CURRENT DIMENSIONS IN LIFE CARE PLANNING

Life Care Planning for the Adult with Traumatic Brain Injury
Life Care Planning for Children With Acquired Brain Injuries
Life Care Planning – An International Perspective
The Role of Standards of Practice for Life Care Planners
The Affordable Care Act – What Effect Does It Have on Life Care Plans?
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This is the first edition of the Brain Injury Professional following the announcement of the formal affiliation of the North American Brain Injury Society (NABIS) and the International Brain Injury Association (IBIA). As a result, one of the expanded benefits is a quarterly subscription to the Brain Injury Professional for both groups. The Brain Injury Professional is the largest circulated publication in the field of brain injury. I welcome our new subscribers and look forward to our partnership in future BIP editions as we move forward together in translating brain injury research into practice.

In each edition, our special edition editors are selected to bring a topic of importance to the field. This includes samples of best practices, current research, relevant legislative issues as well as links to additional resources. In this edition, we revisit life care planning and the important role life care planning makes in evaluating and defining the life-long needs of individuals who experience catastrophic injury or have chronic health care needs as a result of brain injury. Over the last many years, there has been significant evolution of expertise and practice as well as recognition of life care planning as a specialty practice. In this edition, Dr. Harvey E. Jacobs has selected experts to address key issues and practices in life care planning for children and adults both in the U.S. and internationally in the UK and Canada. A review of the development of and most recent updates on standards of practice is also included. This edition also provides an update on the continued evolution of the legal challenges and the impact of the Affordable Care Act ACA, in its current form, in planning and paying for one’s future needs. I want to thank Dr. Harvey E. Jacobs for bringing his usual gold standard to this edition.

I hope you also attend the upcoming International Brain Injury Association’s 12th World Congress on Brain Injury to be held at the Sheraton New Orleans Hotel on March 29-April 1, 2017. As a reminder, for the years that the International Brain Injury Association Conference is in the US, NABIS joins forces with IBIA in offering the professional conference and does not hold a separate medical professional conferences.

The NABIS 30th Annual Conference on Legal Issues in Brain Injury is being held in conjunction with IBIA 2017. Conference Chair’s Simon Forgette, Esq. and Bruce Stern, Esq. have gathered experts on topics such as the admissibility of DTI, case study preparation, pediatric injury, trial psychology and a view from the defense among other. Who should attend include attorneys, neuropsychologists, allied health professionals, expert witnesses and all those involved in brain injury litigation. Attendees will come away from the conference with the essential hands-on tools needed to successfully manage a complex brain injury case. Please refer to the NABIS and IBIA websites for more details www.nabis.org or www.internationalbrain.org.

about the editor in chief

Dr. Debra Braunling-McMorrow 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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This is the second special issue of Brain Injury Professional devoted to Life Care Planning. First addressed in 2006, life care planning continues to articulate and integrate vital services to help optimize the lives of individuals who experience disability. Effective life care planning is a disciplined process based on a consistent methodology and team approach. The conceptual basis of life care planning also addresses many of the unique and dynamic characteristics of brain injury.

In this issue, Jacobs, Katz and Berens discuss clinical and procedural considerations in life care planning for adults with brain injury. It is important to determine what relationships exist between the brain injury and noted disability early in the process. Not all problems may be related to a brain injury, yet at the same time, a brain injury might exacerbate premorbid conditions. Effective life care plans address a variety of medical, neurological, psychological/behavioral, cognitive, aging, vocational, social, leisure and other issues within a dynamic framework that is contextually referenced to the individual’s historic functioning and life quality.

The specialized needs of children are reviewed by Riddick-Grisham, Grandinette and Bonfiglio. The authors note the importance of thorough evaluation, establishing clear medical foundations, documentation of functional capacities and limitations; and careful consideration of a wide range of services, supports and environments relative to the child’s age, nature and extent of the injury, associated injuries and pre-existing conditions. Special attention is paid to education, including Section 504 and more specialized services under IDEA, as well as approaches to preserve families and reduce burnout.

Baptiste and Kerr describe life care planning services in Canada and the United Kingdom. Despite universal healthcare in both countries, many people with disability have incomplete or no access to key services, especially on a post-acute basis. The timing and patterning of available services can also be contrary to individual needs, especially when frequent recertifications are required for chronic conditions. As a result, close care coordination remains essential. The authors also discuss how public and private services are blended when additional resources are available.

Karen Preston explains the continuing quality improvement processes involved in life care planning’s standards of practice. First published in 2000, the most recent edition, Standards of Practice for Life Care Planners: Third Edition (2015), took two years to create with input from multiple constituencies. Each edition has reflected the increased sophistication of life care planning practices as well as the processes involved in creating the standards. The current 14 standards reflect integral interdependence of training, professional self-determination, measurement, validation and information dissemination. They establish clear criteria regarding a life care planner’s expected knowledge, skills, and behaviors.

The dynamic qualities of life care planning extend beyond clinical considerations, to financial, legal and social changes, especially in forensic cases. Bruce Stern discusses the still evolving case law of the Affordable Care Act (ACA) in states with full vs. abrogated collateral source rules. These rules define what financial resources can be considered to cover adjudicated future expenses. Notably, during the course of preparing this article, the future certainty of the ACA has changed. However, collateral support considerations also apply to medical insurance and other financial resources. Life care planners need to be aware of the state specific guidelines in the formulation of their work.

Typically, each issue of Brain Injury Professional includes a book review. This time, we visit the popular website BrainLine, which has become a vital resource for people who experience disability, caregivers, professionals and the public. Launched in 2008, Noel Gunther takes us on a journey regarding its origins and development. Over the years, BrainLine has collaborated with people from all walks of life and in the process BrainLine’s evolution has been guided by its users. This has included establishing Brain Line Military and collateral sites on Facebook, YouTube and Twitter. Last year, people spent over 7 million minutes watching videos on its YouTube channel and this year, almost 2.5 million unique visitors will access the primary site.

