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Perspectives on Care Coordination for Youth with TBI: Moving Forward to Provide Better Care

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Abstract

BACKGROUND: Care coordination aligns services and optimizes outcomes for children with traumatic brain injury (TBI), yet numerous obstacles can impede effective care coordination following a TBI.

OBJECTIVE: The goal of this work is to identify barriers and facilitators to care coordination from the perspective of individuals who care for young people impacted by TBI.

METHODS: Twenty-one care providers participated in semi-structured interviews to gather their perspectives on systems of care coordination for youth with TBI and potential areas for improvement. Using reflexive thematic analysis, researchers identified key themes across interviews.

RESULTS: Three themes were identified: 1) gaps in knowledge; 2) poor collaboration and communication between systems and care providers; and 3) inadequate legislative and policy frameworks that fund and support pediatric TBI. Across themes, participants shared their experiences and ideas to improve each of these areas.

CONCLUSIONS: A structured, consistent, and coordinated system of care for pediatric TBI is critical to ensure optimal outcomes. Protocols that emphasize intentional and productive collaboration between healthcare settings and schools and education for all care providers are cornerstones in improving outcomes for children. Top-down action that develops policy and funding initiatives is needed to ensure equitable, consistent access to appropriate healthcare and educational supports.

Pediatric traumatic brain injury (TBI) is best described as a chronic health concern with post-injury challenges that may require support long after the injury occurred (Babikian et al., 2015; Prasad et al., 2017). Persistent deficits in functional, adaptive, educational and behavioral domains have been identified up to 10 years post-injury (Catroppa et al., 2012) and difficulties are particularly salient during times of developmental transition (Anderson, 2003). Children with TBIs who need ongoing support typically access care through multiple systems (e.g., school, medical, rehabilitative/ancillary care). Yet, these systems are not well-connected, and professionals may not effectively collaborate or communicate to support the needs of the child (Haarbauer-Krupa et al., 2017; Hartman et al., 2015). Families are frequently left to navigate systems of care with little support or direction, often to the detriment of their child's health, education, and quality of life.

Transitions from medical settings to home and school present unique challenges for children with TBI due to varying profiles of strengths and needs, latent symptom development, poorly organized support between medical and educational systems, and poor understanding of short- and long-term learning and functional impacts of TBI (Babikian et al., 2015; Haarbauer-Krupa et al., 2017). Transitional supports are not reliably provided to students with TBI, and when they are, services are minimal, short-term, and focused on medical rather than educational intervention. Information sharing is typically handled by parents rather than medical personnel, and because school personnel are often unaware of the TBI, they often do not connect the injury to observed learning difficulties (Todis et al., 2018). Rousseau et al. (2021) noted that poor information sharing is at the root of problematic transitions from hospital-to-home for patients in general. Due to this pattern of poorly supported transitions, researchers have called for studies to

examine the facilitators that optimize transition outcomes for children with TBI (Glang et al., 2018).

With a worldwide incidence rate estimated between 47 and 280 per 100,000 (Dewan et al., 2016), TBI in young people is a substantial public health concern. A system that provides long-term monitoring and coordination of care is needed to meet the needs of this population. Researchers and practitioners endorse care coordination as a strategy to facilitate connection, organization, collaboration, and communication amongst the many systems that serve children. Care coordination has been defined as: “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a care to facilitate the appropriate delivery of health care” (Schultz & McDonald, 2014). Recent scoping reviews examining care coordination for children with special healthcare needs identified specific strategies that offer promising opportunities to improve care coordination for children with TBI (Davies et al., 2022; Palusak et al., 2022; Shook et al., 2022). When thoughtfully designed and skillfully implemented, care coordination markedly improves outcomes for children with special health care needs such as asthma, cancer, autism, or cerebral palsy (Roman et al., 2020). A coordinated and consistent system of care for pediatric TBI would bridge the gap between organizations and may afford children and families the best possible outcomes.

The objective of this study was to identify barriers and facilitators to care coordination from the perspective of individuals who work directly with or care for young people impacted by TBI. The goal of this work is to inform future research and clinical advancements to improve care coordination across systems (medical, educational, home, community) for children and adolescents with TBI.

METHODS

Participants

Medical professionals, allied health providers, and educators with expertise in pediatric TBI, as well as caregivers and individuals with TBI were interviewed. Attendees from the 2019 Galveston Brain Injury Conference (GBIC) were sent email invitations to participate. The 2019 GBIC conference consisted of a small group of invited persons considered clinical and research experts or care providers for youth with TBI. The goal of the conference was to develop an implementation plan to improve the identification, care, and monitoring of youth who experience TBI. Additional participants for this study were recruited via snowball recruiting – wherein GBIC participants were asked to forward information about this study to persons within their professional or personal circles who might be willing to participate. Participants met inclusion criteria if they were adults who had professional or personal experience related to care coordination for young people with TBI, spoke English, and were willing to participate in a virtual interview over Zoom. All participants provided verbal informed consent prior to beginning the interview and its recording. Participants were not compensated for their time. Twenty-one care providers participated in semi-structured interviews for this study. They represented primarily medical/clinical professionals (e.g., speech-language pathologist, occupational/physical therapist, social worker, physician), but also school professionals, parents of young people who sustained a TBI, and one adult TBI survivor who now works in the field of TBI care. The average age of participants was 50.9 years and 85.7% were female. One participant lived outside of the United States, and the remaining participants reside throughout the U.S. See Table 1 for information about participants.

[Insert Table 1 about here]

Procedures

All study activities were approved by necessary Institutional Review Boards prior to initiation of this project. Interview questions were drafted by the first and third authors, and then colleagues in the field of pediatric TBI were asked to provide feedback and edits. Using the final list of open-ended questions, a semi-structured interview was completed, and each participant was asked to share their perceptions of the state of care coordination for children who have experienced a TBI. Interviews were conducted via Zoom and recorded for later transcription. Interviews lasted between 20 and 40 minutes. The interview guide is included as supplementary material, but fitting with the semi-structured interview style, interviewers could ask related, logical follow-up questions as appropriate to request clarification or expansion. Interviews were completed by an undergraduate student majoring in Speech and Hearing Science who worked with the first author in her lab during the summer of 2021. The lead interviewer was trained in interviewing techniques and completed several practice interviews, received feedback, and continued practice until approved by the first and last authors to begin contacting potential participants. The first author, a certified speech-language pathologist and researcher whose work focuses on pediatric TBI, led one interview.

Data Analysis

Transcription was verified by watching the interview and reading through and editing the transcript created by Zoom. Transcripts were uploaded into NVivo 12 for coding. Coders were a second undergraduate student and a doctoral student in Speech and Hearing Science, both working with the first author. The doctoral student is a school psychologist with 20+ years of experience. Data were analyzed using reflexive thematic analysis, a progressive and iterative process that ensures immersion with the data (Braun & Clarke, 2006, 2019). The two coders

completed the first round of coding by reading all transcripts and taking initial notes regarding identified points related to care coordination reported by participants. The second author then re-reviewed all transcripts and codes, adding and modifying codes as part of the iterative process. Along with the first author, a final reorganization of coding occurred later in analysis as the authors discussed, collaborated, and refined their interpretation of the ideas expressed by participants, generating themes related to the topic of care coordination for youth with TBI. In the analysis presented, and consistent with qualitative methodology (Braun & Clarke, 2021), frequency counts are meant to be a general descriptor related to a theme. The terms “majority” and “most” are used when nearly all participants reported a similar idea, “frequently” refers to more than half of the participants, and “some” or “several” to less than half of the interviewees. Exact quotations from participants are indicated with quotation marks, though often edited for comprehension, and noted with an ellipse to remove repetitions, revisions, or to indicate a shortening of a quotation.

RESULTS

Based on these interviews, researchers identified three key themes related to care coordination for young people with TBI: (a) gaps in knowledge about pediatric TBI, (b) poor communication and collaboration between systems and key care providers, and (c) inadequate legislative and policy frameworks that fund and support pediatric TBI. Within these broad themes, participants discussed barriers to effective care coordination and opportunities to implement changes that would improve care coordination for young people with TBI. In addition to quotes and descriptions of participant responses provided in this manuscript, exemplar quotes for each of these themes are included as supplementary materials.

Gaps in knowledge

Participants reported that lack of understanding about the impacts of a TBI pose a barrier to effective treatment and rehabilitation for children. Gaps in knowledge were reported as present in varying degrees across all stakeholder groups: (a) medical and ancillary care providers, (b) parents, and (c) school personnel. Participants noted that gaps in knowledge may result in under-recognition of the incidence of pediatric TBI and potential long-term consequences an injury poses to the developing brain.

