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Article

UNDER IDENTIFICATION OF STUDENTS WITH LONG TERM DISABILITY FROM MODERATE TO SEVERE TBI: ANALYSIS OF CAUSES AND POTENTIAL REMEDIES

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Abstract: Traumatic brain injury (TBI) has historically been considered a low-incidence disability in public education, and yet estimates indicate that nearly 145,000 children in the United States aged 0–19 are currently living with long-lasting, significant alterations in social, behavioral, physical, and cognitive functioning from a TBI. Comparing this number with the total number of students receiving special education services under the TBI eligibility category found only 26,371 students across all grades. Thus, it appears that a large number of students with significant disability following TBI are not being served under the TBI category, and raises the possibility that many students are not being identified and/or effectively served by educational practitioners in the public-school system. This paper examined the discrepancy between the number of students expected to experience disability using hospitalization data for

moderate-severe TBI and the number of students who receive special education services under the TBI eligibility category.

On average, the number of students actually identified nationally under the Special Education TBI category is only 32% of the students who have moderate-severe TBI across the country. Possible reasons for this discrepancy are explored, including lack of awareness about TBI as a disability, lack of communication between hospital and school, under-reporting of injuries by parents, a narrow definition of TBI that excludes other forms of acquired brain injury, and students with TBI receiving services under alternate disability categories. Recommendations are offered for providing staff training on brain injury, increasing parent awareness of TBI, increasing identification of brain injury in students through screening, and program evaluation of school brain injury protocols.

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Introduction

Although traumatic brain injury (TBI) is considered a low-incidence disability in public education, it is actually a high incidence medical event. National estimates indicate that nearly 145,000 children aged 0–19 are currently living with long-lasting, significant alterations in social, behavioral, physical, and cognitive functioning following a TBI (Zaloshnja, Miller, Langlois, & Selassie, 2008). However, in 2013, the total number of students receiving special education services under the TBI eligibility category was only 26,371 (U.S. Department of Education, 2013), raising concerns that a large number of students with significant disability following TBI are not being served under the TBI category. This discrepancy is worrisome given the extent of learning and behavioral challenges many students with moderate to severe TBI experience. This raises the possibility that many students are not being identified and/or effectively served by educational practitioners in the public-school system.

Children with TBI who return to school with significantly altered learning abilities present unique challenges for educators. Challenges with memory, executive function, attention, concentration, and processing speed can negatively affect a child's ability to learn and perform in school (Ewing-Cobbs, Prasad, & Kramer, 2006; Prasad, Swank, & Ewing-Cobbs, 2017; Gerrard-Morris, Taylor, Yeates, 2010; Hawley, 2004; Moser, Schatz, & Jordan, 2005). Behavioral challenges, impulsivity, and emotional issues are also common after TBI (Barlow et al., 2010; Li, & Liu, 2013; Limond, Dorris, & McMillan, 2009; Ryan et al., 2016) and can negatively affect school performance, perhaps as long as ten years post-injury (Beauchamp et al., 2011). Following TBI, children experience persistent lower life satisfaction, reduced adaptive

functioning, and lower rates of participation in a variety of activities compared with children who have orthopedic injuries, and those differences can persist throughout their formal schooling (Rivara, Koepsell, & Wang, 2012a; Rivara, Vavilala, & Durbin, 2012b). Children with moderate to severe brain injury often experience increasingly severe challenges over time that intensifies the need for academic and behavioral interventions (Beauchamp et al., 2011; Gerrard-Morris, Taylor, & Yeates, 2010; Kurowski et al., 2011; Yeates, Armstrong, & Janusz, 2005). In addition, the long-term effects of lasting mild TBI can result in significant academic deficits over time because of the potential impact of brain injury on students' acquisition of new learning (Prasad et al., 2017). Most children who are hospitalized for TBI are sent directly home from acute medical treatment. Of children hospitalized for TBI, 3.7% receive inpatient rehabilitation (Greene, Kernic, Vavilala, & Rivara, 2014). Students who experience TBI may return to school with physical, cognitive and behavioral deficits that significantly impact their educational performance. Therefore, it is critical for school teams to correctly identify, track, and serve students with TBI.

Why Is It Important to Identify Students with TBI for Special Education Services?