Assembling this special issue has been a distinct privilege and provided me with unique opportunities to work with highly dedicated professionals who donated irreplaceable time to author the associated articles. I am forever indebted to each contributor for his or her work. I hope that this special issue furthers the knowledge and interest of people who are familiar with life care planning and kindles a special interest for people new to this field to learn more.
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Traumatic brain injury (TBI) is not a singular impairment. It originates from many different sources and represents diverse impairments that can dynamically affect almost any aspect of daily life. Hence, comprehensive, contextual and holistic perspectives are required to develop life care plans. As aptly noted 80 years ago, “it is not only the kind of injury that matters, but the kind of head.” (Symonds, 1937).

Multiple factors create the unique multivariate signature of each TBI. This includes the nature of injury onset; the intensity, inflection, nature, and foci of cerebral insult(s); comorbid injuries; the focus, time and quality of initial care; appropriateness of subsequent treatment; premorbid status; age at onset; history of neurological insult; and other issues. Attempting to ascribe TBI outcome to any singular factor is likely to be erroneous. For example, the Glasgow Coma Scale is often used to estimate initial injury severity, but singularly has limited prognostic value.

Similarly, identification of a TBI in an index event (the injury or medical event that originated subsequent disability) alone is often insufficient to ascribe causation. Additional information is required to determine if the TBI is the predominant factor of subsequent sequelae, a concurrent factor, a secondary issue, or inconsequential. Challenges to causation may be more frequently noted in cases of concussion or mild TBI if less direct signs of neurologic impairment are evident, or if there are competing hypotheses of attribution. Deliberations regarding causation are typically the province of treating and evaluating professionals, but sometimes also the life care planner if so qualified. Ultimately, each life care plan relies on the quality of all available case data, treatment, diagnoses, course, and methodology to establish credible foundations. The remainder of this article focuses on cases that involve TBI.

**Traumatic Brain Injury as a Dynamic Process**

The longitudinal course of a TBI is as important as its initial effects. Not all impairments may be evident at the time of onset and secondary complications can surface. Recent literature has identified TBI as a chronic, lifelong disease process (Masel and DeWitt, 2010). TBI may affect pre-existing conditions and alter their previous management protocols. There may be comorbid injuries that contribute their unique impairments, especially when this involves significant orthopedic, spinal cord, burn or other large system injuries. During the process of triage, such injuries may take priority over TBI, or mask neurological, cognitive and behavioral TBI sequelae until their relative stabilization.

Personological, environmental and contextual factors require equal consideration. They play important roles regarding return to premorbid routines and responsibilities. Changes in cognitive, emotional, and behavioral profiles often have more dynamic and pervasive effects on long-term outcomes than initial medical and physical impairments. For example, increased impulsivity, diminished self-awareness and altered moods can affect a broad spectrum of social relationships from intimacy, to community acceptance, to work. Behavioral problems are a primary reason that individuals are rejected from or prematurely
discharged from treatment, or alienated from family and friends. Personal history also interacts with presenting impairments. For example, selected memory or problem-solving impairments may adversely affect someone just entering the job market where new learning is essential. Conversely, a person returning to a long-standing and well-learned position may be less affected by such challenges, though other issues may cloud capacity. Social and cultural values, lifestyles and how the individual is regarded by others require similar consideration. What may be acceptable in one community or social support network may be repulsive in another.

**Life Care Planning Methodology**

The conceptual basis of life care planning addresses many complex issues surrounding TBI. Life care plans characteristically reflect the structure, context and qualitative relationships of the “whole” individual and not just immediate impairments. They document services and supports required to facilitate lost or altered premorbid capacities, preferably within personally relevant daily activity patterns and environments. Sometimes, required services and supports are not locally available, substantial deficits may require specialized services, social support networks may deteriorate, or changes occur relative to personal competency. Still, life care plans emphasize prospective services that support functional capacities and life quality.

Qualified life care planners are required to follow a consistent methodological process to establish reliable and valid findings. This approach has been well reviewed in the literature (Weed and Berens, 2013) and is briefly noted here. Salient steps include:

a. Comprehensive review of all available records and supportive documentation.

b. Interview of the injured party at his/her place of residence when possible, as well as family members or other key collaterals who know the person both before and since injury onset.

c. Direct consultation with treating and/or evaluating professionals to establish foundations for requisite needs and services, in addition to or in support of any identified in the records review and interviewer information.

d. Reference to clinical practice guidelines and relevant research literature, as needed, to further establish recommendations and plan foundations.

e. Identification of personally appropriate, clinically relevant, and accessible services and supports to specifically meet identified recommendations.

f. Documentation of charges associated with each identified recommendation specific to location and service.

g. Practicality in the recommendations relative to presenting needs, individual capacities, available resources and lifestyle.

**Special Considerations When Evaluating an Adult with TBI**

Developmental processes and history often distinguish life care plans for children and adults. Children are in developmental accession, which can be uniquely and longitudinally affected by TBI. Their social support networks and skills repertoires are evolving. Adults have typically reached their medical and neurological asymptote, or are in age-related regression. Adults also have more diverse life experiences that may affect analysis of capacities, presenting challenges and topical treatment approaches.

**Premorbid History**

Clarifying premorbid capacities and limitations is important. Here the goal is amelioration of index event related disability and handicap. Review of pre-morbid records, interviews with the injured party and other sources can substantiate a wide array of past personal capacities and challenges and their current relevance. Understanding the context of previous cognitive, emotional and physical capacities and deficits is required to effectively outline which lifetime care needs are related to the TBI.

**Current Treatment**

Records reflecting current treatment require similar consideration. Not all current medical treatment, medications or other services are necessarily related to the index event; e.g., annual health maintenance and pre-morbid treatment regimens for medical conditions such as hypertension, diabetes, asthma, pain, or other disorders not associated with TBI.

However, changes in personal capacities attributed to the TBI may affect associated treatment compliance or exacerbate premorbid conditions. Hence, a person who now has problems with organization or memory may no longer be able to independently manage medications, diet, prosthetic care or other protocols. Comprehension problems may require longer medical appointments and participation by a second party. Disinhibition may rekindle intervention for previously well controlled episodes of substance abuse, legal or mental health issues. Life care plans may include additional resources in order to re-establish premorbid homeostasis.

