Board, as all activities were limited to analysis of de-identified existing data.

Participant Eligibility

Children and adolescents with ABI are referred to BrainSTEPS from a variety of sources, including healthcare professionals, school personnel, and families/caregivers. BrainSTEPS team members continuously engage in outreach to schools, rehabilitation centers, and healthcare providers to encourage timely referral of youth with ABI. Anyone with knowledge of a student with an ABI can make a referral either via the BrainSTEPS website¹⁶ or by directly contacting a BrainSTEPS team.

Eligible students resided in Pennsylvania and experienced an ABI. BrainSTEPS services target students in Kindergarten through 12th grade, but many teams provide consultation to early intervention providers for children younger than age five. BrainSTEPS consultation continues until students' educational needs are resolved or until appropriate plans are in place to address on-going needs. The goal of the BrainSTEPS program is for teams to conduct annual check-ins with schools and families, to ascertain educational needs until high school graduation. BrainSTEPS services can be reinstated at any time at the request of healthcare providers, school personnel, parents/families, or students. The present study included data from January 2008 through June 2016. Participants included all students who received BrainSTEPS services, regardless of data completeness, consultation services received, or length of program participation.

Data Sources

Data were extracted and de-identified by BIAPA team members and shared electronically with CHOP investigators for analysis. All dates, including date of injury and referral, were converted to month and year only. Free-text notes, which often contained identifying student or family information, were removed to maintain anonymity. Data were classified into two domains: individual, student-level characteristics and BrainSTEPS team activities.

Student-level demographic characteristics included gender, age at injury, and age at referral. Student-level injury characteristics included diagnosis (categorized as concussion/mild TBI; moderate/severe TBI; non-TBI) and mechanism for both traumatic and non-traumatic ABI. Additionally, classroom grade at referral and educational placement at the time of injury and at time of referral were provided. Students' educational placement included: homebound,

preparing for school re-entry, out of district placement, regular education (with and without accommodations), special education, and other.

Table 1 describes activities and services provided by BrainSTEPS team members to students, families, school personnel, and other professionals involved in addressing the educational needs of injured students. Team members document the activities undertaken for each student, as well as the time spent on each activity throughout the duration of a student's program participation.

Data Analysis

Frequencies and percentages were used to describe categorical variables. Mean, standard deviations, and ranges were reported for continuous variables. Fisher's exact tests and chi-square tests were used for bivariate categorical analyses and Student's t-test and one-way ANOVAs were used for comparisons of continuous data. Data were analyzed in SAS (Version 9.3).

RESULTS

Data Quality

There were 3,493 de-identified student records included from the eight year study period (January 2008–June 2016). Most variables examined had low levels of incomplete data (<3%), including medical diagnosis, gender, age at injury and referral, grade at injury, and mechanism of injury. Educational placement at time of referral had the greatest proportion of incomplete data, ranging between 6.0% and 18.3%.

Student Demographics

Student characteristics are described in Table 2. The majority of students were referred for concussions/mild TBI (69.9%). Overall, similar proportions of males and females were referred to BrainSTEPS for concussions/mild TBI, however males were more likely than females to be referred with moderate/severe TBI and non-TBI ($p < 0.001$). Age at injury ranged from 0–19 years, and students with concussions/mild TBI were significantly more likely to be older than students with moderate/severe TBI and those with non-TBI ($F(2, 3378) = 512.22$, $p < 0.001$). Similarly, students with concussions/mild TBI were older at time of referral than students with moderate/severe TBI and those with non-TBI ($F(2, 3378) = 192.63$, $p < 0.001$). While students who experienced concussions/mild TBI were referred to BrainSTEPS within several months of their injury, more than a two year difference between age at injury and referral was observed for students with moderate/severe TBI and non-TBI (2.2 and 3.3 years, respectively).

The most common injury mechanisms for students with concussion/mild TBI were sports-related (59.9%), falls (20.0%), and road traffic injuries (10.3%). However, for students with moderate/severe TBI, the majority sustained road traffic injuries (47.7%), falls (13.7%), and sports-related injuries (9.0%). Among students with non-TBI, the most frequent injury mechanisms included tumors (26.0%), seizure disorders (20.0%), and strokes (17.6%). Across all medical diagnoses, school personnel were the most common referral source.