For students with significant deficits following brain injury, identification for special education is an essential first step to accessing appropriate educational services. The Individuals with Disabilities Education Act (IDEA) defines TBI as:

> an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. Traumatic brain injury applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psycho-social behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma. (20 U.S.C. Sec. 1401 [2004], 34 C.F.R. Sec. 300.8[c][12])

Most states require medical documentation of an event that was likely to have caused a TBI in order for students to be found eligible for TBI under IDEA. Assessments must show a difference between the student's pre-injury and post-injury performance and demonstrate a need for specially designed instruction for the student to benefit from the educational environment. Identifying a student as eligible under the TBI category does not guarantee the provision of specially designed instruction and related services. However, school teams often do not receive the information and training needed to understand the nature of the injury and to help tailor educational services to the student's specific needs (Todis, Glang, & Fabry, 1997). This lack of understanding can result in students receiving fewer or inappropriate services that might not meet their individual needs (Todis & Glang, 2008).

The primary purpose of this paper is to examine the discrepancy between the number of students expected to experience disability following hospitalization for moderate-severe TBI and the number of students who receive special education services under the TBI eligibility category, and to explore potential explanations for this discrepancy. Moderate to severe TBI is defined as a brain injury with either normal or abnormal structural imaging, with a loss of consciousness greater than 30 minutes, post traumatic amnesia greater than one day, and a Glasgow Coma Scale score of 12 or less out of 15 (Abashian & Reyst, 2016). Based on analysis of data for the most current year (i.e., 2013) when both TBI hospitalization data and TBI special education classification data were available, we anticipated that there would be a significant discrepancy between those students receiving services under the TBI classification versus those students with moderate to severe brain injury. Other student populations, such as those with emotional/behavioral disorders, where service gaps are expected between the need for specialized educational services and actual service delivery, have been studied using similar methods (Forness, Freeman, Paparella, Kauffman, & Walker, 2012).

Methods

To conduct an analysis of the number of students with disability following TBI with those receiving special education, we compared three sets of data from 2013, the most recent available year when state and federal sources for these specific statistics aligned. We accessed state-reported statistics on the number of students identified for special education under the TBI category in 2013 and obtained each state's population statistics for that year from US Census data for age groups from 5–24. By comparing the census figures with the Centers for Disease Control (CDC) estimates of national TBI hospitalizations, we derived an estimated hospitalization incidence for moderate to severe brain injury for each state. To be conservative in constructing estimates of the number of students likely to be eligible for special education services under the TBI category, we included only those students with moderate to severe TBI who would likely have a disability substantial enough to require special education services and therefore expected to be eligible under the classification of TBI under IDEA. To do this, we utilized the definition of mild TBI and moderate-severe TBI criteria from the National Center for Injury Prevention and Control (2003). The only state that has studied their hospitalization data using these criteria is Ohio, so we applied these criteria to actual 2014 TBI hospitalization data in Ohio to calculate a rate of hospitalization for moderate-severe TBI by age group (Ohio Brain Injury Program, 2018). These data indicated that for the age group 5-14, 40.9 percent of TBI hospitalizations met the criteria of moderate to severe, and for the age group 15-19, 34.5 percent of TBI hospitalizations met the criteria of moderate to severe.

To get from incidence to prevalence, we multiplied the incidence data times a weighted average of the number of school cohorts from kindergarten through 12th grade and the degree to which any cohort in those 13 years could contribute to prevalence over a 13-year period (see Table 1

below). Thus, the multi-year cohort factor used to determine a prevalence estimate for any given year is 6.5, assuming an average contribution of ages in any given year.

Table 1

Prevalence Calculations for Degree to Which Any Cohort in 13 Years Could Contribute to Prevalence in a Given Year

If a student was this age when injured	Then they could be counted in Spec Ed TBI Count for this # of years if graduating at age 18	Average Contribution to any 1 year of Cohort
5	12.5	0.96
6	11.5	0.88
7	10.5	0.81
8	9.5	0.73
9	8.5	0.65
10	7.5	0.58
11	6.5	0.50
12	5.5	0.42
13	4.5	0.35
14	3.5	0.27
15	2.5	0.19
16	1.5	0.12
17	0.5	0.04
18	0.0	0.00
Average Weighting		**6.50**

We then compared that adjusted number of students living with moderate to severe TBI in the year 2013 in each state with the number of students identified under the TBI category in the year 2013 in each state. These procedures produced an estimate that represents the percentage of students presumed to have moderate to severe TBI who are counted in existing state special education TBI categories.