**Medical Considerations Following TBI**

Survivors of TBI can face diverse medical sequelae. These may be transient or lifelong problems, which can impact activities of daily living (ADL), social interaction and employability. Physiological sequelae may present themselves immediately after trauma or years later (Brown, et al., 2011). Some of the more common problems include balance, ataxia, apraxia, fatigue, thermoregulation, endocrine disorders, respiration, incontinency, appetite, dysphagia, paresis/paralysis, seizures, insomnia, headache, pain, sexual dysfunction, spasticity and changes in any of the senses.

Treatments can include medication, surgery, nerve blocks, physical therapy, occupational therapy, speech therapy, recreational therapy, hippotherapy, music therapy, aquatherapy and other modalities (Archer, 2012; Nudo and Dancause, 2013). Modalities are often combined, hence, problems involving contractures and spasticity may require splinting, casting, nerve blocks and/or surgical intervention (Bell and DiTommaso, 2016). Pain management often requires a combination of pharmacological intervention, skilled therapeutic modalities and counseling (Tyrer and Lievesley, 2003). Durable equipment, such as canes, crutches, and wheelchairs may be necessary and will require fitting, training, periodic maintenance, replacement and upgrading over one’s lifetime.

**Aging**

A number of problems encountered during the aging process are specific to or exacerbated by TBI (Konrad, et al., 2011; Sendroy-Terrill, et al., 2010). People with TBI may be at increased risk of Alzheimer’s disease, non-Alzheimer’s dementia and brain...
atrophy (Dams-O’Connor et al., 2016; Nordström et al., 2014). Cognitive and sensory declines as well as deterioration of balance/ambulation seen with normal aging can be accelerated and magnified following TBI. People with TBI are at greater risk for age-onset depression and suicide. They are more likely to require in-home care and home modifications, admission to assistive living or skilled care facilities, and at an earlier age. Lifetime monitoring may be required to adjust care and living situations according to progressive deterioration.

TBI and Life Expectancy
People with TBI may have reduced life expectancies. As a heterogeneous population, multiple factors impact these findings. Most life expectancy studies have focused on moderate to severe TBI. Here, variables influencing years lost include age at injury; gender; injury severity; disability level at rehabilitation discharge; premorbid employment, drug use and marital status; and quality of medical insurance (Brooks, et al., 2015; Harrison-Felix, et al., 2012; Harrison-Felix, et al., 2012a; Selassie, et al., 2014). Published life expectancy tables, derived from large cohorts of people with moderate and severe TBI who survived at least a year distinguish life expectancy by those who can walk well, have difficulty walking, cannot walk but can feed themselves, and can neither walk nor feed themselves (Brooks, et al., 2015). Individuals with mild TBI who survive more than six months have no reduction in long-term survival compared to unimpaired populations (Brown, et al., 2004; 2005).

Individual estimates of life expectancy should begin with reference to high quality published data. Once a starting point is identified, clinicians may then use their professional judgment to adjust life expectancy due to other individual patient characteristics (Brooks, et al, 2013).

Psychological/Behavioral Symptoms
Psychological/psychiatric/behavioral deterioration occurs for many different reasons following a TBI and creates barriers to socialization, intimacy, education, employment and community tenure. Some of the most prominent challenges include frontal lobe apathy, emotional lability, anger/frustration, depression, anxiety, disinhibition, hyperactivity, dysfunctional sexual behavior, hoarding and immaturity (McAllister and Thomas, 2008; State of Colorado Dept. Labor and Employment, 2012). Common treatment modalities include counseling, behavior analysis, positive behavioral supports, medications, structured environments and mentoring.

Behavioral changes may occur due to direct neuropathology of cerebral areas, disruption of neurotransmitter production/absorption, or damaged neural pathways. The paradoxical effects of medications prescribed to address such imbalances can produce provocative side effects (Levine, 2013). Neuromedical conditions including seizures, pain, insomnia and vertigo may contribute to behavioral aberrations. Alterations in perceptual functioning directly affects how a person perceives and understands his or her world, thereby affecting behavior. For example, a person with visual-spatial deficits who is unaware when they invade someone’s personal space may be labeled socially aggressive. Conversely, acute awareness of one’s lost capacity can procreate anger, resentment, anxiety, depression and other neurobehavioral challenges. Without careful assessment, the actual variables influencing observed behavior can easily be masked by other’s judgment of the person’s “intent.” This can affect proper treatment recommendations, and produce iatrogenic effects.

Cognitive Capacity
Common cognitive impairments include disorientation, distractibility, confabulation, impairments in short and/or long term memory, abstract thought and reasoning, sequencing, initiation and perseveration (Neumann and Lequerica, 2015; State of Colorado Dept. Labor and Employment, 2012). These impairments affect everyday activities such as ADL’s, education, work, community integration and financial management. Each of the primary cognitive domains is multifaceted in organization, operation and effects on performance. Most human performance is not the product of any one specific cognitive ability, but the integration of many different components (Lezak, 2012). Aberration of any individual component can alter performance. Assessing individual cognitive domains in isolation, without reference to other personal capacities, or without regard to personal environments and situations may yield inaccurate assessments. Hence, memory performance may be further affected by other cognitive capacities involving attention/concentration, inhibition/disinhibition, fatigability, comprehension, organization, planning, problem solving, adaptability, multi-tasking, self-monitoring, etc. These later abilities, often labeled as executive functions, relate to higher level cognitive skills used to navigate daily life demands and can reflect a person’s relative independence and resilience. In many situations, difficulties using and managing information is more debilitating than any likelihood of decreased intelligence following TBI.

The diversity of cognitive challenges results in a multitude of treatment and support approaches (Koehle, et al., 2013). Assessment and treatment sessions may be conducted in inpatient or outpatient centers by skilled therapists. Cognitive prostheses consisting of schedules, calendars, tasks-lists, notebooks, and apps are often suggested (Chu, et al., 2014; Cooper, et al., 2013), but careful selection is required and there may still be no guarantee of effectiveness. People may forget to enter pertinent information, not access the prosthesis in a timely manner, forget about it, or find it either irrelevant or too complicated to use. Training the individual is necessary to assure regular use, and continuing in-situ supports may still be required. Pharmacological interventions may also help mitigate cognitive problems (Dougall, 2015).