Physicians initiate referrals to specialists, plan follow-up care and rehabilitation, and educate parents about their child's medical presentation, anticipated acute and rehabilitative treatment, and potential impact of their child's injury. Participants noted that knowledge about mild TBI is particularly lacking within the primary care setting, where physicians' scope of practice tends to be more general, and for providers in rural settings, who might not have access to specialized care clinics.

Participants also noted a "breakdown" in what parents understand about TBI and how the injury may impact their child. Concerns related to early childhood TBIs were raised by Participant 4, who stated that barriers exist because, "...you know little kids hit their heads ... so bumping their head or falling down [is] often seen as something that is natural..." Some interviewees noted that families may not remember verbal information provided during the time of treatment, and therefore lack specific understanding about the injury, rehabilitation, and short- and long-term outcomes. Parents are seen as important advocates for their children's healthcare and education, and poor understanding of their child's injury can result in ineffective advocacy. These issues are magnified if English is not the family's primary language. Participant 21, a medical provider, shared, "I've mentioned how hard it is to just help families learn soon after an

injury, then you add an interpreter in and you're giving like a quarter of the information that you would be able to give if somebody was English-speaking.”

Many participants stated that educators have a poor understanding and lack of training relating to brain development, the potential short- and long-term impacts of pediatric TBI, latent TBI symptom development, effective intervention strategies, and the importance of long-term monitoring. Participant 6 addressed each of these issues, noting, “teachers do not get training in understanding brain injury and development...so unless a teacher has had experience ...with concussion...it can be a barrier.” Participant 17 noted, “transitory challenges for some, long term challenges for others” and “...no predictable sort of trajectory of recovery” makes intervention planning and monitoring in school difficult. Participants felt that sometimes parents and educators are dismissive of mild TBI/concussion due to poor understanding or misinformation about this condition specifically, which is further complicated by the fact that “not all concussions are diagnosed” (Participant 6). Some participants reported that parents do not report their child’s concussion to the school either due to cultural reasons or so that their student athlete is not required to miss sporting events or practice and potentially, “...impact their future [athletic] possibilities at the collegiate level...” (Participant 12). Gaps in knowledge are present not only with classroom teachers, but also with related school service providers and administrators. Negative top-down messaging presented a significant challenge for Participant 12 when working with a school administrator who “didn’t feel like concussions were a thing.” Participant 5 discussed challenges related to school nurses not having training or expertise in TBI, which can create issues if the school nurse is designated as the professional and asked to collect and relay information to the child’s teaching team. Other participants noted that it can be difficult to obtain necessary services within the school district because pediatric TBI is “not as

common” as other diagnoses such as Autism (Participant 15). Participant 7 shared, “even though brain injury is a leading cause of disability in children, according to the Centers for Disease Control, schools nationwide still are not recognizing it as a leading cause of disability in students.”

Facilitators that build knowledge

Most participants stressed the importance of education and training to address gaps in knowledge and promote effective care coordination. Participants noted education: (a) needs to be directed to all care providers, (b) cover pediatric brain development and how an injury impacts a child’s functioning, learning, and future development, (c) stress the importance of long-term monitoring, and (d) provide evidence-based strategies that support children with TBI. Continued training for medical providers in terms of concussions and functional outcomes of all severities of TBI is important to ensure young people with TBI receive appropriate diagnoses and rehabilitative care. One participant shared that care coordination would certainly improve if medical providers were able to diagnose TBI and educate parents about recovery at that same time. Participant 14 stated that relaying information to parents in a uniform, consistent way across medical specialties, and beginning the process of educating parents as early as possible about pediatric TBI, “while all the resources were within reach” would be helpful. One strategy to get important information to parents is a coordinated “mass public health effort” (Participant 1) such as the CDC’s “Heads-Up” campaign (Centers for Disease Control and Prevention, 2007). To focus on educating school professionals, Participant 7 suggested that teacher training programs start requiring a pediatric TBI training component for the degree. Participant 6 noted that she would prioritize, “routine education and training of all community-based educators, care providers, family, friends, prior to the youth going back into the community.” Relating

specifically to early childhood TBI, Participant 4 noted that additional training for community providers that focuses on child development and crucial developmental milestones is needed, so that it is clear when a referral for further evaluation needs to be made.

Poor collaboration and communication between systems and key care providers

Most participants mentioned uncoordinated, inconsistent, or insufficient communication and collaboration between systems and care providers as problematic to care coordination for youth with TBI. Participant 7 succinctly summarized these ubiquitous issues as a “... lack of systematic communication between individuals and entities serving students after an acquired brain injury...lack of information provided to parents by medical providers, ...once their child has been diagnosed, so that they know what to look for, what to let the school know.”

Communication breakdowns can occur when dealing with multiple care providers: “...one of the barriers is just the number of people who may be optimally involved in a child's care...”

(Participant 2) and at important points of transition: “At each level there's issues. ...Going from the [intensive care unit] to the floor, going from the floor to inpatient rehab...to transition home - that's probably the biggest one; and then transitions into school, transitions...from summer to school, from different elementary to middle school, from middle school to high school (Participant 20).”

Participants discussed that poorly coordinated or ineffective communication between medical providers and educators negatively affects transitions from medical settings to school, support provided at school, and ongoing monitoring of progress/issues. Specific problems included inconsistent notification of the school regarding the injury (particularly common with mild injuries), difficulty connecting with the right person at the school, and information not being shared in a timely manner. Participant 3, a specialist working in a medical setting, stated,

“sometimes ... information that we wanted to provide is not shared in a way that’s either useable or understandable by the school system.” Participant 11 felt this is due to “different languages” spoken between the medical and educational systems: “at times we see medical personnel ... prescribing IEPs but...that’s not how it works...” Participant 5, a school nurse, reported that she has reached out to medical providers and was told, “I can’t talk to you because of HIPPA [privacy laws related to health information],” to which she responds, “...you can, and here’s ways that you can do that” to facilitate communication. She added, “those are things...they should know or understand better so that they can have that conversation” and support the child in the school setting. Participant 19’s perspective about communication challenges was different from others in this sample. She has observed that collaboration barriers originate from educators, whose attitude can be, “we’re the educators, we know what to do, we don’t need medical providers telling us what to do with our students.”

Communication and collaboration within the educational system itself was also described as a challenge. Participant 3 and others noted that moving between grades or schools presents challenges as the new educators “learn that child.” Participant 18 and 19 both observed that a child’s experience can vary between teachers, buildings, or districts; there are some educators, schools, and districts “better” at identifying needs and supporting students, and others that are less equipped to intervene appropriately with students who have a TBI.

Facilitators of improved collaboration and communication between systems and care providers

Educational liaisons or care coordinators were mentioned by most participants as having the potential to improve collaboration and communication between medical and educational systems and care providers. Participant 3 noted that her team found an “Individual Recovery Plan” a helpful communication tool. The plan is given to the family at the end of each medical

visit and includes specific information the school needs regarding return-to-learn and return-to-play recommendations. This plan also identifies a point person at the school who takes responsibility for implementing the plan. Use of telehealth or teleconferencing was identified by several participants as a helpful strategy for coordinating communication between medical providers and educators. Participant 10 explained two strategies her team uses to encourage open communication and collaboration amongst professionals. One strategy is assigning both medical and educational professionals to support teams in the structured return-to-learn and long-term monitoring program she coordinates. The other strategy is use of a set of “Community of Practice tools” which aligns medical and educational practices and is available to all care providers online. Participant 3 and several others stated that a step toward improving communication and collaboration is to develop appropriate, understandable, and executable plans of care for young people with TBI, and to then ensure these plans are shared and implemented within and between home, medical, and school systems. Participants noted that educator-to-educator or administrator-to-educator communication is very important to ensure children with TBI are appropriately supported in school.

Inadequate legislative and policy frameworks that fund and support pediatric TBI

As Participant 4 noted, there is not one committed federal policy that coordinates, funds, and hold systems accountable for the long-term care of children and adolescents with TBI. This participant felt the lack of federal coordination is because pediatric TBI does not receive the same political and legislative attention as other public health issues, and because “resources are in the policy...there is no categorical funding stream to reimburse for care coordination.” As a result, parents are often left searching for a systematic support which is largely nonexistent (Participant 7). Additionally, Participant 4 pointed out that policies that do attempt to address the

needs in this population are often inefficient or ineffective due to gaps in services and duplication in efforts between governmental agencies. Healthcare, insurance, and education are all impacted by policy and legislation, and barriers in each of these areas interact within the larger framework. Participants identified wide ranging systemic legislative and policy issues as barriers to care coordination. These include poor funding for programs/agencies to adequately support children with TBI, complicated insurance processes and decreased coverage for inpatient and outpatient services, poorly constructed long-term care and monitoring, lack of return-to-learn protocols, limited availability of services and qualified service providers, and cultural/linguistic/social determinants of health that impact care for young people with TBI. They also discussed the practical challenges related to appointment scheduling, the number of professionals involved in care, and the family's ability to coordinate their own care.

