# **BRAIN INJURY** vol. 14 issue 3 professional

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# from the publisher



Chas Haynes, JD

As those of you who attended the 12th World Congress on Brain Injury earlier this year in New Orleans know, the International Brain Injury Association (IBIA) and the North American Brain Injury Society (NABIS) have formally entered into a strategic partnership through which NABIS will join IBIA as a special section.

This partnership will allow NABIS and IBIA to deliver significantly enhanced membership benefits to the brain injury professionals that make up both organizations. Members of NABIS and IBIA will now have access to a comprehensive set of benefits that combines the strengths of both organizations, providing a more valuable membership experience and the opportunity to be part of a larger and more influential international alliance.

What this affiliation means specifically to Brain Injury Professional is that the publication will see a number of editorial and design enhancements, and in addition BIP will become not only the most widely circulated brain injury publication in North America, but also the world.

It is with great enthusiasm that we welcome Nathan Zasler, MD, to the editorial leadership of BIP, who will join Debra Braunling-McMorrow, PhD, as co-editor. Dr. Zasler brings decades of experience serving at the helm of some of our field's leading peer-reviewed publications to BIP, and he will build upon the outstanding work that Dr. Braunling-McMorrow has done over the last three years. Together, this editorial "dream-team" is working with a new editorial advisory board to develop an exciting four-year editorial calendar with special issues that will address a variety of cutting-edge brain injury topics, including:

- Advances in Post Traumatic Epilepsy,
- Sexuality after TBI,
- Neuro-Optometry,
- Long-term Community Care,
- Movement Disorders, and
- International Models to Improve Care.

We believe BIP's unique editorial format, with each issue focusing on a specific topic and guest edited by a recognized leader in that area, make BIP a unique addition to the brain injury literature. In the coming issues, new internationally focused features will be introduced that will make BIP a global publication. Some of the more domestic features, such as the non-profit news and the public policy update, will be moved to IBIA's electronic publication, the Neuro-Trauma Letter.

In addition to the editorial changes, readers will note that this issue has been redesigned in a more accessible and readable format. With bold graphics and larger tables and figures, we believe this refreshed design compliments the editorial revisions that are already underway and sets BIP apart from all other brain injury publications.

As the field of brain injury continues to mature, BIP is likewise evolving to better meet the educational needs of our multidisciplinary readership. Now more than ever, it is critical for brain injury professionals to share information on a global level in order to accelerate change. It is our hope that Brain Injury Professional will serve as a platform for communication and exchange for researchers and clinicians working to improve the lives of persons with brain injury and their families worldwide.

**Chas Haynes**, JD *Publisher* 

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### from the editor in chief



Debra Braunling-McMorrow, PhD

As an Editor in Chief for the **Brain Injury Professional**, we provide a special edition on pediatric brain injury as a rotating topic on our editorial calendar.

For this edition, Sharon Grandinette, an educator, school reintegration specialist, and expert witness with more than 26 years of experience serving children and their families, has assembled a range of experts to address comtemporary areas. Included are overviews of Neuroeducatonal evaluations, the value of educators and brain injury specialists in pediatric legal cases, and the value of the school nurse in concussion management. In addition, this edition provides very practical guidance for families navigating the school system, outlines challenges in issues of consent with descriptive case scenarios, and provides sidebars with useful resources.

I continue to find it remarkable that after almost 10 years of counting persons with brain injury that we continue to undercount and thereby underserve children with brain injuries. And while it has improved, we still miss counting those most under our watch. The article on the under identification of juveniles with brain injury in the criminal justice system by Gorgons, Nagele, Dettmer and Hooper brings to mind a well-cited article and that the Wall Street Journal covered in 2008 by Wayne Gordon and colleagues on the hidden issues of brain injury and the cascade of social ills kids may fall into as they become adults challenged to make their way in life.

### " As the group of professionals and educators in this edition aim to teach, we need to continue to learn how to better serve our kids. "

Thank you Sharon and all the contributing authors in this very special edition.

In addition, I want to provide acknowledgment in particular to the states of CA, KS, OR, CO, PA, and NY, as well as George Washington University for educational support initiatives, and the Brain Injury Association of America for providing Brain Injury specialists training through the Academy of Certified Brain Injury Specialists (ACBIS). These states and systems serve as models of best practices for pediatric care and education.

On another note, please mark your calendars for the North American Brain Injury Society's 14th Annual Conference on Brain Injury and 31st Annual Conference on Legal Issues in Brain Injury. The medical and legal conferences will be held simultaneously at the Hyatt Regency Downtown, Houston, TX on March 14-17, 2018. Our best wishes go out to the people of Houston and the surrounding communities and those of our staff who live in that area. The Hyatt received no damage during the Hurricane Harvey. NABIS looks forward to supporting the city of Houston.

The medical conference will include "An overview of the medical science of brain injury from an outstanding faculty of researchers and clinicians presenting the very latest in brain injury science, treatment and testing." For our Legal conference, "Attendees can expect the very latest information on brain injury litigation at this three-day hands-on conference considered a "must attend" event for all professionals involved in brain injury litigation. The conference features an all-star cast of top trial attorneys and medical experts who will present a broad array of practical information covering the latest literature, diagnostic testing methods, rehabilitation, case management, trial techniques and cutting-edge demonstrative evidence. Attorneys will also benefit from an overview of the medical science of brain injury".

Due to the success of the Legal Pre-Conference Sessions in 2017 in New Orleans, there will be two legal-specific pre-conference sessions prior to the start of the Annual Legal Conference on Wednesday, March 14, 2018. Additionally, there will be multi-track pre-conference sessions for the medical conference also on Wednesday, March 14, 2018.

#### **Authors Bio**

**Debra Braunling-McMorrow**, PhD, is the President and CEO of Learning Services. She serves on the board of the North American Brain Injury Society as Vice Chair. She has served as a chair of the American Academy for the Certification of Brain Injury Specialists (AACBIS), board of executive directors of Brain Injury Association of America, and several national committees, editorial boards, and peer review panels. She is a published author and lecturer in the field of brain injury rehabilitation for over 30 years. To contact Dr. McMorrow, please email conference@nabis.org.

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### from the guest editor



Sharon Grandinette, MSEd, CBIST

This special issue of the *Brain Injury Professional* is dedicated to acquired brain injuries in the pediatric population, and I am very honored to be the guest editor.

A 13-year skateboarder without a helmet skidded off the sidewalk into on incoming car... a 3 year old slipped through the pool fence and nearly drowned ... a 7 year old was diagnosed with a brain tumor... a 16 year old contracted encephalitis...all of these children acquired a brain injury that impacted functioning. For adults, continued employment after ABI is often at issue, but for children, their job is to be a student. Acquired brain injury (ABI) in children affects educational outcomes and thus, future employment.

As a special educator, children have always been close to my heart, and when I began working in pediatric ABI in 1991, not only did I find my passion; I became aware there were few in my field with an understanding of their unique needs. Although I have worked for over 26 years as a pediatric ABI educator and school reintegration specialist, and I stand on the shoulders of the pioneers who have come before me, there is still a great deal of misinformation regarding assessment, services and outcomes in this population. It is vital that the quest of those pioneers continue, and that professionals in the field are made aware of children's distinct needs in order to move toward a better standard of care leading to improved outcomes. Although there have been previous editions of the BIP focused on the pediatric population, this issue not only identifies their unique profiles, but also outlines specialized services and programs to address their needs. While not every professional working in ABI include children in their practice, it is important to keep in mind that "a child with a brain injury grows up to become an adult with brain injury", and the information can further inform treatment as they move into adulthood.

In the feature article, Neuroeducational Evaluations - The School-Based Answer to Pediatric Neuropsychological Assessments, Crawford, Hotchkiss, and McAvoy discuss the approach school personnel trained in pediatric brain injury use during assessment, and the differences and similarities between neuroeducational and neuropsychological evaluations. They outline the unique profile of children with ABI, why it can take time for deficits to reveal themselves, and share the framework created by the Colorado Department of Education to work effectively with this population.

Despite the fact that for years the pediatric literature has provided a clear set of steps regarding how to reintegrate children back to school following brain injury, the educational team of Mazzarella, Pahr and Tyler, in their article, Helping Families Navigate the School system to Obtain Appropriate Services After ABI provide detailed information to assist professionals in supporting families through this often confusing journey, and include information on training/certification opportunities for educators in pediatric brain injury, as well as a review of model educational programs successfully educating these children.

In the article, The Value of Educators and Brain Injury Education Specialists in a Pediatric Legal Case, two educators (Eagan-Brown and Grandinette) have paired with two brain injury attorneys (Johnson and Shea) to outline the benefits of deposing students' pre and post injury educators, list the issues unique to pediatric brain injury that attorneys should be aware of when trying a case, and why adding a brain injury education specialist to the team of experts can be of benefit.

Gorgons, Nagele, Dettmer and Hooper relate the sobering statistics in their article, Under Identification of Brain Injuries, and the Relationship with Juvenile, (and eventually adult) Criminal Justice Involvement. They explore the association between individuals who sustain a TBI in childhood and its' relationship to adult offending behaviors, as well as issues and recommendations regarding the incarceration of juveniles with TBI.

When it comes to school aged youth and the skyrocketing number of concussions they sustain, one of the most important school team members often over looked is the school nurse. Eagan-Brown, Oro, and McAvoy, in their article School Nurses: Managing Student Concussions and Privacy Concerns explore the valuable contribution school nurses make facilitating effective medical school communication, and a safe Return to Learn (RTL).

In an interview with well known speech pathologist and pediatric BI pioneer Roberta DePompei, Gardner, a school based speech pathologist explores the important role speech and language pathologists play in identifying the screening and rehabilitation needs of children with ABI, and the educational impact that cognitive communicative deficits have on school re-entry, performance and social communication.

Working with the individuals that contributed to this important edition of the BIP allowed me to collaborate with some of the top professionals in pediatric ABI across the U.S. They volunteered countless hours to assure the topics selected were written to provide advancement to other professionals in their knowledge regarding how brain injury can impact the pediatric population, and ways in which their unique needs can be addressed from a variety of professional and clinical perspectives.

I hope this issue brings to the reader a deeper appreciation and understanding of how ABI impacts children and adolescents, and ways that will improve their approach as they work to better their lives and the lives of their families.

#### **Authors Bio**

Sharon Grandinette, MSEd, CBIST is a nationally and internationally recognized consultant, trainer, advocate and expert witness in the field of special education, with a specialty in pediatric acquired brain injury and school reintegration, and has published in the field. She is an adjunct instructor at the California State University Dominguez Hills in the graduate Special Education Credential program. Sharon serves on the executive board of NABIS, and served on the board of the Brain injury Association of CA, where she was chair of the state conference for several years. She was the Executive Director of both the We Can Pediatric Brain Tumor Network and The California Association of Physical & Health Impairments. Sharon was instrumental in the developing the TBI Added Authorization that became a part of the special education credential requirements in CA. She owns and operates Exceptional Educational Services in Redondo Beach, CA. www.helpkingkidsbrains.com.

### Neuroeducational Evaluations - The School-Based Answer to Pediatric Neuropsychological Assessments

• Nicole Crawford, PhD

- Heather Hotchkiss, MSW
- Karen McAvoy, PsyD



#### Underidentification of Traumatic Brain Injury

It is estimated that there are currently 145,000 children aged 0-19 who are experiencing significant long-lasting social, behavioral, physical and cognitive impacts related to a traumatic brain injury (TBI) (Zaloshnja, Miller, Langlois, et al., 2008). However, the number of students identified for special education services under the TBI eligibility category in 2014 was 26,000 (U.S. Department of Education, 2016). This suggests a gross underidentification of students with TBI for special education services. There are a number of reasons for this underidentification including, but not limited to:

- information not being shared with the schools,
- a lack of realization an injury that happened earlier in life could now be impacting a student's learning or behavior in school,
- a lack of training/understanding on behalf of school personnel about the causes and impact of the brain injury, and
- misidentification-some supports may be provided via a formal or informal plan (e.g., health plan, Multi-tiered System of Support (MTSS), a Section 504 plan, or an Individualized Education Program (IEP) under a different special education category than TBI (e.g., Specific Learning Disability, Emotional Disturbance, Other Health Impaired - ADHD). These categories can be limiting, and the breadth of needs of students with brain injury may not be fully identified or addressed.