Context and Structure
Changes in functional capacities due to above noted challenges can compromise the context and structure, essentially the fabric of the injured person’s life. This in turn can further compromise functional capacities, which can further affect context and structure, etc. If unattended, progressive deterioration can occur. Sometimes, noted effects are manageable with appropriate supports; for example, job coaching to sustain employment, modification of daily routines, mentors to bridge social deficits, etc. These approaches may help resolve specific functional deficits and help the person remain in familiar settings where other naturally occurring supports and associated adjunctive benefits promote preserved skills and facilitate overall life quality.

In other cases, greater incapacity can preclude continued participation, with potentially cascading effects. For example,
in addition to losing vital income, job loss also removes the person from a contextually rich environment that supports a wide range of roles, skills and productive activity patterns; access to diverse social networks and reciprocal relationships; mobility; and personal and social validation. This may promulgate other problems related to mood/anxiety, health, participation and behavioral dysfunction.

Similar broad based dysfunction/incapacity may occur with transition to new environments, loss of key friends or family, or other keystones of a person’s life. Successfully addressing associated issues may require holistic and contextual approaches as compared to symptomatic treatment. For example, here, individual psychotherapy and medication may be less effective in addressing depression than helping the person establish meaningful activities of personal interest and social reciprocity. The life care planning and brain injury literature supports the importance of productive and meaningful activity in order to promote physical and emotional well-being, community integration, active engagement and life quality (Berens, 2008; Jacobs, 1997; Reid and Riddick-Grisham, 2015; Weed, 1991).

**Treatment Modalities**

Required services and supports following TBI may transcend commonly considered treatment regimens. Traditional diagnostic and treatment services remain crucial, but may be insufficient, especially when the person with TBI is unable to transfer recommendations to his or her daily life.

In-home 1:1 or close supervision services are sometimes considered for people with significant medical challenges, who require extensive assistance with ADL’s, who wander, have poor judgment, or exhibit significant behavior dysfunction. These “sentry” services, typically provided by direct care level caregivers, often focus on keeping people safe and out of harm’s way. The protective nature of such services, in the absence of other contextual considerations, can sometimes evoke frustration for more active and mobile individuals who consider it “baby-sitting.” Similar effects can occur with placement in traditional day programs that may offer greater respite for caregivers than engagement for participants.

Embedded supports such as mentors, life skills coaches and job coaches work in people’s natural environments on a real-time basis to engender productive outcomes. This can include assuring treatment compliance, organizing / managing households, shopping, planning and participating in community activities, working in job or volunteer positions, problem-solving unexpected circumstances, and other issues. Sometimes, these supports remain for a limited duration until situational mastery is achieved. Other times, continuing supports may be required to sustain productive capacity and safety.

Prosthetic (structured) environments provide supportive and contextually relevant milieus to facilitate personal competencies. They may include community-based “Clubhouse” programs (Jacobs, 1997), day or residential programs for individuals with greater challenges. Well-staffed residential programs may be considered following initial hospitalization or around other clinical epochs/transitions. Their 24/7 operation allows comprehensive evaluations of functional skills, data-based optimization of medication protocols, competency-based training of durable equipment and cognitive prostheses, and pragmatic transition of integrated service plans to support sustainable community integration (Benge, et al., 2010). Again, careful assessment is required to determine the relevancy and proper fit of any considered services included in the life care plan.

**Productive Activity Patterns and Vocational Services**

Well-founded recommendations for productive activity, including vocational or avocational activity, is a well-established tenant in life care plan development. Rehabilitation outcomes research typically focuses on work or vocational activity as the “penultimate” outcome for individuals with disability. Individuals capable of compensated employment may selectively benefit from job coaching, structured or supported employment, vocational rehabilitation counseling, training programs, rehabilitation technology and/or specialized equipment, according to personal needs and abilities (Weed and Berens, 2013).

For individuals with TBI who are not able to competitively work, participating in personally relevant and socially productive avocational activities may help establish a sense of purpose, enhance life quality and facilitate membership in a larger community (Berens, 2008). The venues and services required to facilitate such participation, however, are likely to differ from customary vocational rehabilitation services.

**Summary**

TBI onset may initially invoke medical treatment, but for many, needs and services quickly transcend to other aspects of the injured person’s life and the lives around him or her. The dynamic and interactive relationships involved in life following TBI onset require careful analysis and contextually based treatment, often on a lifetime basis. Carefully constructed life care plans by qualified professionals can provide cogent direction to facilitate functional capacity and life quality.

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ABOUT THE AUTHORS

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According to the Centers for Disease Control and Prevention, traumatic brain injury (TBI) is the leading cause of death and disability in children and adolescents in the United States. More than 60,000 children per year sustain a TBI sufficiently severe to require hospitalization, while many others go unreported. The most common causes of pediatric traumatic brain injury are motor vehicle collisions, falls, sports injuries, and physical abuse. Children also experience non-traumatic acquired brain injuries every year due to stroke, brain tumor, infection, post-surgical complications, etc. This article will focus on children who acquire brain injuries (ABI) from both traumatic and non-traumatic causes.

For more than three decades, Life Care Plans (LCP) have been used to document the future needs of children with chronic disabling conditions. The development of a well-conceived LCP for children suffering from the effects of a brain injury requires a unique perspective that does not pertain to long-term planning for adults. The life care planner must focus on future growth and development and project the child’s needs into adulthood and across the lifespan. In this complex endeavor, the skilled and experienced life care planning professional must have an understanding of the prognosis and available medical and rehabilitative treatments, as well as the resources available to the child and family to allow for access to education and transition to adult years.

**MEDICAL FOUNDATION IN PEDIATRIC BRAIN INJURY LIFE CARE PLANS**

The extent of ongoing symptoms, impairments, functional limitations, and sequelae following ABI’s varies widely depending on the age of the child at the time of injury, the nature and extent of the trauma, pre-existing conditions, and associated injuries. Recognizing the extent of ABI and its future implications can be guided by a thorough review of the available medical records.