Students with concussion/mild TBI were more likely to be referred by family members and physicians than students with moderate/severe TBI or non-TBI, whereas students with moderate/severe TBI and non-TBI were more likely to be referred by rehabilitation providers and county educational service agencies ($p<0.001$).

At the time of injury, most students were enrolled in regular education (Table 3). However, by the time of program referral, most students with concussions/mild TBI were enrolled in regular education either with (38.9%) or without accommodations (23.3%). Nearly one-third of students with moderate/severe TBI were receiving special education (32.4%). The majority of students with non-TBI were enrolled in special education (49.3%), with equal proportions enrolled in regular education with and without accommodations (11.9%).

The greatest proportion of BrainSTEPS team members' time was spent on consultation with school personnel (23.8% of total time) (Figure 1). Example activities included providing consultation regarding modifications to the classroom environment, instructional method, and curricular content; use of behavioral strategies and assistive technology; and demonstration of interventions for school personnel. Communication activities, including communication with families (19.8% of total time) and communication with schools (16.0% of total time) were the next most frequently documented activities. Consultation with the student was frequently documented (12.1% of total time) and team members reported a considerable amount of time spent participating in meetings to address formalized accommodations and modifications to students' educational plans (11.7% of total time).

DISCUSSION

This study describes the characteristics of students and the activities provided by a statewide program to support educational success following brain injury. BrainSTEPS data are particularly unique, as few states have developed such a comprehensive database to track students with brain injury from the time of program referral until high school graduation. These results highlight that data sharing, while protecting the anonymity and confidentiality of program participants, is possible and that a majority of these data are complete, providing a robust source of analytic data and the opportunity to consider innovative ways to utilize these data with other administrative data sources. The extensive time spent by BrainSTEPS team members on consultation and communication with school personnel, indicate the continued need to provide education and consultation to teachers, administrators, and other school personnel to address the academic needs of the growing population students with ABI. Programs such as BrainSTEPS are designed to support families and school personnel in affording students' the opportunity to return to school with the necessary support to attain educational success.

Pennsylvania has established the infrastructure and resources to provide educational school-focused support for youth with ABI. The Colorado Department of Education established a similar model several years ago and recently adopted the BrainSTEPS model statewide, which began providing services in Fall 2016.¹⁷ A similar program has existed in Oregon for over two decades and exclusively provides services to students with TBI.¹⁸ This study offers a comprehensive examination of the activities undertaken by educational brain injury

support teams, as well as the demographic and injury characteristics of students receiving services across an entire state. Since 2007, the BrainSTEPS Program has encompassed key components of two recently published white papers by The National Collaborative on Children's Brain Injury.^{19, 20} BrainSTEPS advocates for the creation of interdisciplinary teams, professional development activities, tracking protocols, establishing academic accommodations, and coordinated communication to support academic re-entry for youth with ABI. With increasing recognition of the burden and significant impact of brain injury,^{3, 21} BrainSTEPS may play an invaluable role in addressing students' educational needs and continuously providing training to school personnel statewide. Importantly, BrainSTEPS provides ongoing support to and monitoring of youth until high school graduation, recognizing that new issues impacting educational success may emerge throughout the period of rapid adolescent brain development, regardless of the severity of pediatric ABI.

In prior studies, both parents and students report that support from teachers, increased knowledge among educators, and understanding the need for and importance of educational modifications, are critical for educational success following ABI.^{22–24} Echoing these needs, our study observed that the largest proportion of BrainSTEPS team members' time was dedicated to in-school activities, including consultation with and training of school personnel regarding educational modifications and communication with school personnel. These data may reflect limitations in the preservice and in-service knowledge and skills of educators regarding needs of students with ABI.^{20, 25} Efforts, such as those undertaken by BrainSTEPS teams, are one way to directly address families' concerns regarding educational engagement and enhance the likelihood of continued academic participation and success.