An additional consideration is that while there are many academic, social and behavioral needs shared by students who are found eligible for special education across categories such as Specific Learning Disability (SLD), Emotional Disturbance (ED) and Traumatic Brain Injury (TBI), a student who has sustained a TBI likely has broader needs than a student with a learning disability or emotional/behavioral issues.

Students who have sustained a brain injury present a unique profile. One cannot categorize the needs of all students who have sustained a brain injury in one particular way. When an injury happens while the brain is still developing, which is well into our 20's, some deficits are obvious right away, while others emerge many years later making it imperative to monitor needs over time. Consequently, it is necessary to have a specific special education category for TBI to represent the ongoing changes associated with the complex and long-term health condition of TBI. In addition, evaluating students and their needs requires a multitude of tools - both formal and informal (including observation in the school setting). Traditional standardized assessments may not be sensitive enough to detect the nuances present in the functioning of a student with a brain injury. Because there may be gaps in some areas of functioning and unevenness in others (splinter skills), traditional tools can miss information or provide only generalized findings that are not discrete or useful.

#### The Role of the School Team

The Individuals with Disabilities Education Act (IDEA), (34 C.F.R. 300.111), states school districts must identify, locate, and evaluate all children with disabilities who need special education and related services. The evaluation must assess the child in all areas related to the child's suspected disability. A school-based multidisciplinary team as well as the parents, make up the IEP team. The IEP team uses the evaluation results to decide the child's eligibility for special education and related services and to make decisions about an appropriate educational program for the child. It is the school's responsibility to

determine eligibility for special education services, including TBI. Other information (e.g., outside evaluations, hospital/rehabilitation records) is considered by the schools and may be added to the information or body of evidence, but nonetheless, it is the school's responsibility to provide data and determine eligibility within the context of education.

Many medical professionals and parents mistakenly believe that when assessing in the realm of brain injury or other areas of neuropathology, school professionals are not adequately trained to provide such evaluations. There is a common belief that pediatric neuropsychologists are best suited for questions related to neurological underpinnings as they relate to learning, behavior and social skills in schools. According to Miller and Maricle (2014) and Silver, Blackburn, Arffa, et. al (2006), outside clinical pediatric neuropsychological evaluations often assess intellectual ability, academic performance, memory, sensory, motor, visual spatial processing, language, processing speed, attention and executive functions. What medical professionals and parents may not understand is that properly trained and empowered schoolbased multidisciplinary teams, which include teachers, occupational therapists, physical therapists, speech language therapists, school psychologists, social workers, school nurses, vision and hearing specialists, etc., can also provide assessments in intellectual ability, academic performance, memory, sensory, motor, visual spatial processing, language, processing speed, attention and executive functions. Additionally, school-based professionals have a unique knowledge of the school setting as well as expertise in special education law and eligibility. Moreover, the members of the multidisciplinary team also have daily observation, and exquisite understanding of how these cognitive areas are "functionally" manifested in the school setting and effect learning and behavior. The school professionals use the results of the school-based assessment to identify interventions, accommodations, and supports that are the best fit for that particular student and environment.

There are many undeniable positives to school-based multidisciplinary teams assessing students with brain injury or other neurocognitive disorders, which include:

- School-based multi-disciplinary team assessments are available to all students at no cost. Unfortunately, there is frequently a shortage of clinical pediatric neuropsychologists and wait times for an outside neuropsychological assessment can be from six months to over a year. Additionally, a neuropsychological evaluation is often cost-prohibitive for many families.
- Student data collected in the school setting is relevant to current functioning and aligned with educational or behavioral areas of concern. Diagnoses from the Diagnostic and Statistical Manual of Mental Disorders (DSM) or information from a neuropsychological report may have limited utility if it overemphasizes medical terminology (Miller and Maricle, 2014) or may not directly translate into meeting the eligibility requirements of special education or even the need for special education services (Miller, 2013). Functional educational impact and the need for special education services must be assessed by the school-based multidisciplinary team. An outside neuropsychological evaluation cannot stand alone as a comprehensive special education evaluation.
- Parents are an essential part of the team and a long-term partnership is created. Many times, students spend much of their grade school careers in one school system, and a partnership between the parents and the school-based team is advantageous. If an outside neuropsychologist recommends that a child "be placed in a special education program" but the child does not actually qualify for special education services (due to the fact that special education eligibility is governed by complex federal

regulations, not simply by the presence of objective data), it creates a situation that can be confusing and frustrating for parents and can lead to acrimony.

- School-based special education evaluations are well-rounded and consider the whole child by gathering multiple pieces of formal and informal data, including formal cognitive and academic assessments, observations in multiple school settings and social situations, teacher, parent and student interviews/reports, response to intervention data and a history of performance and behavioral data. Classroom observations, peer interactions, and student response to school-based stimuli are all important aspects of understanding the student's abilities and their deftness for learning and behaving. Outside neuropsychological reports frequently incorporate limited school data, and when included, it is commonly general perceptions provided by the parents or statewide standardized test scores which may not provide an accurate reflection of how the child is performing in the school setting or as compared to their same aged peers. When a neuropsychologist is available and working with the family, communication is essential. The sharing of data about school performance, learning, behavior and a reflection of how the child is performing in the school setting compared to same aged peers is necessary for an accurate reflection of a child's functioning across environments.
- The school-based multidisciplinary team typically has unique and valuable information about, and experiences with, the child that is essential to the special education evaluation in relation to the child's cognitive, academic, emotional and behavioral strengths and weaknesses. Personal and long term knowledge of the child, his/her abilities and the history of academic records are all valuable sources of pre- and post- functioning performance for a student with a brain injury. The outside neuropsychologist, however, may only have short-term contextual knowledge of the child within the assessment setting (Fletcher-Janzen, 2005).
- The school-based multidisciplinary teams and many school psychologists are trained in and able to robustly assess the functional impact of cognitive deficits in the school setting and are in possession of relevant, day-to-day, information about how the deficits impact the student's ability to function in the academic setting. School psychologists who do not believe they possess the expertise to provide the in-depth evaluation required when assessing a student with a TBI may choose to enroll in an online school neuropsychology specialization. This additional training, however, is at their own expense and time.

It is clear that when both an outside neuropsychologist and a schoolbased multi-disciplinary team are available, close communication and collaboration is essential. When that happens, as it does in numerous communities, the needs of the student (both objectively and functionally) are well defined and met. However, there is a reality that far more families have access to a school-based multi-disciplinary team than they do to a neuropsychologist. With just a small amount of specialized training, school-based multi-disciplinary teams can provide both the functional AND objective assessment information of neurocognitive deficits and are available to all students at no cost to parents. While neuropsychologists can provide objective testing data, they are limited in their availability and, when one is available, they rarely have access to the school setting wherein many of the functional impacts of the student's neurocognitive deficits will be manifest. Further, since these professionals typically do not work in schools, they may only have cursory knowledge of special education law. Lastly, they are often cost-prohibitive to families.

As the number of students with possible neurocognitive deficits rise due to wider awareness and better medical management, intentional and concerted brain based training to all school-based related service providers is a responsible solution. A hybrid between neuropsychological testing (testing by a neuropsychologist) and psychoeducational testing (testing by multi-disciplinary team of schoolbased professionals) leads to a neuroeducational model. One such approach is represented by the TBI Consulting Team Model where the goal is to make available to schools statewide a group of trained, multidisciplinary, school-based consultants to provide in-service training and ongoing consultation to educators of children with TBI (Glang et al., 2010). It is beyond the scope of this article to go into depth on each state's model but there are a handful of states that have developed such models (Colorado, North Carolina, Oregon, and Pennsylvania). The TBI consulting team model was adopted in the mid-1990's by the state of Oregon. Pennsylvania has had the BrainSTEPS School Consulting Team model (www.brainsteps.net) for over a decade, and Colorado has recently developed their own BrainSTEPS consulting teams.

Another example is in the state of North Carolina. The Department of Public Instruction Exceptional Children's Division has addressed the TBI training needs of its school-based personnel since 1993 by providing systematic professional development to school psychologists, special education teachers, and related-school-based personnel (Hooper, 2003; Hooper, Walker, & Howard, 2001). In this model, participants are asked to participate in a didactic component that addresses three broad core competencies: (1) Increase the knowledge base of school psychologists and other school-based personnel in the area of TBI; (2) Increase the skills of school psychologists in neurocognitive assessment of students with TBI; and (3) Increase the intervention skills of school psychologists for students with TBI.

The state of Colorado has adopted a neuroeducational model entitled The Building Blocks of Brain Development and has committed to the statewide training of school-based related service providers at no cost to schools. The model below outlines Colorado's neuroeducational framework which has been manualized and can be replicated in other state departments of education. The intention of the Colorado neuroeducational model is to build on the expertise of neuropsychology with the accessibility of the school-based multi-disciplinary team. The result is breadth and depth and most importantly, the ability to more quickly and comprehensively assess and support students with neurocognitive deficits in a school setting.

**FIGURE 1** 

Members of the school-based multidisciplinary team are able to assess and consider:

- each child's individual pattern of strengths and weaknesses;
- the school and classroom environment; and
- effective intervention programming and classroom supports.

When the brain injury is more recent, the child's cognitive functioning, academic skills and emotional/behavior adjustment are frequently changing, with the most change observed in the first few years post injury (Morrison, 2010). Due to unevenness in performance and recovery of brain functions in children with brain injury, frequent monitoring is recommended for changes in academics, behavior and social functioning (McCoy, Gelder, Van Horn, et al., 1997).

This profile of learning makes it essential for communication and collaboration among the school team, parents, rehabilitation team and any outside providers in order to effectively support the child across various settings. Schools have daily access to the child, which provides the ability to constantly monitor and observe changes during a variety of different tasks and situations as well as various cognitive, academic and social demands to guide in the timely adjustment of accommodations, supports and targeted interventions.

#### The Building Blocks of Brain Development -A Framework for Neuroeducational Evaluation & Intervention

We have learned a tremendous amount of information in past decades about how the brain functions, however, there is still no one agreedupon model that truly captures the complexities of this remarkable organ.

In an effort to support school-based multidisciplinary teams in completing thorough neuroeducational evaluations that produce rich data for the special education eligibility process, the Colorado Department of Education (CDE) along with the Colorado Brain Injury Steering Committee, applied the most current research on brain function, neuroanatomy and assessing the various brain processes and developed a user-friendly framework titled, the Building Blocks of Brain Development.

#### Neuroeducational Evaluation is More than Just Assessment

Due to schools being the foremost service provider for children, the school-based neuroeducational evaluation not only focuses on how a child is functioning in the context of special education eligibility but also on the consideration of what the results mean for the child in the classroom setting. D'Amato, Rothlisberg and Work (1999) have emphasized that the purpose of any evaluation is to provide effective intervention.



**Building Blocks of Brain Development** 

CO Brain Injury Steering Committee: Adapted from Miller, 2007; Reitan and Wolfson, 2004; Hale and Fiorello, 2004

This framework aligns the:

- eligibility criteria for the special education category of Traumatic Brain Injury (TBI), as defined by IDEA,
- definitions of the typical cognitive and behavioral impacts of brain injury,
- formal and informal neuroeducational assessments that can be used in the school setting, and
- strategies and interventions to address the unique needs of students with brain injury.

Essentially, each area of impairment within the definition of TBI is a "building block" which follows the neurological growth or maturation of the brain. Within the framework, each building block is defined. The framework then specifies how each building block affects learning and behavior, what a deficit in the building block "looks like" in the classroom setting, school-based assessment suggestions to evaluate student functioning, and strategies or interventions to address the deficits. Even though the original development of the Building Blocks framework was to support TBI assessments and interventions, the model applies to all acquired brain injuries as well as other conditions impacting neurocognitive functioning.

When considering the many neurocognitive processes (or building blocks) a person develops over time, it is important to understand the hierarchy of functions in their development. That is to say, the development of one process or function precedes, at least in part, the development of another. Thus, the building blocks and subsequent processes are cumulative and compounding. Meaning, that our brains develop each building block in a progressive manner, but each building block continues to mature and become more complex over time.

The Building Blocks of Brain Development (see FIGURE 1) explains, in a simplistic manner, the interaction between the more basic or fundamental skills, and the higher-order cognitive skills. This is not an exhaustive list of cognitive functions; rather the building blocks represent the areas most commonly affected by brain injury.