A common medical tool for evaluating the child’s initial level of cognitive functioning is the Glasgow Coma Scale. The scale runs from 3 to 15 with lower scores indicating a profound brain injury and higher scores generally indicative of a better outcome. Review of diagnostic testing including brain CT scans, MRI’s, PET scans, EEG’s, and cerebrovascular studies can provide an understanding of the underlying structures that have been injured. Neuropsychological testing provides delineation of the ongoing cognitive and linguistic impairments.

Further delineation of functional capabilities is provided by Functional Independence Measurement for Children (WEEFIM) as utilized in most rehabilitation facilities. WEEFIM measures the relative independence of patients in 18 areas with regards to mobility and daily activities including eating, grooming, dressing, bladder and bowel management, bathing, transfers, ambulation, and cognition including comprehension, expression, social interaction, problem-solving, and memory. Scoring reflects the child’s independence from completely dependent to completely independent in each category.

Physician and other professional recommendations include future medical and rehabilitative care needs including all anticipated future medical visits, surgical procedures, therapies, adaptive and medical equipment, assistive technology, daily and medical supplies, medications, and hospital care. LCPs should cover all applicable needs resulting from the injury precipitating its design. There should also be consideration of the child’s daily care needs. A nurse, either RN or LPN, is needed for children with severe brain injuries who have skilled care needs including monitoring of vital signs, respiratory evaluation and management, tracheostomy and gastrostomy tube management, tone, and spasticity management, contracture prevention, pressure ulcer prevention, and medication provision. For children...
severely injured, especially those in a persistent vegetative or minimally conscious state, 24 hours per day nursing care is likely needed. For children with mild traumatic brain injuries, supervision by a family member, certified nursing assistant (CNA), or attendant may be sufficient according to the child’s presentation. The state’s Nurse Practice Act may also guide the level of care required (Table 1).

There may be a variety of living environments to be considered for children with significant impairments following ABI. If there is sufficient family support, a home environment is usually medically preferred. Not only does this provide a greater quality of life, but the risk of infection with organisms with multiple antibiotic resistances is usually much less at home with dedicated staff than long-term care facilities such as nursing homes or group homes. Single-level home settings with a barrier-free design may be best. Stairs are usually a challenge when providing care for children with mobility impairments and present a safety barrier. There also needs to be sufficient space for equipment, therapies and care/treatment/nursing staff. A ceiling mounted lift device between the child’s bed and the tub or shower greatly facilitates daily care. Children with severe brain injuries usually need to be transported in a van with a wheelchair lift or rails. Adapted safety seats are often needed.

Ongoing motoric, cognitive, linguistic, and psychological issues may impede the educational process for a child with ABI. The child may need an Individualized Education Program (IEP) or other services to facilitate the educational process. Developing skills leading to employment may also be impeded. An ongoing rehabilitation process including physical, occupational, speech, and recreational therapies; psychological services; and vocational testing and counseling can facilitate eventual employment. A job coach may also be needed during initial employment to identify areas of concern and provide guidance.

#### TABLE 1

<table>
<thead>
<tr>
<th>Typical Skilled Care Needs</th>
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<tr>
<td>Monitoring vital signs and acute medical conditions</td>
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<tr>
<td>Medication provision</td>
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<tr>
<td>Pressure ulcer prevention and management</td>
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<td>Tone management and continence prevention</td>
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<td>Bladder management program</td>
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<tr>
<td>Management of suprapubic catheter or intermittent catheterization program</td>
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<td>Gastrostomy tube feedings and maintenance</td>
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<td>Tracheostomy tube management</td>
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<td>Ventilator management</td>
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### SCHOOL SERVICES AND THE IMPORTANT ROLE THEY CAN PLAY IN REHABILITATION AND EDUCATION

Di Scala and Savage (2003), in the data from the National Pediatric Trauma Registry found that many children discharged from acute hospitalization with 1-3 impairments are sent home, while those with 4 or more impairments may be sent to a rehabilitation facility. However, due to poor funding, limited rehabilitation facilities for children, and the distances to them, most families take their children home, and back to school. As a result, schools have become the “rehabilitation centers” for children with brain injury.

Schools can offer varied levels of supports to students with ABI when medical evidence is verified, based on assessed need. For students who are experiencing mild deficits, interventions and accommodations can be provided in general education classrooms via a Student Study Team, or a more formal Section 504 Accommodation plan. Accommodations can include rest breaks, shortened assignments, visual aids or cue cards, and extended time on tests and assignments, to name a few. Since Section 504 is an anti-discrimination, civil rights statute, general education teachers must allow and support these accommodations in their classrooms.

Students with brain injuries causing more significant impact to their functioning may require special education services. The Individuals with Disabilities Education Act (IDEA) is the federal law that mandates specialized supports and services for students with disabilities. Under that law, there are 13 eligibility categories under which children with identified disabilities birth to age 22 can be served based on assessment findings, including but not limited to: Intellectual Disability, Orthopedic Impairment, Specific Learning Disability, and Emotional Disturbance. There are two categories that specifically apply to children who acquire a brain injury. Brain injuries caused by non-traumatic events (stroke, brain tumor, etc.), would most likely meet criteria under the category of Other Health Impaired (OHI), defined as (the list is not exhaustive):

...having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that — (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and (b) adversely affects a child’s educational performance.

IDEA-97: 20 U.S.C. 1401(3); 1401(30))

Until 1991, children with Traumatic Brain Injury (TBI) were placed in one of the other categories that most closely resembled their presenting deficits. That year, however, TBI was added to the list of special education eligibility categories under which a student could be served. The educational definition of TBI is:

“…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; psychosocial 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 300.7(c)(12)

Discussion section of the Federal Register (Vol. 57, No. 189, p. 44842, Tuesday, September 29, 1992) it is stated: “The definition of traumatic brain injury does include an acquired injury to the brain caused by the external physical force of near-drowning.”

