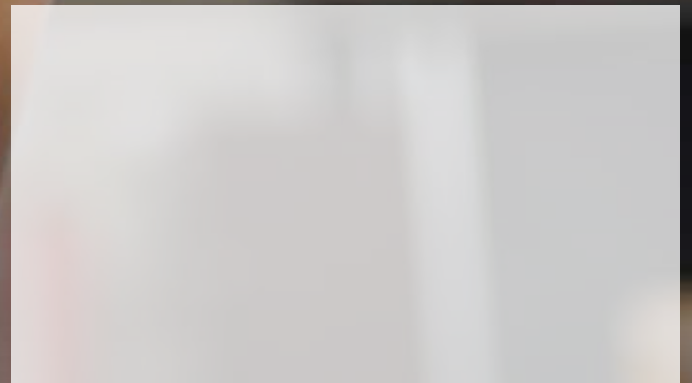


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Beth S. Slomine, PhD, ABPP

Editor Bio

Dr. Beth Slomine is Co-Director of the Center for Brain Injury Recovery and Assistant Vice President of Psychology at Kennedy Krieger Institute. She is Professor of Psychiatry & Behavioral Sciences at Johns Hopkins University School of Medicine and has a secondary appointment in the Department of Physical Medicine & Rehabilitation. She is a licensed psychologist, board certified clinical neuropsychologist, and board certified subspecialist in pediatric neuropsychology. Research interests include neurobehavioral measurement, outcomes, and interventions following pediatric neurological injury. Dr. Slomine has authored >85 peer-reviewed manuscripts, numerous book chapters, and co-edited a textbook entitled *Cognitive Rehabilitation for Pediatric Neurological Conditions*.

from the editor in chief

As Co-Editor-in-Chief, I am delighted to introduce this issue of *Brain Injury Professional* entitled “Innovative Strategies for Brain Injury Education for Patients, Families, and Friends. Providing effective education to patients and families is critical for brain injury professionals from all disciplines. Guest editor, Dr. Christine Koterba, an exceptionally talented board-certified pediatric neuropsychologist, brings together brain injury experts from a range of disciplines who share relevant research and practical clinical advice to enhance our understanding and meaningful implementation of education about brain injury for patients, families, peers, and educators.

The feature article, entitled “Working with Families Following Pediatric Acquired Brain Injury: Conceptual and Practical Considerations in Advancing Research and Practice,” sets the stage for the articles that follow. In this article, Sarah Knight, Taylor Jenkin, and Adam Scheinberg provides an overview of their clinical research program that focuses on their work partnering with clinicians, patients, and families to make meaningful and impactful changes to service delivery with a specific focus on pediatric brain injury.

Other articles expand on specific topics and resources related to patient and family education. Shannon and Beaulieu provide an overview of valuable Model Systems Knowledge Translation Center resources for educating patients with brain injury and their families. The article by Lieb, Monnin, Pagnotta, Krouse, and Talley describe educational programs designed for peers of children with brain injury. McCart and Piccolini DeSalvo provide resources for educating the educators. Botchway-Commey and Koterba take a lifespan development approach to highlight specific facts and recommendations for individuals of all ages with sleep-wake disturbance after traumatic brain injury. The issue also includes an expert interview with Dr. Barbara Wilson, a clinical neuropsychologist who has worked in brain injury rehabilitation for over 45 years. Lastly, our technology editor, Dr. Stephen Trapp, summarizes and evaluates the web-based traumatic brain injury education from the Model Systems Knowledge Translation Center.

Finally, mark your calendars for two exciting conferences.

The 5th Annual Conference on Pediatric Brain Injury, organized by the International Pediatric Brain Injury Society (IPBIS), will be held in Glasgow, Scotland from September 18-21, 2024. The education program will focus on issues related to pediatric brain injury. For more information on this conference and other IPBIS events go to www.ipbis.org.

The 15th World Congress on Brain Injury will be held in Montreal, Canada from March 19-22, 2025. The International Brain Injury Association (IBIA) World Congress is the largest gathering of international professionals working in the field of brain injury. For more information, go to braininjurycongress.org.

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Christine Koterba, PhD, ABPP

from the **guest editor**

As brain injury professionals, we use our clinical expertise to share vital information to those who love and care for our patients with brain injury. Sharing accurate information regarding diagnosis and prognosis can impact outcomes, provide justification for rehabilitation services, and can aid in medical decision making¹. Moreover, most families have no prior knowledge of what a brain injury is, how a brain injury can impact a person's life, or what is expected in the future. We, as brain injury experts, are tasked with an important job to take all we know about brain injury and translate it for families, caregivers, friends, and others. When caregivers understand their loved one's injury, prognosis, and options for treatment, they are able to engage in clinical decision making along with the medical team¹.

While critical, the process of educating families and those caring for people with brain injury is extremely challenging due to a number of factors. Families are often in shock, overwhelmed, confused, and stressed. Most have limited to no knowledge of brain injury or what to expect over the course of recovery. My family and I shared this experience when my younger sister experienced a brain hemorrhage almost 20 years ago. Over the course of a month in the intensive care unit, my family and I were given jargon-heavy information and felt scared, lost, and confused. My sister did not survive her injury and even after almost 2 decades, I often wonder what life would have been like for her had she survived her severe brain injury. When I started my training as a pediatric neuropsychologist, my personal experience drew me to working with children with brain injury and finding ways to help their families navigate a foreign journey. Like others who are drawn to neurological rehabilitation, I have devoted my training and career to learning about brain injury through research and clinical work. In working with families of children with brain injury, I have come to understand that brain injury is a chronic condition that is often associated with persistent impairments impacting individuals and their families over many years^{2,3}. Despite our best efforts, families often leave the hospital struggling to navigate new systems, and often feel lost and unsure of what the future will hold³. As they progress through levels of care from inpatient to outpatient, many caregivers report receiving less support over time, even as the caregiving demands are increasing^{5,6}.


Knowing the value of educating those who love and care for survivors of brain injury, I was excited to guest edit this edition on Innovative Strategies for Brain Injury Education. The authors focus on the importance of educating caregivers, schools and teachers, and peers. They share novel approaches for disseminating education using newly developed tools, as well as free and widely available resources through TBI Model System Translation Center. They focus on important areas of education, such as injury recovery, ways to support the person with brain injury, and specific areas of impact such as sleep and learning. Finally, I was honored to interview Dr. Barbara Wilson, a pioneer in the world of brain injury rehabilitation, to hear about her pearls of wisdom for those of us who support survivors of brain injury and their families. I hope that readers will be as inspired as I was and will find new ways to share their vast knowledge with all of those who support, love, and care for our patients with brain injury.

Editor Bio

Christine H. Koterba, PhD, ABPP, is a Pediatric Neuropsychologist at Nationwide Children's Hospital (NCH) and a Clinical Associate Professor of Pediatrics at The Ohio State University. She is the attending inpatient neuropsychologist at NCH and provides neuropsychological consultation and assessment in inpatient and outpatient settings. She is also involved in the pre- and post-doctoral neuropsychological training programs. Her clinical interests include pediatric neuropsychology, acute recovery from brain injury, illnesses (COVID-19, long COVID), and other conditions that impact neurological functioning, and pediatric rehabilitation.

References

1. Boegle K, Bassi M, Comanducci A, et al. Informal Caregivers of Patients with Disorders of Consciousness: a Qualitative Study of Communication Experiences and Information Needs with Physicians. *Neuroethics*. 2022;15(3):24. doi:10.1007/s12152-022-09503-0
2. Horn, T.C.B.; Lundine, J.P.; Busch, T.A.B.; Benkart, R.A.B.; Taylor, H.G.; Koterba, C.H. Long-Term Outcomes of Pediatric Traumatic Brain Injury Following Inpatient Rehabilitation. *J. Head Trauma Rehabilitation* 2023, <https://doi.org/10.1097/htr.0000000000000886>.
3. Masel, B.E., & DeWitt, D.S. (2010). Traumatic Brain Injury: A Disease Process, Not an Event. *Journal of Neurotrauma*, 27(8), 1529-1540.
4. Manskow US, Arntzen C, Damsgård E, et al. Family members' experience with in-hospital health care after severe traumatic brain injury: a national multicentre study. *BMC Health Serv Res*. 2018;18(1):951. Published 2018 Dec 7. doi:10.1186/s12913-018-3773-7
5. O'Callaghan AM, McAllister L, Wilson L. Experiences of care: perspectives of carers of adults with traumatic brain injury. *Int J Speech Lang Pathol*. 2011;13(3):218-226. doi:10.3109/17549507.2011.549240
6. Karpa J, Chernomas W, Roger K, Heinonen T. Families' Experiences Living with Acquired Brain Injury: "Thinking Family"-A Nursing Pathway for Family-Centered Care. *Nurs Res Pract*. 2020;2020:8866534. Published 2020 Aug 3. doi:10.1155/2020/8866534



Working with Families Following Pediatric Acquired Brain Injury (ABI): Conceptual and Practical Considerations in Advancing Research and Practice

Sarah Knight, PhD • Taylor Jenkin, PhD
Adam Scheinberg, PhD

Acquired brain injury (ABI) is the leading cause of death and acquired disability in children^{1,2}. In the last 20 years, research has debunked prior thinking that sustaining a brain injury early rather than later in life led to better outcomes. It is now understood that early brain injury can lead to profound effects on child functioning, with the full effects of the brain injury often not realized immediately and instead emerging across the course of the child's development³. A large body of research literature tells us that the long-term consequences of paediatric ABI are complex and variable and can include interrelated changes in cognitive, behavioral, psychosocial, physical, and family functioning. Variability in outcomes following paediatric ABI prompted research into predictive factors, leading to our current understanding that a complex interplay of factors such as age at injury, injury severity, pre-injury functioning, and environment account for the nature and extent of disability following ABI⁴. In particular, family plays an important role in accounting for outcomes following paediatric ABI⁵. Until recently, the paediatric ABI literature has mirrored a biomedical model, predominantly describing domain-specific, often decontextualized interventions, such as computerized cognitive training and physiotherapy programs to improve balance or walking⁶. However, an increasing number of studies adopting more family-focused, contextual, and multimodal approaches, have emerged in the paediatric ABI literature^{7,8}.

A paradigm shift is underway in paediatric ABI rehabilitation, underpinned by two recent trends: (1) the ongoing evolution of family-centred service and system views of health and (2) the growing use of knowledge translation and codesign approaches in advancing knowledge and improving service delivery. Here we discuss conceptual and practical considerations on how these broader trends are influencing our work with families following paediatric ABI in both research and practice. These movements hold great promise for better meeting the needs of children with ABI and their families now and into the future.

Our Context

We are clinician researchers from the Victorian Paediatric Rehabilitation Service (vprs.org.au) and the Murdoch Children's Research Institute (mcri.edu.au) in Australia. The VPRS is a statewide service, delivering inpatient and outpatient rehabilitation using an interdisciplinary approach, emphasizing partnerships with children, adolescents, and families. Our clinical research program uses integrated knowledge translation and co-design methodology, and we work in partnership with clinicians and people with lived experience and their families with the aim of making meaningful and impactful changes to service delivery.

We have found qualitative and mixed methods approaches particularly useful in many of our projects⁹⁻¹¹. This approach enables in-depth investigation of the feelings, experiences, and stories of family members, rehabilitation clinicians and others involved in supporting children with ABI. Within our research program, we have found that qualitative research provides opportunities for young people, families, and others to share insights that can be challenging to elicit with quantitative methods. Consequently, our research and knowledge translation initiatives are increasingly guided by areas of importance and relevance to families. The content we share here is shaped by our experiences in authentically working with families in clinical care and as research partners, as well as our non-systematic review of the current literature.

The Lived Experience of Families Following Pediatric ABI

Given the complex and wide-ranging impacts of paediatric ABI on children and their families, it is unsurprising that parents and other family members are often overwhelmed by the “steep learning curve” of understanding ABI and its impacts on their child and family^{9,12}. Oftentimes, families can feel like they lack a “road map” to anticipate the future¹³. When a child has an ABI, their family faces the tough challenge of focusing on both present and emerging needs, as paediatric ABI has both immediate and longer-term impacts that present across a child’s development¹². Families receive information from a range of service providers across the care continuum, sometimes leading to confusion, as illustrated by the following quote from a mother of a young person with ABI who was interviewed for a qualitative research project during their inpatient stay:

“I got really confused... I felt like I was hearing two lots of conflicting things from different health professionals around the recovery of brain injury.”