Access to Healthcare Services

Many participants emphasized the complexities required to navigate medical and rehabilitation systems following TBI. Participant 11 stated, "I think the driver for the [care coordination] barrier tends to be around funding. And as we see a shift in...insurance and rehab, and how that works, there's been less time to do some coordination of care between [the] medical setting back to school. So, funding, time, and then understanding ... the need." Participants discussed that time needed to schedule and attend appointments presents significant challenges for families. Participant 16, a parent, noted that her child "was out of hospital for a long time before we even knew that you could coordinate appointments."

Accessing appropriate care can be challenging for a variety of reasons including physical proximity to specialists, insurance coverage, and cultural/linguistic/social determinants of health. Several participants noted that families who reside in rural areas often have either poor access to

specialists or have difficulty continuing care for their child with a TBI because of the time and travel commitment involved in seeking such care. Participant 6 noted that children from more rural areas face unique issues related to transitioning back into their home and school. “You see [a] big discrepancy. So, in ... large urban settings, we have really excellent teaching hospitals and ... rehabilitation programs and kids get really fantastic care there. For those who are in smaller communities, they're often taken from their community and sent to an urban center for rehabilitation, but then that also makes it more challenging for them to reintegrate back into their home communities from the perspective of...finding good therapy...in rural areas.” Difficulty treating and continuing care with culturally or linguistically diverse populations was noted by several interviewees. Participant 18 noted that caring for a child whose family does not speak English as their first language presents challenges because, “it’s hard enough explaining some of these things to people in English...it’s another thing to do it if either one of us is speaking through an interpreter.” Participant 3 relayed a professional experience of “losing” families to follow-up. “I have a story of a [non-English speaking] father who worked really hard, came back to the follow up appointment but [it was] the wrong day, and the wrong time, in the wrong building.... We found out that he was there, but nobody was able to help facilitate him getting to the right place in a way that was effective...So, I think...that’s another barrier. Making sure we understand ... the low resource, second language, poverty-related issues and how they come into play when we’re thinking about [TBI].”

Participants also discussed how insurance issues often impact rehabilitation and long-term monitoring efforts. Participant 21, an occupational therapist, noted consistent issues with the authorization process and billing codes, which is a first necessary step to ensuring that services and equipment are approved and covered. Participant 18 noted that care may be delayed

because of insurance processing, and Participant 11 spoke of shifts in rehabilitative insurance coverage which equates to “less time...in a...real rehab setting.” Several participants noted that often families experience significant difficulty working with insurance companies to cover acute or rehabilitative medical care and equipment. Participants shared that this seems especially true for families who have Medicaid; families who carry third party/private insurance tend to be better supported than other types of insurance. Participant 16, a parent, noted, “The most difficult thing for us is ... I don't know if equipment and stuff like that would count but ... they always say every [TBI] is different, so a lot of stuff isn't covered... they won't even consider covering it; they don't want to set that precedent.” Parents often have little choice in treatment, as insurance dictates what services and providers are covered, and few have the financial freedom to seek treatment from an out-of-network provider or trial an alternative treatment that is not covered. Participant 16 found what she believed to be the most appropriate care for her daughter and had to pay out of pocket for “other therapy places - things outside the box” because they were not covered by insurance.

Educational Policy and Practices

Educational systems have difficulty supporting the needs of children with TBIs for a variety of reasons. Many problems are rooted in educational policy and funding, which determines resources, services, and supports available within the schools. Participant 6 discussed the lack of resources available to teachers, stating, “I find that teachers are usually very supportive, but...they don't necessarily have the in-class supports.” Participant 18 addressed the strains schools experience when trying to stretch resources to meet the needs of this population: “[the children with TBI] end up...going back into the school system to get their PT and OT... And while [it] makes some sense...that's a huge burden for... a school, which is ... not designed

to do rehab. It's designed to teach..." Several participants discussed concern with the appropriate identification of TBI as a disability. Participant 6 noted that not all countries have a special education disability category specifically for TBI, which is problematic in terms of appropriately identifying the etiology of learning issues and accessing needed supports. Participants identified problems related to lack of screening protocols for children who experienced a TBI in early childhood as well as identification of mild TBIs in school systems. Participant 6 noted that a lack of diagnosis means services cannot be accessed, "...the moderate-severe kids obviously have had a diagnosis...or at the very least they've been in outpatient rehab...but for the mild kids, ... we know that not all concussions are recognized... [or] diagnosed unless the kids go to the ER." Other issues are rooted in educational practice. Participant 20 noted that students with TBI often require greater levels of support initially, and less support as time goes on. Thus, it can be difficult for schools to adapt quickly to the changing needs of students. Often children with mild TBI, who may only need short-term accommodations, are left struggling in the classroom without supports.

Strengthening legislative and policy frameworks to support pediatric TBI

Participant 4 addressed care coordination, funding, and policy issues extensively in her interview, making several recommendations for improvements. To fund care coordination from the top down, she suggested care providers and policymakers work together to identify TBI as a category of eligibility under Title 5 of the Maternal and Child Health Services program, and then mandate care coordination under that article. Further, she suggested the "Medicaid reimbursement rate should be the same as private insurance." Participant 4 also emphasized the importance of creating federal policies to support children who experience a TBI. She discussed "coordinated" efforts between federal agencies such as the Center for Medicare and Medicaid,

U.S. Department of Education, Office of Head Start, Children's Bureau (an office of the Administration for Children and Families), and the Centers for Disease Control and Prevention to align focus and identify gaps and duplications across agencies. She noted that legislative action will result in resources filtering down to state and local levels, allowing TBI professionals and advocates to map out appropriate community-level supports. Participant 11 supported a review of existing care coordination models available to other children with special healthcare needs to determine how effective models of care could be applied to pediatric TBI.

Educational policy dictates the specifics of how a school district responds to and supports a child who has experienced a TBI. Participant 10 and colleagues developed a "tip sheet" which she described as, "best practices that can be implemented under the existing IDEA law that can help students with [TBI, because] oftentimes schools don't know about these things that they could do that are totally within the law. You know, things like...having more frequent re-evaluations or more frequent modifications to an IEP that might be necessary for the student with TBI, especially in the early stages of recovery." This document is being disseminated through The National Collaborative on Children's Brain Injury and provided to school professionals with the hope of informing best practice relating to pediatric TBI. Participant 6 stated, "early brain injury is in fact a neurodevelopmental disability and it needs to be approached as such." He recommended a re-evaluation and access to intervention "at every developmental transition point across the lifespan."

DISCUSSION

This study identified barriers and facilitators to appropriate care coordination from the perspective of care providers who have experience working or living with young people with TBI. Analysis of semi-structured interviews with twenty-one individuals who work with and care

for young people impacted by TBI generated three primary themes: (a) gaps in knowledge about pediatric TBI, (b) poor communication and collaboration between systems and key care providers, and (c) inadequate legislative and policy frameworks that fund and support pediatric TBI. Participants offered several practical recommendations to address these barriers to care coordination, providing directions for future research and improvements to clinical care.

While medical, academic, and public knowledge about pediatric TBI has increased markedly in the last 20 years, persistent gaps in knowledge limit care coordination and long-term outcomes. Health care providers and educators must have an understanding of TBI if they are to provide effective services. Improving the knowledge of pediatricians and urgent care physicians is essential because these are typical medical entry point for cases of mild pediatric TBI (Arbogast et al., 2016). Online resources (e.g., the Centers for Disease Control and Prevention's Heads Up training: <https://www.cdc.gov/headsup/index.html>) or easily shareable reference cards may be practical and efficient solutions to educate physicians and help them to support families who have children with TBI (Daugherty et al., 2021; Silverberg et al., 2020). Similarly, addressing gaps in knowledge for educators is essential to provide an optimal continuum of care for youth with TBI (Hartman et al., 2015; Liptzin et al., 2016). In line with past research, many participants noted that educators do not have knowledge about brain development, how a TBI impacts the growing brain, short- and long-term impacts of a TBI on learning and functioning, and how to intervene with a child who has had a TBI. Davies et al., (2013) found that there is little TBI-specific education in teacher training programs nationwide. A structured professional development program for educators that includes evidence-based interventions, supportive feedback during an implementation period, and ongoing consultation may offer the best approach to provide tools educators need to develop an intervention plan (Glang et al., 2010).

There are several examples of structured TBI support programs nationwide that could be used as models to deliver professional development and expert consultative support to educators (Glang et al., 2010; Glang et al., 2018; Myers et al., 2018).