Parents, teachers, physicians, and rehabilitation professionals can refer children to their public school for a multidisciplinary
Assessment to determine eligibility under one of 13 categories. Under a section of the IDEA called CHILD FIND, it is a school district's responsibility to locate and assess any child suspected of having a disability. If an evaluation determines a student is eligible, an array of services can be offered, as children are entitled to FAPE (Free Appropriate Public Education) at no cost to the parents. Di Scala & Savage's findings also found that due to limited knowledge about brain injury in the educational community and poor communication between the medical community and schools at the time of discharge, less than 2% of children ages 0-19 with TBI were referred for special education services. Unfortunately, 13 years later, this still holds true. TBI is the most misidentified and under-identified disabling condition as compared to all other special education eligibility categories due to a lack of adequate teacher and school psychologist training.

Appropriate assessment will determine a child's present functioning levels. Information is presented to the parents at an Individual Education Plan (IEP) meeting by the educational evaluation team and goals are written into this legal document to address all areas of suspected disability. Since goals drive placement and services, the IEP team determines whether the child will be provided service in the general education classroom (push-in model), or pulled out for individual or small group intervention in a Learning Center/resource room (pull-out model). Students with more significant needs may receive specialized academic instruction in special education classrooms for part or all of their day. Once a placement is determined, the IEP team should meet frequently to address the often rapid changes that students with ABI experience, especially initially, and adjust goals and classroom placement accordingly.

In addition to goals and placement, the IEP must outline needed accommodations and/or modifications as well as additional supports and "related services" students might require in order to receive educational benefit. "Related Services" includes transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education...” [IDEA, 1997, section 300.24(a)]. It is important to note that related services are provided in order for the student to benefit from their education, and therefore, goals developed and services provided must be educationally relevant, meaning that they must address skills that are impacting learning and education.

Related Services can include, but are not limited to:
- Language and speech
- Audiology
- Interpreting services
- Occupational and physical therapy
- Psychological services
- Counseling, including rehabilitation counseling
- Orientation and mobility services for students with visual impairments
- School health and school nurse services
- Social work services in the schools
- Parent counseling and training
- Medical services for diagnostic or evaluation purposes only, early identification and assessment of disabilities in children
- Recreation, including recreation therapy

This list is not exhaustive, and some states may offer additional services to students. However, even if a service is not listed, it is to be provided by the school if found necessary for the child to benefit from his/her education. For example, neuro optometric deficits are common after ABI, and developmental optometry or vision therapy may be provided by the school as a related service.

**KEEPING THE FAMILY INTACT AND HEALTHY**

Every parent looks forward to their child conquering major developmental milestones. Households around the world have boxes of old videos and photographs documenting the child's first steps, first words, first day of kindergarten, learning to ride a bicycle, learning to drive and high school and college graduation. While toddlers and preschoolers need constant supervision, school age children become gradually ready for more independence as they travel through teen years to eventually arrive at the transition to young adult.

Many families involving a child with a ABI will never get to such milestones. Their lives often continue to be focused on daily tasks such as medication administration and helping their child with basic functions such as dressing, grooming and feeding. There are often multiple doctor visits, school meetings and therapy sessions that can consume their days. In their dual role of parent and extended caregiver, they have to monitor, advocate and communicate on behalf of their loved one; their child.

In many instances, instead of looking forward to a time when their child will develop skills that perpetuate greater independence and less parental supervision, they look to the future with heightened anxiety about who will replace them when they are no longer able to care for their child.

Caregiver burnout is a constant concern and should be adequately addressed in the LCP by the inclusion of support services in the home. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and
unconcerned. Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able -- either physically or financially. Caregivers who are “burned out” may experience fatigue, stress, anxiety, and depression (Web MD 2016). The National Alliance for Caregiving (2015) research reveals that 38% of caregivers report high emotional stress from the demands of caregiving.

The inclusion of respite care and other home supports in the LCP can play a major role in keeping the family unit intact and healthy. The Council on Accreditation (2016) states that respite care reduces caregiver stress, promotes the well-being and safety of care recipients, and contributes to stable families.

No two family units are alike, and there is no simple formula for life care planners to rely on when addressing home care supports. The planner considers the unique needs of each child and family.

**BUILDING BLOCKS OF FOUNDATION IN LIFE CARE PLANS FOR CHILDREN WITH ABI**

Webster defines foundation as “an underlying base or support.” In life care planning it is important to create the necessary foundation to support the opinions outlined in the LCP. For a LCP to be useful in clinical or legal setting, it must have a medically appropriate foundation (Figure 1.).

Life care planners do not work in isolation, but depend upon the skills and knowledge of other professionals to collaboratively determine the immediate and future needs of children with brain injuries. Although it is common for life care planners to consult with a child’s current treatment providers, there are times when additional experts such as a physician, therapist or psychologist are also utilized to identify specialized needs. These treatment providers and experts help to provide the medical or psychological projections in the LCP.

Observations made during a family interview can be especially helpful in developing LCP opinions. Issues of home accessibility and equipment use are noted. Family dynamics including family stressors and caregiver supports can be incorporated into the foundation for the need for future respite services and family counseling.

Using the medical records, the planner can identify diagnoses, pre-existing or co-morbid conditions, response to treatment, achievement of functional outcomes and medical complications with related treatments. This information can be useful in supporting items in the LCP. For example, if the planner notes that a neuropsychologist who evaluated the child with TBI made several recommendations for behavioral therapy, the planner can in part rely on those recommendations to support the need for behavioral therapy in the LCP.

Medical bills are frequently reviewed and relied upon in the development of the LCP opinions. They can be particularly helpful in providing historical documentation of the frequency of disability-related complications and the associated treatment costs. In the child with an ABI, one might see complications such as repeat VP- shunt infections or the re-hospitalization for treatment of a seizure disorder. Again, the historical documentation of these complications and the related treatment costs can in part serve as the foundation for their inclusion in the LCP.

School records including the IEP can provide a basis for opinions regarding what may or may not be included in the school setting. Documentation in the school records can also provide insight into the child’s educational achievements.