An average delay of over a year was observed between age at injury and age at referral to BrainSTEPS. Further study is needed to elucidate whether this is an artifact of these data, which include the period of program start-up, or whether efforts to further disseminate information to healthcare and rehabilitation providers are necessary. Increased knowledge of program services among healthcare and rehabilitation providers may enhance the timely referral to the program and reduce the time to program initiation among injured students. Fewer than 20% of students were referred to the program by medical and rehabilitative program staff, however, referral from medical rehabilitation providers may enable BrainSTEPS teams to connect with families more quickly and enhance the ability to support students' return to school following ABI.⁹ Successful examples of referrals by hospital personnel to educational support programming exist for youth recently diagnosed with cancer^{26, 27} and chronic illnesses,²⁸ suggesting that early access to educational support, facilitated by healthcare providers, is feasible. While most students were referred to the program by school personnel or families, further research is needed to understand the motivation for these referrals and the factors involved in referral delays and how efforts to improve earlier program referral could be implemented.

The intensive nature of communication efforts required to address the post-injury needs of youth following ABI are clearly highlighted by these data. In particular, BrainSTEPS team members spent extensive time communicating with families to identify areas of educational strengths and needs. Families require effective and extensive communication regarding educational activities and developing comprehensive plans for school reintegration and

success.^{24, 29, 30} A unique opportunity exists for professionals, such as BrainSTEPS team members, to work with families to identify areas of academic concern with the goal of facilitating effective collaboration within the educational system.

Interestingly, there were several activities that comprised a limited proportion of BrainSTEPS team members' time, including consultation with students and meetings regarding formalized educational modifications (e.g. IEP and 504 plans). It is unclear from these data whether the limited time documented on such efforts reflects how team members record activities or how team members' activities are classified. Based on team members' informal reports, one possibility is that BrainSTEPS teams perform these activities in the context of more frequently documented activities. Further, because teams operate locally, variability may exist in how teams document their activities. Enhancing the complete and standardized documentation of BrainSTEPS activities is an important avenue for future programmatic efforts. Additionally, understanding the outcomes associated with each activity may help inform continued refinement of program implementation. Efforts to describe the specific activities that take place in the context of consultation and communication may help to identify the outcomes realized through these activities.

Although the majority of students (70%) referred to BrainSTEPS experienced concussions/mild TBI, many students across all ABI types experienced a change in educational placement following their injury, specifically an increased proportion of students who were enrolled in special education at time of referral. However, Glang et al. suggest that frequently students with TBI, who qualify for special education services, fail to receive necessary educational support.⁹ BrainSTEPS team members may play a critical role in addressing students' unmet educational needs. Further, while homebound services are intended to be short-term accommodations during the early recovery period, more than 10% of students continued to receive homebound services, despite the prolonged time between injury and referral. Presently, data on educational placement following BrainSTEPS participation is limited, but this is an important outcome for both future programmatic and research purposes.

This study has several limitations. First, we analyzed data that were not specifically collected and designed for research purposes. While much of the data, particularly demographic and injury-specific data were complete, several data fields were less reliably complete and inconsistent, including educational placement. Program efforts to track educational placement data longitudinally have been limited by program capacity and financial constraints. These data may be particularly useful for identifying the specific needs of students with ABI, tracking changes in needs, and documenting programmatic success. This suggests several areas of continued refinement in data collection procedures, such as seeking additional sources of administrative data, including school and medical records, to augment the existing data collection processes and address additional outcomes. Second, given the voluntary nature of BrainSTEPS team membership and the variable amount of time members dedicate to this program, team members necessarily must prioritize school, family, and student contact over data entry tasks. There is a need for funding directed to program staff to provide dedicated time to conduct BrainSTEPS activities, including the creation of funded team leader positions to oversee BrainSTEPS teams' activities.

Additionally, given the number of students injured and referred to the program annually, funding is necessary to continue to provide comprehensive services to referred youth and to enhance longitudinal data collection efforts. Finally, these data do not comprehensively represent all Pennsylvanian youth with ABI. There is no system presently in place to automate referral of eligible students upon medical or rehabilitation discharge. Therefore, these data are not generalizable to the experience or demographics of students not participating in the program.