The Building Blocks of Brain Development framework is color-coded for ease of use and proceeds from foundational processes (indicated in orange) to more complex functions (indicated in green, blue and purple). At the base of the chart is the orange, fundamental level. These are critical in all learning and behavior; they are also the most sensitive to being impacted by a brain injury. The intermediate level (as seen in green) depends on the fundamental building blocks in order to develop and become more complex. The higher order thinking FIGURE 2 skills (as seen in blue) rely on the lower levels to be solidly in place in order to fully develop and be available. And finally our top cognitive processes of overall achievement (as seen in purple) is the peak of functioning. This highest level allows us to operate in our many environments and to be productive citizens - and it is wholly dependent on the three preceding levels being intact and working in concert to produce our desired outcome, which is reasoning and overall functioning.

A brain injury may cause disruption or gaps in one or more building blocks, impacting our learning and behavior, and ultimately our overall achievement. Due to the inter-relatedness and integrated nature of our brains – just one building block that is not functioning well can affect all of the others, as depicted in FIGURE 2. The Building Blocks of Brain Development framework aligns with the special education eligibility criteria - more specifically, the following building blocks:

- Fundamental Processes Level memory, processing speed, attention, inhibition, sensory-motor
- Intermediate Processes Level language processes (expressive, receptive, social pragmatic), learning processes, visualspatial processes.
- Higher Order Processes Level social emotional competency, executive functions (initiation, planning, organization, mental flexibility, reasoning/judgment)

As stated earlier, it is important to have assessment tools available to school-based multidisciplinary teams that are sensitive enough to identify a student's functioning levels within each of the building blocks. To assist school-based multidisciplinary teams in completing a neuroeducational evaluation, the Building Blocks of Brain Development framework includes a wide range of assessment suggestions, broken down by each building block, which can be administered by school professionals.

The formal and informal neuroeducational assessments identified within each building block can assist multidisciplinary teams in conducting a full neuroeducational evaluation, by identifying cognitive strengths and weaknesses, providing data to help determine eligibility for special education services and assist in the development of student specific intervention plans.



O Brain Jojury Steering Committee: Adapted from Miller, 2007; Reltan and Wolfson, 2004; Hale and Florelb, 2004

The suggested neuroeducational assessments are commonly available in the school setting and/or are frequently part of training programs or practice for the various professional members of the multidisciplinary team. The assessments identified within the framework are just suggestions and are not endorsed by the Colorado Department of Education (CDE). This collection is not an exhaustive list and is always changing with revised editions and new tools being added each year. In an attempt to maintain this ever changing collection, the CDE and the Colorado Brain Injury Program have teamed to develop a website that provides a dynamic and user friendly way to access the Building Blocks of Brain Development framework. The Colorado Kids Brain Injury Resource Network website is available at: www. cokidswithbraininjury.com.

While the online framework provides the neuroeducational evaluation tools, there is also a manual, available electronically. The manual defines and fully illustrates each building block. It is called the Brain Injury in Children and Youth: A Manual for Educators, and is available for free on the CDE website: http://www.cde.state.co.us/ cdesped/sd-tbi and the CO Kids Brain Injury Resource Network: http://cokidswithbraininjury.com/). The manual provides a detailed explanation of how each building block may be affected in the school setting if a brain injury occurs. In addition, an extensive list of accommodations, strategies and interventions for each building block are provided in the manual.

It is important to note that the Building Blocks of Brain Development framework represents one of several possible conceptualizations of how neurocognitive processes are organized. Despite the simplicity of the building blocks framework, it describes the deep complexity of neurocognitive functioning and inter-relatedness. Currently, there is no optimal model of neurocognitive development agreed upon by the majority of researchers, though much debate occurs, and it is understood that parts of this framework can be theoretically challenged.

#### Conclusion

The Building Blocks of Brain Development framework created by the Colorado Department of Education (CDE), along with the Colorado Brain Injury Steering Committee, is a framework for parents, schoolbased multidisciplinary teams and outside providers to identify, understand and address the effects of brain injuries in students. The framework provides common language and understanding for communication about a student's level of functioning within the school, home, and community environments. Educators can apply the framework to identify skill deficits through neuroeducational assessment and address those deficits through appropriate educational interventions and supports. Ultimately, all students can benefit from the increased awareness gained from this simple tool about the interaction between brain processes, learning and behavior.

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Heather Hotchkiss, MSW, is a Brain Injury Specialist at the Colorado Department of Education (CDE). She provides consultation and training on brain injury in addition to Fetal Alcohol Spectrum Disorder (FASD). She brings over 25 years of leadership experience in school mental health and special education services for children in CO. Heather is involved nationally - serving as a board member and president elect for the National Association of State Head Injury Administrators (NASHIA) and a member of the National Collaborative on Children's Brain Injury. Heather has functioned in a variety of capacities including: teacher assistant, mental health clinician in locked facility schools, behavior specialist, school social worker, State Mental Health Consultant, a member on numerous legislative work groups, Response to Intervention/Positive Behavior Interventions and Supports Coordinator, and Special Education Director. She is dually credentialed as a Licensed School Social Worker and Special Education Director in Colorado.

**Karen McAvoy**, PsyD, is dually credentialed as a clinical and school psychologist. She has been involved with the Colorado Department of Education as a Brain Injury Consultant since 2010 and was instrumental in the crafting of language leading to the stand alone special education eligibility for Traumatic Brain Injury (TBI) in the state of Colorado in 2013. Karen has 27 years in education; 20 of those years in a school district holding positions as school psychologist, coordinator of the TBI team, coordinator of mental health services and coordinator of manifestation determinations. Karen provides trainings to Colorado school districts on neuroeducational assessment and intervention, understanding the function of skill deficit in behavior and executive dysfunction and is an adjunct professor in the University of Colorado Denver School Psychology PsyD program.

### Helping Families Navigate the School System to Obtain Appropriate Services after Acquired Brain Injury

#### • Peggy Mazzarella, MA • Cynthia Pahr, MEd, CBIST • Janet Tyler, PhD, CBIST

When a child sustains an acquired brain injury (ABI), parents and families are thrown into a new and unfamiliar world. They are forced to deal with complex medical systems while their child is hospitalized and receiving rehabilitation care. If their child has not required special education services in school prior to the injury, they will now be dealing with a system of support that is unknown to them. Navigating a new system of support and understanding school services is a daunting process. Professionals who work with these parents and caregivers are in a primary position to help educate and direct them through some difficult first steps of the process. To do this effectively and efficiently, professionals should have an understanding of the services available for students with ABI in the education setting and how one goes about obtaining those services.

#### Communication and Collaboration are Essential

Historically, communication between hospitals and schools has been weak, with both systems struggling to understand one another's perspectives and procedures. Research has shown that students hospitalized with brain injury who had documented cognitive and behavior impairments as a result, were rarely recommended by medical staff for referral to special education at the time of discharge (DiScala & Savage, 2003). This has resulted in under-identification and limited referrals for students with brain injury for educational support services. Developing policies and procedures that promote effective communication and discharge planning is crucial in ensuring that students will receive needed supports when they return to school following brain injury (Glang et al., 2008).

Equally important is the ongoing communication required once the student is discharged from the inpatient setting and re-enters the school setting. Providing school personnel with updated information regarding any medical or rehabilitation services will help ensure the student's school records are up-to-date, and any needed adjustments to educational programming are made. Frequent communication between those delivering outpatient and school-based therapies is essential to guarantee coordinated and effective service delivery.

Additionally, the degree of collaboration between the child's parents and educators has been found to be a critical factor influencing school success for children (Sharp, Brye, Llewellyn, & Cusick, 2006). Professionals can help families by talking to them about the importance of being a proactive advocate for their child, developing a non-adversarial working relationship with educators, and establishing a system of ongoing communication.



#### First point of contact after ABI

The student's school should be informed of the ABI immediately so that preparation can begin for the return to school. If the child is hospitalized, the hospital social worker can assist the family in contacting the student's school to determine how support can be initiated and provided. An appropriate school staff member (school psychologist, school nurse, school counselor) should be designated as the point person in order to obtain all records (medical, neuropsychological, rehabilitation therapies, etc.) with parent's written consent. Ideally, this person should have training in, or have access to, a brain injury education specialist (a special educator who has obtained certification/training in TBI and/or is certified by the Academy of Certified Brain Injury Specialists through the Brain Injury Association of America.) Upon discharge from the hospital, the hospital teacher and/or treating therapists should inform the school representative about student's current functioning levels. Best practice indicates school personnel visit the child while an inpatient to observe therapies and attend the discharge meeting to learn about the injury. This will allow for a better understanding of the child's physical, cognitive, and psychosocial status and possible need for outpatient therapy, in order to properly prepare for successful school reintegration.

#### **Understanding Service Determination**

Prior to the student's discharge, or immediately upon the family informing the school of the injury, parents should make a written request to their child's school principal or special education director for a comprehensive evaluation for special education services and provide current medical, rehabilitation, and other pertinent records. When available, discharge summaries should be sent to the school, as

they are critical in understanding the student's injury and current levels of functioning. School districts are mandated to conduct full assessments to determine eligibility under The Individuals with Disabilities Education Act of 2004 (IDEA), however, not all students with ABI require an extensive evaluation in order to determine eligibility. If up-to-date testing was carried out before the student returns to school, or the child presents with very obvious disabilities, information from those evaluations can be used to determine eligibility. If a student is determined to be eligible for special education under the IDEA, they will receive an Individualized Education Plan (IEP), which will include goals to address unique areas of need, services to address the goals, and accommodations and/or modifications to help the student access the curriculum.

To be eligible for special education services, students must meet the following educational definition of TBI that IDEA provides:

> "...an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking;

judgment; problem-solving; sensory, perceptual, and motor abilities; psycho-social behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma." [34 Code of Federal Regulations §300.8(c)(12)]

Most states define TBI using the same verbiage as the federal law, while other states have expanded their definition to include non-TBIs (e.g., brain tumors, strokes, brain infections, near drowning). Professionals working with families of students with brain injury should be familiar with their state's definition. Each state's Department of Education website will provide the current definition of TBI. If the state definition is limited to TBI, students with non-traumatic injuries may qualify for services under the category of Other Health Impaired. School officials will help parents with this process. The National Association of State Head Injury Administrators has included a document on their website that provides a state by state review of how TBI is defined by law or otherwise determined for special education and related services (see https://www.nashia.org/pdf/state\_ education\_tbi\_definitions\_criteria.pdf).

In some states, a school district may find the student eligible under Section 504 of the Rehabilitation Act of 1973. Section 504 is a broader based civil rights law that provides students with disabilities access to accommodations and services. If a student with a mild injury does not qualify for special education, a 504 Plan is another avenue for students to receive support at school. While a student on a 504 Plan is eligible to receive many of the same services provided under IDEA, an IEP affords more protections, as well as specially designed instruction. For students with significant needs or those who require more than accommodations, a 504 Plan may be inadequate to meet their unique needs.

#### **STARK&STARK** ATTORNEYS AT LAW **Experience You Can Trust in Brain Injury Law** With over 30 years of experience in the area of head and brain injuries, nationally recognized Stark & Stark attorney Bruce H. Stern devotes himself to obtaining the compensation his injured clients deserve and to providing them with personal guidance to coordinate and promote the healing process. Bruce H. Stern, Esq. bstern@stark-stark.com www.StarkInjuryGroup.com www.BrainInjuryLawBlog.com 1-800-53-LEGAL Follow Us: $(\mathbf{f})(\mathbf{y})(\mathbf{in})$ 993 Lenox Drive, Lawrenceville, NJ 08648

TABLE 1 (below) outlines some of the support services that may be available to students with ABI in an education setting. For additional information see http://idea.ed.gov/explore/view/ p/,root,regs,300,A,300.34,a,.html and https://sites.ed.gov/idea/ regs/b/a/300.34.

When the student first returns to school, services such as speech, occupational, or physical therapy may be authorized as an outpatient service post-discharge. The services recommended by the hospital team are provided under a "medical model" and paid for by insurance providers or Medicaid. The interventions are clinical in nature and support functioning in all areas of life-home, community, and school. In contrast, in the educational model, students are entitled to receive therapies deemed "educationally relevant" and are provided to enable students to access the curriculum and educational environment, and to benefit from instruction. While most medical rehabilitation therapies are discontinued within the first year post-injury, the effects of TBI on the child's cognition, behavior, and adjustment to newly acquired deficits frequently persist, and can worsen over time (CDC Report to Congress, 2014), thus school-based therapies are likely to continue to be needed for some students for longer periods of time.