Results

Only one state, Massachusetts, met or exceeded the expected numbers of students identified for services under a TBI eligibility based on our analysis. Massachusetts had 8,875 students identified under the TBI category, which far exceeds what would be projected using our model. This is because Massachusetts uses a different, more expansive definition for its TBI category that includes students with any type of neurological disability:

> Neurological Impairment - The capacity of the nervous system is limited or impaired with difficulties exhibited in one or more of the following areas: the use of memory, the control and use of cognitive functioning, sensory and motor skills, speech, language,

> organizational skills, information processing, affect, social skills, or basic life functions. The term includes students who have received a traumatic brain injury (Massachusetts Department of Elementary and Special Education, 2018).

In fact, according to a review by the National Association of State Head Injury Administrators (Vaughn, 2014) five additional states by that time had begun including some other types of acquired brain injury into their TBI category (New York, North Carolina, Ohio, Vermont, and Wisconsin). Because these six states had begun including both TBI per the federal definition (external force) and other forms of non-traumatic brain injuries (cancer, hypoxia, drug overdose), these six states were excluded from the rest of the national comparison.

Table 2 illustrates that the majority of the other 44 states significantly under-identify students with moderate to severe TBI who would be expected to meet the criteria for special education under IDEA. The total number of students identified nationally was 14,102. Based on our estimates as noted above, we would expect there to have been 44,597 students identified as TBI. On average, the number of students actually identified nationally in the 44 states under the TBI Special Education category represents only 32% of the students who have moderate-severe TBI across those states. This under-identification of TBI ranged from 19% being accurately identified in Connecticut, to 75% being accurately identified in Wyoming. Overall, we estimate that 30,495 students, or 68% of the students who should meet the IDEA definition for TBI, have not been classified appropriately.

Table 2

TBI Students Undercounted as a Percentage of Projected TBI Prevalence

Actual Number School Identified Prevalence (IDEA, 2013) 44 states[1]	Estimated 44 State Population of Individuals Ages 5-9 (2013)[2]	Estimated 44 State Population of Individuals Ages 10-14 (2013)[2]	Estimated 44 State Population of Individuals Ages 15-19 (2013)[2]	CDC TBI National Hospital-ization Estimates Ages 5-14 = 21.1 per 100,000 (2013)[3]	CDC TBI National Hospital-ization Estimates Ages 15-19 = 64.3 per 100,000 (2013)[3]	Estimated Total Annual 44 State Incidence Students with TBI 2013	Estimated Moderate to Severe TBI Ages 5-14 = 40.9%[4]	Estimated Moderate to Severe TBI Ages 15-19 = 34.5%[4]	Total 1 year Moderate to Severe TBI All Age Students	Estimated State Prevalence Moderate-Severe TBI = Incidence X 6.5 (based on weighting Table 1)	Number of Students with Moderate-Severe TBI NOT counted in State TBI Classifica-tion	Percent Projected Moderate-Severe TBI Population Accurately Classified
14,102	17,231,835	17,229,402	17,523,401	7,271	11,268	18,539	2,974	3,887	6,861	44,597	30,495	32%

Note. [1] U.S. Department of Education (2013); [2] U.S. Census Bureau, American Fact Finder (2013); [3] Taylor, Bell, Breiding, Xu, (2017); [4] Ohio Brain Injury Program (2018).

Figure 1 illustrates a relative comparison of states on under-identification of brain injury. Thirteen states classified only 19% to 30% of students expected to have moderate-severe TBI under the special education category of TBI; eighteen states classified 31% to 40% of those students; nine states classified 41% to 50% of those students, and only four states appropriately classified 51% or more of those students. Even if the expected number of students eligible for the TBI category is over-estimated by our calculations, there remains a significant chance that the

actual number of students being served under the TBI category is much smaller than the number of students who likely need such services.