CONCLUSION

This study offers insight into the implementation of a comprehensive statewide brain injury educational support program and demonstrates the feasibility of tracking educational support services provided to a cohort of students and their families following ABI. Importantly, this study identifies several areas of potential programmatic and research enhancements, including increased outreach to healthcare providers to enhance timely program referral, expanded data acquisition to include sources of administrative data, and identifying sources of support to track longitudinal outcomes. This study also identifies opportunities for additional research, including understanding the content of documented team activities and examining youth-, parent-, and educator-reported outcomes to measure success across diverse domains. Such efforts may help BrainSTEPS identify and define educational advocacy and support best practices for youth with ABI. These data would provide the comprehensive details necessary to help predict the specific needs of students over their academic careers and would assist in developing appropriate plans for enhancing students' educational success following ABI.

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References

1. Faul, M., Xu, L., Wald, M., Coronado, V. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.
2. Centers for Disease C, Prevention. Nonfatal traumatic brain injuries related to sports and recreation activities among persons aged <=19 years—United States, 2001–2009. MMWR Morb Mortal Wkly Rep. 2011; 60(39):1337–42. [PubMed: 21976115]

3. Zhang AL, Sing DC, Rugg CM, Feeley BT, Senter C. The Rise of Concussions in the Adolescent Population. *Orthop J Sports Med.* 2016; 4(8):doi: 10.1177/2325967116662458
4. Fay TB, Yeates KO, Wade SL, Drotar D, Stancin T, Taylor HG. Predicting Longitudinal Patterns of Functional Deficits in Children with Traumatic Brain Injury. *Neuropsychology.* 2009; 23(3):271–82. DOI: 10.1037/a0014936 [PubMed: 19413442]
5. Anderson V, Catroppa C. Memory outcome at 5 years post-childhood traumatic brain injury. *Brain Inj.* 2007; 21(13–14):1399–409. DOI: 10.1080/02699050701785070 [PubMed: 18066942]
6. Ewing-Cobbs L, Barnes M, Fletcher JM, Levin HS, Swank PR, Song J. Modeling of longitudinal academic achievement scores after pediatric traumatic brain injury. *Dev Neuropsychol.* 2004; 25(1–2):107–33. DOI: 10.1080/87565641.2004.9651924 [PubMed: 14984331]
7. Schwartz L, Taylor HG, Drotar D, Yeates KO, Wade SL, Stancin T. Long-term behavior problems following pediatric traumatic brain injury: prevalence, predictors, and correlates. *J Pediatr Psychol.* 2003; 28(4):251–63. DOI: 10.1093/jpepsy/jsg013 [PubMed: 12730282]
8. Taylor HG, Yeates KO, Wade SL, Drotar D, Stancin T, Minich N. A prospective study of short-and long-term outcomes after traumatic brain injury in children: behavior and achievement. *Neuropsychology.* 2002; 16(1):15–27. DOI: 10.1037/0894-4105.16.1.15 [PubMed: 11853353]
9. Glang A, Todis B, Thomas CW, Hood D, Bedell G, Cockrell J. Return to school following childhood TBI: who gets services? *NeuroRehabilitation.* 2008; 23(6):477–86. [PubMed: 19127001]
10. Bullock LM, Gable RA, Mohr JD. Traumatic brain injury: A challenge for educators. *Prev Sch Fail.* 2005; 49(4):6–10. DOI: 10.3200/PSFL.49.4.6-10
11. Arnett AB, Peterson RL, Kirkwood MW, Taylor HG, Stancin T, Brown TM, et al. Behavioral and cognitive predictors of educational outcomes in pediatric traumatic brain injury. *J Int Neuropsychol Soc.* 2013; 19(8):881–9. DOI: 10.1017/s1355617713000635 [PubMed: 23790158]
12. Ewing-Cobbs L, Prasad MR, Kramer L, Cox CS Jr, Baumgartner J, Fletcher S, et al. Late intellectual and academic outcomes following traumatic brain injury sustained during early childhood. *J Neurosurg.* 2006; 105(4 Suppl):287.doi: 10.3171/ped.2006.105.4.287 [PubMed: 17328279]
13. Schilling EJ, Getch YQ. Getting My Bearings, Returning to School: Issues Facing Adolescents With Traumatic Brain Injury. *Teaching Exceptional Children.* 2012; 45(1):54–63. DOI: 10.1177/004005991204500108
14. Gfroerer SD, Wade SL, Wu M. Parent perceptions of school-based support for students with traumatic brain injuries. *Brain Inj.* 2008; 22(9):649–56. DOI: 10.1080/02699050802227162 [PubMed: 18608201]
15. Mohr JD, Bullock LM. Traumatic brain injury: Perspectives from educational professionals. *Prev Sch Fail.* 2005; 49(4):53–7. DOI: 10.3200/PSFL.49.4.53-57
16. Brain Injury Association of Pennsylvania Inc. BrainSTEPS (Strategies Teaching Educators, Parents, & Students). 2016. [cited 2016 August 3]. Available from: www.brainsteps.net
17. Brain Injury Alliance of Colorado. Case Management Denver, CO: Brain Injury Alliance of Colorado. 2016. [cited 2016 September 30]. Available from: <http://biacolorado.org/case-management>
18. The Center on Brain Injury Research & Training. The Center on Brain Injury Research & Training Projects Eugene. OR: University of Oregon; 2016. [cited 2016 September 30]. Available from: <http://cbirt.org/our-projects/>
19. Gioia GA, Glang AE, Hooper SR, Eagan-Brown B. Building Statewide Infrastructure for the Academic Support of Students With Mild Traumatic Brain Injury. *J Head Trauma Rehabil.* 2015; doi: 10.1097/HTR.0000000000000205
20. Glang A, Todis B, Sublette P, Eagan-Brown B, Vaccaro M. Professional development in TBI for educators: The importance of context. *J Head Trauma Rehabil.* 2010; 25(6):426–32. DOI: 10.1097/HTR.0b013e3181fb8f45 [PubMed: 21076243]
21. Chan V, Pole JD, Keightley M, Mann RE, Colantonio A. Children and youth with non-traumatic brain injury: a population based perspective. *BMC Neurol.* 2016; 16:110.doi: 10.1186/s12883-016-0631-2 [PubMed: 27439699]