#### Conclusion

Effective school reintegration of a student with ABI requires immediate and ongoing planning.

#### TABLE 1

Service Type	Why it may be needed	What it may look like
Specialized Academic Instruction	Relearning information lost New learning challenges Additional support and repetition	Homebound instruction (per physician's prescription) Instruction in separate classroom setting Special education teacher providing support in general education classroom
Adapted Physical Education	Gross motor difficulties related to successful participation in physical education	Small group or individual sessions to work on developing discrete skills
Assistive Technology	Gross/fine motor problems Speech difficulties Executive function issues	Mobility aids, augmentative/alternative communication, access to computers or technology devices
Audiology Services	Significant hearing problems surface upon return to school	Audiological evaluation conducted; supports for hearing recommended within school setting. Deaf, Hard of Hearing services may be initiated if significant hearing loss is present
Behavior Support	Aggressive behavior Obsessive behavior	Applied Behavior Analysis supervision by a behavior specialist to help teachers and staff implement a Behavior Intervention Plan
Mental Health Services	Intensive, ongoing counseling support is merited	One-to-one counseling by a mental health clinician Parent & family counseling Parent & family training & coaching
Occupational Therapy	Fine motor problems Sensory processing difficulties Executive function issues	Small group or individual sessions Consultation within classroom to student/teacher to support carryover of skills into the learning environment Provision of adaptive materials
Orientation and Mobility Services	Vision Impairment Blindness	Computers, low-vision and video aids, large print materials, Braille books, Braille writers, and audio books
Physical Therapy	Gross motor difficulties Seating issues Safety concerns in navigating campus	Individual sessions on campus (lunch area, walkways, play equipment, in classroom, etc.) to maximize safety and physical access for school based activities
Psychological Services	Depression; suicidal ideation, difficulty adjusting to disability	Counseling by school psychologist or marriage and family therapist
School Health Services	Medical supports needed during the school day	Nurse support for medication administration and other medical procedures
Speech/Language Therapy	Speech intelligibility Processing of language Social pragmatics	Small group or individual sessions Consultation within classroom to support carryover of skills into the learning environment

Professionals can assist families by encouraging them to become informed about the educational supports available and initiate the collaboration process with their child's school as soon as possible. Ongoing updates to the child's plan and services are critical as the child improves, or new consequences surface from the injury. Supports should always be individualized to the child's abilities, and flexibility and ongoing evaluation is key to addressing the child's changing needs, motivation, learning tasks and school environments.

Families should be provided a point person or case manager in the school system to help them navigate the various school environments and support services to address their child's changing learning, behavioral and physical needs. Ongoing communication between school personnel, medical providers and the family creates a flow of appropriate supports to affect the most positive outcome of recovery for the student.

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### A Review of Select Programs Addressing the Needs

#### **BrainSTEPS**

BrainSTEPS (Strategies Teaching Educators, Parents, and Students) Brain Injury School Consulting Program is a consultation and training program available in Pennsylvania and Colorado serving students in grades K-12 with acquired brain injury. The purpose of the program is to ensure these students receive appropriate educational supports. BrainSTEPS consulting teams assist and train school staff to develop and implement educational programs, academic interventions, and strategies. It also monitors referred students annually until graduation.

BrainSTEPS was modeled after long running brain injury school consulting programs developed in Kansas and Oregon, and was created in 2007 by the Pennsylvania Department of Health. It is jointly funded by the Pennsylvania Department of Health, and the Department of Education-Bureau of Special Education, and implemented by the Brain Injury Association of Pennsylvania. In 2016, BrainSTEPS was adopted by the Colorado Department of Education with funding from the Colorado Traumatic Brain Injury Trust Fund.

In 2013, an additional BrainSTEPS model to address students with concussion was developed. BrainSTEPS: Return to Learn Concussion Management Team (CMT) model trains school-building teams to manage students following concussion for the initial weeks prior to making a BrainSTEPS referral for those students who do not recover in the typical trajectory. The CMT Academic and Symptom Monitors track student academics and symptoms following concussion and assist teachers with implementation of academic adjustments until recovery. If, at 4 to 6 weeks the student has not recovered, the CMT refers the student to their local BrainSTEPS team for further evaluation. Over 1,300 PA school-based Return to Learn Concussion Management Teams have been trained. BrainSTEPS CO will begin training CMTs in the fall of 2017. www.brainsteps.net

### The Brain Injury Learning Center-One School District's Answer

In California, the San Diego Unified School District created a Brain Injury Learning Center (BILC) that offers one to one intervention for students with recent brain injuries not ready to return to a large school or a classroom setting after hospital discharge. The BILC's mission is to collaborate with the hospital to effectively transition students with recent significant brain injuries from hospital to school and to provide diagnostic evaluations and cognitive instruction to determine the child's educational needs before integrating them back to the school setting. Evaluations may include a psychoeducational evaluation to determine any cognitive, academic, social, and behavioral deficits, as well as physical limitations or health needs the child may present with and determine their present levels of functioning. Assessments for school based Speech, Occupational and Physical therapies, as well as Adapted Physical Education may also be appropriate. All of the student's service providers and assessors are supported by a Certified Brain Injury Specialist Trainer (CBIST), earned from the Academy of Certified Brain Injury Specialists (ACBIS) through the Brain Injury Association of America.

Students attend the BILC for approximately 2 1/2 months until the evaluations are complete. Then, determination of qualification for special education via an Individualized Education Plan (IEP) or a Section 504 accommodation plan (for those students who can be served in a general education setting) is made to support their assessed needs. Students may continue to attend the BILC if they demonstrate continuing progress and/or might benefit from a longer stay. When ready, and proper supports are identified and put in place, the student may return to their home school, or another appropriate educational setting supported by a special education teacher with training and education credentials in Traumatic Brain Injury. Their goal is to reinforce effective strategies and provide guidance to teachers to work effectively with these students in the classroom. The BILC allows students more time to heal in a quiet, supportive learning environment, often necessary after an injury to the brain. This welldesigned model has increased the success of many students upon return to school, and also supports their transition to post secondary options.

#### A Publically Funded Private Special Education School for Children with Brain Injury

The International Academy of Hope (*i*HOPE) (www.iHOPEnyc.org ) is the only private special education school for students with acquired brain injury in New York City. It was developed to address the unmet need of children left with significant deficits as a result of a BI. *i*HOPE offers a multi/inter-disciplinary model incorporating special education with all the necessary related services (PT, OT, SLP, Vision, Hearing, Assistive technology and adaptive communication, etc.) in one location, with 120 full time professionals currently serving over 50 students. Therapies are provided in 60-minute sessions, and many students receive between 15-20 hours of school-based therapy on a weekly basis based upon assessed need. The *program includes* the school, a clinic, an extended day program, as well as a research center, and funding is provided by the child's public school via the IEP process.

iHope stands as a world-class model of best practices in the delivery of brain injury education services to children and adolescents and is poised to offer leadership, share its expertise, and dramatically improve the outcomes for the many American youth affected by brain injury.

### of Educators, and Students with Brain Injury

#### **Coastline Community College-ABI Program**

Coastline Community College in Newport Beach, CA established the nations' first ABI program in 1978 to provide cognitive and psychosocial retraining for adults who have sustained ABI. Eligible participants must have sustained their ABI after age 13 and have a means of communication. The one-year program is offered 4 hours per day, 5 days per week, and offers two 16-week semesters and a 5-week summer session. Students learn strategies to compensate for deficits in verbal skills, memory, figural skills, critical thinking attention and organization, use of technology, and also offers neuroeducational assessment, counseling for students and their families and future planning development for employment, training or volunteering. www.coastline.edu/students/students-with-disabilities/acquiredbrain-injuries/

#### Graduate Program for Educators in Brain Injury

George Washington University prepares special education teachers to serve school age children and youth with brain injuries via on-line and in-class opportunities by offering a Graduate Certificate in Brain Injury: Transition Services. Core courses address Programs, Policies and Procedures; Brain function and impact of BI on Learning and Education; Instructional Methods and Strategies, Family Partnerships for Systems Change; and Interdisciplinary and Interagency Services Coordination. They also offer a Master's degree in Brain Injury and the coursework from the certificate can be rolled over into the Master's program. www.gsehd.gwu.edu

#### **Certified Brain Injury Specialist**

Another avenue for educators to receive training in brain injury is through the Academy of Certified Brain Injury Specialists (www. ACBIS.pro), which offers a voluntary national certification program for both direct care staff and professionals working in brain injury services through the Brain Injury Association of America (BIAA). ACBIS provides the opportunity to learn important information about brain injury, to demonstrate learning in a written examination, and to earn a nationally recognized credential.

ACBIS offers three certification options representing distinct levels of experience and supervisory skills: Certified Brain Injury Specialist (CBIS), Certified Brain Injury Specialist Trainer (CBIST), and Provisional Certified Brain Injury Specialist (PCBIS), which is recommended for teacher training programs. ACBIS offers training in the basics of understanding the physical, cognitive, neurobehavioral, and psychosocial consequences of injury, and includes detailed information on ABI in the pediatric population as well as school issues and solutions.

### One State's Approach to Certifying Educators in Pediatric Traumatic Brain Injury

In 2009, the state of California's Commission on Teacher Credentialing (CTC) sought to address a need many of their school districts facedmost of their special educators' teacher preparation programs were not routinely offering classes to address the needs of children with Orthopedic Impairments, Other Health Impairments and Traumatic Brain Injury. Although California's Physical and Health Impairment Credential (PHI) certified educators in these eligibility areas, few held the credential, and PHI credential programs available were limited. Those teachers who earned their mild-moderate or moderate severe special education credentials were often not trained or authorized to serve these populations.

To address this shortcoming, the CTC developed the Added Authorization in Special Education (AASE) to address the needs of these populations. California's AASE in Traumatic Brain Injury can be added to a special education teacher's existing credential(s), via additional online coursework offered by two institutions in the state (www.pointloma.edu; www.maderacoe.k12.ca.us). The training consists of instruction, observation, and fieldwork experience.

The four-targeted standards for the TBI-AASE include:

- 1. Characteristics of Students with TBI
- 2. Teaching and Learning for Students with TBI
- 3. Behavior and Emotional Strategies for Students with TBI
- 4. Collaborating with Other Service Providers

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### The Value of Educators and Brain Injury Education Specialists in a Pediatric Legal Case

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#### Introduction

The Centers for Disease Control (2017) considers traumatic brain injury (TBI) a prominent disabler of youth. Following discharge from hospital or rehabilitation and subsequent return to school, children have one primary role, to acquire new learning that will lead to successful post-high school options. However, following a brain injury (BI) of any severity, students often experience fluctuating levels of functioning. Some of the impairments are temporary, while others may leave the student with life-long deficits. Many brain injuries are caused by a tortious situation resulting in legal action. Utilizing a Brain Injury Educational Specialist (BIES), as well as deposing the student's teachers during the litigation process are valuable additions to the team of experts typically used in pediatric BI legal cases.

Emerging research demonstrates even mild pediatric TBIs (concussions) have the potential to result in long-term risks in behavior and cognitive performance (Rivara et al., 2012; Taylor et al., 2015). During a legal case, one might receive records that report a medical diagnosis of "mild TBI". However, this medical diagnosis may not equate to the actual functioning of the child in a real-life setting. The same is often true in moderate to severe brain injury (BI) cases, even when deficits are more apparent. Although legal case files often include medical and school records (pre-and post-injury grades, work samples, absences, disciplinary records, standardized test scores), as well as

neuropsychological evaluations and medical/rehabilitation consults, they do not provide an accurate picture of the child's daily school performance.

#### **Issues Unique to Pediatric Cases**

Prior knowledge and previously acquired skills are not commonly disrupted following a BI. Rather it is the ability to acquire and utilize new information that is often impacted. Furthermore, the brain continues to mature through the mid- to late- 20's (Giedd et al., 1999). It is not until the previously injured areas of the brain are tasked to process complex information under increasing demands that new deficits may emerge (Babikian, Merkley, Savage, Giza, & Levin, 2015; Prasad, Swank, & Ewing-Cobbs, 2017). Each year may unveil new learning challenges, causing the child to fall further behind their peers. Social, behavioral and emotional issues often surface which significantly impact not only educational performance, but also home and community functioning. Hence, it is thought to be good practice to wait as long as possible to litigate a child's case following injury, allowing time for the brain injury to fully reveal the entire extent of the acquired deficits.