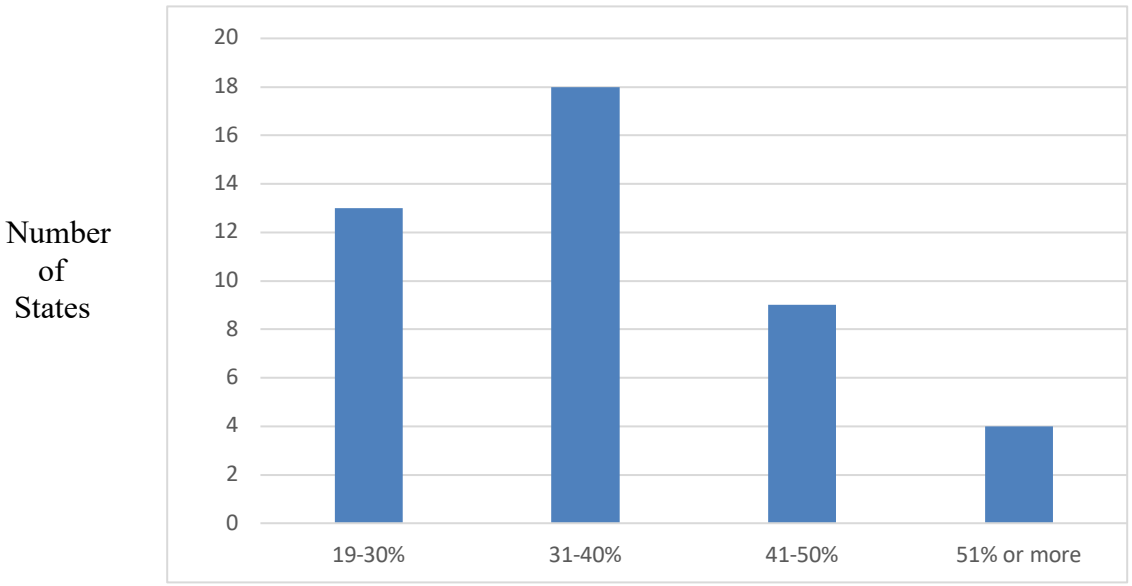

Figure 1. Number of states classifying accurately students expected to have moderate-severe TBI under the TBI special education category.

Discussion

The purpose of this study was to examine the potential discrepancy between the number of students being identified and served under the IDEA eligibility of TBI and the projected number of students with TBI living with disability based on national hospitalization rates and disability estimates. The evidence gathered in this investigation provides the first formal evaluation of the available data to confirm the discrepancy. As expected, our analysis suggests that there are more students with moderate to severe brain injury who are likely to need special education services than who are actually receiving it.

Findings from a recent survey of State Special Education Directors provide some explanation of this striking discrepancy (Glang et al., 2015). Special Education Directors identified the following reasons for the under-identification of students with TBI: (a) lack of awareness about TBI as a disability, (b) lack of communication between hospital and school, (c) under-reporting of injuries by parents, and (d) a narrow definition of TBI that excludes other forms of acquired

brain injury. Perhaps most importantly, sixty percent of State Directors reported students with TBI receiving services under alternate disability categories including Other Health Impaired, Specific Learning Disability, Emotional Disturbance, Intellectual Disability, and Multiple Disabilities. This is a critical point because although students with TBI might be receiving special education services under a different IDEA eligibility (Glang, et al., 2015), they likely are not receiving specially designed instruction that meets the needs of students with TBI.

The discrepancy between the number of students being served under the TBI eligibility category and the projected number of students with TBI living with long-term disability could also be attributed to inadequacies in tracking students with TBI prior to entering the special education system. The likelihood of under-identification is particularly great for children injured at a young age (Report to Congress, 2018). Like older students, these children may be identified for services under a different eligibility category. In addition, because parents and healthcare providers lack knowledge about specialized support services for young children who experience TBI they may not make referrals at the time of injury.

It also is possible that students with moderate to severe TBI end up in other settings, such as private schools or juvenile justice programs, secondary to other factors such as severe behavioral difficulties or legal involvement. Further, Prasad et al. (2017) suggest that students often "grow into their disability," experiencing more challenges as expectations increase as they age. Each of these factors could contribute to the lower numbers of students identified in the eligibility category of TBI for nearly all states.