22. Gagnon I, Swaine B, Champagne F, Lefebvre H. Perspectives of adolescents and their parents regarding service needs following a mild traumatic brain injury. *Brain Inj.* 2008; 22(2):161–73. DOI: 10.1080/02699050701867381 [PubMed: 18240045]
23. Sharp NL, Bye RA, Llewellyn GM, Cusick A. Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disabil Rehabil.* 2006; 28(12):767–78. DOI: 10.1080/09638280500386668 [PubMed: 16754574]
24. Roscigno CI, Fleig DK, Knafl KA. Parent management of the school reintegration needs of children and youth following moderate or severe traumatic brain injury. *Disabil Rehabil.* 2015; 37(6):523–33. DOI: 10.3109/09638288.2014.933896 [PubMed: 24969697]
25. Davies S, Fox E, Glang A, Ettel D, Thomas C. Traumatic brain injury and teacher training: A gap in educator preparation. *Phys Disabil.* 2013; 32(1):55–65.
26. Katz ER, Varni JW, Rubenstein CL, Blew A, Hubert N. Teacher, parent, and child evaluative ratings of a school reintegration intervention for children with newly diagnosed cancer. *Child Health Care.* 1992; 21(2):69–75. DOI: 10.1207/s15326888chc2102_1 [PubMed: 10117965]
27. McCarthy AM, Williams J, Plumer C. Evaluation of a School Re-entry Nursing Intervention for Children With Cancer. *J Pediatr Oncol Nurs.* 1998; 15(3):143–52. DOI: 10.1177/104345429801500303 [PubMed: 9699451]
28. Koontz K, Short AD, Kalinyak K, Noll RB. A Randomized, Controlled Pilot Trial of a School Intervention for Children with Sickle Cell Anemia. *J Pediatr Psychol.* 2004; 29(1):7–17. DOI: 10.1093/jpepsy/jsh002 [PubMed: 14747361]
29. Andersson K, Bellon M, Walker R. Parents' experiences of their child's return to school following acquired brain injury (ABI): A systematic review of qualitative studies. *Brain Inj.* 2016; 30(7): 829–38. DOI: 10.3109/02699052.2016.1146963 [PubMed: 27057776]
30. Savage RC, Pearson S, McDonald H, Potoczny-Gray A, Marchese N. After hospital: Working with schools and families to support the long term needs of children with brain injuries. *Neuro Rehabilitation.* 2001; 16(1):49–58. [PubMed: 11455103]