TBI specific educator knowledge is required to identify and implement necessary academic supports (Davies, Fox, Glang, Ettel, & Thomas, 2013; Savage et. al., 2009). Lack of teacher BI knowledge can lead

to obstacles for a student upon return to school including: poor communication between parents, health care providers, and schools; delayed identification of social or cognitive-communicative impairments until the child declines academically, socially, and behaviorally; or failing to appreciate prior baseline functioning (the child performs adequately, although not as well as prior to the BI and simply "falls through the cracks" (Grandinette, 2012).

#### Benefits of a Brain Injury Educational Specialist as an Expert Witness

A BIES can be an invaluable litigation tool for evaluating and effectively presenting a child's comprehensive, ongoing, and future educational needs. This individual possesses the unique skills to review medical, assessment, and educational information, and form expert opinions, drawing from a specialized pediatric brain injury perspective to ensure the full effects of a child's BI are understood.

Retaining and engaging a BIES as early as possible, long before the litigation process begins provides the best opportunity for that child to receive appropriate educational support services at school to ensure an optimal outcome. This is particularly true given the current litigation climate in which mitigation of damages is frequently raised as a defense in an attempt to reduce or eliminate the damages awarded to a child who suffered a BI (CACI 3930; Model Civil Jury Instructions 5.3). The BIES can:

- Guide parents and school to identify and access proper school/ community supports
- Work with the family to initiate the referral process for a school evaluation
- Offer school staff training
- Contribute recommendations regarding curriculum, accommodations, IEP goals, and school-based therapies
- Monitor student progress over time to ensure compliance in the delivery of services

In addition to providing school supports, the BIES through parent/ teacher interviews, home/school observations, and review of onsite school files, gathers valuable information not typically found in requested records received. Information includes prior and current functional status, pre and post injury medical/family history, and academic, adaptive, social, and behavioral functioning levels. The compiled information reveals critical information pertaining to actual performance in both academic and non-academic locales. Furthermore, the BIES's comprehensive approach culminates in a detailed report comparing the student's prior and current functioning and future needs in all settings that can inform the other experts' work. As a result, a BIES offers an incredible advantage to the child's case that will only return dividends as the case moves forward.

Following a moderate TBI from a MVA one year ago, a 9th grade student, whose medical records indicated a brain bleed and loss of consciousness for 20 hours at the time of injury, was assessed by a neuropsychologist for a legal case. The findings indicated the student presented with intelligence and speed of processing skills that fell within the high average range. In isolation, these results depicted a very different profile than what was occurring in his daily life. After both school and home observations, and subsequent interviews with teachers and parents, substantial evidence was gathered by the BIES indicating the student exhibited severe challenges during the school day, affecting not only class work, but also social interactions. While the student could easily generate answers based on prior knowledge, he exhibited great difficulty applying new information, was frequently off task, could not follow multistep directions, and required continual prompting by teachers. Investigation into the school records revealed that two years prior, the student had excelled in school with straight A's, but now struggled to maintain C's and D's, and had received detention for speaking out in class five times that year. This highlights a common thread in BI cases. Students tend to perform well in testing situations taking place in a private room with no distractions, one-toone oversight, and prompting to remain on task. However, the same student may not exhibit this cognitive profile in a real-life setting that includes a classroom full of students, numerous distractions, multi-step directions, and multiple teachers. The home observation uncovered evidence that he struggled to follow routines related to chores, homework, organization, and self-care. The BIES was able to capture these functional impairments, crucial information when determining damages in a legal case.

#### The Benefits of Deposing Teachers

The child's pre-and post injury teachers yield critical and insightful testimony. Their testimony can support neuropsychological testing, allowing the clinician to clinically correlate their test protocol with the real-world learning abilities and disabilities that the child experiences daily. In addition to neuropsychologists, this testimony assists other experts such as the life care planner and vocational specialist, when forming their opinions regarding the child's likely functional levels, needs, and future outcomes had the injury never occurred.

In a recent case, a truck driver who did not see him due to a blind spot injured a child. As part of the case, an unbiased investigator interviewed the teacher, and her deposition was taken by the defense quite some time after the injury.



- Q. Do you recall Christopher?
- A. Yes. He was a student in my class when he was in 3rd grade and then later again when he was in 5th grade.
- Q. Have you kept in touch with Christopher since he graduated from your 5th grade class?
- A. No.
- Q. What did you tell the investigator?

A. I did tell him I remembered Christopher and I noticed differences. The reason I remembered Chris vividly is because he reminded me very much of my own son: Big boy, quick-witted; quick with a response, not always at appropriate times; didn't like to do homework. After the accident, Chris was different, and at first I knew it was because of his recent accident, but he didn't really get much better over time. The quick-wit was gone. He was not quick to reply, still didn't like doing homework, but definitely, yes, there was a difference.

### **Q&A** Excerpts from the deposition

#### Q. Can you give me any examples?

A. It's been a long time, but I just have this impression of a young man, very similar to my son, who was always quick with the repartee, always had something to say back. Afterwards, he was just quiet, sullen and withdrawn. I missed the boy he was before the accident.

An approach when interviewing or deposing teachers can include "notice" questions. Not, "What did you notice?" but rather, "Did you notice...?"

Q: You said you noticed that after the accident Christopher was much quieter. Is that an accurate description of the difference?

A. Yes.

Questions framed around many of the recognized BI symptoms are very compelling. The answers afford numerous opportunities for assessors to demonstrate real time correlation with their test data.

Q. Did you notice any other differences that he exhibited after the accident?

Specific questions might include, "Did you notice ....."

- Problems with memory, attention, concentration, tracking, processing, direction following, distractibility, impulsiveness?
- Subjects that became more difficult?
- Difficulties with:
  - Completing assignments and/or turning in homework?
  - Organization and time management?
  - Withdrawal, isolation or socialization with peers/teasing?

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While this line of questioning provides important information, one cannot rely solely on teachers to recognize the impact a BI has on classroom functioning. Most teachers have not been trained to identify or academically support students with BI (Glang, Dise-Lewis, & Tyler, 2006). Utilization of a BIES ensures the jury is presented with an accurate picture of the child's functions in daily settings, and serves as a bridge connecting other experts' findings.

Brain injury is regularly referred to as a hidden disability in students because many re-enter school and appear to have returned back to normal. Often, school staff remains unaware that a BI occurred, unless notified by the parents. Even when notified, many educators do not have the training in the specific nuances and educational needs of students following a BI. Therefore, including the expertise of a BIES in legal cases will ensure that the current and future impacts of the child's BI are recognized and well substantiated.

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### The Under-identification of Brain Injuries and the Relationship with Juvenile (and Eventually Adult) Criminal Justice Involvement

- Kim Gorgens, PhD
- Drew Nagele, PsyD, CBIST
- Judy Dettmer, PhD
- Stephen Hooper, PhD

Traumatic Brain Injury (TBI) is a significant public health problem in both the adult and pediatric populations, with 2.8 million TBI's each year resulting in more than 2.5 million Emergency Department visits, 282,000 hospitalizations, and 50,000 deaths (Taylor, Breiding, & Xu, 2017). By definition, a TBI occurs when an external force alters the functional integrity of the brain such that an individual is functioning differently following the injury, and can occur in mild (concussion), moderate or severe brain injuries. These functional differences can be temporary or permanent, and may contribute to many of the behaviors that create legal difficulties for an individual. The many cognitive characteristics that can be seen following a brain injury, such as impulsivity, poor problem solving and decision-making, slow processing speed, poor judgment, inability to interpret social cues efficiently or accurately, inattention, and cognitive fatigue, can lead to the maladaptive behaviors for both children and adults, and can result in legal challenges and, perhaps, incarceration in the prison system for adults, and placement in a juvenile justice facility for children and adolescents (New York Model Systems, 2006).

It is important to note that these data are only reflective of TBI and those that seek medical attention. A study by Corrigan and Bogner found that approximately 42% of individuals who meet the Center for Disease Control and prevention definition of brain injury did not seek medical attention (Corrigan, Bogner 2007). Additionally, these data are specific to TBI and do not included non-traumatic mechanisms of injury such as stroke, brain tumor, anoxia, etc. who can present with similar challenges. Unfortunately, nationally, data on non-traumatic brain injury is limited.

#### The Prevalence of TBI in the Justice System

#### Adult Justice System:

More than 1.5 million individuals are in state and federal custody (Department of Justice, Bureau of Justice Statistics, 2014). The prevalence of individuals with a history of TBI in those settings has been consistently demonstrated to be disproportionately high. One of the first studies to investigate the rates of TBI in offender populations was conducted by Slaughter, Fann, and Ehde (2003) who reported the rate to be 87% in a county jail setting. Schofield et al. (2006) then reported the TBI prevalence in all offender populations to range from 25-87% and, later, Williams et al. (2010) documented the prevalence of TBI in those settings to be 65%. In a more recent study, Ferguson, Pickelsimer, Corrigan, Bogner, and Wald (2012) found that 65% of male inmates, and 72% of female inmates, reported at least one TBI resulting in a change in consciousness. Finally, some of the current authors studied the incidence of TBI in a mental health transition unit at a county jail and found the incidence of TBI among a sample of offenders with a co-morbid mental illness to be 96% (Gafford, McMillan, Gorgens, Dettmer, & Glover, 2015).

#### Juvenile Justice System:

As to younger offenders, McKinlay et al. (2013) looked at the relationship between individuals who experienced a TBI during childhood and adult offending behavior and found that those who experienced childhood TBI were more likely, as adults, to have an offending history. Kaba et al. (2013) reported that 67% of adolescent detainees in NYC jails reported a history of at least one brain injury. The association between brain injury and the juvenile justice system is complicated by the observation that many children and adolescents within this system also have high rates of mental illness and substance abuse disorders (Perron & Howard, 2008), most of which pre-date their involvement with the juvenile justice system (Corrigan & Deutschle, 2008). The presence of brain dysfunction in childhood is associated with a greater risk for the development of a psychiatric disorder, far more so than with other physical injuries (e.g., Yule, 1970). Perron and Howard (2008) found significantly greater psychiatric distress, earlier onset of substance abuse behavior, and more lifetime substance abuse and suicidality in a population of young people with TBI. TBI can also negatively affect a child's cognitive ability (Prasad, Swank, & Ewing-Cobbs, 2016). For example, adolescents with TBI and conduct-disorders have been found to have a high rate of learning disabilities (Robbins,

Beck, Pries, Jacobs, & Smith, 1983), generalized problems with language performance (Stellern, Marlowe, Jacobs, & Cossairt, 1985), and suspected executive dysfunction (e.g., impulsivity), with each of those disabilities being linked to recidivism in adjudicated delinquent boys (Haynes & Bensch, 1981).

#### Vulnerabilities:

Individuals with a history of TBI also have lengthier and more frequent involvement with the criminal justice system. Williams et al. (2010) reported that individuals with a history of TBI enter the justice system earlier (up to 4 years) and have longer and more frequent stays in custody. Piccolino and Solberg (2014) found that persons with a history of TBI were more likely to use correctional, medical and psychological services were also more likely to commit prison rule violations and were less likely to complete substance abuse treatment programs. In their study, individuals with a history of TBI also had higher recidivism rates than those without a history of TBI (51% and 33% respectively; Piccolino & Solberg, 2014). Kaba et al. (2013) reported that detained youth with TBI were more likely to be users of mental health services. And, because brain injury can lead to impaired decision-making abilities, memory dysfunction, impaired executive functioning skills, including the ability to plan, assess behavior risk, organize, remember, and connect consequences to actions, youth with brain injury may have a reduced capacity to detect unsafe situations. As a result, they have greater vulnerability to victimization or being taken advantage of by peers or malevolent adults.

#### **Recommendations to Address the Challenge of TBI in the Juvenile Justice System**

Without appropriate identification, diagnosis, treatment, and supports of youth following brain injury, they are at risk for dropping out of school, abusing substances, and being victimized. They may fail at relationships, be unable to obtain or maintain employment or housing, and/or be involved in the psychiatric or criminal justice systems. Early screening for brain injury can lead to appropriate diagnosis, treatment, and support within school and community settings. This becomes particularly important as youth are transitioning from secondary to post-secondary settings that provide much less structure and support. In the absence of appropriate identification, youth are often unaware they sustained a brain injury, the impact it can have on their functioning, nor the supports and resources they may require in order to live independently and successfully in the community. Additionally, if professionals fail to view youth through the lens of brain injury, they will not strategically apply appropriate interventions. Without brain injury specific interventions, professionals may unwittingly contribute to the cycle of failure for these youth. Accurate and early identification of brain injury and corresponding rehabilitation interventions could lead to decreased involvement with the criminal justice system, a goal worth striving toward.