Parent education is important in optimizing a child's recovery and outcomes (Adams, 2010) and parents report positive experiences when they are included as key partners (Rowlandson & Smith, 2009). The better parents understand their child's TBI, the more effective advocates they are in medical and educational arenas. Unfortunately, parental knowledge is often lacking. Participants in our study noted that stressed parents sometimes do not retain important information imparted during medical treatment. Suggestions for "optimal parent education" are included in the CDC guidelines for the management of mild TBI (Lumba-Brown et al., 2018) and the CDC's TBI and Heads Up webpages mentioned above. Future research should assess whether comprehension and retention improves with use of evidence-based teaching strategies, like supplementing verbal information with written notes and using the "teach-back" method (Slater et al., 2017), a practice of asking parents to summarize information in their own words so that care providers can ensure understanding and identify misunderstandings. Research also identifies the importance of providing written instructions in the family's native or preferred language, using interpreters to communicate with patients and families when necessary, and providing written directions at appropriate reading levels (Jimenez et al., 2020; Samuels-Kalow et al., 2012). These recommendations relate directly to concerns raised by participants in our study who discussed social and cultural barriers some families experience and how these determinants perpetuate gaps in knowledge.

In addition to gaps in knowledge, participants reported that poor communication and collaboration within and across organizations hinders effective care coordination for children

with TBI. Several participants spoke of communication “hiccups” within the healthcare system, noting that improved communication within the system overall, especially targeting the coordination between medical disciplines and providers, would result in focused treatment efforts and offer more streamlined medical care (Vermeir et al., 2015). Similar communication difficulties exist within the educational system. Improving communication at every level from central office administrators to building level specialists and teachers would help to ensure children with TBI receive appropriate supports so they do not “fall between the cracks.” Because transitions can be challenging for students with TBI, a system that tracks and monitors students as they transition between grades and buildings is important for continuity in educator-to-educator communication and intervention.

Communication and collaboration between systems presents challenges as well, as each has its own processes, protocols and standards. One participant aptly characterized this barrier between healthcare and educational systems as “speaking different languages.” It can be difficult to translate medical recommendations into educational supports, especially when collaboration and communication is lacking. Health care providers, who are often unaware of legal requirements for special education services and of the resources schools can offer, sometimes make recommendations that are beyond the scope of educational practice (Haarbauer-Krupa et al., 2017). The hierarchy in schools and variability of roles make it difficult for those outside the system to know who to contact and what information to share. There is also great inconsistency in processes between districts and school buildings. The literature on medical-to-school transition identifies consistent and specific communication between hospital and school as critical (Davies et al., 2022; Todis et al., 2018) in supporting students with TBI. Hartman et al. (2015) noted that it is helpful for healthcare providers to generate written documents for schools

that are clear, free of jargon, and describe diagnosis, prognosis, expected recovery and recommendations. Participants in this study noted that identifying a key point person or care coordinator would help to streamline communication and maintain open lines of communication between care providers. This strategy is consistent with recent scoping reviews examining successful strategies for children with special healthcare needs (Davies et al., 2022; Palusak et al., 2022).

A third theme identified in these interviews was inadequate legislative and policy frameworks that fund and support pediatric TBI. Participants observed lack of top-down political efforts and legislative support, which result in poorly funded or absent initiatives specific to pediatric TBI. Barriers were identified in terms of both healthcare access and educational policy and practices.

Healthcare systems vary internationally, and while many industrialized countries provide universal healthcare, this is not the case in the United States. Though improvements have been made in the last two decades in the U.S., continued socioeconomic, ethnic, and cultural inequalities in both healthcare access and quality (Agency for Healthcare Research and Quality, 2021). Consistent with findings that appropriate treatment facilitates recovery, and inadequate or delayed access to rehabilitative care negatively impacts functional outcomes (Downing et al., 2021; Eliacin et al., 2018), participants in this study endorsed the critical need for a system of timely, appropriate, accessible, and affordable care for all youth who experience a TBI. Consistent with recent recommendations (e.g., Shook et al., 2022), telementoring, telehealth, and other types of videoconferences may offer providers and families flexible access to specialized care and expert guidance to support care coordination. To improve insurance coverage, research needs to identify effective treatment protocols and interventions for pediatric TBI. Additionally,

researchers and clinicians must consider social determinants of health that may leave certain families more vulnerable to gaps in healthcare access such as language barriers, financial/insurance barriers, or education barriers. These challenges may result in families being unable or unprepared to advocate for necessary services and supports for their child.

As highlighted by participants in these interviews, clinicians, educators, and policy makers must address educational policies that may be barriers for students with TBI in terms of accessing supports or accommodations during recovery and in the long-term. Funding for education has changed over the decades in attempts to provide more equitable resources, quality of education, and opportunities, yet educational inequalities continue to widen due to resource and opportunity challenges amongst groups (Horsford et al., 2019). Participants in this study spoke about funding limitations which impact resources allocated to support students with TBI, and they proposed policy-related, top-down solutions to address these limitations. Additionally, the under identification of children with TBI in schools is problematic, resulting in significant unmet academic needs, social and emotional issues, and functional limitations (Davies, 2016; Dettmer et al., 2007; Haarbauer-Krupa et al., 2017). Improving the systematic screening and identification processes for TBI in schools is necessary to ensure that student needs are identified and that needed accommodations and/or interventions designed to address learning, social-emotional, and functional deficits are implemented. Dettmer et al. (2007) suggested use of a formalized screening tool to facilitate educational identification of students in schools who need immediate support and/or who do not yet have formal diagnoses. Other researchers have recommended inclusion of TBI target questions on background questionnaires when conducting evaluations (e.g., kindergarten screenings) to identify a past history of TBI (Davies, 2016; Lundine et al., 2019). Another strategy to address current policy-related barriers in the

educational system is establishment of Return to Learn (RTL) procedures for students with TBI. Critical components of a successful RTL protocol include: (a) interdisciplinary teams, (b) systematic communication between medical staff, educational systems and families, (c) an individualized plan for the student, (d) accommodations, extra learning supports, and a schedule tailored to the student, (e) short-and long-term progress monitoring at home and in school, and (f) modifications to support and services based on the student's changing needs (Anderson et al., 2021; Kemp & O'Brien, 2022; Kingery et al., 2017; McCart et al., 2020). Participants in this study stressed that these components should be mandated and funded, meaning that federal and state departments of education need to modify educational policy relating to TBI. Reducing policy-related barriers in the educational setting should improve both the identification of students with TBI and the ability to serve their needs appropriately and effectively.

Limitations and Conclusions

There are limitations to this study that should be considered as this work moves forward. Initial recruitment for this study involved a small group of professionals with experience in pediatric TBI. Though snowball recruitment extended invitations to participate, it is possible that individuals with certain types of experiences (i.e., negative care coordination experiences) may be more likely to participate. However, in the full review of all transcripts, it is necessary to note that participants spoke about proactive opportunities to improve care coordination and offered both their experiences and ideas to improve care coordination. Though participants in this study represented various regions within the United States, only one participant spoke of experiences outside the U.S. Future research should consider how care coordination differs across countries, so that successful strategies might be trialed and adopted based on international experiences. Additionally, themes identified in this study are based on the experiences of those who

participated in interviews, and while these ideas are consistent with known challenges identified in the existing literature, there are surely other opportunities not identified in this work.

Documenting the insights and experiences of care providers – professionals and family members – who have worked or lived with a young person with TBI will increase the understanding of factors that pose challenges and those that can positively influence coordinated care efforts for children and adolescents with TBI. Key care providers indicate that improving gaps in knowledge, enhancing coordination and communication between systems and care providers, and enacting legislative and policy frameworks to support funding and support for pediatric TBI would improve care coordination for young people with TBI. Consideration of these factors overall may lead to better communication, reduction of unmet needs, and improved service access and long-term outcomes for children with TBI.