Figure 1.
Proportion of Time Spent on Activities as Reported by Program Team Members.

Table 1**Activities of the Program Team Members**

Consultation Activities	Description/Examples
Consultation with School Personnel	<ul style="list-style-type: none"> Assist school with developing Educational Plan Provide consultation regarding modification of curricular content, such as reduced assignment length, permitting extra time, scaffold lesson instruction, change testing format, providing timelines for completing assignments, providing verbal assignments, Provide consultation regarding modification of instructional methods, such as repetition, multimodal instructional methods, direct instruction, changing instructional delivery from lecture to cooperative learning, audiobooks, task analysis Provide consultation regarding use of assistive technology, such as enlarged print; software, and utilizing a frame to guide reading on a page Provide consultation regarding student's environment, such as permitting frequent breaks, preferential seating, identifying peer to assist in hallway transitions, providing noise cancelling headphones Provide consultation regarding use of behavioral strategies, including social scripts, Goal-Plan-Do-Review, positive behavior support focused on teacher's instructional method, developing teacher/student agreed upon cueing system, identifying in-school support person who student can freely access when student feels angry, scared, anxious, upset, etc. Application of "BrainSTEPS Supports Framework" to assist in obtaining comprehensive information regarding student's symptoms such as time of day, content area, course difficulty, and type of academic work required to determine specific necessary academic adjustments
Communication with family	<ul style="list-style-type: none"> Discuss family concerns regarding student Assist in organizing records Provide training and resources Provide parents with informal checklists to determine student's strengths/areas of need Input student information into program database including history of/current cognitive or behavioral health issues.
Communication with school	<ul style="list-style-type: none"> Discuss school concerns regarding student Provide training and resources Secure copies of past/present educational records Provide teachers with informal checklists to complete regarding student's strengths/areas of need
Consultation with student	<ul style="list-style-type: none"> Assess student's concerns, strengths, and areas of need Observe students in various classroom settings to assist in formation of recommendations Assist student with study skills, utilization of cueing systems, executive function skill training, creation of visual daily schedules, and facilitate use of checklists Assign student a trusted "Touch base" teacher to assist with organization 5 minutes prior to school & before school ends
IEP/504/Chapter 15 Service Agreement Meeting	<ul style="list-style-type: none"> Attend IEP meetings or IEP pre-planning meetings to provide ABI expertise regarding cognitive, behavioral, communication, perceptual, sensory, memory, attention, information processing, judgment, and abstract thinking Make recommendations to school-based IEP team Attend 504 meetings to provide ABI expertise regarding implementation of 504 Plans and appropriate formal academic accommodations based on student's academic needs and/or symptoms to school team
Information sharing among team	<ul style="list-style-type: none"> Meet monthly to review case with program teams

Consultation Activities	Description/Examples
	<ul style="list-style-type: none">Information sharing via conference calls, email and video conferences throughout the month
Records review	<ul style="list-style-type: none">Compile report recommendations and research educational strategies for recommendations to students
Consultation with medical professionals	<ul style="list-style-type: none">Communicate to determine medical concerns

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Table 2

Sample Demographics (N=3493)