Unsurprisingly, families report unrecognised and unmet needs for information and emotional support from professionals over time that relates to their child’s stage of development and the ongoing, changing, and emerging impact of their disability¹⁴. The unmet needs of families following ABI are highly concerning, as the bidirectional effects on child and family wellbeing are well-evidenced⁵.

Evolving System Views and Family-Centred Approaches in Paediatric ABI Rehabilitation

Together with our growing recognition of the emotional impact and needs of families following paediatric ABI, we are seeing the adoption of a more pragmatic focus on everyday lives and social contexts in paediatric rehabilitation¹⁵. This contemporary approach involves working in partnership with families¹⁶ and adopting biopsychosocial system views, such as the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) Framework⁷. In the last decade, a more accessible interpretation of the ICF framework known as the “F-words for child development”, has spread globally as an accessible language for rehabilitation clinicians and families to develop a shared understanding of the child in context¹⁷. The ‘f-words’ include: functioning, family, fitness, fun, friends, and future.¹⁸

A family-centred approach recognizes that “(i) parents are the experts on their child’s health, abilities and needs, (ii) every family is unique, and (iii) optimal child functioning occurs within a supportive family and community context”¹⁹.

With the growing evidence supporting the central role that families play in facilitating rehabilitation and recognition of the need to take a developmental, contextual approach²⁰, the role of health professionals has evolved. Their roles has changed from the “expert” who is “fixing” problems in the traditional biomedical sense to the expectation that they “work *with* patients and families, rather than just doing *to* or *for* them”²¹. Health professionals are now expected to act as collaborators, guides, facilitators, active listeners, or coaches. Stemming from these principles, we have moved from traditional biomedical approaches of information provision or one-way information giving, to bidirectional information sharing to support shared decision-making. In keeping with this, Jenkin et al. 2022²² recently highlighted the value of creating space for children with ABI and their families to discuss their needs, values and priorities, as well as the importance of clinicians developing an understanding of the families’ unique contexts.

Universally, the digital era and democratism of health information means that we are moving towards more engaging and complex ways to work with families. As a result, family-centred approaches continue to evolve with new advances in technology, and research is beginning to demonstrate the efficacy of online approaches for working with families following paediatric ABI²³. Within and beyond the family system there are many targets for intervention following ABI, including family communication, parenting styles, family coping strategies, parental distress, family resources, and other social determinants of health, highlighting the importance of rehabilitation models to address the various systems impacting child and family outcomes⁵.

Paediatric rehabilitation services have universally embraced family-centred care as the foundational and gold standard approach to service delivery. However, its implementation varies considerably across Australia and internationally. Service providers describe ongoing challenges to ‘doing it well’, particularly for ‘harder-to-reach families’¹¹. With an increasing body of research evidence available to guide practice²⁴, along with growing expectation that services are evidence-based and accountable, the substantial ‘know-do gap’ has become increasingly realised. Unfortunately, it has become increasingly clear that most of the existing research evidence never makes it into the everyday practice of working with children with ABI and their families.

How are we closing the know-do gap in paediatric ABI rehabilitation?

Knowledge translation (KT) methodologies that partner knowledge users with researchers²⁵ are only just beginning to be used in paediatric ABI research. KT is defined by the Canadian Institute of Health Research (CIHR) as:

“A dynamic and iterative process, that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the specific knowledge users.”²⁶

In the past, the “know-do” gap has been conceptualised as a linear issue with knowledge transfer, where there is sufficient research evidence, but the problem occurs when translating it into practice (a paradigm known as end-of-project KT)²⁷.

More recent approaches to KT also recognise that much of the knowledge created does not address real-world problems and priorities. Therefore, unlike end-of-project KT, integrated KT(iKT) involves active collaboration between researchers and research users (e.g., health professionals, people with

lived experience of ABI, family members) in all parts of the research process²⁷. Partnering with children with ABI and their family members and clinicians through co-design processes challenges the traditional way academics have conducted paediatric ABI research, requiring researchers to work with rather than on those in practice settings. The use of iKT means that knowledge and research are shaped into practical, accessible knowledge products for the people who are going to use them.²⁸

iKT is inherently dynamic and flexible in nature, so there is no 'right' way to do it²⁷. However, "the doing of KT requires a unique skill set including an understanding of the health care context" (p.9)²⁹. Researchers must also have a tolerance for and flexible approach to managing the 'messiness' of balancing the needs of knowledge users with the research priorities, which may change throughout the iterative, dynamic and complex iKT process.²⁹ While iKT represents a more impactful approach with great potential for enhancing rehabilitation services to better support children with ABI and their families, the investment in the costs and resources (e.g., project staffing, training, lived experience consultancy) required is a necessary consideration for researchers.

At the Victorian Paediatric Rehabilitation Service and Royal Children's Hospital, Melbourne, Australia, we are using an iterative, multimodal approach to improving translation of research evidence into clinical care for children with ABI. The first phase involved working with an integrated clinical and lived experience advisory group (CLEAG; made up of young people with lived experience, family members, clinical managers, and members of an interdisciplinary rehabilitation team) to prioritise focus areas where obvious gaps existed between clinical practice at VPRS and evidence-based guidelines²⁴. Using a mixed methods approach, the clinical and lived experience advisory group prioritised key areas on which to focus our iKT 'energies'. Key areas identified included: family wellbeing, engaging families as active partners in collaborative goal setting, and providing ABI education to teachers. The next stage of research involved using a widely used implementation approach, known as the Behaviour Change Wheel³⁰, to identify factors influencing practice change, and co-design targeted interventions that are acceptable, practical and sustainable.

Throughout the ABI Translation initiative, young people with ABI and family members, clinicians, and others who play key roles in supporting children following ABI (e.g., teachers, service managers, community organisations) have been engaged as authentic partners from the beginning. Rather than including end users or 'actors' solely as traditional study participants, we are working with them in various roles.

Holland Bloorview Kids Rehabilitation Hospital adopts a similar approach and has developed a useful framework for guiding family engagement in research: <https://hollandbloorview.ca/sites/default/files/2021-03/RFEC-FrameworkGuide.pdf>.

Table 1. Roles of End Users in ABI Translation Initiative

Role	Description
Lived Experience Advisor	Consultants, advisory committee members
Research Partner	Co-supervisors of PhD students, co-investigators
Lived Experience Educator	Consultants providing lived experience expertise to researchers, clinicians, students and other families

They emphasise the importance of engaging with families as Advisors, Partners and Lived Experience Educators across the full five stages of the research lifecycle from: *Think (Conceptualise), Plan, Do (Conduct), Share (Disseminate) to Use (Implement)*.

In a recent project, our research team partnered with Heads Together for ABI (<https://www.headstogether.org.au/>), a community non-for-profit organisation, and VPRS, on a community-led, impact-focused research project: Project HOPE (Heads Together Online Peer Education). HOPE is a co-designed, online peer education resource where families with lived experience of paediatric ABI share their stories through video, providing information and support to other families who are adjusting to living with paediatric ABI. Heads Together for ABI led HOPE's preliminary development in consultation with families, VPRS clinicians, and researchers. Following the development of the HOPE website, we collaborated with Heads Together to conduct a mixed-methods study exploring HOPE's acceptability and usability from the perspective of end-users. End-users in this project were the rehabilitation clinicians who will introduce HOPE to families, and the families who will use HOPE in the early stages following paediatric ABI. Through in-depth qualitative interviews, we inductively explored clinicians' and parents' experiences using HOPE, including areas of importance to them. This rich qualitative information will guide future optimisation of HOPE, and has provided us with an important understanding of how clinicians and parents think that HOPE should be best implemented in clinical practice.

Kate Heine, director of Heads Together for ABI (a reflected on her experiences partnering with our team in in Project HOPE: *"Partnering with MCRI and VPRS over the past 5 years has been an incredibly rewarding process. Being able to bring the voices of young people and families directly to the clinicians and researchers, and feeling so heard and respected, has been deeply impactful for all the people involved. They feel as though their lived experiences, while traumatic and challenging, are serving a greater purpose in educating and improving the path for all the families to come. I have no doubt that this experience has changed both their sense of self-worth and their concept of what's possible"*.

iKT is gathering global momentum as an innovative way to overcoming the challenges of closing the existing knowledge-to-practice gap in paediatric ABI research. For example, novel co-design approaches are starting to be used in the field of ABI to co-develop new education resources (e.g., for teachers to improve their understanding of ABI³¹) and also to adapt existing evidence-based family-based interventions to other contexts³². Applying a systems approach in this way ensures that children with ABI, families and others in the child's community receive usable and acceptable evidence-based ABI information, education, and support, and scales up the 'reach' of existing evidence-based interventions beyond their local context.

Conclusion

The 21st century has seen important advances in our understanding of the impact of ABI on child and family development, as well as changing perspectives on family-centred approaches, and greater focus on actively reducing the know-do gap through researcher-clinician-family partnerships. Together, these advances dramatically increase the likelihood that our clinical and research practices can be more impactful in meeting the needs of child with ABI and their families. Ensuring best practice care of children with complex conditions such as ABI relies on implementing up-to-date research evidence into everyday practice. Systematic approaches that embrace complexity and actively involve key partners (e.g., patients, families, clinicians, educators) at all key stages, are needed to facilitate this process. Given the huge opportunity for progress in this area, it is an exciting time for clinicians, researchers, and families to be working in partnership to co-design and implement innovative, evidence-informed, system-based approaches to working with children with ABI and their families along the developmental trajectory and continuum of care.

References

1. Araki T, Yokota H, Morita A. Pediatric Traumatic Brain Injury: Characteristic Features, Diagnosis, and Management. *Neurol Med Chir (Tokyo)*. Feb 15 2017;57(2):82-93. doi:10.2176/nmc.ra.2016-0191
2. Dewan MC, Mummareddy N, Wellons JC, 3rd, Bonfield CM. Epidemiology of Global Pediatric Traumatic Brain Injury: Qualitative Review. *World Neurosurg*. Jul 2016;91:497-509.e1. doi:10.1016/j.wneu.2016.03.045
3. Anderson V, Catroppa C, Morse S, Haritou F, Rosenfeld J. Functional plasticity or vulnerability after early brain injury? *Pediatrics*. Dec 2005;116(6):1374-82. doi:10.1542/peds.2004-1728
4. Greenham M, Botchway E, Knight S, et al. Predictors of participation and quality of life following major traumatic injuries in childhood: a systematic review. *Disabil Rehabil*. Jun 2022;44(12):2591-2607. doi:10.1080/09638288.2020.1849425
5. Fischer JT, Bickart KC, Giza C, Babikian T. A review of family environment and neurobehavioral outcomes following pediatric traumatic brain injury: implications of early adverse experiences, family stress, and limbic development. *Biological psychiatry*. 2022;91(5):488-497.
6. Catroppa C, Anderson V. Traumatic brain injury in childhood: Rehabilitation considerations. *Devel Neurorehabil*. 2009/01/01 2009;12(1):53-61. doi:10.1080/17518420802634476
7. Wade SL, Fisher AP, Kaizar EE, Yeates KO, Taylor HG, Zhang N. Recovery trajectories of child and family outcomes following online family problem-solving therapy for children and adolescents after traumatic brain injury. *Journal of the International Neuropsychological Society*. 2019;25(9):941-949.
8. Holthe IL, Rohrer-Baumgartner N, Svendsen EJ, et al. Feasibility and Acceptability of a Complex Telerehabilitation Intervention for Pediatric Acquired Brain Injury: The Child in Context Intervention (CICI). *J Clin Med*. May 3 2022;11(9):doi:10.3390/jcm11092564
9. Jenkin T, D'Cruz K, Anderson V, Scheinberg A, Knight S. Family-centred service in paediatric acquired brain injury rehabilitation: perspectives of children and adolescents and their families. *Disabil Rehabil*. Sep 15 2022;1-12. doi:10.1080/09638288.2022.2121864
10. Collins A, D'Cruz K, Jackman A, et al. Engaging children and adolescents with acquired brain injury and their families in goal setting: The family perspective. *Neuropsychol Rehabil*. Jan 2023;33(1):1-23. doi:10.1080/09602011.2021.1977154
11. Botchway EN, Knight S, Muscara F, et al. Rehabilitation models of care for children and youth living with traumatic brain and/or spinal cord injuries: A focus on family-centred care, psychosocial wellbeing, and transitions. *Neuropsychol Rehabil*. May 2022;32(4):537-559. doi:10.1080/09602011.2020.1833945
12. Gan C, Gargaro J, Brandys C, Gerber G, Boschen K. Family caregivers' support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers. *NeuroRehabilitation*. 2010;27(1):5-18. doi:10.3233/nre-2010-0577
13. Savage RC, DePompei R, Tyler J, Lash M. Paediatric traumatic brain injury: a review of pertinent issues. *Pediatr Rehabil*. Apr-Jun 2005;8(2):92-103. doi:10.1080/13638490400022394
14. Keetley R, Radford K, Manning JC. A scoping review of the needs of children and young people with acquired brain injuries and their families. *Brain Injury*. 2019/07/29 2019;33(9):1117-1128. doi:10.1080/02699052.2019.1637542
15. King G, Imms C, Stewart D, Freeman M, Nguyen T. A transactional framework for pediatric rehabilitation: shifting the focus to situated contexts, transactional processes, and adaptive developmental outcomes. *Disabil Rehabil*. Jul 2018;40(15):1829-1841. doi:10.1080/09638288.2017.1309583
16. King G, Williams L, Hahn Goldberg S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child Care Health Dev*. May 2017;43(3):334-347. doi:10.1111/cch.12435
17. Cross A, Soper AK, Tomas V, et al. Exploring 10 years of dissemination of the F-words for Child Development: A multifaceted case study. *Child Care Health Dev*. Sep 2022;48(5):751-762. doi:10.1111/cch.12983
18. Rosenbaum PL. The F-words for child development: functioning, family, fitness, fun, friends, and future. *Dev Med Child Neurol*. Feb 2022;64(2):141-142. doi:10.1111/dmnc.15021
19. Rosenbaum P, King S, Law M, King G, Evans J. Family-centred service: A conceptual framework and research review. *Family-Centred Assessment and Intervention in Pediatric Rehabilitation*. 2014:1-20.