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References

- Agency for Healthcare Research and Quality. (2021). *2021 National Healthcare Quality and Disparities Report*. <https://www-ncbi-nlm-nih-gov.proxy.lib.ohio-state.edu/books/NBK578532/>
- Anderson, D., Gau, J. M., Beck, L., Unruh, D., Gioia, G., McCart, M., Davies, S. C., Slocumb, J., Gomez, D., & Glang, A. E. (2021). Management of return to school following brain injury: An evaluation model. *International Journal of Educational Research*, *108*, 101773. <https://doi.org/10.1016/j.ijer.2021.101773>
- Anderson, V. (2003). Outcome and management of traumatic brain injury in childhood: The neuropsychologist's contribution. In B. Wilson (Ed.), *Neuropsychological Rehabilitation* (pp. 217–252). Swets & Zeitlinger Publishers.
- Arbogast, K. B., Curry, A. E., Pfeiffer, M. R., Zonfrillo, M. R., Haarbauer-Krupa, J., Breiding, M. J., Coronado, V. G., & Master, C. L. (2016). Point of health care entry for youth with concussion within a large pediatric care network. *JAMA Pediatrics*, *170*(7), e160294. <https://doi.org/10.1001/jamapediatrics.2016.0294>
- Babikian, T., Merkley, T., Savage, R. C., Giza, C. C., & Levin, H. (2015). Chronic aspects of pediatric traumatic brain injury: Review of the literature. *Journal of Neurotrauma*, *32*(23), 1849–1860. <https://doi.org/10.1089/neu.2015.3971>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>

- Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health, 13*(2), 201–216.
<https://doi.org/10.1080/2159676X.2019.1704846>
- Catroppa, C., Godfrey, C., Rosenfeld, J. V., Hearps, S. S. J. C., & Anderson, V. A. (2012). Functional recovery ten years after pediatric traumatic brain injury: Outcomes and predictors. *Journal of Neurotrauma, 29*(16), 2539–2547.
<https://doi.org/10.1089/neu.2012.2403>
- Davies, S. C. (2016). School-based traumatic brain injury and concussion management program: TBI project. *Psychology in the Schools, 53*(6), 567–582.
<https://doi.org/10.1002/pits.21927>
- Davies, S. C., Lundine, J. P., & Justice, A. (2022). Care coordination for children with special healthcare needs: A scoping review to inform strategies for students with TBI. *Journal of School Health, 92*(3), 270–281. <https://doi.org/10.1111/josh.13132>
- Davies, S., Fox, E., Glang, A., Ettel, D., & Thomas, C. (2013). Traumatic brain injury and teacher training: A gap in educator preparation. *Counselor Education and Human Services Faculty Publications, 25*.
- Dettmer, J. L., Daunhauer, L., Detmar-Hanna, D., & Sample, P. L. (2007). Putting brain injury on the radar: Exploratory reliability and validity analyses of the screening tool for identification of acquired brain injury in school-aged children. *Journal of Head Trauma Rehabilitation, 22*(6), 339–349. <https://doi.org/10.1097/01.HTR.0000300229.13490.c7>

- Dewan, M. C., Mummareddy, N., Wellons, J. C., & Bonfield, C. M. (2016). Epidemiology of global pediatric traumatic brain injury: Qualitative review. *World Neurosurgery*, *91*, 497-509.e1. <https://doi.org/10.1016/j.wneu.2016.03.045>
- Downing, M. G., Hicks, A., Braaf, S., Myles, D., Gabbe, B., Cameron, P., Ameratunga, S., & Ponsford, J. (2021). Factors facilitating recovery following severe traumatic brain injury: A qualitative study. *Neuropsychological Rehabilitation*, *31*(6), 889–913. <https://doi.org/10.1080/09602011.2020.1744453>
- Eliacin, J., Fortney, S., Rattray, N. A., & Kean, J. (2018). Access to health services for moderate to severe TBI in Indiana: Patient and caregiver perspectives. *Brain Injury*, *32*(12), 1510–1517. <https://doi.org/10.1080/02699052.2018.1499964>
- Glang, A., Todis, B., Ettl, D., Wade, S. L., & Yeates, K. O. (2018). Results from a randomized trial evaluating a hospital–school transition support model for students hospitalized with traumatic brain injury. *Brain Injury*, *32*(5), 608–616. <https://doi.org/10.1080/02699052.2018.1433329>
- Glang, A., Todis, B., Sublette, P., Brown, B. E., & Vaccaro, M. (2010). Professional development in TBI for educators: The importance of context. *Journal of Head Trauma Rehabilitation*, *25*(6), 426–432. <https://doi.org/10.1097/HTR.0b013e3181fb8f45>
- Haarbauer-Krupa, J., Ciccio, A., Dodd, J., Ettl, D., Kurowski, B., Lumba-Brown, A., & Suskauer, S. (2017). Service delivery in the healthcare and educational systems for children following traumatic brain injury: Gaps in care. *Journal of Head Trauma Rehabilitation*, *32*(6), 367–377. <https://doi.org/10.1097/HTR.0000000000000287>
- Hartman, L. R., Tibbles, A., Panaccia, A., & Lindsay, S. (2015). A qualitative synthesis of families' and students' hospital-to-school transition experiences following acquired brain

- injury. *Global Qualitative Nursing Research*, 2, 233339361561430.
<https://doi.org/10.1177/2333393615614307>
- Horsford, S. D., Scott, J. T., & Anderson, G. L. (2019). *The politics of an education policy in an era of inequality. Possibilities for democratic schooling*. Routledge.
- Jimenez, N., Fuentes, M., Frias-Garcia, M., Crawley, D., Moore, M., & Rivara, F. (2020). Transitions to outpatient care after traumatic brain injury for hispanic children. *Hospital Pediatrics*, 10(6), 509–515. <https://doi.org/10.1542/hpeds.2019-0304>
- Kemp, A. M., & O'Brien, K. H. (2022). Critical elements of return to learn for students with concussion: A scoping review. *Journal of Head Trauma Rehabilitation*, 37(2), E113–E128. <https://doi.org/10.1097/HTR.0000000000000695>
- Kingery, K. M., Narad, M. E., Taylor, H. G., Yeates, K. O., Stancin, T., & Wade, S. L. (2017). Do children who sustain traumatic brain injury in early childhood need and receive academic services 7 years after injury? *Journal of Developmental & Behavioral Pediatrics*, 38(9), 728–735. <https://doi.org/10.1097/DBP.0000000000000489>
- Liptzin, D. R., Gleason, M. C., Cicutto, L. C., Cleveland, C. L., Shocks, D. J., White, M. K., Faino, A. V., & Szeffler, S. J. (2016). Developing, implementing, and evaluating a school-centered asthma program: Step-up asthma program. *The Journal of Allergy and Clinical Immunology: In Practice*, 4(5), 972-979.e1. <https://doi.org/10.1016/j.jaip.2016.04.016>
- Lumba-Brown, A., Yeates, K. O., Sarmiento, K., Breiding, M. J., Haegerich, T. M., Gioia, G. A., Turner, M., Benzel, E. C., Suskauer, S. J., Giza, C. C., Joseph, M., Broomand, C., Weissman, B., Gordon, W., Wright, D. W., Moser, R. S., McAvoy, K., Ewing-Cobbs, L., Duhaime, A.-C., ... Timmons, S. D. (2018). Centers for Disease Control and Prevention Guideline on the Diagnosis and Management of Mild Traumatic Brain Injury Among

- Children. *JAMA Pediatrics*, 172(11), e182853.
<https://doi.org/10.1001/jamapediatrics.2018.2853>
- Lundine, J. P., Ciccio, A. H., & Brown, J. (2019). The speech-language pathologists' role in mild traumatic brain injury for early childhood-, preschool-, and elementary school-age children: Viewpoints on guidelines from the Centers for Disease Control and Prevention. *American Journal of Speech-Language Pathology*, 28(3), 1371–1376.
https://doi.org/10.1044/2019_AJSLP-18-0295
- McCart, M., Karns, C., Ramirez, M., Dawson, M., & Glang, A. (2020). Returning to school after a concussion. *Frontiers for Young Minds*, 8, 20. <https://doi.org/10.3389/frym.2020.00020>
- Myers, R. K., Eagan-Brown, B. L., Conway, A. T., Nagele, D. A., Vaccaro, M. J., Kendi, S., & Zonfrillo, M. R. (2018). Examining a statewide educational consulting program for pediatric brain injury. *Clinical Pediatrics*, 57(6), 645–655.
<https://doi.org/10.1177/0009922817732146>
- Prasad, M. R., Swank, P. R., & Ewing-Cobbs, L. (2017). Long-term school outcomes of children and adolescents with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 32(1), E24–E32. <https://doi.org/10.1097/HTR.0000000000000218>
- Roman, S. B., Dworkin, P. H., Dickinson, P., & Rogers, S. C. (2020). Analysis of care coordination needs for families of children with special health care needs. *Journal of Developmental & Behavioral Pediatrics*, 41(1), 58–64.
<https://doi.org/10.1097/DBP.0000000000000734>
- Rousseau, A.-F., Prescott, H. C., Brett, S. J., Weiss, B., Azoulay, E., Creteur, J., Latronico, N., Hough, C. L., Weber-Carstens, S., Vincent, J.-L., & Preiser, J.-C. (2021). Long-term