Characteristics	Medical Diagnosis ^a				Missing Diagnosis ^a (n=82)	p-value (excl. missing)
	Concussion/Mild TBI (n=2441)	Moderate-Severe TBI (n=635)	Non-Traumatic Brain Injury (n=335)			
	n (%)	n (%)	n (%)	n (%)		
Gender						<0.001
Male	1146 (46.9)	424 (66.8)	210 (62.7)	50 (61.0)		
Female	1295 (53.1)	211 (33.2)	125 (37.3)	28 (34.1)		
Missing	0	0	0	4 (4.9)		
Age at injury, mean (SD), yrs ^b	13.7 (2.7)	10.6 (5.7)	7.5 (5.2)	12.4 (4.6)		<0.001
Age at referral, mean (SD), yrs ^c	14.1 (2.5)	12.8 (4.1)	10.8 (4.1)	13.1 (3.9)		<0.001
Classroom grade at referral						<0.001
Not school age	6 (0.3)	39 (6.1)	34 (10.2)	1 (1.2)		
Pre-K/K (half & full)	19 (0.8)	101 (15.9)	77 (23.0)	1 (1.2)		
Elementary School (grades 1–5)	276 (11.3)	102 (16.1)	115 (34.3)	14 (17.1)		
Middle School (grades 6–8)	698 (28.6)	124 (19.5)	53 (15.8)	14 (17.1)		
High School (grades 9–12)	1411 (57.8)	247 (38.9)	48 (14.3)	36 (43.9)		
Post-High School	2 (0.1)	2 (0.3)	1 (0.03)	0		
Missing grade	29 (1.2)	20 (3.2)	7 (2.1)	16 (19.5)		
Mechanism of Injury						
Traumatic Injury						
Sports	1439 (59.0)	57 (9.0)	0	0		
Falls	487 (20.0)	87 (13.7)	0	0		
Road traffic	251 (10.3)	303 (47.7)	0	0		
Abuse/Assault ^d	56 (2.3)	54 (8.5)	0	0		

Characteristics	Medical Diagnosis ^a					Missing Diagnosis ^a (n=82)	p-value (excl. missing)	
	Concussion/Mild TBI (n=2441)		Moderate-Severe TBI (n=635)		Non-Traumatic Brain Injury (n=335)			
	n (%)	n (%)	n (%)	n (%)	n (%)			n (%)
Hit with object/person ^e	96 (3.9)	11 (1.7)	0	0	0	0		
Pedestrian accident	0	44 (6.9)	0	0	0	0		
Firearm	0	18 (2.8)	0	0	0	0		
Skull fracture	0	2 (0.3)	2 (0.6)	0	0	0		
Birth trauma	1 (0.04)	2 (0.3)	0	0	0	0		
Fire	1 (0.04)	0	0	0	0	0		
Suicide attempt	0	1 (0.2)	0	0	0	0		
Non-Traumatic Injury								
Tumor	2 (0.1)	5 (0.8)	87 (26.0)	0	0	0		
Seizure disorder	0	6 (0.9)	67 (20.0)	0	0	0		
Stroke	0	2 (0.3)	59 (17.6)	0	0	0		
Encephalus	0	1 (0.2)	18 (5.4)	0	0	0		
Anoxia	0	0 (0.0)	19 (5.7)	0	0	0		
Surgery	0	8 (1.3)	4 (1.2)	0	0	0		
Infection ^f	0	0	10 (3.0)	0	0	0		
Near drowning	0	1 (0.2)	8 (2.4)	0	0	0		
Congenital anomaly	0	2 (0.3)	6 (1.8)	0	0	0		
Hydrocephalus	0	1 (0.2)	7 (2.1)	0	0	0		
Aneurysm	0	0	7 (2.1)	0	0	0		
AVM	0	1 (0.2)	6 (1.8)	0	0	0		
Medical treatment	0	1 (0.2)	5 (1.5)	0	0	0		
Meningitis	0	0	6 (1.8)	0	0	0		
Toxic or metabolic injury	0	0	5 (1.5)	0	0	0		
Hemorrhage	0	1 (0.2)	3 (0.9)	0	0	0		
Poisoning	0	1 (0.2)	2 (0.6)	0	0	0		
Lightning strike	0	0	2 (0.6)	0	0	0		
Subarachnoid cyst	0	0	2 (0.6)	0	0	0		