**CONCLUSION**

A Life Care Plan for a child following ABI requires an explicit medical foundation to delineate medically necessary and appropriate daily, medical, and rehabilitative care. The plan should anticipate future medical issues and complications and provide the recommendation to prevent or timely deal with these secondary medical issues.

Creating a reliable LCP requires a foundation that draws from the experience and education of a life care planner who works collaboratively with treatment providers and other allied health experts. This can result in a plan that accurately forecasts future lifetime needs of the child. The LCP can then serve as a roadmap for the family to utilize as they oversee their child’s medical care, as well as decisions about family supports and future living arrangements.

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Imagine building a house with no framework or design; you would not have a home. The Life Care Planner is often likened to a housing contractor and architect, because just as your home, a life care plan needs to be well planned, designed and constructed. Because of the diversity of needs and challenges that can follow brain injury (BI), many people are involved in the life care plan “building process.” Support needs and costs following BI are often life-long and go beyond direct medical care. It is especially important to understand the resources required to promote function and performance over the person’s lifespan.

Life Care Planning, as it is practiced by Certified Life Care Planners (CLCP) in Canada, Care Experts in the United Kingdom (UK), and CLCP’s in the USA, all adhere to a specific methodology involving standards of practice, scope of practice, and Codes of Ethics. This enables life care plans that are comprehensive and consistent with well-reasoned practice and evidence. Key practices include careful review of all available records; meeting with the person experiencing disability; talking with treating professionals, consulting professionals and family, as appropriate; identifying personally appropriate and accessible services, along with associated charges; and practicality in recommendations relative to personal capacities and lifestyle. Effective plans delineate the objectives, steps, resources, and timing associated with all services and supports required for the person's life.

Given the notable differences in health service delivery systems, it is not unusual for people to ask why a life care plan is needed for individuals with disability due to BI in Canada and the UK. Both Canada and the UK have access to basic healthcare that is funded via public rather than private means. All hospital and most primary services are universally available to all citizens and permanent residents of each country; essentially from the beginning to the end of life. Because of this public funding, the “patient” does not see a bill for hospital treatment or medical monitoring visits at a doctor's office (Health Canada, 2016). Access to such healthcare is considered a basic right; much like primary and secondary education is in our mutual countries. Hence, in both Canada and the UK, no one “goes broke” if they have a serious health condition, or less.

In this article, we describe our two “sister” systems in Canada and the UK. This includes how life care planning is practiced as a professional sub-specialty of rehabilitation in these two countries, and why uncovered care costs can still be substantial and need to be discerned, despite “universal” access.

The Functional Approach
Adding the concept of function as a key component of what constitutes a “health condition” was a fundamental part of international changes that the World Health Organization (WHO) instituted in 2001. The WHO’s International Classification of Function (ICF) frames health issues as those that occur beyond hospitals and direct medical care (World Health Organization, 2001). The ICF considers activities a person can or cannot perform and the person’s participation level (domestic chores, childcare, intimate relations, school, work and community association participation). Importantly, function was framed to include personal and environmental factors, nested within the grouping called “contextual factors;” considered an integral component of health. This means that
the psychosocial, behavioural, relationship and environmental components of BI, as well as specific challenges emanating from such factors are all part the functional approach in a life care plan. Typically, these are mostly the “invisible” areas of performance following BI and are too easily neglected when care costs focus strictly on physical function.

This systematic analysis of functional factors provided by the ICF is universally available to all professionals seeking an evidence-based direction (Law 2002). This improves the homogeneity of emerging life care planning research. Multiple functional losses and/or capacity variations following BI result in notable life changes that often require a variety of supports that can incur significant cost. These costs are medically justified but not specifically “medical” in nature. More often than we like to acknowledge, the responsibility for addressing these functional losses are carried by family, friends and other community members especially for people with disability following BI who are based in the community. When these long-term needs and costs are overlooked, the person with BI risks future safety concerns, secondary complications (including social marginalization, mood disorders, and addictions) as well as re-injury. The “chain of risks” frequently needs to be mediated by access to long-term supports. Otherwise, one problem or situation can lead to another. For example, the risk of a fracture from a fall due to balance issues, or addiction due to impulse-management problems.

**Canadian Care Costing**

By definition a life care plan is “dynamic” (Weed and Berens, 2010), likewise, Canada's publicly funded health care system is dynamic. The overall term for the Canadian care system is “Medicare,” not to be confused with Medicare programs in the USA. There have been a number of changes since Medicare was introduced in 1968 and changes will likely continue in response to changes within medicine and throughout society. Concurrently, this evolution also occurs in the field of life care planning at both individual and at systems levels. Regardless of the dynamic features of Medicare, the basics for Canada's healthcare remain the same, i.e., universal coverage for medically necessary health care services is provided on the basis of need, rather than the ability to pay (Health Canada, 2016).

This universal access is mostly perceived as social advancement by Canadians, as it reflects this country's values of fairness and equity and is fundamentally similar to the UK with regard to healthcare access. However, we are aware that universal health coverage has been an area of political and social struggle in the US. More recently, threats to the Canadian public health system by multinational corporations and private clinics bankrolled by business interests have also become regarded as a real risk (Canadian Doctors for Medicare, 2016).

What happens when health problems continue beyond the direct medical needs and negatively impact a person's life trajectory and future function? In Canadian law, there were a series of cases in 1978, known as “the trilogy” where the Supreme Court outlined Canadian law on costs of future care (Klinger, et al., 2004). The court stated that the award for future care is based on what is reasonably necessary to promote the mental and physical health of the plaintiff (Slater, 2012).

**The UK Experience**

Citizens of the UK proved themselves demonstrably proud of their National Health Service (NHS) when London hosted the summer Olympics. However, the vast majority of people who enter NHS services as a patient are often completely unaware of the clinical pathway they enter. The appointed pathway guides them through treatment programmes and then back into the community. For those with long-term care needs, the National Framework for NHS, continuing Healthcare and NHS-Funded Nursing Care are key. This is not only a vehicle for long term care, but it is also important as an interface to a number of other care pathways across health and social care services.
Following hospitalization, patients are discharged home and often provided with limited services. Vital therapy is invariably provided on a minimum session basis for a fixed period of time. The patient is then discharged to the care of his or her general practitioner who will refer them back for additional services if needs change. Quite often, this turns into a vicious cycle of “toing and froing” through healthcare provision.