There are collaborative strategies that should be considered to help prevent youth with brain injury from entering the criminal justice setting or, if they are involved already, to promote better outcomes.

The latter includes prevention of future involvement in the adult criminal justice system.

Those strategies include:

 Providing medical evidence of the brain injury and education to schools on screening and appropriate assessment measures (e.g., psychoeducational, neuropsychological) to help identify children/youth with brain injury before the cycle of failure begins. For students with significant deficits following brain injury, identification of 504 accommodation and/or special education needs is an essential first step for the engagement of appropriate intervention services. Identifying a student under the TBI eligibility category does not guarantee the provision of appropriate services; however, when a school team has no information about an injury or does not understand the nature of the injury, teachers are much less likely to tailor educational services to the student's specific needs (Todis, Glang, & Fabry, 1997). Without teacher education, students receive fewer or no services (Todis & Glang, 2008).

- Connecting youth with documented brain injury to their State's Vocational Rehabilitation agency, which under the Workforce Investment Opportunity Act (WIOA - US Department of Labor, 2014), is charged with helping students with disabilities aged 14-21 with Pre-Employment Transition Services designed to assure successful transition into the adult role of competitive integrated employment.
- Developing infrastructure within schools to better serve children/ youth with brain injury, particularly those with social-behavioral and/or psychiatric sequelae. This infrastructure should include protocol for concussion management, systematic screening, and professional development. (Dettmer, Ettel, Glang, & McAvoy, 2014; Gioia, Glang, Hooper, & Eagan Brown, 2015).
- 4. Educating juvenile justice professionals, including police and security personnel on issues related to brain injury. Some studies suggest that persons with TBI experience more problems in correctional facilities with respect to following rules, engaging in antisocial behaviors, and an overall inability to adjust to incarcerated life (Solliday-McRoy, 2004).
- 5. Developing mechanisms for screening for brain injury as youth enter the juvenile justice system. Some states are currently doing this with the support of grant funding from the US Department of Health and Human Services, Administration for Community Living, TBI Program. That includes programs in Alabama, Colorado, and Pennsylvania. Texas and South Carolina have developed a standard screening protocol. Screening should become part of the practice standard for juvenile justice settings across the country.
- 6. Developing mechanisms for conducting neuropsychological screening evaluations, and when warranted, for conducting or referring for more in-depth psychological and neuropsychological assessments. Comprehensive screening and assessment of neuropsychological function is important. Problems with attention, language, visual-spatial abilities, memory, and regulatory abilities for both cognitive and emotional functions can contribute to an individual's involvement in the system, dictate how they perform within the system, and how they adjust as they return to their communities.
- 7. Developing a model for comprehensive competency to stand trial (CST) evaluations. Defendants with a history of TBI involved in the judicial process warrant the special attention and consideration of justice professionals. In particular, TBI may impair a defendant's CST. The presence of a brain injury may also have relevance to the sentencing phase of the trial process.
- 8. Providing education about TBI and its' impact to the family and support systems. TBI can have a significant impact on the entire family system. The parents of youth with TBI frequently report extreme distress that can result in family violence from or towards the injured person.
- 9. Screen for risk of suicide. Rates of suicide and self-harming behavior are higher among individuals with a TBI than the general population. As such, training and awareness in suicide risk assessment and intervention is crucial for clinicians serving individuals with a history of TBI in juvenile justice system settings.

#### Conclusion

Brain injury is a major public health crisis. When not identified, it can lead to negative consequences that can include criminal justice involvement. The brain injury community can reduce the number of individuals incarcerated by taking the simple steps outlined, When implemented appropriate supports and services can be mobilized early on in order to prevent the worst outcomes for youth with brain injury.

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Restore Neurobehavioral Center is a residential, post acute healthcare organization dedicated exclusively to serving adults with acquired brain injury who also present with moderate to severe behavioral problems. Services range from intensive inpatient neuro-rehabilitation and transitional community re-entry services to long term supported living services. Restore Neurobehavioral Center, located in a suburb north of Atlanta, is the site of our inpatient post acute neuro-rehabilitation program as well as one of our supported living sites. We operate two other community living sites, Restore-Lilburn (GA) and Restore-Ragland (AL).

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### School Nurses: Managing Student Concussions and Privacy Concerns

• Brenda Eagan Brown, MEd, CBIS • Suzanne Oro, RN, MSN, NCSN • Karen McAvoy, PsyD

School nurses serve in a primary role as the gatekeepers and advocates for student healthcare needs, bridging both educational and healthcare requisites in the school setting. According to the National Association of School Nurses, for those schools who have access to a school nurse, these professionals should serve as key members of the school-based return to learn (RTL) concussions management team. School nurses understand the medical diagnosis of concussion, can monitor student concussion symptoms over time, and facilitate communication between the health care provider and school (Diaz & Wyckoff, 2009). However, Lyons et al. (2017) recently found that of 144 schools surveyed in Washington state about RTL concussion management processes, parents reported they were the parties who felt obligated to relay information between school and healthcare providers. Furthermore, the researchers discovered that an overarching barrier to RTL was communication between the parties involved in the student's management (Lyons et al., 2017). Schools and healthcare providers are currently being inundated with skyrocketing concussion identification rates (Chen et al., 2017). Therefore, schools should implement RTL policies and procedures for managing these concussions during the school day to not only facilitate potentially faster recovery, but to ensure a comprehensive, safe return to full participation in academics, sports, physical education, and physical play at recess.

Many schools do not have RTL procedures in place to consistently manage student concussions (of both athletes and non-athletes). Established procedures would create a consistent process for easily managing student symptoms upon school notification that a concussion occurred. First, school-based RTL procedures should include an immediate school nurse facilitated written parent consent form under the Family Educational Rights and Privacy Act (FERPA). Furthermore, the school should also ask the parent to sign Health Insurance Portability and Accountability Act (HIPAA) consent so the outside medical provider can disclose information to the school. Having these forms signed for every student who experiences a concussion would allow the school nurse to communicate and collaborate with all designated healthcare professionals involved in the student's concussion care. Additionally, it allows them to share daily academic and symptom monitoring data with the healthcare providers to ensure decisions are made using comprehensive and current academic and symptom school day data. Physician return to play/sports clearance decisions would be better informed if they included school input about how the student is performing during the school day. A physician would not clear a student to return to school/ physical activities if they were provided academic and symptom data from teachers revealing the student was still highly symptomatic while engaging in school activities.

Next, school nurses could be the designated individual responsible for ensuring the concussion date of injury and date of resolution (if recovery occurs) is noted in the student's educational and health files. Unfortunately, these two processes do not regularly occur in all schools, but could easily resolve many issues that the authors have experienced in their respective roles. Keeping track of past concussions, and their resolution trajectories provide the backstory, should learning, attentional or behavioral issues arise later in the student's academic career, and provide the needed evidence of a BI if the student should require school based interventions.

School nurses and administrators frequently face situations involving privacy rights of students and must learn to effectively bridge the FERPA and HIPAA divide. According to the *Joint Guidance on the Application of the FERPA and the HIPAA to Student Health Records (2008)*, student health records at school fall within the confines of FERPA, not the HIPAA Privacy Rule. While in most cases FERPA will require parental consent for information to be shared with an outside physician, it would permit a school official to strictly verify whether the doctor wrote an excuse or some other document, as long as other information from the student's education records is not disclosed.

Scenario

The school nurse calls the parent of a middle school student who has fallen from the bleachers in choir

class, impacting the back of her head and resulting in symptoms of a concussion, including confusion, slurred speech, and headache. The school nurse monitors the student, as the parent travels to the school to take their child for medical assistance. Prior to the parent's school arrival, the school nurse receives a call from the student's primary care provider (PCP) who is requesting current information on the student's status and the situation. The parent contacted the PCP immediately, and made arrangements to bring the student directly to the doctor. Is the school nurse able to share this information without a signed consent or parent permission?

The health and safety emergency exception to FERPA's general consent requirement allows school personnel to disclose information to appropriate parties when there exists a threat to the student as clarified in the guidance document *Family Educational Rights and Privacy Act (FERPA) and the Disclosure of Student Information Related to Emergencies and Disasters (June 2010)*. Additionally, disclosures under this provision are valid only while the threat to the student exists and does not constitute a release of the student's information for ongoing treatment and or future care. More specific information regarding the release of student information for health and safety exceptions to FERPA may be obtained from the website https:// studentprivacy.ed.gov.



### Scenario

School personnel are increasingly concerned for a high school student who sustained a concussion

four weeks prior and is still exhibiting symptoms including lack of ability to concentrate, report of headaches, and is at times, irritable in the academic setting. The parent provided a letter to the school nurse from the student's physician indicating the student was cleared from the concussion after two weeks and indicated the student could return to their normal activities in the school setting including physical education and sports. In addition, the school nurse secured a signed release of information from the parents allowing her to communicate freely with the physician for continuity of care at the time of the diagnosis.

The school nurse, concerned for the continued recovery of the student informs the parent of the on-going symptoms to which the parent replies, "We are not seeing this at home". The school nurse calls the physician's office to report the continued presence of concussion symptoms observed by school staff in the academic setting. Upon learning this new information, the physician immediately revokes the concussion Return to Play clearance and communicates with the parent the need for continued activity restrictions as well as continued monitoring to promote healing from the concussion. The parent informs the school that they are rescinding the original signed consent allowing exchange of health information, accuses the school nurse of violating privacy rights of the student under HIPAA and files a complaint to the State's Board of Nursing against the nurse's license.



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As explained in the U. S. Departments of Education and Health and Human Services on FERPA and HIPAA (http:// www2.ed.gov/policy/gen/guid/fpco/ doc/ferpa-hipaa-guidance.pdf), the HIPAA Privacy Rule does not apply to records that are protected by FERPA. Additionally, there is generally no distinction between a "health" record and an "academic" record at the k-12 level in FERPA.

Additionally, the nurse had a signed release of information from the parent provided at the time of diagnosis allowing exchange of health information between the physician's

office and the school for the purposes of continuity of care. Should the nurse continue to communicate with the physician office with the parent withdrawn release, it would constitute a FERPA violation unless the communication falls within the health and safety exception in FERPA described in scenario one.

These case scenarios highlight the pivotal role played by school nurses in facilitating effective school-medical communication. Given that the purpose of Return to Play legislation is to prevent the premature return of a student back to any sports related physical activity to minimize further risk of injury to the brain, sometimes resulting in brain damage or death, there are times when the school nurse has a moral and legal responsibility to communicate important, and/or dissenting data to a medical professional in order to keep a student safe.

The critical take away message is that all schools should establish two processes that occur immediately following the notification that a student experienced a concussion to facilitate medical to school communication. First, a FERPA release permission form should be provided to all parents/guardians granting the school permission to contact the medical provider. Second, the school should maintain open and ongoing communication and collaboration with the medical provider through the student's recovery. The medical to school communication link is strengthened when educational institutions have school nurses on staff whose role is to connect both entities to support students with health care needs in the classroom setting.

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#### **Author Bios**

**Brenda Eagan Brown**, MEd, CBIS has worked as a TBI educational consultant for 22 years. She is the State Program Coordinator for BrainSTEPS Brain Injury School Consulting Program in PA and an adjunct professor at the George Washington University. She is currently in a Mind-Brain doctoral program at Johns Hopkins University.Brenda is published, regularly presents at the national/international levels, and has received multiple awards in the field of TBI. She has trained over 1,300 Return to Learn Concussion School Teams, co-led the 1st National Concussion Return to Learn Consensus, and is co-creator of www.getschooledonconcussions.com. Her brother sustained a severe TBI when they were teenagers, which is where her passion for helping students began.

**Suzanne Oro**, MSN, RN, is a Nationally Certified School Nurse and a Fellow of the Johnson and Johnson School Health Leadership Program. She currently works as Director of Health Services for Cherry Creek Schools in Colorado and is a member of their BrainSTEPS team. Her practice focus addresses health disparities in vulnerable populations, specifically Title One elementary schools, and implementing population and community-wide health programming to promote health.