- outcomes after critical illness: Recent insights. *Critical Care (London, England)*, 25(1), 108. <https://doi.org/10.1186/s13054-021-03535-3>
- Rowlandson, P. H., & Smith, C. (2009). An interagency service delivery model for autistic spectrum disorders and attention deficit hyperactivity disorder. *Child: Care, Health and Development*, 35(5), 681–690. <https://doi.org/10.1111/j.1365-2214.2009.00956.x>
- Samuels-Kalow, M. E., Stack, A. M., & Porter, S. C. (2012). Effective discharge communication in the emergency department. *Annals of Emergency Medicine*, 60(2), 152–159. <https://doi.org/10.1016/j.annemergmed.2011.10.023>
- Schultz, E. M., & McDonald, K. M. (2014). What is care coordination? *International Journal of Care Coordination*, 17(1–2), 5–24. <https://doi.org/10.1177/2053435414540615>
- Silverberg, N. D., Iaccarino, M. A., Panenka, W. J., Iverson, G. L., McCulloch, K. L., Dams-O'Connor, K., Reed, N., McCrea, M., Cogan, A. M., Park Graf, M. J., Kajankova, M., McKinney, G., & Weyer Jamora, C. (2020). Management of concussion and mild traumatic brain injury: A synthesis of practice guidelines. *Archives of Physical Medicine and Rehabilitation*, 101(2), 382–393. <https://doi.org/10.1016/j.apmr.2019.10.179>
- Slater, B. A., Huang, Y., & Dalawari, P. (2017). The impact of teach-back method on retention of key domains of emergency department discharge instructions. *The Journal of Emergency Medicine*, 53(5), e59–e65. <https://doi.org/10.1016/j.jemermed.2017.06.032>
- Todis, B., McCart, M., & Glang, A. (2018). Hospital to school transition following traumatic brain injury: A qualitative longitudinal study. *NeuroRehabilitation*, 42(3), 269–276. <https://doi.org/10.3233/NRE-172383>
- Vermeir, P., Vandijck, D., Degroote, S., Peleman, R., Verhaeghe, R., Mortier, E., Hallaert, G., Van Daele, S., Buylaert, W., & Vogelaers, D. (2015). Communication in healthcare: A

narrative review of the literature and practical recommendations. *International Journal of Clinical Practice*, 69(11), 1257–1267. <https://doi.org/10.1111/ijcp.12686>

Tables

Table 1. Participant demographics and relation to pediatric TBI.

Supplementary Material

1. Coordination of Care for Youth with Traumatic Brain Injuries Interview Template
2. Major themes and additional example quotes

Table 1. Participant demographics and relation to pediatric TBI.

Participant	Gender	Age	State/Country of Residence	Relationship to pediatric TBI	Highest Level of Education	Profession
1	Female	66	Georgia, USA	Clinical; Research	PhD	Health Scientist, Speech-Language Pathologist
2	Female	47	Maryland, USA	Medical professional	MD	Physician
3	Female	54	Maryland, USA	Medical professional	PhD	Neuropsychologist
4	Female	54	Georgia, USA	Community Support	PhD	Senior Director of Program Development
5	Female	56	Illinois, USA	Clinical (schools); concussion care coordination in the school setting	Masters	Registered Nurse/Certified School Nurse

6	Female	58	Ontario, Canada	Clinical; Research; Former director of a community based pediatric TBI program	PhD, and post- doctoral studies	Speech-Language Pathologist, Researcher
7	Female	48	Pennsylvania, USA	Personal (sibling); Clinical; Research	PhD	Head administrator for state-level TBI program
8	Female	57	Maryland, USA	Clinical; Certified Brain Injury Specialist	MPT	Physical Therapist
9	Female	32	Maryland, USA	Clinical	Clinical Doctorate in Physical Therapy	Physical Therapist
10	Male	67	Pennsylvania, USA	Clinical; Research	PsyD	Neuro Rehabilitation Psychologist
11	Female	54	Colorado, USA	Clinical	Bachelor's of Science in Social Work	Social Worker; Director of Strategic Partnerships

12	Female	60	Nebraska, USA	Clinical (schools)	M.Ed., M.S., CCC-SLP, CBIS	Special Education Team Leader, Speech- Language Pathologist, Retired School District Administrator
13	Female	53	Maryland, USA	Personal (self); Clinical	Post-Master's	School Psychologist
14	Female	41	Maryland, USA	Clinical	Bachelor's of Science in Nursing	Nurse Care Manager
15	Female	39	California, USA	Parent/Caregiver	Bachelor's	Caregiver
16	Female	54	Ohio, USA	Parent/Caregiver	High School Diploma	Caregiver; Disabled (legally blind)

17	Female	55	Alabama, USA	Clinical	Master's- Rehabilitation Counseling	Consultant
18	Male	56	California, USA	Clinical; Research	M.D.	Pediatric Neurologist
19	Female	49	Ohio, USA	Clinical	Master's	Speech-Language Pathologist
20	Male	42	Utah, USA	Clinical	M.D.	Physician
21	Female	26	California, USA	Clinical	OTD	Occupational Therapist

Major Themes	Example Quotes (Participant Number Noted)
Gaps in Knowledge	<p>1: I think there's also a breakdown about what parents understand about TBI and if their children experience it, how it impacts their health, and learning, and social participation so parents don't always understand that, um especially for mild TBI doctors don't always explain it and schools don't always know that a child has a TBI</p> <p>1: for conditions like diabetes there's one specialist and endocrinologist for TBI there's multiple specialists emergency room doctors pediatricians neurologists and concussion clinics and they aren't all on the same page (of) about the kind of information they give out to parents at the time of injury and schools um, so I think that that is one of the biggest issues.</p> <p>6: teachers do not get training in understanding brain injury and development, neuro developmental disabilities, i'm sure they don't either in in the US, maybe they do, but certainly they don't here [in Canada]. So unless a teacher has had experience or even personal experience with concussion it's it can be a barrier, I find that teachers are usually very supportive, but they don't have the background they don't have the training and they don't necessarily have the in class supports.</p> <p>18: most of the parents are not medically sophisticated, although we have actually probably a higher demographic in terms of education in patients who actually come to these clinics, then, like the patients, we see in the ED but, in any case (it's a lot of) it's a lot to manage, managing the child at home, while still trying to seek the resources required, and of course the parents may have their own jobs and other things other children</p>

3: support sometimes that information that we wanted to provide is not shared in a way that's either useable or understandable by the school system and (and) sometimes it gets to the administrators of the school system and doesn't fully get down to kind of the classroom teachers and so the suggestions that we recommend are not necessarily implemented.

14: I really would like to focus on that support for the families, the coping and having that time (and and) and even, and I feel like it needs to start rather Inpatient um preparing them for what reality is going to be like when they get home, I feel like we focus so much on the medical side of things we lose track of the coping of the family, and you know you know how well is this going to translate when they get home, you know, or they're going to feel lost, and so you know I feel like we need to prepare them more while they're inpatient.

19: I think educating families and parents, and teachers, that even if kids are not showing the need for some of those supports early in recovery, that there's that really significant chance of growing into symptoms and having increased challenges, related to that early injury, that are important to consider.

6: if resources were not a barrier, I think that I would want to see routine education and training of all Community based educators, care providers, family, friends, prior to the youth going back into the Community.

1: there's not an understanding in kids the TBIs are chronic or can be a chronic health condition.

9: the recovery is a lot longer than most people realize.

<p>Poor Collaboration and Communication</p>	<p>10: there are huge barriers between medical rehabilitation professionals and educators in the ways that we think the ways we conceptualize our interventions and the ways that we try to help each other. So, despite the best intentions of many medical rehabilitation professionals oftentimes our attempts to help miss the mark in educational settings because we don't always understand best how, You know, teachers, can learn what we want to teach them or communicate with them and we don't understand what's possible within those settings and how to actually work within school settings.</p> <p>11: we speak different languages in the medical setting vs school setting. And so, at times we see ((pause)) medical personnel like prescribing IEPs but you, that's not how it works. So the school team makes that determination with medical input and guidance. I think that's all very important but it's kind of like seeing what's (what's) the medical person's role vs the school's role? How can they learn each other's language and coordinate better? I think that there's just some kinda cultural language difference too.</p> <p>11: A lot of kids are not being seen [in a rehab setting], they're being seen in general kinda settings within children's hospitals, and then they don't think they (they don't know) to coordinate with the school and the school maybe isn't even aware the kid had a brain injury so they're not reaching out.</p> <p>18: figuring out a way to get the different medical disciplines to coordinate in clinic, and there are both sort of, medical barriers to that, that the different specialties may not acknowledge each other's expertise, or may even feel like they're in competition with each other</p>
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4: really having pediatric providers is really crucial. We have a lot of kids who are on Medicaid or in rural areas who're seeing a family physician or some type of advanced practice nurse, so a lot of those people really care for the entire lifespan but they don't really have specific training again in pediatrics to be able to support young children.

5: if (if) the emergency room can definitely encourage, strongly encourage, whatever they need to do on how they practice that referral process to refer them back to the school as well as their primary provider that would then heighten that awareness of, hey the school is really important to contact in the midst of all of this.