20. Ylvisaker M, Adelson PD, Braga LW, et al. Rehabilitation and ongoing support after pediatric TBI: twenty years of progress. *J Head Trauma Rehabil*. Jan-Feb 2005;20(1):95-109. doi:10.1097/00001199-200501000-00009
21. Institute for Patient and Family-Centred Care. What is Patient- and Family-Centred Care? . <http://www.ipfcc.org/about/ipfcc.html>
22. Jenkin T, Anderson VA, D'Cruz K, Scheinberg A, Knight S. Family-centred service in paediatric acquired brain injury rehabilitation: Bridging the gaps. *Front Rehabil Sci*. 2022;3:1085967. doi:10.3389/frsc.2022.1085967
23. Wade SL, Narad ME, Shultz EL, et al. Technology-assisted rehabilitation interventions following pediatric brain injury. *J Neurosurg Sci*. Apr 2018;62(2):187-202. doi:10.23736/s0390-5616.17.04277-1
24. Knight S, Takagi M, Fisher E, et al. A Systematic Critical Appraisal of Evidence-Based Clinical Practice Guidelines for the Rehabilitation of Children With Moderate or Severe Acquired Brain Injury. *Arch Phys Med Rehabil*. Apr 2019;100(4):711-723. doi:10.1016/j.apmr.2018.05.031
25. Palmer VJ, Weavell W, Callander R, et al. The Participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Med Humanit*. Sep 2019;45(3):247-257. doi:10.1136/medhum-2017-011398
26. Canadian Institutes of Health Research. About knowledge translation. Accessed 13/8/2023. <http://www.cihr-irsc.gc.ca/e/29418.html>.
27. Bowen S, Graham ID. Integrated knowledge translation. *Knowledge translation in health care*. 2013:14-23.
28. Gagliardi AR, Berta W, Kothari A, Boyko J, Urquhart R. Integrated knowledge translation (IKT) in health care: a scoping review. *Implement Sci*. Mar 17 2016;11:38. doi:10.1186/s13012-016-0399-1
29. Straus SE, Tetroe J, Graham ID. Introduction Knowledge translation: What it is and what it isn't. *Knowledge Translation in Health Care*. 2013:1-13.
30. Michie S, Atkins L, West R. The behaviour change wheel. A guide to designing interventions 1st ed *Great Britain: Silverback Publishing*. 2014;1003:1010.
31. Saly L, Providenza C, Al-Hakeem H, et al. The Teach-ABI Professional Development Module for Educators About Pediatric Acquired Brain Injury: Mixed Method Usability Study. *JMIR Hum Factors*. May 15 2023;10:e43129. doi:10.2196/43129
32. Wade SL, Jones KM, Corti C, et al. Adapting intervention approaches to new contexts: Three case studies of international adaptation of the Teen Online Problem Solving (TOPS) program. *Rehabil Psychol*. Nov 2021;66(4):356-365. doi:10.1037/rep0000414

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Family and Caregiver Brain Injury Education – Leveraging Model Systems Knowledge Translation Center Resources

Tracy Shannon, PsyD
Cynthia Beaulieu, PhD, ABPP

If you work with persons with traumatic brain injury (TBI) long enough, you will undoubtedly come across the following words, “I know you don’t have a crystal ball, but...” When working with persons with moderate to severe TBI and their families, practitioners are commonly asked to provide prognosis regarding potential recovery trajectories and functional outcomes. While this may not seem all that daunting of a task, many seasoned practitioners have identified common pitfalls when answering these questions. For example, practitioners may be perceived as overly harsh when trying to emphasize severity of injury and possible functional limitations or perceived as providing “false hope” when describing potential positive outcomes. If practitioners attempt to avoid the question all together, families then are charged with the responsibility of finding and digesting relevant research while also trying to “put out the fires” associated with having a loved one in the hospital (e.g., maintaining the household, identifying financial implications of the hospital stay, and communicating/ updating employers, family members and friends about the progress and setbacks, etc.).

As neuropsychologists and rehabilitation psychologists, we are often consulted to evaluate and treat persons with TBI. Responsibilities can include: devising behavioral treatment plans to target maladaptive behavior, providing support for families as well as persons adjusting to disability following TBI, completion of capacity evaluations when discrepancies emerge between persons with TBI, their families and/or the treatment team regarding the treatment plan, and assisting with alignment of the treatment team, persons with TBI, and their families when needed. One of the most important roles involves providing information about brain injury, and strategies to support patients throughout their recovery. When discussing information about recovery or strategies to manage sequelae from TBI, practitioners often provide current evidence-based information to answer the practical and common questions such as, “Will he ever be independent?”

Will she be able to go back to work?, Will they drive again?, and How long will recovery take?” In some cases, the way information is provided can be just as, if not more, important as what information is provided.

Earlier in my career, I asked the mother of a patient with TBI what we, as a team, could do to improve our TBI rehabilitation program. She responded with very specific and helpful feedback. Specifically, she commented that the entire experience was very overwhelming. She noted that she often forgot information and facts almost as quickly as she asked the questions. She felt that getting handouts and handbooks was fine, but again, found the information too overwhelming. She said the last thing she wanted to do was spend the night reading when she went home at the end of the day. She then said “it would have been great if someone could have sat down with me and presented the information in an “old school” power point format.” She went on to discuss her personal learning style and that having the information presented in a more “academic way” would have been a better fit for her personally. This was a turning point for me as I realized the need to provide specific and concrete information to families in a way that fits with their learning style. Before this, I primarily provided verbal information, but after getting this valuable feedback, I realized that I needed to change how I provide critical information to better meet the needs of individual caregivers and families.

Fortunately, the Model Systems Knowledge Translation Center (MSKTC) is a free and widely available web-based resource that has answers to frequently asked questions (FAQ) associated with TBI for caregivers, persons with TBI, and practitioners. Information on the MSKTC website summarizes 30 years of longitudinal research from over 15 Model Systems programs targeting TBI, as well as spinal cord injury and burn. Model Systems Centers were established in 1987 and are sponsored by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR).

Model System centers conduct research with persons across the continuum of recovery following TBI. Research findings are then used to develop and refine practical informational resources for persons with TBI and their families at various time points post-injury. MSKTC offers information in a variety of forms such as fact sheets, videos, PowerPoints and links to associated research articles to allow families and persons with TBI to access information in multiple ways. Resources cover topics such as functional outcomes, behavioral and cognitive changes, impact on relationships (e.g., return to intimacy of TBI, parenting after TBI, etc.).

Essentially, using MSKTC resources for families of persons with TBI is completing a necessary loop in which families can learn from those who came before them and whose loved ones have contributed to existing research. That said, the TBI Model Systems data has some important limitations. For example, because of the nature of the sites and patient populations involved, information primarily applies to those ages 16 and higher and does not address other forms of acquired brain injury (e.g., stroke, anoxic injuries, etc.). Additionally, in some cases applying large-scale research findings to specific individuals can be challenging and may not be relevant depending on the nature of an individual's injury and other characteristics. Despite limitations, for rehabilitation practitioners, TBI Model Systems outcome studies can be a valuable tool to teach caregivers and families about their loved one's injury. In our disorders of consciousness (DOC) program, we frequently use MSKTC resources to help caregivers understand a confusing and unclear phase of recovery following severe TBI. We initially start by learning about the person with TBI and their family, as pre-injury characteristics are an important consideration for treatment and education. Next, we provide a basic overview of the injury itself, define common terms, and answer questions about the goals and purpose of inpatient rehabilitation, along with introducing the roles of team members. Throughout their admission, we provide information regarding TBI recovery and ways that caregivers can best support the person with TBI. Areas we address depends on the individual's recovery and presenting concerns, and the questions and areas of interest of the family. In many cases, various MSKTC resources are used to help reinforce important concepts.

Thanks to the feedback I described above, I have modified my role to include an optional educational session (or in some cases more than one session) with family, potential caregivers, and anyone else the family would like to be present. The presentation includes functional outcome data based on scholarly articles that used the TBI Model Systems' national database (Hammond, et al, 2019; Whyte et al, 2013). The session also includes reviewing and operationalizing the different terms that were being discussed daily by different team members (e.g., coma, minimally conscious state,

nonresponsive wakeful state, emergence, CRS, FIMS, PTA). For this discussion, the MSKTC's Facts About the Vegetative and Minimally Conscious State After Severe Brain Injury is particularly helpful as it discusses: differences between levels of consciousness, different levels of care, financial implications of severe injury, need for guardianship, and other relevant topics. (Sheer et. al 2007). Not all families find this style helpful and while families know an optional education session is available, it is not a mandatory aspect of the rehabilitation stay. As repetition and review can be helpful, I am also available to provide education more than once or to additional caregivers. Additional considerations are included in table 1.

References

1. Hammond, Giacino, Richardson, Sherer, Zafonte, Whyte, Arciniegas, & Tang (2019). Disorders of Consciousness due to Traumatic Brain Injury. *Journal of NeuroTrauma* 36: 1136-46. DOI: 10.1089/neu.2018.5954
2. Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury was developed by Sherer M, Vaccaro M, Whyte J, Giacino JT, Childs N, Elfert B, Katz, DI, Long DF, Novak P, Cho S, & Yablon SA and the Consciousness Consortium in 2007.
3. TBIMS National Database: •Title: Traumatic Brain Injury Model Systems National Database •Author: Traumatic Brain Injury Model Systems Program •Distributor: Traumatic Brain Injury Model Systems National Data and Statistical Center •Persistent identifier: DOI10.17605/OSF.IO/A4XZB •Date: 2020 •URL: <http://www.tbimsc.org> •Version: <https://osf.io/a4xzb/>
4. TBIMS Annual Presentation: Traumatic Brain Injury Model Systems National Data and Statistical Center, 2020 Traumatic Brain Injury Model Systems Annual Presentation [PDF File]. Retrieved from <https://www.tbimsc.org>
5. Whyte J, Nakase-Richardson R, Hammond FM, et al. Functional outcomes in traumatic disorders of consciousness: 5-year outcomes from the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems. *Arch Phys Med Rehabil* 2013;94(10):1855–60.