Characteristics	Medical Diagnosis ^a					Missing Diagnosis ^a (n=82)	p-value (excl. missing)
	Concussion/Mild TBI (n=2441)	Moderate-Severe TBI (n=635)	Non-Traumatic Brain Injury (n=335)				
	n (%)	n (%)	n (%)	n (%)	n (%)		
Lesion	0	0	1 (0.3)		0		
Other mechanism of injury	104 (4.3)	26 (4.1)	9 (2.7)		0		
Missing mechanism of injury	4 (0.2)	0	0		82 (100)		
Last Known Program Status							
Active ^g	1490 (61.0)	325 (51.2)	181 (54.0)		57 (69.5)		<0.001
Annual update only	480 (19.7)	113 (17.8)	88 (26.3)		5 (6.1)		
Graduated	287 (11.8)	108 (17.0)	31 (9.3)		7 (8.5)		
Moved	53 (2.2)	44 (6.9)	18 (5.4)		7 (8.5)		
No parent permission	52 (2.1)	22 (3.5)	8 (2.4)		4 (4.9)		
Parent removed	65 (2.7)	9 (1.4)	4 (1.2)		0		
Homeschooled	2 (0.1)	1 (0.2)	0		0		
Dropped out	10 (0.4)	10 (1.6)	2 (0.6)		2 (2.4)		
Deceased	2 (0.1)	3 (0.5)	3 (0.9)		0		
Referral Source							
School personnel & School-based Concussion Management Team	1461 (59.9)	331 (52.1)	205 (61.2)		49 (59.8)		<0.001
Family	468 (19.2)	101 (15.9)	43 (12.8)		9 (11.0)		
Acute care hospital/Physician	280 (11.5)	51 (8.0)	19 (5.7)		6 (7.3)		
Rehabilitation Service Providers & Advocates	123 (5.0)	85 (13.4)	30 (9.0)		5 (6.1)		
Other	76 (3.1)	27 (4.3)	10 (3.0)		0		
Intermediate unit staff	14 (0.6)	33 (5.2)	24 (7.2)		2 (2.4)		
Missing	19 (0.8)	7 (1.1)	4 (1.2)		11 (13.4)		

^a 82 students were missing medical diagnosis, but had other available data.

^b 43 cases are missing age at injury, Range 0–19 years

^c 44 cases are missing age at referral, Range 0–21 years

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p Abuse/Assaults includes abusive head trauma.

e Hit with object/person includes hitting head on objects, head-butting by another person, and collisions with animals, where intent to cause harm (i.e. assault) was not specified.

f Infection includes both bacterial and viral exposures.

g Active program status indicates that students were currently receiving program services at the time of data export.

Table 3

Summary of Educational Placement by Medical Diagnosis

Educational Placement	Concussion/Mild TBI n=2441	Moderate-Severe TBI n=635	Non-Traumatic Brain Injury n=335	Missing Diagnosis n=82	Total N=3493
Placement at Time of Injury					
Regular Education	2224 (91.1)	505 (79.5)	258 (77.0)	75 (91.5)	3062 (87.7)
Special Education	216 (8.9)	130 (20.5)	76 (22.7)	7 (8.5)	429 (12.3)
Placement at Time of Referral					
Special Education	224 (9.2)	206 (32.4)	165 (49.3)	16 (19.5)	611 (17.5)
Regular Education	568 (23.3)	104 (16.4)	40 (11.9)	22 (26.8)	734 (21.0)
Regular Education (with accommodations)	950 (38.9)	72 (11.3)	40 (11.9)	20 (24.4)	1082 (31.0)
Regular Education with formal 504/Chapter 15 Service Agreement in place	90 (3.7)	18 (2.8)	11 (3.3)	3 (3.7)	122 (3.5)
Homebound	244 (10.0)	85 (13.4)	33 (9.9)	0	362 (10.4)
Other	50 (2.1)	42 (6.6)	15 (4.5)	3 (3.7)	110 (3.1)
Out of district placement	5 (0.2)	10 (1.6)	2 (0.6)	1 (1.2)	18 (0.5)
Preparing for re-entry back to school	30 (1.2)	27 (4.3)	9 (2.7)	2 (2.4)	68 (1.9)
Missing Placement	280 (11.5)	71 (11.2)	20 (6.0)	15 (18.3)	386 (11.1)