11: A lot of kids are not being seen there, they're being seen in general kinda settings within children's hospitals, and then they don't think they (they don't know) to coordinate with the school and the school maybe isn't even aware the kid had a brain injury so they're not reaching out. So I think that's a big part of it. And families to me, at that point of time of transition, are just so overwhelmed, that they (they) aren't thinking either about how do we pull the teams together, how do we then, you know, pull medical and school teams.

5: There's a lot that we have to do as practitioners and so, to you know (to) make sure that we understand all of these things that we have to do and (and, and) manage is (is) quite an undertaking. So, I think if we can close the gap on communication, that might probably be the easiest approach. Is if we're all communicating and working together than that (that) information piece will (will, or that information barrier will) decrease.

3: support sometimes that information that we wanted to provide is not shared in a way that's either useable or understandable by the school system and (and) sometimes it gets to the administrators of the school system and doesn't fully get down to kind of the classroom teachers and so the suggestions that we recommend are not

necessarily implemented. 5: There's a lot that we have to do as practitioners and so, to you know (to) make sure that we understand all of these things that we have to do and (and, and) manage is (is) quite an undertaking. So, I think if we can close the gap on communication, that might probably be the easiest approach. Is if we're all communicating and working together than that (that) information piece will (will, or that information barrier will) decrease.

1: there's multiple specialists emergency room doctors pediatricians neurologists and concussion clinics and they aren't all on the same page (of) about the kind of information they give out to parents at the time of injury and schools

2: I think one of the barriers is just the number of people who may be optimally involved in a child's care and trying to facilitate communication among medical providers, back to families in a way that they understand, you know, certainly, then also to the to the school, so the school has a good understanding of medical concerns and our take on needs without overstepping the bounds of the educational system and, and their role in determining a child's needs in that setting.

5: I think the communication between the medical community outside of the school and the (the) very small medical community that does hopefully exist in the school, with a school nurse hopefully, and some athletic trainers especially at the high school level. I think the communication is better between athletic trainers and the medical communication (community), but I think there's still a gap where a (a) primary provider may not think about calling or contacting or getting permission to speak with the school, the key coordinator at the school level.

5: as school nurses will get that response from primary providers, “oh, I can’t talk to you because a HIPPA” and we’ll continually say, “no you can, and here’s ways that you can do that”.

7: the top barriers that we encounter would be ((pause)) lack of systematic communication between individuals and entities serving students after an acquired brain injury, lack of information provided to parents by medical providers and upon, or once their child has been diagnosed, so that they know what to look for, what to let the school know.

2: having more medical, electronic medical records connect with each other has really helped almost more passively with coordination of care because I le-, even if I’m not talking to the other provider, I can see their notes, I can see sort of what they were thinking so that is certainly helpful.

8: another area that's really challenging and isn't talked about very much is possibility of you know administering this care in a setting where English isn't the primary language, you know, because it's hard enough explaining some of these things to people in English when it's my primary language and it's their primary language it's another to do it if either one of us is speaking through an interpreter, and I bet it's a pretty hard job for the interpreter also, so I think that's another one, we don't see it much because we don't have many of those patients at least, knowingly seeking care on our clinic but i'm sure they're out there and they're you know, going through a system that's probably less suited to take care of at least the complicated cases, you know the mild, this straightforward cases probably be getting better, okay, but the complicated ones, which are like the ones we see in our clinic probably just fall through the cracks in these other communities.

19: I think sometimes the barriers are that we're the educators, we know what to do, we don't need medical providers telling us what to do with our students.

10: and because there are huge barriers between medical rehabilitation professionals and educators in the ways that we think the ways we conceptualize our interventions and the ways that we try to help each other. So, despite the best intentions of many medical rehabilitation professionals oftentimes our attempts to help miss the mark in educational settings because we don't always understand best how, You know, teachers, can learn what we want to teach them or communicate with them and we don't understand what's possible within those settings and how to actually work within school settings.

19: a consistent, either point person or at least a program that has a coordinated, consistent, and well thought out kind of, trajectory of care, almost like a plan of care...care map or something like that, where we follow all those kids in a consistent way. For example, we're trying to develop one here at *Hospital's Name*, in terms of consistent reaching out years after injury, at sort of like, danger or, important transition points. So that if a preschooler hasn't been seen in a few years but yet they're transitioning to middle school, we wanna bring those kids back in and check and assess their needs. Transition to high school, any social needs or those kinds of things.

16: I know, sometimes we've really felt like, that we'll be in the room and they'll be talking and they kind of exclude us with stuff and it's like well wait a second were the ones that's with her all the time.

2: having more medical, electronic medical records connect with each other has really helped almost more passively with coordination of care

	<p>10: thoughtfully structuring meetings so that they can include all the relevant parties, you know, using telehealth where necessary, is really important.</p> <p>18: a positive coming out of COVID is that it may be that Telehealth or give us an opportunity to get into some of those underrepresented areas because they're geographically, not very convenient to where we are, but we found, we can do a lot with telehealth and so doing something with telehealth.</p>
<p>Inadequate policy and legislative framework</p>	<p>10: there are best practices that can be implemented under the existing IDEA law that can help students with brain injury and oftentimes schools don't know about these things that they could do that are totally you know within the law. You know, things like. You know, having more frequent you know re-evaluations or more frequent modifications to an IEP that might be necessary for the student with tbi, especially in the early stages of recovery so.</p> <p>1: During my clinical time we were able to keep individuals in rehab longer and set up this process and implement it and follow up as well that has totally changed</p> <p>16: ...A lot of stuff isn't covered... where with stroke, it is because there's a lot of data to back stroke there's a lot of data for cerebral palsy you know for muscular dystrophy and other things and we just find it really hard with the tbi.</p> <p>17: youth need access to good care that they may not be able to get ...neuropsychological assessments and the ability to access a neuropsychologist that's qualified in a state is a huge challenge</p> <p>18 we're lucky we have a multi-disciplinary clinic here but it's not easy to get that together, and I think there are insurance impediments, particularly for mental health providers...there are specialties that we don't have direct access to all the time</p>

18: it's very challenging for the I think the parents to find the time to navigate the system it's not like navigating just a single specialty usually they run into insurance issues, even with good insurance sometimes getting mental health involved is difficult.

18: sometimes there, there are financial disincentives every time you put another specialty into a referral clinic. Somebody has to be primary and everybody else gets less so there's, there's financial structural impediments to doing it.

19: I feel like depending on the primary medical setting that is providing care or medical ((pause)) division that's providing care for patients that, some of our kids have great access to great social work support and others do not. So that can be a burden too on our, (on us) as therapists to help ((pause)) reach out to other people to help with transportation, or resources for community and things like that.

21: there seems to be a misunderstanding of what um what OT'S can do to help and insurance seeing that as beneficial and not experimental so I think that's my biggest like policy barrier is, is focusing on that.

3; some of our families are unable to attend those follow up meetings. Often before Covid because of distance and time requirements, there's insurance there you know, there's ((pause)) and some families just live way too far away to come back to have those kinds of follow-up in our facility.

3: there's equity issues associated with that in a way for more lower resourced families to get services that they otherwise would not be able to (to) get. Especially with even things like parents taking time off work to come to the hospital to come to the medical appointment....one of the main things is kind of the social determinants of health and

health equity. And I think ((pause)) the children who have Medicaid for example may have more needs, and more unmet needs, and I think we need a way to make sure that they get the services, (lower resource families get the services) that they need. And maybe the extra support that they need.

3: Making sure we understand kind of the low resource, second language, poverty related issues and how they come into play when we're thinking about brain injury. Many kids who have brain injuries have brain injury to begin with because perhaps they're living in a place that's less safe, they're not getting the supervision they need because their families are needing to work multiple jobs. So you know it came from a prevention standpoint all the way through management. We need to think about how to improve those resources.

4: Culturally speaking. For many of my clients we work with that are African American. Really, understanding and accepting that their child has challenges and having providers who are culturally responsive or having early intervention providers do not look like the families or not have the same lived experience as the families.

6: rural versus urban settings are also, you see big discrepancy so in urban settings, large urban settings we have really excellent teaching hospitals and teaching hospital rehabilitation programs and kids get really fantastic care there for those who are in smaller communities they're often taken from their community and sent to an urban Center for rehabilitation, but then that also makes it more challenging for them to reintegrate back into their home communities from the perspective of you know, finding good therapy again in in rural areas

2: we have fractured (pause) settings of care because of the inherent nature of educational systems being different of the way medical care is set up.

4: in the birth to 5 arena kids are not in formal public school, so a barrier is to get the health care provider to really work with childcare centers and early intervention programs um sometimes they're not hold in high regard, and so when a child is identified and referred they're not taking it as serious as those referred by the school system.