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Table 1 Considerations for Family Education

Encourage the family to invite additional family members and/or caregivers, if possible
Find a time that works best for the family
Schedule the initial meeting for about 1-2 hours and plan to review current stage of recovery, outcomes, limits of existing research, etc.
Create a space for questions and give lots of opportunities for attendees to ask questions
Focus on translating the available research and information in family-friendly language to make it more accessible, manageable, and relatable
Understand that some families may desire less education and information and some may desire more

Peer Education Following Pediatric Brain Injury

Sophie Leib, PhD • Kara Monnin, PhD
Caitlin Pagnotta, CCLS • Rochelle Krouse, CTRS
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Outcomes for Children after Acquired Brain Injury

Following acquired brain injury (ABI), children may experience cognitive, physical, and emotional challenges, which can persist for months and sometimes years after the injury. While physical impairments often recover first, many children continue to experience significant difficulties with cognitive, social, and emotional functioning. Social difficulties in particular can negatively affect overall well-being, quality of life, and academic outcomes and can similarly impact caregiver wellbeing^{1,2}.

Social difficulties after pediatric ABI vary, but often include challenges relating to peers, initiating conversation, and understanding nuances in social behavior. Injury-related activity restrictions may also reduce opportunities for socialization. Following ABI, children are also at a greater risk for bullying and victimization because of new physical and cognitive challenges. Cognitive symptoms, including lack of insight, impulsivity, and disinhibition, can also negatively impact peer relationships³.

Predictors of Recovery—Support Network

Although each child with ABI is unique, three general factors predict outcomes. The first two involve the injury itself and pre-injury functioning. In most cases, children with more severe injuries and those with pre-existing cognitive and psychosocial difficulties tend to have greater difficulties after ABI, than those with less severe injuries and no pre-injury difficulties. The third predictor, and the focus of this piece, involves a child's support network and access to resources, which may play the most significant role after the initial recovery phase⁴.

Research suggests that a supportive social network can improve outcomes for children with ABI and foster resilience, even in the case of severe injuries⁵. Education to the most critical members of social networks typically starts with immediate family members and caregivers. As highlighted in the feature article in this edition, caregivers receive education during their child's initial hospitalization and learn ways to facilitate recovery.

Research shows that when caregivers have a greater understanding of the effects of brain injury, they are more likely to implement recommendations and attend follow-up appointments⁶. However, children's support systems go beyond the family. Peer relationships and friendships are essential, though at times overlooked, aspects of child development and brain injury recovery⁷. Among children with ABI, those who have stronger peer networks and more social connectivity have more favorable outcomes across many areas of functioning than those who do not⁷. Given the well-documented social and emotional challenges after ABI, as well as the critical role of children's social networks, efforts to better support peers after a friend's ABI may help ultimately improve recovery.

Overview of Peer Education/Support Programs after Pediatric TBI

Few formal programs specifically include a component for peer-education after ABI. One example is the BrainSTEPS program, established by the Pennsylvania Department of Health (brainsteps.net). As part of this program, BrainSTEPS staff (school psychologists, consultation staff, and/or school nurse coordinator, etc.) complete a comprehensive analysis of the needs of a student with a brain injury. The team then provides education on a peer's injury, what to expect, and ways to support them as they return to school. The format of this program includes direct education within classrooms, and/or meetings with teachers to provide tips/strategies for classroom peers. Children who participated in this program were more likely to graduate high school, pursue a 4-year-college education, and attend post-secondary education than children who did not participate⁸. Additional peer-based programs for ABI (i.e., the Social Peer Mentor Program; Making Connections after Brain Injury; geared more towards teenagers and adults) provide specific mentorship training to peers, community members, and in some cases, survivors of brain injury^{9,10}. Trainings include modules on challenges after ABI and skills to work on with a peer (social resources, planning, communication, etc.). Although research is limited, some findings suggest these programs can help improve quality of life¹¹. However, the few existing programs are largely geared to adult populations and may not be applicable to children, who's social and relationship skills are still developing¹².



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Children’s Hospital-Based Peer Education

A child’s hospital team can play a unique role in providing education and support to friends and classmates of a student with an ABI. Alongside medical doctors, providers including pediatric psychologists, neuropsychologists, therapeutic recreation therapists, and child life specialists meet a patient and family early in the hospitalization. Providers often form close relationships with children and families, and develop an understanding of the impact of the brain injury and relevant pre-injury factors (i.e., family, culture, education, values, etc.). A close working relationship and patient-centered care facilitates opportunities to communicate with families, as well as friends and classmates about expectations for recovery and ways to support children with ABI. Education for peers can be individualized and can specifically address challenges after ABI (e.g., social, emotional, and cognitive changes), as well as physical impairments and activity restrictions.

For example, the physician team works with the patient and peers to explain activity restrictions (i.e., avoiding bright lights, loud noises, no participation in gym class, keeping both feet on the ground, etc.) and why these restrictions are important. The therapeutic recreation team helps the patient and peers brainstorm alternative activities that are safe and fun for the patient during ongoing recovery. The communication between the hospital team and friends/classmates can reduce the burden on families to disseminate injury related information.

Recognizing the critical need for peer education, the psychosocial team at our institution provides peer and classmate education through a variety of mechanisms. We facilitate visits from close friends and help prepare them both before and during their visit. We address what to expect in terms of the hospital setting, what their friend may look like or how they might act, and ideas for appropriate activities. If in-person visits are not possible, we host virtual meetings with friends to provide more information about their friend’s ABI, coping strategies, and the best ways to interact with them when they return home. Both in-person and virtual visits give peers a “safe space” to learn about their peer with ABI and ask questions.

In addition to meeting with peers, our child life specialist spearheads ABI education for children’s classmates and their school team. As highlighted in another article in this edition, “Educating the Educators: Education for Schools and Teachers”, school reintegration programs are associated with fewer behavior problems, better adjustment, and increased knowledge for classmates and teachers¹³. At our institution, we create school re-entry programs that fit each individual patient’s needs, as well as those of their family, classmates, and school. Sometimes school reintegration education sessions only include close friends and their parents, and other times they may include an entire class or several classes. When providing school re-entry support and education, we prepare the teacher(s) or counselor so they know what to expect during the school re-entry process. This helps build their knowledge and confidence and empowers them to support children with ABI and their peers.

The varying expertise of multidisciplinary team members in Table 2 highlights how we use our unique skill sets to support patients, families, and peers of children with ABI.

Case Example—J

A 13-year-old boy was admitted after sustaining a severe TBI due to an All-Terrain Vehicle collision. The patient also had orthopedic injuries, and required multiple surgeries (including a craniectomy to address his significant brain swelling). He was in the intensive care unit for approximately one week before transitioning to a general medical floor and subsequently the inpatient rehabilitation floor. As he recovered, he displayed many common symptoms of a severe TBI including balance and mobility challenges, language and communication deficits, and significant cognitive and emotional changes. These changes included confusion and agitation, aggression, impulsivity and anxiety. He was very well-supported by his parents and siblings during his extended hospitalization, and his family worked closely with the medical and psychosocial team to understand the impact of his brain injury on his functioning and develop strategies to support him. The care team also organized having friends send in pictures, and his family brought in familiar items to his hospital room to promote comfort and support orientation.

Table 1 Goals and Information Provided in Peer Education

Goals of Peer Education	<ul style="list-style-type: none"> • Provide psychoeducation • Address and validate emotional reactions of peers about the child’s brain injury • Discuss worries or fears that peers may have about their friend and the injury • Answer questions related to their friend and their injury • Prepare peers to help support their friend in their ongoing recovery
Information Provided in Peer Education	<ul style="list-style-type: none"> • Function of the brain and information about the peer’s specific brain injury • Physical, emotional, cognitive, and communication implications of the brain injury • Activity restrictions in order for peers to help keep the child safe • Suggestions for safe activities to engage in for the patient and peers • Pictures, videos and information about the hospital, the patient, medical equipment, and new tools the patient may utilize at school

Table 2 Example Peer Education Team

Position	Role
Pediatric Neuropsychologist	Educate peers on age appropriate information about the brain injury itself and how the brain works; cognitive changes, how thinking skills may be different after the injury; what to expect for cognitive recovery; provide ways peers and the school can help the child recovery ¹⁴
Pediatric Psychologist	Educate peers on emotional, behavioral, and social changes after the injury; provide trauma-informed care and support for peers who may have experienced trauma themselves (e.g., if others have been injured or died as a result of a motor vehicle collision); help process changes in independence, functioning, and activity level; provide ways to support emotional and behavioral functioning
Child Life Specialist	Develop individualized plan for peer support and education; create individualized resources for patient, family, and school; work with schools to encourage peers to send cards, pictures, photos, etc., during the hospitalization; develop educational materials for the school (e.g., pictures, videos, information about the injury and hospital, medical equipment, etc.); provide education regarding activity restrictions and safe activity alternatives
Physical Medicine and Rehabilitation	Provide a developmentally-appropriate overview of the medical aspects of the brain injury and other related injuries and/or medical changes; provide individualized and patient-focused recommendations for activity restrictions (avoiding bright lights/loud noises, limiting participation in gym class/recess/sports (adaptive options possible), recommendations to “keep two feet on the ground”).
Therapeutic Recreation	Provide recommendations for age appropriate alternative activities based on activity restrictions; discuss these ideas with patients and peers; practice and model safe activities with the patient while they are in the hospital, so they can share these ideas with peers once they are home. Examples of alternative activities include: Board/card games, bean bag toss activity, table games (ping pong, air hockey), puzzles, fishing, arts and crafts, mini golf, baking/cooking, listening to music, seated yoga, etc.

During his last week on the inpatient rehabilitation unit, the patient’s team (medical, psychosocial, and family) organized a visit for the patient’s two best friends. Prior to seeing the patient, the team met with his friends to prepare for the visit in a developmentally appropriate context. The child life specialist shared pictures of the patient and brought a replica of the helmet that wore to protect his brain. The medical and therapeutic recreation teams discussed his current injuries and the reasoning behind activity restrictions. The psychology and neuropsychology teams talked about how and why the patient may act differently, and provided his friends with specific ideas of topics to discuss with the patient. Overall, the visit went well. After discharge, the hospital team coordinated with the patient’s school and conducted a zoom meeting with the patient’s classmates. During this meeting, the psychosocial team described the patient’s injury and talked about the parts of the brain that were involved. They provided specific details on how and why his brain injury impacts what he says and does, along with ideas for ways to interact with him. His classmates were very engaged and asked questions that ranged from “Will he be allowed to play football?” to “will he remember me?” to “does he still know how to read?” to “how can I help him at school?” The team answered their questions and also acknowledged the many “unknowns” in pediatric TBI. They also provided a safe space for processing emotions and grief about their friend’s injury, and offered follow-up resources and education materials created. Several weeks after discharge, the patient’s family reported that despite ongoing emotional and behavioral challenges, the patient had returned to school and short intervals of visits with his closest friends. Recommendations and supports continue to be provided to the patient’s family and friends as he reaches new steps in his recovery.