**Karen McAvoy**, PsyD, is dually credentialed as a clinical and school psychologist. She has been involved with the Colorado Department of Education as a Brain Injury Consultant since 2010 and was instrumental in the crafting of language leading to the stand alone special education eligibility for Traumatic Brain Injury (TBI) in the state of Colorado in 2013. Karen has 27 years in education; 20 of those years in a school district holding positions as school psychologist, coordinator of the TBI team, coordinator of mental health services and coordinator of manifestation determinations. Karen provides trainings to Colorado school districts on neuroeducational assessment and intervention, understanding the function of skill deficit in behavior and executive dysfunction and is an adjunct professor in the University of Colorado Denver School Psychology PsyD program. Karen is also the author of REAP-a community-based multi-disciplinary team approach to concussion management and is the Director of Psychology at the Rocky Mountain Hospital for Children Center for Concussion.





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# BIP expert interview



Roberta DePompei, PhD, CBIST

### with Roberta DePompei, PhD, CBIST From Acute Care to School: What's Missing?

**Roberta DePompei**, PhD, is a recently retired Distinguished Professor, Interim Dean of the College of Health Professions, and Director of the School of Speech-Language Pathology at the University of Akron. Her major area of research and interest is in cognitive-communicative challenges to the individual with brain injury and the impact of brain injury on the family system. An advocate for the needs of youths with brain injuries and their families, she is on numerous national and international task forces and committees. She has helped to develop support groups and a community based collaborative of agencies to problem solve issues for this population. Widely published, and a national and international presenter, Dr. DePompei is recognized for her unique and innovative approaches for functional community inclusion. She was awarded the Sheldon Berrol, M.D. Clinical Service award by BIAA in July of 2002. She received the Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation in March, 2004; Fellow of the American Speech-Language-Hearing Association in 2006; the Legends Award from the North American Brain Injury Society in 2008, award for lifetime achievements in TBI from the National Task Force on Children's Issues after ABI in 2012 and was honored with the Ontario Speech Language Association's Mark Ylvisaker Distinguished Lecturer award in October, 2015.

#### Can you summarize the role that an SLP plays in the rehabilitation of a child with an ABI?

Oftentimes the Speech-Language Pathologist is only thought to be the person who corrects mispronunciations of words (articulation) or who collaborates when there is a swallowing issue for a child with ABI. What is usually ignored is the essential role the SLP plays in working with the child/adolescent with ABI when cognitive-communicative and social communication issues are present.

The SLP is trained to enhance expressive and receptive language abilities, which forms the basis for memory, problem solving, organization and executive functioning skills. Language is the cornerstone for most learning and when the child with ABI presents with cognitive-communicative challenges (which can emerge over time as the child develops) the SLP should be involved.

#### What is the educational impact of cognitive-communication deficits?

As learning is the job of children and adolescents, having the ability to successfully use language for learning is a major skill needed to be successful in the education system. Additionally, we know that social communication skills are key to performing well with others in home, at school, and in the community. Social communication can be defined as the synergistic emergence of social interaction, social cognition, pragmatics (verbal and nonverbal), and receptive and expressive language processing. All of these aspects can be affected after ABI and are integrated with the cognitive communicative abilities that the SLP is trained to support.

#### In acute care, when should an SLP screen a child with a TBI?

When should they not? If we acknowledge that cognitive-communication and language acquisition are critical developmental skills for ALL children, then it should be imperative that a screening be completed and a baseline for cognitive communicative abilities be established when there is an ABI. There should be a protocol for screening children with mild to severe ABI and the SLP, as a valued team member, should be included routinely.

Knowing the increased cognitive-communicative demands of a full-day school placement, what can the acute care SLP do to obtain an accurate representation of a child's need for a school referral?

It is important to collect information concerning distractibility, task completion levels, expressive and receptive language competence, and social awareness. This can be obtained if the child has been placed in functional situations, such as: sitting and communicating in a lounge area, working in therapy in a noisy area such as PT or OT, or visiting the gift shop or cafeteria. A school referral should list how any areas of concern that may impact academic success based upon those functional/social observations.

#### Can social communication deficits be assessed in a hospital environment?

Functional assessment of social communication occurs wherever the child is trying to communicate. Therefore, if the child is in the hospital, that is the social environment where he should be assessed. He will communicate wherever there is a need to do so. The child interacts with nurses, the family, therapists, aides—and most of these interactions are social in nature. Thus, there is always an opportunity to evaluate social skills wherever the child is. The hospital referral should then contain requests for both academic and social language and cognitive communicative evaluations by the school.

In working in the home-hospital school for a large school district, I have only once been contacted upon initial re-entry for a Speech/Language assessment. There seems to be a disconnect from one setting to the next. What are the barriers to transition of care services from the acute setting to the school system?

Goodness, this is a question that has been asked for over 40 years! It seems that medical and educational personnel believe they live in separate worlds with varying "rules". In both settings, we blindly follow the same concepts.

- 1. There is an "identified patient" or "identified student;"
- 2. There is an expert who diagnoses the problems and prescribes treatment;
- 3. This expert decides when the treatment worked or did not work and discharges the child when the interventions are deemed completed.

The only difference is that the school is concerned with educationally relevant needs and the hospital is concerned about medically relevant needs. School based LAS services are provided so that a child can access the educational curriculum and socialization skills required in that setting. I submit that the above concept does not work for the child and family with ABI. A functional basis that is concerned not with weaknesses but emphasizes strengths and supports, within the context where the child communicates, is a more successful means for support. This positive therapeutic method provides a more successful approach that denies some of the barriers suggested above.

#### In acute care - what are some starting points?

The acute care team should:

- 1. Obtain parental permission and send referrals to the school.
- 2. Communicate with school personnel early in the hospitalization process (do not wait until discharge).
- 3. Accept parents as partners in this process and help them to become successful advocates for their child.
- 4. Post ABI, a child should be followed for years until the chance for any developmental stalls are eliminated.

#### In schools – what are some starting points?

- 1. Develop and routinely use a protocol that includes screening for language, cognitive-communication and social interactions.
- 2. Establish lines of communication with specific individuals at hospitals and home to ease communication.
- 3. Post ABI, a child should be followed for years until the chance for any developmental stalls are eliminated.

#### Final thoughts?

We need to consider the medical, educational and social needs regardless of where the child is located. As professionals, we all sat in the same classroom and learned the same information. Why now does the setting where we work determine what is best for the child? When there are ongoing medical or educational concerns, all team members should remain in the circle of care.

All members should be aware that the child likely requires ongoing support and do what is necessary to assist them in accessing ongoing services, regardless of the setting. Take the extra steps necessary to assure there is communication between hospital and school personnel regarding the child's needs, and that school personnel have an understanding of the deficits children with ABI may present with and how they can impact school performance.



#### About the Interviewer

**Melissa Gardner**, MS, CCC-SLP is a Speech-Language Pathologist in Los Angeles, CA, and currently pursuing her CBIS. She has worked in the home-hospital educational setting with students with ABI, conducting evaluations and providing therapy leading to school re-entry. Melissa was recently hired at the Diagnostic Center of Southern California, one of three regional assessment centers in the state. They are the foremost providers of specialized assessment, training, and technical assistance to all state Local Education Agencies, and is operated by the California Department of Education's State Special Schools and Services Division.



### literature review

#### Falling Away From You-One Family's Journey Through Traumatic Brain Injury

#### By Nicole Vinson Bingaman

Convergent Publishing, LLC 4445 Corporation Lane, Suite 227, Virginia Beach, VA 23462, 2015

On November 22, 2012 life unexpectedly changed for the Bingaman family. Through no choice of their own, the Bingamans embarked on an unintended journey. The journey began in the still of the night on Thanksgiving Eve. Like many families, the Bingamans were looking forward to getting together for a family meal that included Keith and Nicole and their three sons, Taylor, Tanner and Avery. Nicole, had planned to make each of the Bingaman boys' favorite dishes. But rather than sitting down to enjoy Nicole Bingaman's time tested and son approved recipes, the Bingamans found themselves huddling together at Geisinger Medical Center where Taylor, the oldest of the Bingaman boys, was fighting for his life. Taylor had fallen down a flight of stairs, sustaining a catastrophic, and potentially fatal, traumatic brain injury (TBI).

Falling Away From You is the book, written by Taylor's mother, Nicole Vinson Bingaman (Nicole), which chronicles the family's journey from their home in Mifflinburg, Pennsylvania to Geisinger Medical Center in Danville, to Bryn Mawr Rehabilitation Hospital, and later to Paoli Hospital, then back to Bryn Mawr, and returning to Geisinger, then finally home. The book, while including some of the author's journal entries is characterized as a love story even though fear, frustration, helplessness, learning, hope, gratitude, resilience and the Bingaman family's adaptation to Taylor's injury, survival and recovery are ever present. Of no less importance, Falling Away From You is a book members of the medical community, brain injury professional, lawyers, family members of TBI survivors, as well as the general public, are likely to find interesting because it is a first person, emotion laden story offering a portal to the complex and unfamiliar world of TBL Early on the author Nicole Bingaman sets out her goals which reflect the emotional tone of the book.

"I hope that you can hear my heart. I hope to give you a glimpse of what life is like for traumatic brain injury survivors and those who love them. I hope to give you some inspiration and strength in your present journey and those to come. I hope to educate you about some of the things that I did not know, so that you may better understand what TBI actually means. I also hope that bits and pieces of my broken heart are healed in the process."

While describing Taylor's injuries, his treatment, his vulnerabilities, and recovery process, Nicole also shares how important it is that survivors of TBI have someone advocating for them throughout the process of their care. The importance and benefits of establishing guardianship and power-of-attorney are also noted. The author also stresses that every brain injury is unique, though they all may have common elements. This is an important idea for readers to grasp early on lest they think that a "one size fits all" approach to recovery becomes an expectation.

As she describes Taylor's injury, their complications and his care, Nicole shares the emotional weight that a TBI places on a family system. She does not do this citing family systems theory or dispassionate academic sources. Rather, she draws the reader into the family milieu as it evolves throughout the course of Taylor's (and the entire family's) journey.

She shares her fears, the doubt she had about following the instincts that drove her to speak up on her son's behalf when his treatment team "rounded" each morning. Nicole describes the essential importance of learning, speaking up and respectfully insisting that the people treating Taylor get to know him and think about him as a person, not simply a patient in a comatose state, confined to a net enclosed hospital bed, unable to advocate or take care of his most basic needs.

The anecdotes that contribute to the authenticity of the story Nicole tells have relevance for every survivor of major TBI as they are about what her son, his younger brothers and what she and her husband Keith, experienced and continue to work through, now that Taylor has returned home.

Some of the practical problems that are likely to impact every survivor of TBI and their family are met head on, adding authenticity to Nicole's telling of Taylor's story. For example, the challenges posed by the Bingaman's lack of knowledge about TBI and the urgent need to learn about it while at the same time coping with Taylor's life threatening injuries are discussed in some detail. Additionally, the emotional upheaval related to having learned to trust a group of strangers, Taylor's treatment team, then leaving them to move forward with a new team, at a different facility, as part of the next step in the course of treatment is part of Nicole's story of adaptation. Coping with the anxiety caused by ambiguity that never quite goes away, despite a trend toward recovery is well described. The drive to overcome helplessness during Taylor's treatment and rehab process, yet remaining hypervigilant but hopeful, are themes that we expect will resonate with readers throughout the book.

Writing that survivors of TBI have a right and their family members have a need to have their injured loved one be cared for with respect and in a manner honoring privacy, dignity and pre-injury sensitivities, is also an important, ever present theme in Falling Away From You. Concerns about rights and dignity are particularly important as members of the Bingaman family work at coming to grips with Taylor's limitations, his being in a coma, wearing mittens, a helmet or requiring a tracheostomy to ensure a patient's safety. These and other safety measures are indicators of good, informed treatment while at the same time they are ever present reminders of vulnerability, lack of predictability and the often-present emotional disinhibition that accompanies TBI. The stories told about advocacy and striking a balance between speaking up and Nicole's fear of alienating the people treating Taylor, can be a useful addition to the information given to family members of survivors of TBI.

The chapter of the book describing the Rancho Los Amigo Scale (The Scale) while very short, may be useful to readers who are not members of the rehabilitation community, especially if introduced with professional guidance. Family members of persons with TBI often wonder how treatment teams assess a patient's needs, progress and status. As a practical matter the chapter about the Scale may serve to begin conversations that demystify evaluative processes, enable communication and facilitate family education. The Scale may be of great value to attorneys representing the interests of persons with TBI because of its wide usage and plain language.