Implications for Practice and Policy

Provide staff training on brain injury. The first step for proper identification of students with TBI is increasing awareness among school staff about TBI and its effects on children in the school setting (Todis, McCart, M., & Glang, A., 2018). Schools can raise general awareness of TBI through the use of educational posters, email blasts, and other group-based methods of education. However, it is possible that even when teachers are aware of a prior TBI, they may not in later years associate new problems with an old TBI. If teachers receive brain injury training, they would be better able to identify physical changes (tiredness, headaches, lack of focus or interest, sensitivity to light or noise, etc.), cognitive changes (inability to learn new material, memory problems, organizational problems, distractibility, etc.), emotional changes (moodiness, depression, anxiety, etc.), and behavioral changes (frustration, irritability, aggression, inability to deal with normal situations, etc.). Additionally, teachers and other staff should be trained to realize that the effects of a TBI will vary from student to student, and sometimes from day to day for an individual student. Some children are misidentified as infants or toddlers as having a developmental delay, when in fact their challenges resulted from a brain injury. Useful information about TBI is available to educators from a variety of websites (e.g., see www.cbirt.org, www.tbi.cidd.unc.edu, www.brainline.org, www.BrainSTEPS.net,

www.cokidswithbraininjury.com, www.youthbraininjury.obaverse.net, www.neuroskills.com/education-and-resources/ , and http://www.cdc.gov/headsup/ for resources to address TBI in schools).

General awareness training should focus on the potential for undiagnosed/unidentified TBI, and the associated systems and services available to address the educational needs of students with TBI. For example, the Columbus City Schools (CCS) in Ohio developed a TBI Program that includes awareness activities and designated, trained staff to help identify and serve affected children in the district. With this training, paired with a systematic screening process, plus a procedure for notifying the school that an injury has occurred, CCS significantly increased the numbers of students referred for TBI consultation, from 11 students per year at the start of the program, to an average of 166 students per year in years 4 through 7 (Davies, 2016).

For many children, the eventual effects of a TBI can emerge many years after injury or become more significant over time as the child becomes less able to meet the increasingly complex demands of higher grades (Prasad et al., 2017). To be effective, training for educators must include information about the long-term effects of TBI on learning and behavior and the impact of childhood TBI on the family. In addition, effective training includes information and practice with evidence-based interventions, and continued mentoring, feedback, and consultation in the school setting. Program development models that incorporate brain injury consultation in the school setting can help teachers feel more prepared and knowledgeable in working with students with TBI (Glang, A., Todis, Sublette, Brown, & Vaccaro, 2010; Myers et. al 2018).

Professional development and TBI awareness programs for staff, especially regular and special education teachers, should also address the issue of alternative or misclassification of students with TBI. Professional development should include information about how a TBI differs from other educational disabilities, such as a learning disability, which tends to be stable in its effects on learning. With TBI, a child might remember what they learned before the TBI, but have difficulty learning new information after the injury. Because TBI is typically an injury acquired after birth, children often struggle with how their life has changed, leading to emotional issues that interrupt both the educational process and their capacity to develop relationships and navigate their social surroundings. Thus, a brain injury is not just a medical issue; it affects everything going forward about how a student is able to learn, grow, develop, and transition to adult roles. Training about these and other issues that affect students with TBI can help a school properly identify and serve those children.

Increase parent awareness of TBI. Parents of students should be included in any TBI awareness campaign. Both school staff and parents are vital participants in the early identification of students who might be eligible for special education or other accommodations.

Schools can raise parental awareness of TBI through programs similar to those used in staff awareness campaigns by targeting brain injury education materials to parents. Schools can also include brain injury awareness materials in their regular procedures required under IDEA's Child Find requirements. Some children with TBI will not qualify for services under IDEA standards, but they might qualify for services under different federal laws. Any outreach to parents should include information about all applicable laws, and parents should be educated about the requirements for and availability of services via special education (i.e., individual education plans), Section 504 legislation (i.e., 504 plans), student health/accommodation plans, and other methods that include all children with TBI.

Increase identification of brain injury in students through screening. Identification of students with TBI can be improved through the use of screening procedures (Dettmer, Ettel, Glang, & McAvoy, 2014). Typically, children are assessed for eligibility using traditional psychoeducational assessments that can miss key areas of functioning (e.g., specific forms of memory, executive dysfunctions, attention), lessening the chances of linking the sequelae of TBI to educational performance. Use of an effective screening tool followed by appropriate assessment that captures information about the effects of TBI on learning will lessen the likelihood that children with TBI remain unidentified or misidentified in school (Dettmer, et al., 2014; Minnesota DOC Intake Screening Tool, 2015).