References

- Rosema S, Crowe L, Anderson V. Social function in children and adolescents after traumatic brain injury: a systematic review 1989-2011. *J Neurotrauma*. 2012;29(7):1277-1291. doi:10.1089/neu.2011.2144
- Rosema S, Muscara F, Anderson V, Godfrey C, Eren S, Catroppa C. Young adults’ perspectives on their psychosocial outcomes 16 years following childhood traumatic brain injury. *Social Care and Neurodisability*. 2014;5(3):135-144.
- Lebby PC, Pollock M, Mouanoutoua A, Lewey JH. Performance of Children and Adolescents With Brain Injury on the Lebby-Asbell Neurocognitive Screening Examination for Children and Adolescents. *J Child Neurol*. 2015;30(10):1255-1262. doi:10.1177/0883073814556886
- Yeates KO, Taylor HG, Walz NC, Stancin T, Wade SL. The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. *Neuropsychology*. 2010;24(3):345-356. doi:10.1037/a0018387
- Holland JN, Schmidt AT. Static and Dynamic Factors Promoting Resilience following Traumatic Brain Injury: A Brief Review. *Neural Plast*. 2015;2015:902802. doi:10.1155/2015/902802
- Lundine JP, Ciccio AH, Koterba C, Guernon A. Factors that Influence Follow-Up Care for Families of Children with Acquired Brain Injury: A Scoping Review. *Brain Inj*. 2022;36(4):469-478. doi:10.1080/02699052.2022.2051741
- Yeates KO, Gerhardt CA, Bigler ED, et al. Peer relationships of children with traumatic brain injury. *J Int Neuropsychol Soc*. 2013;19(5):518-527. doi:10.1017/S1355617712001531
- Riccardi JS, Eagan-Johnson B, Vaccaro M, Ciccio AH. Academic and post-secondary participation of students with ABI after the BrainSTEPS program. *Brain Impairment*. 2022;23(3):262-277. doi:10.1017/BrImp.2021.10
- Hanks RA, Rapport LJ, Wertheimer J, Koviak C. Randomized controlled trial of peer mentoring for individuals with traumatic brain injury and their significant others. *Arch Phys Med Rehabil*. 2012;93(8):1297-1304. doi:10.1016/j.apmr.2012.04.027
- Hibbard MR, Cantor J, Charatz H, et al. Peer support in the community: initial findings of a mentoring program for individuals with traumatic brain injury and their families. *J Head Trauma Rehabil*. 2002;17(2):112-131. doi:10.1097/00001199-200204000-00004
- Struchen MA, Davis LC, Bogaards JA, et al. Making connections after brain injury: development and evaluation of a social peer-mentoring program for persons with traumatic brain injury. *J Head Trauma Rehabil*. 2011;26(1):4-19. doi:10.1097/HTR.0b013e3182048e98
- Levy BB, Luong D, Perrier L, Bayley MT, Munce SEP. Peer support interventions for individuals with acquired brain injury, cerebral palsy, and spina bifida: a systematic review. *BMC Health Serv Res*. 2019;19(1):288. Published 2019 May 8. doi:10.1186/s12913-019-4110-5
- Prevatt FF, Heffer RW, Lowe PA. A review of school reintegration programs for children with cancer. *J Sch Psychol*. 2000;38(5):447-467.
- Watson WD, Lahey S, Baum KT, et al. The role of the Neuropsychologist across the stages of recovery from acquired brain injury: a summary from the pediatric rehabilitation Neuropsychology collaborative. *Child Neuropsychol*. 2023;29(2):299-320. doi:10.1080/09297049.2022.2086691

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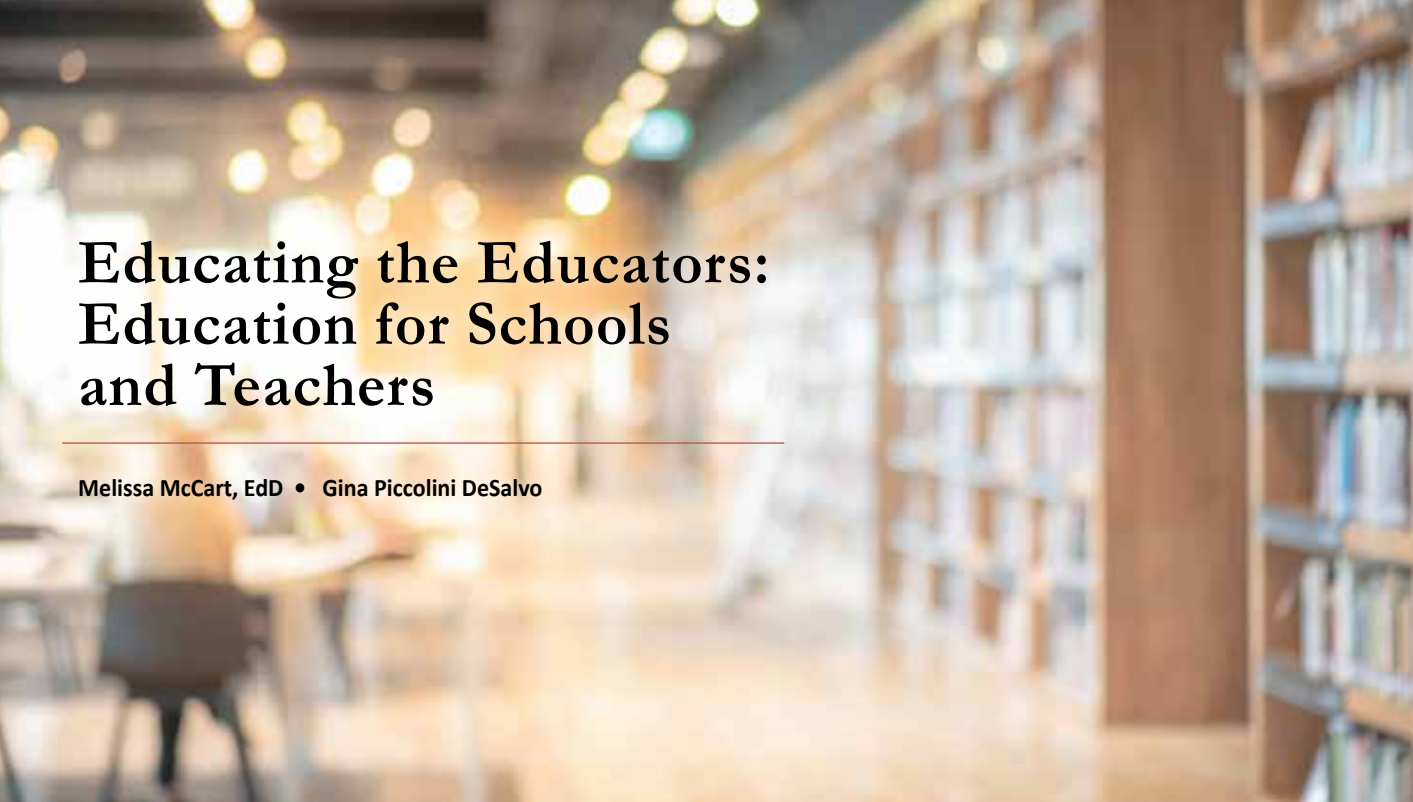
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Educating the Educators: Education for Schools and Teachers

Melissa McCart, EdD • Gina Piccolini DeSalvo

Current Landscape

Each year, approximately 895,000 U.S. children ages 0–19 years sustain a traumatic brain injury (TBI) that requires hospitalization or emergency treatment, a rate of 1,092 per 100,000 population.¹ The effects of TBI on children can be life-altering, affecting every aspect of their functioning from academic performance to cognitive ability, behavior, and social functioning.²⁻⁴ In 1990, in the United States, the Education for All Handicapped Children Act of 1975 was reauthorized as the Individuals with Disabilities Education Act (IDEA),⁵ and TBI was added as a disability category. Since the 1990 reauthorization more than three decades ago, focus on the needs that children who sustain TBI have when they return to school (RTS) and sports has increased. Until recently, the research in this area has largely been descriptive, focusing on the transition from hospital to schools and developing responsive systems of support for re-entry to school.^{6,7} It is well documented that professionals such as teachers and psychologists lack the skills and knowledge necessary to work effectively with students who have sustained a TBI.^{8,9} TBI continues to be a complex issue, with multiple factors influencing its recognition and identification. However, in the past ten years, some development and research has been done in the area of education for educators.

Issues and Implications

Researchers have been documenting significant gaps in educator knowledge about childhood TBI since the 1990s.⁸⁻¹³ This lack of knowledge, combined with misconceptions about TBI, can negatively affect how educators work with students with TBI. Ettel et al.⁹ surveyed teachers to gauge their knowledge, skills, and self-efficacy about TBI. Shockingly, they found that teacher preparedness to work with students with TBI had not improved significantly since TBI became a disability classification in 1990.

Teachers play a pivotal role in the special education process, actively contributing to the identification of students with educational disabilities. Concerns persist among TBI experts about the misidentification and under-identification of students with TBI.¹⁴ Without a comprehensive grasp of how TBI manifests within the school environment, educators run the risk of failing to identify students who require essential special education services, and they can inadvertently adopt inappropriate educational methods.¹⁴⁻¹⁶ Failure to accurately identify students for the TBI classification in special education impedes educators' ability to offer tailored, appropriate support to students with TBI.⁹

Comprehensive pre-service and in-service TBI training programs are critical for educators. Suitable TBI training equips educators with the knowledge and skills they need to actively engage in the special education identification process and provide necessary services to students. Through TBI training, educators develop a specialized skillset tailored to the unique needs of students with TBI, which ultimately enables them to deliver a free and appropriate public education to these students.

Resources and Current Training Programs

The Center on Brain Injury Research and Training (CBIRT) at the University of Oregon has developed a free virtual training program for educators. *In the Classroom after Concussion: Best Practices for Student Success* is an 8-module online course that provides helpful information, practical strategies, and resources for educators working with students with brain injury. The course is designed for classroom teachers, special educators, school psychologists, counselors, therapists, administrators, and others supporting students with brain injury. Since 2018, more than 4,000 educators have accessed the online course. Although some emerging resources are available (Table 1), very few have evidence of efficacy.

Table 1. Resources

Program	Description	Link
Return to School	This site is designed for educators, parents, and community providers who support students with TBI, who can register for upcoming events, view past webinars, and download resources.	returntoschool.org
In the Classroom	This 8-module course provides information, strategies, and resources for educators working with students with TBI. The course is designed for classroom teachers, special educators, school psychologists, counselors, therapists, administrators, and others supporting students with brain injury.	learn.cbirt.org
BrainSTEPS	BrainSTEPS provides brain injury–related consultation and training to school staff, students, and parents in all Pennsylvania public schools.	brainsteps.net
In the Classroom College	This one-module course provides information about the academic effects of concussion in college students, what academic and environmental accommodations can help, and the role college faculty can play in supporting college students with brain injury.	learn.cbirt.org
Get Schooled on Concussions	This site provides support to educators working with students with TBI.	getschooledonconcussions.com
REAP	The REAP (Reduce/Remove, Educate, Accommodate/Adjust, Pace) protocol is a multidisciplinary approach to RTS that provides support to students, their families, health care providers, and schools.	www.braininjurysafetynetsc.com/reap-manual

However, *In the Classroom After Concussion: Best Practices for Student Success* has been evaluated twice^{15,16} and showed statistically significant changes in educator knowledge, application, and self-efficacy both times.^{15,16} Educators who complete this training program are more proficient at monitoring potential post-injury learning and behavioral challenges. With this knowledge and training, educators are also well positioned to comprehend parental concerns and perspectives, which can improve collaborative partnerships.¹⁵

Next Steps

More information about current RTS models is needed to better support educators in their work with students who have sustained a TBI. The Centers for Disease Control and Prevention funded the study of two current RTS programs. The efficacy of the Central Oregon TBI (COR-TBI) RTS model from the University of Oregon and the School Transition after Traumatic Brain Injury (STATBI) project implementing BrainSTEPS will be analyzed for four years. The goal of these studies is to provide evidence that these programs positively affect outcomes for students with TBI.

The studies will evaluate the effects of RTS programs by examining student outcomes in health, cognitive, and social domains.¹⁷ This research evaluates existing models of support for students with brain injuries to help close the research-to-practice gap, creating a way to replicate results through dissemination. Researchers hope to find evidence that the COR-TBI and STATBI/BrainSTEPS RTS models positively affect students with TBI. These studies will conclude in 2024, with results forthcoming.

Given the complex challenges that students, families, and educators encounter when dealing with TBI, it is imperative to adopt a comprehensive approach at the national and state levels to effectively address these issues.⁶ Urgent attention is required in the area of educator training and professional development in TBI. Experts are optimistic that generalized evidence-based tools such as CBIRT's *In The Classroom* and models such as COR-TBI Return to School and BrainSTEPS can be widely used across districts and states to support students with TBI and their educators. Using these evidence-based tools to “educate the educators” is a promising initial step toward addressing these critical needs.