18: You know our demographics are not representative we're highly skewed toward Caucasian, highly educated, because of where our clinics are, and I think there are even bigger impediments, for you know, Latinos and blacks and you know, people of color to A. access, our services geographically get to where we are and B. pay for the services and then C. understand them

3: from a telehealth perspective, you know I think this year with Covid has helped us to see the incredible value of telehealth. We've had the opportunity to (in our clinic to) see families from other states. With the emergency (state of emergency) and some of the kind of loosening of licensing laws and ability to gain temporary licenses in different states. And I think that's been invaluable when we started this for psychology they were working on trying to get a compact where you would be licensed in one state and provide telehealth services to multiple states and my state of Maryland was very opposed to this. Just last month the compact called side pack was enacted in our state and so I've applied and encouraged all my neuropsychologists to apply which will allow us to provide telehealth services to eighteen states hopefully soon to be twenty-four states. I think the more we can reduce those barriers of telehealth the better. I think there's still barriers related to payment and in some states where we can't do this and certainly there's issues with families having devices and the Wi-Fi they need to participate. But I think that telehealth is an invaluable resource and a way to much more easily insert medical professionals into settings like the home and the school so that

they can more easily provide that communication. And I think we can (whatever we can) do to advocate to reduce those barriers even you know some of that is direct care but some of that is also just allowing providers to be able to provide training to (to) others in the field. And I (and you know I) think (I think) there's equity issues associated with that in a way for more lower resourced families to get services that they otherwise would not be able to (to) get.

Especially with even things like parents taking time off work to come to the hospital to come to the medical appointment. So I think telehealth, is kind of an invaluable resource.

4: And then culturally we're trying to normalize some of these behaviors, like seeking help early, when you suspect a problem - you know that, that it's not, a curse or something you should be embarrassed about so that when people are, are exposed to trauma and they need help and that they have a support system that now accepts treatment and early intervention.

4: I think that we need to look at Title 5, and have TBI as a categorical eligibility, and then, to make sure that care coordination is provided under Title 5. Also Medicaid reimbursement rate should be the same as private insurance. Because a lot of time, care coordination does not occur because there is no categorical funding stream to reimburse for care coordination and no one else really has the money to do it and really to do the work, but when you can pay for that, then you can assign a person or a social worker, or whatever to then to be responsible as the home of care coordination for those children. I would say to make you categorically eligible across Title 5 and then put some money behind it, to pay for an actual care coordinator to do the work

4: in my experience minority children are late-identified and they receive very few supports and services. We really, really need to be intentional about our efforts and to have a culturally responsive system, right, and not to wait so late for children, in particular, black males to receive services because the outcome is so negative. I think we just forget about those children. And they're just out there in the air, you know nobody's taking care of those kids that the system needs to be intentional about being culturally responsive for, for minority children and, in particular, black children and LatinX children because they're not receiving services in a timely manner and that they are receiving comprehensive services that will support them to be successful.

6: I would also suggest that there needs to be more focus on gender specific, sex and gender specific rehabilitation, we know that there are differences in outcomes in males and females, and those who identify as male and female, so the LGBTQA community is is also you know very, very important... And I think issues around social relationships and intimate relationships and sexuality, should also be a really key component of, I think both education and rehabilitation, because we know that kids and particularly young women with disabilities are at substantial risk of exploitation and abuse, we know that kids with brain injuries are at greater risk of ending up in the justice system if they're not supported, we know that if they have the support people with brain injuries can do all kinds of amazing things you know brain injury itself is not a life sentence, but it's having access to the right diagnosis and the right care at the right time and the family support.

18: when you think about kids with more severe injuries. They might go through their acute rehab but then there's not really like an outpatient rehab setting mostly for kids they end up kind of going back into the school system to get their PT and OT

18: a huge burden for you know, a school, which is, you know not designed to do rehab it's designed to teach, and every kid who has a unique learning need creates a strain on, on the school system, you know with limited resources, so I think that's, that's another thing that's a little bit different you know, in the adult side I think there's a lot of outpatient kind of rehab clinics and stuff like that, and on the peds side usually gets dumped back into the hopper of school, which can be great if you're in a great school district, or it can be really crappy if you're in other school districts.

1: families navigate two systems of care, the health care system in the school system for children and there's a breakdown between those two systems. And I think there's also a breakdown about what parents understand about TBI and if their children experience it, how it impacts their health, and learning, and social participation so parents don't always understand that, um especially for mild TBI doctors don't always explain it and schools don't always know that a child has a TBI. And those are all barriers in the communication process as children go back to school and go on with their life after brain injury. A brain injury is an unexpected event parents don't expect that it's going to happen and that's part of it it's different from a developmental diagnosis, or something like asthma um so there's much work to do in that communication process.

14: So, when it comes to discharge, I feel like the barrier is there's not enough time for coping and training,

18: it's a lot to manage, managing the child at home, while still trying to seek the resources required, and of course the parents may have their own jobs and other things other children, so there, it's very challenging for the I think the parents to find the time to navigate the system it's not like navigating just a single specialty usually they run into insurance issues, even with good insurance sometimes getting mental health involved is difficult.

6: I would say a big barrier I think it's getting better but it's still a big barrier is the recognition of the need for long term monitoring literally across all transition points basically across the lifespan that early brain injury is in fact a neuro developmental disability and it needs to be approached as such.

7: Parents are overwhelmed after a child's brain injury. They feel there's often not good supports that can help (help) them coordinate and contact systems of care, if there are systems of care available.

7: Mental health is huge. The mental health piece in care coordination is the biggest lacking piece that I encounter. Trying to find medical providers, or health, (mental health) providers, who understand brain injury, and the cycle of (not cycle) but ((pause)), you have to have an understanding of brain injury in order to help individuals after a brain injury. And it, so, having expertise, mental health providers with expertise, in pediatric brain injury would be huge. It's so hard to find mental health providers who understand brain injury

6 I would advocate for again, keeping in mind that you know we do view brain injury as a, it's a chronic disease according to meets the criteria of a chronic disease, according to the World Health Organization, so that means that it needs to be supported across the lifespan and we need to build in access to support. Often what happens is with kids is

that we front end load all the supports, which is fantastic and we get them back to school, we get them back to the Community, but then you know they transition

11: if we had the funding for it every family would get a resource or care coordinator, resource navigator, care coordinator, someone that they can just call, help them understand, how the school stuff works, help them understand kind of what those community resources are. And that that person not be available (they would be available) as needed kinda lifelong, or into adulthood, because, as we know, they may do fine for a long time. So maybe they need some resources initially and then it's like okay we got this. And then the kid transitions to middle school, no we don't have this anymore or you know, beyond. So I think having that kind of attachment to a (a) care coordinator through all that process would be great.

10 it really does take an organized top-down approach to, to implement these kinds of strategies, I know in many states there's been attempts at it, but they don't always stay ongoing

6: there needs to be a reevaluation and access to intervention available at every developmental transition point across the lifespan

6: And we're all about trying to fix the child and teach the child strategies and that's really important, but I think it's also helpful to modify the environment and to raise awareness about the communication practices and educational practices that can facilitate or act as barriers to success for children with brain injuries.

11: let's look at what infrastructure exists. How do we train up that infrastructure, to be very effective in working with kids with brain injury, and not recreate a separate model, over here that then needs additional funding? It's like, we already have a funding mechanism, we already have these people in place, let's train them.

20: I would also have more intensive outpatient cognitive-based therapies available. Because that's oftentimes the long-term need and insurance is a huge barrier, as well as outpatient therapies in my area are a huge barrier because there's a waitlist that's crazy, and it always is and cog rehab in pediatrics is not as common as it should be.

4: Resources are in the policy. There needs to be at the federal level policies where they are coordinated, right, so we talked with (Center for Medicare and Medicaid Services/CMS) Medicaid to identify what is there, what has been done to provide for children, you talk to the department of education and what is currently in IDEA policies. You want to have Office of Head Start, Children's Bureau, and CDC at the table. All those programs, need to be really aligned. They should identify service gaps and duplications. They will need to coordinate services at the federal level. They should develop federal policies that include best practices and evidence informed. They should talk about what should occur and once they mandate what should occur, resources will start to trickle down at the state and local level so that people can start to address services for people affected by TBI, but until there's a federal mandate to do something nothing meaningful will occur for these families. And then federal policies also start to allocate some funds towards TBI. But if that doesn't happen, it's just at the whim of people who care, who want to do it. I would, I would definitely say to get some policies created at the federal level.

19: If money were no object, I think every child with a brain injury would benefit from a care manger, who is well versed and understands brain injury and would be able to help coordinate all the aspects of care, including psychosocial, academic, medical, and would follow that child and adolescent through the life cycles. Because a lot of families are lost to care a few years out of their injury and aren't really kept within the circle of long-term management. And that's often when more challenges arise as kids get older. So I think having a care manger or (a care manger or) at least programmatically, ((pause)) following those kids long term would be ideal.