Screening for TBI involves asking an informant (usually the parent for younger children; older children can answer for themselves) a series of questions designed to determine whether a child has ever received a blow to the head that might have caused a brain injury. These screening questions should be asked at least annually. Questions such as, "has your child ever been involved in a motor vehicle crash?" or "has your child ever had a concussion, been knocked out, or lost consciousness?" then trigger follow-up questions or assessments to determine whether the child should be evaluated for a TBI. Several screening tools have been developed that schools can use as part of a program to better identify and serve students with TBI. One such tool is the OSU TBI-ID screening tool available at no cost at http://ohiovalley.org/tbi-id-method/ (Corrigan & Bogner, 2009). It is based on the CDC's framework to provide a systematic identification method. Because any screening method contains the potential for errors (i.e., false positives and false negatives), we recommend using a tool that has been validated for this purpose. The Columbus, Ohio City Schools developed their own screening tool that asks questions to determine whether a child might have experienced a TBI (Davies, 2016). If the screen suggests that a child might have experienced a TBI, further assessment is conducted, followed by special education or accommodations for eligible students. Other available screening tools include the Brain Check Survey (see http://www.lobi.chhs.colostate.edu/survey.aspx) (Dettmer, Daunhauer, Detmar-Hanna, & Sample, 2007) and the Brain Injury Screening Questionnaire (Cantor, et al., 2004).

After implementation of a screening process, schools should establish a protocol for connecting children flagged by the screening tool to school and medical/rehabilitation systems that can address the learning problems caused by the TBI. That protocol should consider the types of referral, the referral process, the need for assessments, and all available sources of support. Children who have a TBI can be eligible for a variety of services and supports, including special education, classroom accommodations, behavior support plans, health plans, and return to play (student athletes) supports.

Several challenges in screening children and adolescents for TBI should be noted. Because there is considerable symptom overlap between TBI and other disabilities (eg, executive function–related disabilities, learning disabilities), a screening measure may lack adequate specificity with regard to TBI (Iverson, Langlois, McCrea, & Kelly, 2009, Schwab et al., 2007). In addition, most studies examining efficacy of screening tools have focused on adults. Finally, screening tools cannot be used in isolation but should be integrated with a detailed evaluation of the student's skills to determine whether the TBI has resulted in functional impairment with adverse educational impact.

Program evaluation of brain injury protocols. Evaluation of programs that schools put in place to raise aware of TBI and to train teachers on TBI learning strategies is needed to ensure that protocols used by schools actually benefit students, and that information is collected to assist with refinement of protocols. Schools should ensure that data collection for program evaluation includes baseline information from before the implementation of a TBI program (number of students identified under the TBI category, child-specific educational performance prior to injury, pre-training surveys, etc.) and information from after implementation of the program (number of students identified under the TBI category, re-classification of children to the TBI category from other special education categories, post- training surveys, number of staff trained, etc.). It would also be helpful to know how many students with TBI receive 504 services, how many do well with those learning supports, and how many who start with 504 services go on to need special education services. Understanding the implications of under-identification is essential. Further, strengthening data collection about TBI in other systems, such as the juvenile justice system, mental health/psychiatric system, and drug/alcohol system, and tying those data back to school programming and supports is also essential. Those data should be reviewed annually by school professionals to facilitate the processes by which students are screened, assessed, identified, and served following a TBI.

Limitations

The primary limitations of this analysis involve the sources of data. The large discrepancies suggested between TBI hospitalization data, estimates of long-term disability caused by TBI, and the projected numbers of students who should be served under the TBI category are, in large

part, based on population and disability estimates. TBI hospitalization data do not specify length of stay, making it difficult to understand injury severity of students admitted to the hospital; thus, the extrapolation of actual data from Ohio hospitalizations were used to generate projections of injury severity and subsequent extent of disability. While we acknowledge that our numbers are largely estimates, we also would note that the magnitude of the discrepancies between those being served under the TBI special education eligibility and the projected number who should be candidates for such services are very large and warrant further inquiry.

Summary and Conclusion

The discrepancy between expected and actual numbers of students being served under the special education eligibility category of TBI is puzzling at best, and the estimated magnitude of this discrepancy is worrisome. Exploring the underlying reasons for this apparently large discrepancy in the number of students who are being served via the TBI special education eligibility will likely afford an increase in the number of students who are identified following a TBI, and will contribute to systematic improvements in how the educational needs of these students and their families are met.

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