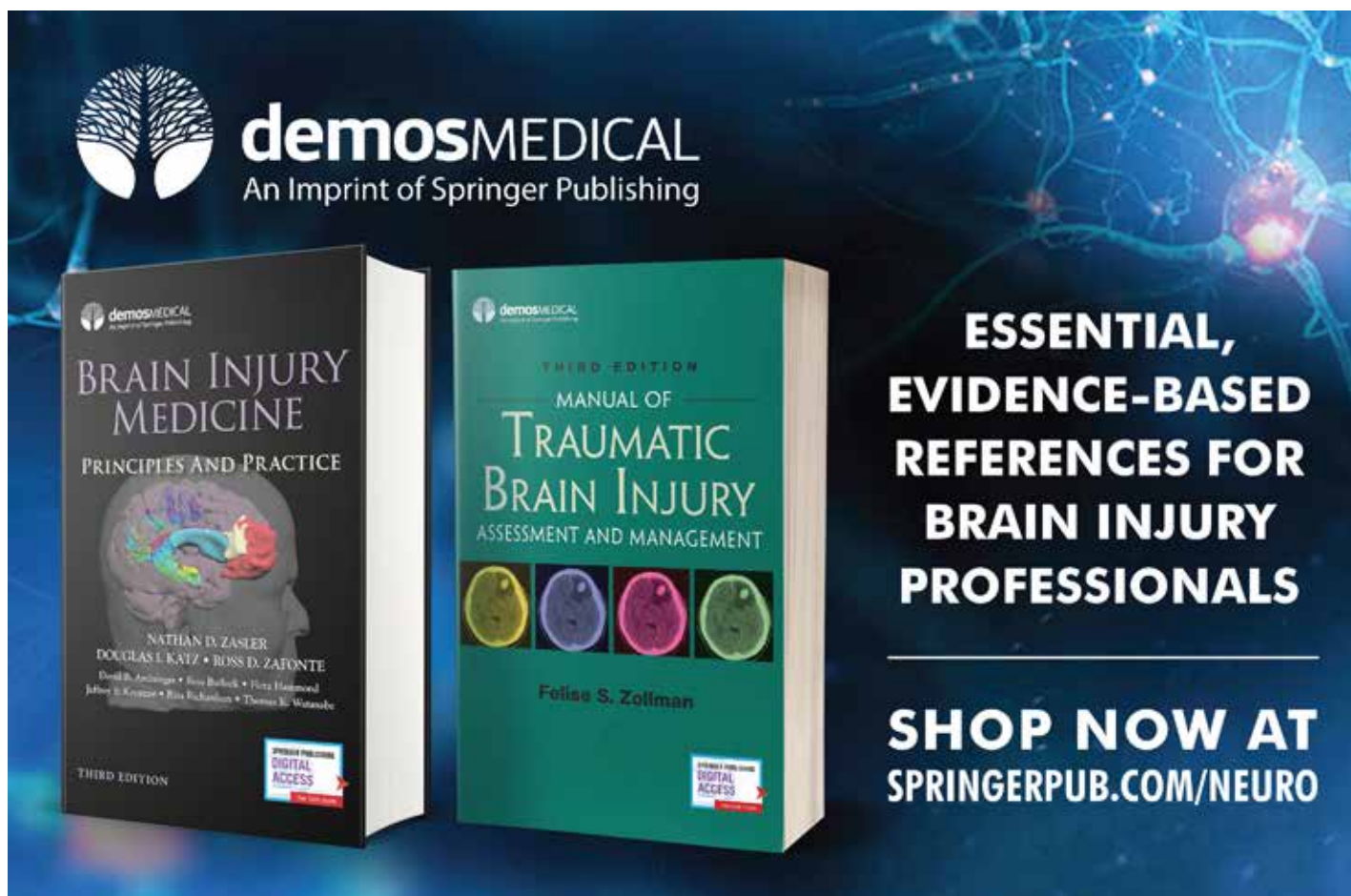
References

1. Children's Safety Network. *Non-fatal traumatic brain injury-related visits to the emergency department, U.S. infants, children, and adolescents ages through 19*. 2023, February. <https://www.childrensafetynetwork.org/resources/fact-sheet-tbi-among-infants-children-adolescents-treated-ed>
2. Babikian T, Merkle T, Savage RC, Giza CC, Levin H. Chronic aspects of pediatric traumatic brain injury: Review of the literature. *J Neurotrauma*. 2015;32(23):1849-1860. doi:10.1089/neu.2015.3971
3. Haarbauer-Krupa J, Pugh MJ, Prager EM, Harmon N, Wolfe J, Yaffe KC. Epidemiology of chronic effects of traumatic brain injury. *J Neurotrauma*. 2021;38:3235-3247. doi:10.1089/neu.2021.0062
4. Jones KM, Prah P, Starkey N, et al. Longitudinal patterns of behavior, cognition, and quality of life after mild traumatic brain injury in children: BIONIC study findings. *Brain Inj*. 2019;33(7):884-893. doi:10.1080/02699052.2019.1606445
5. Individuals with Disabilities Education Improvement Act of 2004. P.L. 108-446, 20 U.S.C. § 1400 et seq. 2004;
6. Dettmer J, Ettl D, Glang A, McAvoy K. Building statewide infrastructure for effective educational services for students with TBI: Promising practices and recommendations. *J Head Trauma Rehabil*. 2014;29(3):224-232
7. Gioia GA. Medical-school partnership in guiding return to school following mild traumatic brain injury in youth. *J Child Neurol*. 2016;31(1):93-108. doi:10.1177/0883073814555604
8. Davies SC, Fox EE, Glang A, Ettl D, Thomas C. Traumatic brain injury and teacher training: A gap in educator preparation. *Phys Disabil*. 2013;32(1):55-65.
9. Ettl D, Glang AE, Todis B, Davies SC. Traumatic brain injury: Persistent misconceptions and knowledge gaps among educators. *Except Educ Int*. 2016;26(1):1-18. doi:10.5206/eei.v26i1.7732
10. Farmer JE, Johnson-Gerard M. Misconceptions about traumatic brain injury among educators and rehabilitation staff: A comparative study. *Rehabil Psychol*. 1997;42(4):273.
11. Glang A, Ettl D, Todis B, et al. Services and supports for students with traumatic brain injury: Survey of State Educational Agencies. *Exceptionality*. 2015;23(4):211-224. doi:10.1080/09362835.2014.986612
12. Kahn LG, Linden MA, McKinlay A, Gomez D, Glang A. An international perspective on educators' perceptions of children with Traumatic Brain Injury. *NeuroRehabilitation*. 2018;42(3):299-309. doi:10.3233/nre-172380
13. Linden MA, Braiden H-J, Miller S. Educational professionals' understanding of childhood traumatic brain injury. *Brain Inj*. 2013/01/01 2013;27(1):92-102. doi:10.3109/02699052.2012.722262
14. Nagele DA, Hooper SR, Hildebrandt K, McCart M, Dettmer J, Glang A. Under-identification of students with long term disability from moderate to severe TBI. *Phys Disabil*. 2019;38(1):10-25. doi:10.14434/pdps.v38i1.26850
15. Glang AE, McCart M, Slocumb J, et al. Preliminary efficacy of online traumatic brain injury professional development for educators: An exploratory randomized clinical trial. *J Head Trauma Rehabil*. 2019;34(2):77-86. doi:10.1097/htr.0000000000000447
16. McCart M, Glang AE, Slocumb J, Gau J, Beck L, Gomez D. A quasi-experimental study examining the effects of online traumatic brain injury professional development on educator knowledge, application, and efficacy in a practitioner setting. *Disability and Rehabilitation*. 2020;42(17):2430-2436. doi:10.1080/09638288.2019.1578423
17. Ciccio A, Nagele D, Chen Z, et al. Cognitive, social, and health functioning of children with TBI engaged in a formal support program. *NeuroRehabilitation*. 2023;52(4):613-624. doi:10.3233/NRE-220208

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The advertisement features a dark blue background with a glowing neural network pattern. On the left, two books are displayed. The first book, 'Brain Injury Medicine: Principles and Practice', has a black cover with a brain illustration and lists authors Nathan D. Zasler, Douglas L. Katz, and Russ D. Zafonte. The second book, 'Manual of Traumatic Brain Injury: Assessment and Management', has a green cover and lists author Felise S. Zollman. Both books have a 'Springer Publishing Digital Access' badge. The DemosMedical logo, 'An Imprint of Springer Publishing', is at the top left. On the right, white text reads: 'ESSENTIAL, EVIDENCE-BASED REFERENCES FOR BRAIN INJURY PROFESSIONALS' and 'SHOP NOW AT SPRINGERPUB.COM/NEURO'.

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Sleep-Wake Disturbances in Individuals with TBI: Facts and Recommendations

Edith Botchway-Commey, PhD
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An Overview of Sleep Disturbances in Young People with TBI

Sleep is essential for health and wellbeing. It plays a crucial role in the maturation of the developing brain and aids in recovery following a traumatic brain injury (TBI). When we close our eyes and drift into sleep, we embark on a hopeful journey, believing that we will awaken rejuvenated and full of energy. However, for 25 to 40% of typically developing young people (i.e., children and adolescents) and adults, this optimism is dashed by the presence of sleep wake disturbances (SWD).¹⁻⁴

SWD are even more prevalent among people with TBI, affecting between 40% to 70% of young people^{5,6} and about 46% of adults with TBI.^{7,8} Survivors of TBI often present with an increased risk of mental health problems (e.g., depression and anxiety), cognitive deficits (e.g., executive dysfunctions), fatigue, and poor quality of life.^{5,7-9} Because of this, it is essential for providers to understand the impact of brain injury on sleep and how best to counsel caregivers and persons with brain injury. Sleep can be disrupted in the acute and post-acute recovery stage following TBI and for the purposes of this article, we will primarily focus on the post-acute phase (e.g., after discharge from the hospital and/or inpatient rehabilitation).

Causes of SWD in TBI have not been well-established, and some potential mechanisms have been proposed: including the fact that TBI interferes with the development of stable sleep habits (in young people), disrupts brain regions (e.g., hypothalamus) and hormonal systems (e.g., melatonin) underpinning sleep and wake, and increases risk of sleep-related comorbid conditions (e.g., depression).^{7,10,11} Compared to adults without TBI, the brains of adults with severe TBI have been found to produce less melatonin (a hormone that regulates daily sleep-wake cycles) at the acute¹⁰ and long-term post-injury (about 6 years),¹¹ and melatonin release is also later (about 1.5 hours delay) in these adults.¹¹ This disruption in amount and timing of melatonin release may impact both sleep onset, maintenance, and sleep duration after TBI. One study involving children however contrasted these results by reporting an increase in melatonin levels in the acute stage following severe TBI, which was interpreted as reflecting a response to oxidative stress and/or inflammation due to severe TBI.¹² While more studies are needed to understand the origins of SWD in people with TBI, studies have established that common SWD in TBI include insomnia (i.e., difficulty falling asleep, maintaining sleep, or feeling unrefreshed in the morning despite having enough opportunity to sleep), daytime sleepiness (i.e., a tendency to inadvertently fall asleep during the day), and sleep apnea.^{7,9,13}

SWD in TBI has been linked to several factors, including age at injury,^{8,14,15} time since injury,^{9,16} injury severity,^{8,13,14} and gender;^{8,17} although most results are mixed due to methodological differences. SWD in TBI have also been associated with depression, fatigue, and pain (although the directionality of these relationships remains unknown),^{5,7,8} as well as poor executive functioning, internalising and externalising behavior problems, and poor quality of life.^{5,7-9} Evaluating and addressing sleep issues in people with TBI is hence crucial to mitigate their negative effects on physiological, psychological, and functional recovery following a TBI.

Identifying Sleep Disturbances in People with TBI

Sleep is not always prioritized after TBI possibly because of the presence of more concerning physical and physiological issues (e.g., mobility challenges) and a lack of awareness about sleep issues, especially in people with more severe TBI. SWD can emerge in the days to weeks following TBI¹⁸ and may persist indefinitely if not treated.^{5,8,9} An evaluation of SWD in young adults who experienced TBI during childhood revealed an approximate prevalence rate of 40%,^{19,4,23} and established a connection between SWD and heightened symptoms of fatigue, depression, and diminished health-related quality of life; highlighting the need to routinely screen for and treat sleep-related issues in survivors of TBI.

Although developmental patterns of SWD have not been extensively studied in the context of people with TBI, several studies in healthy individuals have documented that SWD can vary across the lifespan.^{4,20,21} For example, pre-scholars (3 – 5 years) may present with difficulty falling asleep independently, multiple and prolonged night waking, and night-time fears and nightmares. School-aged children (6 – 12 years) are more likely to present with insomnia, daytime sleepiness, sleep-walking, and teeth grinding (which may indicate upper respiratory problems). Adolescents (13 – 18 years) often present with insomnia, daytime sleepiness, restless leg syndrome, and delayed sleep phase syndrome (i.e., habitual sleep-wake times that are delayed usually more than two hours, relative to conventional or socially acceptable times), and adults (18+ years) often report insomnia, sleep apnea, and restless leg syndrome have been reported. While research on these patterns is limited in people with TBI, being mindful of these developmental patterns is essential for early detection and treatment of SWD following TBI.