Chapters toward the middle of the book describe Taylor's gains in rehab. While Taylor was beginning to walk with maximum assistance his gains were seen by his family coupled with the things he still could not do. This coupling of gains and losses was painful to observe. Nicole shares recalling that just a few weeks before falling, Taylor had been strong, healthy, and vibrant. Seeing him totally dependent on others was a difficult adjustment. Similarly, when, in the midst of trying to begin to normalize things by going food shopping, Nicole describes receiving a phone call telling her that Taylor was taken by ambulance to Paoli Hospital because he was having seizures. This vignette ushers readers into the reality of just how unpredictable things may be for a person and their family who are coping with a major TBI.

Throughout the book the importance of the support, emotional presence and the love of family and friends is described. There are too many examples of love to describe them in this review but the following include thoughtful gifts e.g. making sure the electric bill back home was paid as well as, Taylor's friends sending gift cards for Tanner and Avery, Taylor's "little brothers", were memorable. The important message in these parts of Nicole's narrative is that while Taylor was the identified patient, friends and family intuitively understood that his injuries were a blow to the entire family. The Bingaman family was never forgotten and the warm fabric of their familial and friendship systems was an ever-present source of sustenance.

While the outpouring of support expressed by friends and relatives helped propel the Bingaman's through some of the most difficult times during Taylor's journey, Nicole discusses that this support sometimes presented unexpected challenges. One example Nicole recounts is the difficulty she experienced reconciling her internal doubts about Taylor's future with comments she perceived as expressing "false hope." Though she readily acknowledges all expressions of support were wellintentioned, Nicole describes how phrases such as "I know he is going to wake up and be himself" and "there is a reason for everything" came across in her mind as being "misplaced." Rather, Nicole insightfully points out the value of simple expressions of connection and support such as "I love you" or I am here" were refreshingly, and genuinely helpful.

Readers will quickly learn that the Bingaman's support system was extensive and very active. The challenge of keeping everyone informed about Taylor's progress was creatively addressed using social media. The Bingaman family used Facebook postings to address questions raised by friends, to clarify any misperceptions they believed people were having about Taylor's condition, and to report on major events in Taylor's recovery process. As a byproduct of using Facebook to communicate with the large audience interested in how Taylor and the rest of the family were doing, keeping everyone informed helped manage the frequency of visitors, which became particularly important as Taylor's disinhibition emerged and his reduced capacity to tolerate too much stimulation became apparent.

Nicole describes how she found herself wending her way through the alien language of health insurance policies and the competing needs of Taylor's physicians, hospital billing departments and insurance company personnel. This part of the Bingaman story is not unfamiliar to people involved in treating, caring for or advocating for persons with TBIs. The importance of health insurance coverage as a basic right is never clearer than when an injured or ill individual's family find themselves struggling in the the complex web woven by insurers, acute care hospitals, rehab facilities and other essential providers e.g. ambulance services. Patient advocates, skilled formally trained social workers and lawyers can be especially helpful to family members mired in information overload and the realization that the cost of recommended or non-elective treatment have the potential of leading to financial bankruptcy and emotional devastation.

Upon completion of 400-some pages describing the Bingaman family's journey, as told primarily through Nicole's point of view, the final chapters of the book provide readers an opportunity to see the Bingaman's world from two additional perspectives, those of Taylor's brothers, Avery and Tanner. While Nicole chronicles the family's turbulent voyage that began when Taylor was injured on Thanksgiving Eve 2012, there is great value and much to be learned from reading about the uniqueness and power of the sibling relationship and how Taylor's TBI impacted them.

Falling Away From You is an engaging narrative, that in our opinion is a recommended read for anyone interested in learning about how one family came to grips with a major TBI. Some readers may feel the length of the book is an issue or that it is written from too personal a point of view. To the contrary we believe that the story told by Nicole Vinson Bingaman is insightful, brave and authentic. Perhaps most importantly, while Taylor and his family are back home, they continue to face the challenges of his TBI, with realism, optimism, grace and most importantly love. The story Nicole tells is testimony that for the Bingaman family, love and commitment continue to win.

#### About the Author



**Steven E. Perkel**, DSW, ACSW, LCSW is the founder and Principal Consultant of Steven E. Perkel & Associates, LLC. Dr. Perkel received his doctorate from the University of Pennsylvania. On a more personal note Steve reports that he is interested in storytelling, writing, reading and teaching. His consulting activities grew out of his outpatient and hospital based

private clinical practice, as well as an interest in persuasive communication. Over several decades, Steve has had opportunities to provide crisis management services and psychotherapy to individuals and their families who sustained catastrophic injuries, including TBI. Steve also is proud to say that the people I have served have also been some of my best teachers. As a believer in the power of family teamwork, Steve acknowledges the valuable conceptual and research assistance provided by Ben Perkel, his research assistant as they each read and discussed Falling Away From You. Steve can be reached at sperkel@stevenperkel.com.



### literature review

#### Manual of Traumatic Brain Injury Assessment and Management 2nd Edition

By Felise S. Zollman, MD, FAAN, FAAMA

The Manual of Traumatic Brain Injury Assessment and Management 2nd Edition lives up to its claim of being a comprehensive, evidenced-based guide for the diagnosis, treatment, and long-term management of traumatic brain injury (TBI). This thorough, rehabilitation-focused book will serve as a detailed reference for physicians, nurses, psychologists, counselors, physical and occupational therapists, speech-language pathologists, and case managers, amongst others. The content is applicable to experienced providers and early-career practitioners alike, as well as medical and graduate students. Indeed, given the easily digestible yet extensive content, it would be a welcome addition to the syllabus of any medical or graduate school course focused on TBI rehabilitation.

The book's organization lends to its ready usefulness as a clinical guide and educational text. The individual chapters are succinct, with clearly marked sub-sections that facilitate information gathering. At the conclusion, each chapter also includes key points and additional readings, which further facilitates learning. There is some redundancy between chapters, but this is not extensive and is a commonality in most multi-author compendiums. The chapters are also formatted to parallel the continuum of rehabilitation care, starting with acute injury and spanning to community reintegration, which creates a logical flow of information.

The 2nd edition contains updated content, formatting, and several new chapters. Chapter content has been revised to include the most recent evidence-based research and current best practices. The references are up-to-date and from peer-reviewed journals and respected sources such as the CDC, with only a few less traditional sources such as Wikipedia. New chapters include anoxia in TBI, assistive technology, screening for emotional distress, and neurobehavioral sequelae. The exceptional quality of content is supported by the contributing authors, who include internationally renowned clinicians and researchers on TBI management.

The editor has done an excellent job at providing empirically-supported information on a variety of clinical issues encountered across the spectrum of TBI rehabilitation. The book is divided into five broad content areas. Part I – Core Concepts – covers fundamental concepts such as nomenclature, epidemiology, severity classification, and neuropathology. Part II - Mild Traumatic Brain Injury - includes chapters on diagnosis and evaluation, sports-related concussion, second impact syndrome, postconcussion syndrome, imaging, somatic disorders, and PTSD. Part III - Moderate to Severe Traumatic Brain Injury - contains chapters addressing pre-hospital care, neurosurgical management, disorders of consciousness, nutritional issues, rehabilitation therapies, cognitive impairment, visual dysfunction, behavioral management, and prognosis, amongst others. Part IV - Complications and Long-Term Sequelae - addresses common complications and long-term rehabilitation challenges, including endocrine dysfunction, spasticity and movement disorders, posttraumatic seizures, headache, neuropsychiatric sequelae, and sleep disturbances. Part V - Special Considerations and Traumatic Brain Injury Resources - addresses issues such as life care planning, return to work, forensic involvement, alcohol use, and issues pertaining to specific populations such a military personnel, pediatric patients, and older patients.

There are several unique content areas that are commonly neglected in other TBI references, including highly relevant chapters on injury prevention, sexuality, community resources, and community integration. There is also a detailed, multi-chapter discussion of sportsrelated concussion that includes sports-specific recommendations for football, boxing, soccer, baseball, ice hockey, and cheerleading. One particularly unique aspect of this book's content is the inclusion of a chapter written by a survivor. The author, a 40-year-old woman, sustained a severe TBI at age 17 consequent to a motor vehicle accident. Her eloquent narrative of physical and emotional recovery serves as a powerful reminder of the deeply personal and profound journey that underlies TBI rehabilitation. As practitioners, it is all too easy to focus on the myriad of symptoms and sequelae that overshadow the individuals we help. Her words serve as a powerful reminder that practitioners and patients alike are motivated by hope

- "My position, borne of experience, persistence, and hard work, is that you don't have to just live with the devastation of traumatic brain injury. There are always options. There is always hope. There is always possibility."

Although an overall excellent resource, there are several relevant topics that are underemphasized or absent in this edition. A revision of the book would be strengthened by including a more substantive discussion of malingering and symptom magnification in mild TBI. This topic is only briefly discussed in the chapter on confounding factors in postconcussive disorders. The chapter on post-injury alcohol abuse would be strengthened by expanding the discussion to include abuse of prescription medication and illicit substances, which is an increasingly common problem, particularly for opioid medications. In addition to return to work, a well-rounded discussion of return to productivity would ideally include return to academics, a topic that is highly relevant to young adults. Finally, TBI is a shared experience that affects family, caregivers, and community. Ideally, the book should include a chapter devoted to the impact of injury on family and caregiver functioning, as high levels of distress are well-documented in this population. Notwithstanding these minor issues, the overall content is quite thorough.

In sum, the Manual of Traumatic Brain Injury Assessment and Management 2nd Edition is an excellent clinical text for both experienced and early-career practitioners, as well as students. Readers have the expertise of world-renowned clinicians and researchers at their fingertips. The succinct format allows for ready access of complex information. Perhaps of greatest value is the book's practical focus on assessment, treatment, and prevention, which makes it an invaluable resource for practitioners. This text should be a welcome addition to the bookshelf of any practitioner working with individuals with TBI.

#### About the Reviewer



Ana Mills is a clinical psychologist and assistant professor in the Department of Physical Medicine & Rehabilitation at Virginia Commonwealth University Medical Center. Dr. Mills specializes in neuropsychological assessment and psychotherapeutic treatment of individuals with acquired brain injury. Her research activities include investigating the efficacy of promoting resiliency after TBI. She has authored a number

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### SCARLETT LAW GROUP

Scarlett Law Group is a premier California personal injury law firm that in two decades has become one of the state's go-to practices for large-scale personal injury and wrongful death cases, particularly those involving traumatic brain injuries.

With his experienced team of attorneys and support staff, founder Randall Scarlett has built a highly selective plaintiffs' firm that is dedicated to improving the quality of life of its injured clients. "I live to assist people who have sustained traumatic brain injury or other catastrophic harms," Scarlett says. "There is simply no greater calling than being able to work in a field where you can help people obtain the treatment they so desperately need."

To that end, Scarlett and his firm strive to achieve maximum recovery for their clients, while also providing them with the best medical experts available. "As a firm, we ensure that our clients receive both the litigation support they need and the cutting-edge medical treatments that can help them regain independence," Scarlett notes.

Scarlett's record-setting verdicts for clients with traumatic brain injuries include \$10.6 million for a 31-year-old man, \$49 million for a 23-year-old man, \$26 million for a 7-year-old, and \$22.8 million for a 52-year-old woman. In addition, his firm regularly obtains eight-figure verdicts for clients who have endured spinal cord injuries, automobile accidents, big rig trucking accidents, birth injuries, and wrongful death.

Most recently, Scarlett secured an \$18.6 million consolidated case jury verdict in February 2014 on behalf of the family of a woman who died as a result of the negligence of a trucking company and the dangerous condition of a roadway in Monterey, Calif. The jury awarded \$9.4 million to Scarlett's clients, which ranks as

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one of the highest wrongful death verdicts rendered in recent years in the Monterey County Superior Court.

"Having successfully tried and resolved cases for decades, we're prepared and willing to take cases to trial when offers of settlement are inadequate, and I think that's ultimately what sets us apart from many other personal injury law firms," observes Scarlett, who is a Diplomate of the American Board of Professional Liability Attorneys.

In 2015, Mr. Scarlett obtained a \$13 million jury verdict for the family of a one year old baby who suffered permanent injuries when a North Carolina Hospital failed to diagnose and properly treat bacterial meningitis that left the child with severe neurological damage. Then, just a month later, Scarlett secured an \$11 million settlement for a 28-year-old Iraq War veteran who was struck by a vehicle in a crosswalk, rendering her brain damaged.

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