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Table 1 Screening Tools to Assess SWD after TBI

Clinical interviews	Interviews could include questions about sleep patterns and sleep hygiene. For young people, ask question about the family’s sleep-wake routine, parenting style, and attachment style/soothing methods used by caregivers (especially for younger children). ^{22,23}
Validated questionnaires	Questionnaires used in adult TBI studies include the Pittsburgh Sleep Quality Index, Epworth Sleepiness Scale, and Insomnia Severity Scale, Functional Outcomes of Sleep Questionnaire, and sleep diaries. Questionnaires used in young people include the Sleep Disturbance Scale for Children, Children’s Sleep Habits Questionnaire, and the Pediatric Daytime Sleepiness Scale.
Wristwatch actigraphy	Actigraphy can track nightly sleep patterns and should be used for a minimum of 7 days in both young people and adults.
Polysomnography assessment	A full polysomnography can provide a more detailed assessment of sleep architecture.

Clinicians are encouraged to discuss sleep with families of people with TBI, highlighting the increased risk to sleep problems associated with TBI. With support from clinicians, individuals and families can increase their knowledge and confidence in addressing SWD following brain injury. Clinicians and researchers can screen for SWD using tools outlined in Table 1. When SWD are suspected and/or identified, clinicians have an important role in providing recommendations to help improve sleep issues, as outlined in recommendations section below. General recommendations can be applied across age groups and specific recommendations can be provided based on the person’s age. Notably, the screening tools and recommendations listed below are not specific to those with TBI. However, these tools are useful for recovery following TBI, given the increased risk of SWD and the importance of sleep for brain health.

Recommendations/tips for managing SWD in young people and adults with TBI.

Clinicians can educate individuals with TBI and their families on optimal strategies for managing SWD, using the recommendations outlined below. Age-specific recommendations have also been provided below.

Across all age groups:

- **Provide opportunities to get enough sleep.** People with TBI should have enough opportunity to get the amount of sleep recommended based on their age each/most nights.²⁴ The National Sleep Foundation provided guidelines outlining the recommended sleep duration for individuals, categorized by their age: 1-2 years (9-16 hours), 3-13 years (7-12 hours),¹⁴ to 17 years (7 – 11 hours), 18+ (7 – 9 hours).²⁴ We however advise that individual variabilities in sleep patterns and the impact of TBI on sleep-wake patterns should also be considered when following these recommendation since some people may require more sleep weeks to months after TBI.
- **Maintain regular sleep and wake times.** Regular sleep and wake times allow the person with TBI to get sufficient sleep each night. Sleep times may vary based on the individual’s age-related physiological readiness for sleep.

- **Limit screen time and access to electronic devices at bedtime.** Turn off electronic devices (e.g., phones, computers, or TVs) at least two hours before bedtime. Electronic devices can be highly stimulating, which can make it hard to unwind and be ready to sleep. In addition, the blue light emitted from devices can interfere with the body’s natural circadian rhythm by suppressing melatonin production, making it more difficult to fall asleep.²⁵ This may be more pronounced following TBI which can lead to increased light sensitivity.
- **Set up a soothing sleep environment.** People with TBI may be more sensitive to noise and light, which can affect sleep. Reducing noise and light levels at night-time and avoiding cognitive work (e.g., homework, paying bills) or high energy activities about two hours before can facilitate sleep. Bedrooms should also be comfortable, dark, cool, and quiet.

Pre-scholars and school-aged children (3-12 years)

- **Maintain a consistent bedtime routine and sleep hygiene.** Establish a bedtime routine that is the same every night and includes calm and enjoyable activities, such as a bath and bedtime stories.
- **Set limits.** Set clear limits if children stall at bedtime (e.g., asking for more books to be read at bedtime).
- **Avoid caffeine and sugary foods/drinks.** Limit or avoid foods that contain high levels of caffeine and/or sugar as consumption of caffeine and sugary foods in young people may disturb their sleep (e.g., shorter sleep duration),²⁵ leading to daytime sleepiness.

Adolescents (13 – 18 years)

- **Increase exposure to daylight or sunlight.** During the teenage years, the adolescent’s brain produces melatonin later in the evening causing circadian rhythm shifts (by one or two hours). This shift leads to teenagers falling asleep later at night and waking up later in the morning, which can make it harder to fall asleep and wake up. Sometimes this delay in the sleep-wake cycle affects a person’s daily activities.

Increasing exposure to sunlight first thing in the morning can help with melatonin production in teenagers (e.g., eating breakfast outside instead of indoors).

- **Set limits.** Collaboratively establish time limits for any stimulating activities (such as homework or screen time) with teenagers. Highly stimulating activities could be replaced with more relaxing activities in the evening (e.g., reading).
- **Offer extra help.** Help teenagers optimize after-school schedules to create more time for relaxation and sleep. Jointly review the teenager's weekly schedule and determine if they are overcommitted. If necessary, help reduce their involvement in activities, and avoid early morning appointments or training sessions on the weekend.
- **Encourage short naps.** Short afternoon naps after school can be a rejuvenating practice. Naps around 20 – 30 minutes typically do not disrupt nighttime sleep.
- **Mental health.** Regularly assess stress and anxiety, as these factors may contribute to sleep disturbances.

Adults (18 and up) – Similar to adolescent recommendations with a few additional considerations.

- **Engage in daytime activities that enhance sleep at night.** Limit daytime napping (aim for 10 – 20-minute naps) and get exercise/physical activity during the day. Limit or avoid alcohol, nicotine, caffeine, and sugar (avoid at least 5 hours before bedtime).
- **Get into a good routine** Set a regular sleep and wake time and try to stick to this routine every day (even on weekends). Use an alarm to ensure waking on-time, if helpful. Create a relaxing bedtime routine, which could include taking a warm bath, putting away electronic devices, and listening to music or guided meditation before bed.
- **Prioritize sleep in the bedroom.** If it takes longer than 30 minutes to fall asleep, get out of bed and do something relaxing until you are ready to sleep (e.g., listen to relaxing music or read a book).

Conclusion

TBI heightens the likelihood of SWD, which, in turn, increases risk of unfavorable outcomes across various functional domains. Fortunately, SWD can be assessed and managed using some of the assessment strategies, and care recommendations outlined in this article. Collaborating with people with brain injury and their families to recognize and address issues early can enhance sleep outcomes and promote overall recovery following TBI.

References

1. Ophoff D, Slaats MA, Boudewyns A, Glazemakers I, Van Hoorenbeeck K, Verhulst SL. Sleep disorders during childhood: a practical review. *Eur J Pediatr.* 2018;177(5):641-648.
2. Waters KA, Suresh S, Nixon GM. Sleep disorders in children. *Med J Aust.* 2013;199(8):S31-S35.
3. Du M, Liu M, Wang Y, Qin C, Liu J. Global burden of sleep disturbances among older adults and the disparities by geographical regions and pandemic periods. *SSM Popul Health.* 2024;25:101588. doi:10.1016/j.ssmph.2023.101588
4. McArdle N, Ward S V, Bucks RS, et al. The prevalence of common sleep disorders in young adults: a descriptive population-based study. *Sleep.* 2020;43(10). doi:10.1093/sleep/zsaa072
5. Botchway EN, Godfrey C, Anderson VA, Catroppa C. A systematic review of sleep-wake disturbances in childhood traumatic brain injury: Relationship with fatigue, depression, and quality of life. *J Child Psychol Psychiatry.* 2019;34(4):241-256.

6. Luther M, Cordts KMP, Williams CN. Sleep wake disturbances in children surviving neurocritical care with traumatic brain injury: A systematic review. *Neurocrit Care.* 2019;31(1):S304. doi:10.1007/s12028-019-00857-7
7. Aoun R, Rawal H, Attarian H, Sahni A. Impact of traumatic brain injury on sleep: an overview. *Nat Sci Sleep.* 2019;Volume 11:131-140. doi:10.2147/NSS.S182158
8. Ouellet MCC, Beaulieu-Bonneau S, Morin CM. Sleep-wake disturbances after traumatic brain injury. *Lancet Neurol.* 2015;14(7):746-757.
9. Luther M, Cordt PM, Williams CN. Sleep disturbances after pediatric traumatic brain injury: a systematic review of prevalence, risk factors, and association with recovery. *Sleep.* Published online 2020:1-29.
10. Seifman MA, Gomes K, Nguyen PN, et al. Measurement of Serum Melatonin in Intensive Care Unit Patients: Changes in Traumatic Brain Injury, Trauma, and Medical Conditions. *Front Neurol.* 2014;5. doi:10.3389/fneur.2014.00237
11. Grima NA, Ponsford JL, St. Hilaire MA, Mansfield D, Rajaratnam SM. Circadian Melatonin Rhythm Following Traumatic Brain Injury. *Neurorehabil Neural Repair.* 2016;30(10):972-977. doi:10.1177/1545968316650279
12. Marseglia L, D'Angelo G, Manti S, et al. Melatonin Secretion Is Increased in Children with Severe Traumatic Brain Injury. *Int J Mol Sci.* 2017;18(5):1053. doi:10.3390/ijms18051053
13. Gagner C, Landry-roy C, Laine F. Sleep-wake disturbances and fatigue after pediatric traumatic brain injury: A systematic review of the literature. *J Neurotrauma.* 2015;32(20):1539-1552.
14. Bogdanov S, Brookes N, Epps A, Naismith SL, Teng A, Lah S. Sleep Disturbance in Children with Moderate or Severe Traumatic Brain Injury Compared with Children with Orthopedic Injury. *Journal of Head Trauma Rehabilitation.* 2019;34(2):122-131.
15. Ekinci O, Okuyaz C, Günes S, et al. Sleep and quality of life in children with traumatic brain injury and ADHD: A comparison with primary ADHD. *The International Journal of Psychiatry in Medicine.* 2017;52(1):72-87.
16. Sumpter RE, Dorris L, Kelly T, McMillan TM. Pediatric sleep difficulties after moderate-severe traumatic brain injury. *Journal of the International Neuropsychological Society.* 2013;19(7):829-834. doi:10.1017/S1355617713000465
17. Tham SW, Fales J, Palermo TM. Subjective and objective assessment of sleep in adolescents with mild traumatic brain injury. *J Neurotrauma.* 2015;32(11):847-852.
18. Eisenberg MA, Meehan WP, Mannix R. Duration and course of post-concussive symptoms. *Pediatrics.* 2014;133(6):999-1006.
19. Botchway EN, Godfrey C, Anderson V, Nicholas CL, Catroppa C. Outcomes of Subjective Sleep-Wake Disturbances Twenty Years after Traumatic Brain Injury in Childhood. *J Neurotrauma.* 2019;36(5):669-678. doi:10.1089/neu.2018.5743
20. Vriend J, Corkum P. Clinical management of behavioral insomnia of childhood. *Psychol Res Behav Manag.* 2011;4:69-79.
21. Kocavska D, Lysen TS, Dotinga A, et al. Sleep characteristics across the lifespan in 1.1 million people from the Netherlands, United Kingdom and United States: a systematic review and meta-analysis. *Nat Hum Behav.* 2020;5(1):113-122. doi:10.1038/s41562-020-00965-x
22. Sadeh A, Tikotzky L, Scher A. Parenting and infant sleep. *Sleep Med Rev.* 2010;14(2):89-96. doi:10.1016/j.smrv.2009.05.003
23. Brand S, Hatzinger M, Beck J, Holsboer-Trachsler E. Perceived parenting styles, personality traits and sleep patterns in adolescents. *J Adolesc.* 2009;32(5):1189-1207. doi:10.1016/j.adolescence.2009.01.010
24. National Sleep Foundation. How Much Sleep Do You Really Need? <https://www.thensf.org/how-many-hours-of-sleep-do-you-really-need/>.
25. Calamaro CJ, Yang K, Ratcliffe S, Chasens ER. Wired at a Young Age: The Effect of Caffeine and Technology on Sleep Duration and Body Mass Index in School-Aged Children. *Journal of Pediatric Health Care.* 2012;26(4):276-282. doi:10.1016/j.pedhc.2010.12.002

Author Bio

Dr. Edith Botchway-Commy is a Neuropsychology researcher whose work focuses on understanding sleep, mental health, and cognitive outcomes in young people with neurodevelopmental conditions, such as traumatic brain injury. She completed a masters in Cognitive Neuropsychology from the VU University, Amsterdam, and a PhD with the University of Melbourne in 2019. Edith is currently a postdoctoral researcher with the Brain and Mind Group at the Murdoch Children's Research Institute (Melbourne, Australia), and also works as a Research Analyst with Mind Australia, a community-based mental health care provider.



BIP expert interview

Pearls of Wisdom for Brain Injury Providers

An Interview with Dr. Barbara Wilson

Barbara Wilson is a clinical neuropsychologist who has worked in brain injury rehabilitation for 45 years. She has published 34 books, 205 peer reviewed papers, 124 chapters and 8 neuropsychological tests. She has won many awards for her work. She was for many years editor of the journal "Neuropsychological Rehabilitation" which she founded in 1991. 1996 she established the Oliver Zangwill Centre for Neuropsychological Rehabilitation. A rehabilitation centre in Quito, Ecuador is named after her. The UK Division of Neuropsychology has named a prize after her. She is a Fellow of The British Psychological Society, The Academy of Medical Sciences and The Academy of Social Sciences. She is honorary professor at the Universities of Hong Kong, Sydney, East Anglia and Fernando Pessoa University, Portugal.

You have made such a large impact on the field and have been so open to sharing your personal stories, which for many, including myself, has been a source of inspiration in the work that I do. To help provide some education to professionals working with those with brain injury, can you share some of the pearls of wisdom you have learned along the way?

"I am always on the side of the patient and the family, we are in this profession to help the patients and their families, not in it to further our careers. I think that's where I differ from some other people I work with. They may try to publish in the right journals, or develop academic models, but I've never felt the need for that. I feel that it could be me, it could be one of my children who is the brain injured person, so I always come at it from that point of view. I believe the families feel like I am on their side.

The families want to talk to someone who understands what they are going through, and they often want a diagnosis too. There are two patients I worked with, a man and a woman, both of whom had Balint's Syndrome. Both were registered blind but they were not blind at all. The man loved it when I said you are not blind, you have Balint's syndrome, he was proud of that diagnosis. The main thing about Balint's is they can't localize in space, so they can't reach for the right object. People who are visually impaired have a different representation of the world. I used to get frantic about people trying to help these patients with a white stick or a guide dog. This is totally inappropriate for that diagnosis. So, I guess, one of my pearls of the wisdom, is to be on the side of the patient and the families; by understanding them and offering an appropriate diagnosis, you can make a huge difference."

This edition focuses on ways that we as clinicians educate patients and families but they also educate us. What are some of the most memorable things patients with brain injuries and their families have taught you?

"Well I think almost every patient teaches you something. One person that comes to mind is Kate, who won't mind me using her name, she is still improving after 22 years. Originally she had ADEM, which is an autoimmune encephalitis. At first she used to communicate with a letter-board. She was very fast and good at it, and she used it to make contact with those around her. However, she was determined to speak again, but after 6-years of Speech Therapy, the therapist gave up and said there was nothing more she could do. Kate, though, was so determined that after 14 years, she threw away the letter board and started to speak. She is perfectly intelligible even though her speech is a little strange.

I have also learned that whatever our training says, you have to be flexible and adaptable. The patients' goals are not necessarily the goals we expect them to have. This woman I mentioned before with Balint's syndrome, I thought her goals would be being able to sit on a chair or feed herself, but what she really wanted was to read a story to her two young children. We have to work on, the goals our patients think are important. One man, I worked with was an opera singer with locked-in syndrome who could move only one eye. All of our communication was with eye-blinks, it took forever, it wasn't difficult, but it was slow. I thought he would have a terrible quality of life, but he didn't. I once asked him, "what do you do every day?" He blinked saying, "I go through all of the roles that I've ever played and I imagine I have a cinema in my house, I play films to myself". These patients make you feel very humble, as they learn to live with their conditions. One professional I know, asked an audience of doctor, psychologists and therapists if they would want to die if they had locked-in syndrome. About 70-75% of the audience said yes, they would want to die. Now, when patients with locked-in syndrome are asked the same question, only around 2% want to die. That's why living wills are dangerous, because people change their minds! Most patients teach you things, whatever you are doing."

As you describe in your publications and talks, neurorehabilitation requires multidisciplinary team efforts and collaboration, but this can sometimes be challenging, especially when disagreements arise. What is your advice for handling this, especially for newer clinicians getting into multidisciplinary team work?

Well, I don't know if I have the answer to that, but I certainly like working with other disciplines and in teams. For example, with occupational therapy, I think they are practical problem solvers. Some of them aren't good at publishing their findings, whereas psychologists are. So we can play to our strengths. Sometimes, the disagreements are about who should be treating patients? Should it be the OT, the PT, the psychologist? Well, I don't think it matters, it has to be someone that is good! And that is all that really matters! Another disagreement arises because we have different terminology. The OT's may talk about body awareness disorders, whereas psychologists typically use other diagnostic terms. So collaboration is important, and everyone can come up with mutually understood terms and have the same way to communicate what is happening. My main thing is if somebody can treat the patient, let them do it, whatever their profession. The strength of psychology is our ability to evaluate and write-up findings and we need to combine our different strengths.

One of the biggest problems is funding, this usually comes from the purchase holders. Some of the medics, who have power, say “well, he does not need rehab,” and they may stop people from coming to us because they think people don’t need rehab. It is a fight, my whole career has been a fight for getting our patients the services they need. I work with families but not as much, say, as in India where there are 12 qualified neuropsychologists for a population of over 1 billion people. They have to work through the families. Wherever you are in the world, funding is a problem!

A lot of your work has been in single case experimental designs, as many of our readers may not consider themselves researchers, could you talk a little more about what that looks like?

I certainly believe in SCEDS (single-case experimental design). If you ask a question about groups such as, “how many patients improve if you do an intervention? Then you need to use a group design”. Most of the time in rehab, however, we are faced with an individual and the question becomes “is this person improving, and, if so, is it because of what we are doing or would s/he have improved anyway?” One of the ways to answer this question is a SCED. Two main types of SCEDS I’ve used are reversal designs such as: “A-B-A-B,” where A is the baseline, and B is the treatment (or variations on this). If the baseline keeps improving, you don’t have to do anything, as the patient is getting better anyway. If, however, you manage to get a stable baseline, and the patients improves with your treatment, this is evidence that your treatment is working. This of course needs to be confirmed or disconfirmed. The other type of SCED I often use is the multiple baseline design. You might be treating multiple problems a time or in multiple settings. The main principle is to stagger the introduction of treatment. I’ve used this with people in physiotherapy, in different settings, etc. one thing I think is good about psychologists is the constant need to evaluate. Medics may say, “well-it’s well established so we’ll do it anyways,” but the single-case experimental design can often tell us if it something is working or not.

What do you think is one of the biggest issues facing brain injury rehabilitation today, one thing we can see is funding and advocacy, is there anything else you can see?

I think we have to fight, we mustn’t be afraid to challenge the system. The reason I cannot move to another country to work is because I know the enemy in Britain, I know how to fight the enemy. I wouldn’t be able to do that in America, or Greece or Spain. I’ve always been a fighter, I haven’t come through in the same way as many successful people, I had a very disadvantaged childhood, but it doesn’t seem to hold me back. We always have to remember, we are in in for the brain injured people and their families; they aren’t in it for us.



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About the Interviewer

Christine H. Koterba, PhD, ABPP, is a Pediatric Neuropsychologist at Nationwide Children’s Hospital (NCH) and a Clinical Associate Professor of Pediatrics at The Ohio State University. She is the attending inpatient neuropsychologist at NCH and provides neuropsychological consultation and assessment in inpatient and outpatient settings. She is also involved in the pre- and

post-doctoral neuropsychological training programs. Her clinical interests include pediatric neuropsychology, acute recovery from brain injury, illnesses (COVID-19, long COVID), and other conditions that impact neurological functioning, and pediatric rehabilitation.

Empowering Families and Clinicians: Web-based TBI Education from the Model Systems Knowledge Translation Center

Stephen Trapp, PhD, MEd



Seeking medical information online can yield disastrous results. Inaccurate articles are abundant and our tendency to rely on data that confirms our expectations can lead us to wildly invalid conclusions. This is no less true for those seeking information online about life after a brain injury. To solve this problem, the Model Systems Knowledge Translation Center (MSKTC) created a user-friendly, educational website (<https://msktc.org/TBI>) offering evidence-based information on living with a TBI. The present review summarizes and evaluates aspects of this web-resource. The MSKTC website is administered by the American Institutes for Research and funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. Drawing from a long history of high-quality research from the Traumatic Brain Injury Model Systems, the content of the website is rooted in a strong evidence base and aptly translated for a range of audiences. Topics include what to expect during acute inpatient treatment to matters associated with daily living and community integration. The diversity and breadth of topics offer a relevant spread of information for a multitude of TBI stakeholders.

A major strength of the website lies in its educational content on daily living. For those adjusting to the day-to-day consequences of TBI, the information on rehabilitation techniques, assistive technologies, and coping strategies align well with best practices and the current understanding of brain injury. Expected content, such as cognitive and mood changes, are well represented and nuanced topics, such as sexual functioning and exercising your right to vote post TBI are offered as well. Together, the MSKTC website offers an excellent source for basic and more advanced topics pertinent to those affected by TBI.

The website also excels in providing an assortment of educational presentations. Fact sheets, infocomics, and slideshows cater to a range of learning preferences. Fact sheets are particularly noteworthy for their succinct yet comprehensive coverage of important topics. The infocomics offer an approachable educational format with excellent strategies and activities to enhance


rehabilitation. Although these resources have great value to non-clinical caregivers, clinicians can utilize these resources to refresh their educational handout options or educate their allied colleagues from other medical specialties.

The website has a mostly user-friendly interface with clear navigation menus, search functionality, and well-organized content. It is clear MSKTC had accessibility in mind when designing the website, yet next-step website development could benefit from incorporating more contemporary strategies from Web Content Accessibility Guidelines 2.2 and the World Wide Web Consortium. For example, missing alt attributes and misordering of heading elements can create barriers for individuals using screen readers and other assistive devices. Altogether, the MSKTC website demonstrates thoughtfulness towards accessibility and - like all websites - can benefit from ongoing accessibility-focused redesigns.

Together, the MSKTC website addresses the need for evidence-based educational resources online. Its depth of content, diverse educational formats, and rehabilitation coverage make the website a valuable option for non-clinical and clinical persons supporting those living with a TBI as well as those with a TBI.

Author Bio

Stephen K. Trapp, PhD, is a rehabilitation psychologist and Director of the Center of Health Creation at the Metrodora Institute. His clinical and research efforts focus on a range of neurorehabilitative conditions, rehabilitation technology, and cross-cultural topics. Among other roles, he is the Technology Editor for Brain Injury Professional and affiliated with the Department of Psychiatry at the University of Utah.



Traumatic Brain Injuries in Personal Injury Cases

“We have been told a lot of TBI cases are being missed,” says Kyle Kinberger, Chief Revenue Officer at HMR, the leading plaintiff-oriented medical funding company. “Many law firms lack the manpower and screening tools to assess them.”

Traumatic brain injuries are a contributing factor to a third (30.8%) of all injury-related deaths in the United States, and motor vehicle injuries are a leading cause of traumatic brain injury deaths. “The lifetime economic cost of TBI, including direct and indirect medical costs, was estimated to be approximately \$76.5 billion (in 2010 dollars)” according to the *CDC*.

A study published online in *JAMA Neurology* on January 6, 2020 suggests “early initiation of care after a concussion may be warranted to expedite recovery time.”

“There’s a saying that if you’ve seen one brain injury — you’ve seen only one brain injury. The reason is that brain injuries differ so much in severity, types and causes, and happen to individuals with varying education levels, mental health, and physical health.” says Dr. C. Alan Hopewell, Ph.D., who is a neuropsychologist at Advantage Health Systems.

Physiatrists and Neurologists tell us they can provide admissible evidence that demonstrates an injury caused by a TBI. An attorney will then get all the medical records including a review by a neuropsychologist.

If a plaintiff is uninsured or cannot afford their deductibles, HMR can help by paying the physiatrist or neurologist directly for their services, and then wait for the case to conclude before they are paid back from proceeds of the legal case.

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A wide-angle photograph of the Glasgow cityscape. The River Clyde flows through the center, with several bridges crossing it. In the background, a mix of modern glass-fronted buildings and older stone structures are visible under a blue sky with scattered white clouds. The water in the river is calm, reflecting the sky and buildings.

2024
Glasgow

A photograph of the Calgary cityscape. The prominent feature is the Calgary Bow, a red, curved pedestrian bridge with a lattice-like structure, extending over the Bow River. In the background, modern high-rise buildings are visible against a blue sky with light clouds. The water of the river is dark and reflects the surrounding city.

2026
Calgary

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