For individuals who experience disability following BI, accessing specialist treatment is often equivalent to a “post code lottery” (like a zip code in the USA), as required community-based services are either not available or insufficiently available. Some counties have local specialist units and community professionals such as occupational therapists, physiotherapists, speech and language therapists, and case managers experienced in the needs of people with BI. However, the number of sessions that specialist therapists provide are limited, which often truncates treatment efficacy. If a patient is pursuing a claim for damages, a joint agreement for privately funding services can be made via the Rehab Code (The Rehabilitation Code, 2016). In non-forensic cases the insurer, typically vehicle insurance or professional indemnity, will directly fund these services. When liability has been agreed in favour of the claimant in a lawsuit, the client then often has the means to privately pay for services above and beyond what is available via NHS and Local Authority.

Historically, when resources were not available, a person with BI could end up in a unsuitable long term placement. The recent Care Act 2014, however, now gives local authorities clearer guidance as to their responsibilities to provide long-term care to patients with complex needs (Canada Health Act, 2016). To ensure that assessment is carried out in an appropriate and proportionate manner, the local authority must regard: (a) the wishes and preferences of the individual to whom it relates; (b) the outcome the individual seeks from the assessment; and (c) the severity and overall extent of the individual’s needs (Reg. 3(2)). This new approach is outcome oriented and requires assessment techniques that are “flexible and can be adapted to best fit with the person’s needs, wishes and goals.” In situations of private funding, local authorities are still expected to provide an independent overview to ensure that clients are not being deprived of their liberty, and that their wishes and choices are taken into account.

Even when all services are covered via private funding, insurers providing services through the rehab code and other payment sources historically fell into the trap of thinking that a fixed amount of sessions could be enough, without considering long-term support and maintenance programmes that may continue to be required. To prevent this, case managers are now often secured to pursue continuing assessment and manage ongoing treatment needs. In the process, case management has become an integral part of both public and private long-term care systems in the UK.

Unlike the USA and Canada, the term “Life Care Planner” is not recognized in the UK and the same role is fulfilled by what is known as “Care Experts.” Care Experts are the main Registered Nurses or Occupational Therapists with experience in the field of Brain Injury.

Case Example
A 14 year-old-girl who went into hospital for a routine tonsillectomy in 2003 suffered hypoxic brain damage during the surgery. This left her physically impaired, unable to manage any element of her daily life, limited limb function, unable to mobilise, fed via a stomach tube, incontinent and unable to communicate verbally. After a year of funded hospital care, she was discharged home to the care of her mother. Her mother was limited by her own disability as she was wheelchair dependent due to paraplegia. Public funds provided a day centre during weekdays with transportation. It also commissioned a care agency to provide awake staff care at night and 2-1 coverage in the morning and evening for her hygiene needs when she was not at the day centre. Unfortunately, the agency frequently couldn’t fulfil the care plan services. When this occurred, the burden of care constantly fell on the mother, which increased the mother’s own health concerns.

A case was brought against the hospital for medical negligence and settled in 2014. As part of the compensation process, a case manager was initially appointed to try and improve the situation by liaising with the agency and sourcing house adaptations. Then, in October 2014, a Personal Health Budget (PHB) scheme was introduced nationally which enabled the young woman to appoint a provider who could employ a dedicated care team for her. The care plan, including cost of care, was approved by a government body. Services were expanded from this initial plan using compensation money from the lawsuit so that staff could double up during the evenings and weekends to enable her to attend youth clubs, take days out with her mother and have holidays. Needless to say, this young lady and her mother’s quality of life has been improved greatly.

Conclusion
In both Canada and the UK, effective life care planning involves consideration of the multiple public and private funding streams that may be required in a case. It equally involves identifying available specialty resources with requisite knowledge about BI. As a result, both life care planners and case managers face significant challenges. Whereas case managers may principally focus on a client’s immediate needs, the life care planner, much like an architect, provides a longitudinal map that envisions the composite situation including changing needs across life stages and associated with aging.

Public systems cannot and will not manage these integrated needs without the input of skilled professionals, and experienced and certified life care planners / care experts often fill this gap. Unfortunately, there are many areas where people still fall between the cracks in our systems and effective advocacy and service delivery can be an overwhelming task. Here, comprehensive life care plans can be one of the most valuable tools to individualize care needs for the person who experiences disability following BI, as well as for their families.

In summary, long term care needs and supports that enable safe and effective function over a lifetime, and are within reason, can be a significantly costly component of healthcare for BI that is not covered through any public health plan in Canada or the UK. It is within this context that our countries share challenges for ensuring reasonable remuneration with strong and credible life care plans. Life care plans need to consider the context of the person’s particular life over their anticipated...
lifespan, possible changes and challenges to their condition over time, including possible degeneration, and the nature, culture, and personally relevant circles of support that define life quality.

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People who experience disability following a brain injury often require lifetime care. For some, this may mean occasional assistance with certain activities, while for others it may mean complex medical, social, cognitive, and psychological care provided continuously. Life care planners frequently analyze a case and compile the future care needs and costs, which provides a road map for navigating future care. It is used by attorneys during litigation to determine how much money should be awarded. This information is also used by injured persons, by their families, by care providers, and by trust fund managers to monitor the care being rendered, to make sure that needs are being properly addressed, and to ensure proper expenditures. The process used by life care planners has evolved over the years to become a reliable and consistent methodology to ensure accurate estimates for the future. Life care planners proactively work together to create standards for practitioners to follow that will lead to the most reliable and accurate estimates that can be used in litigation and as a road map for implementing future care following litigation or in other venues. This article provides an overview of the standards of practice for life care planners, how these standards were created, and how they continue to evolve.

Defining Standards of Practice: Knowledge, Skills, Behaviors

Standards of practice provide a general guide for how to approach performing a role. They outline the basic steps that should be taken and provide information regarding needed background and training for performing the task. They offer a way for practitioners to evaluate their own skill and for other people to determine whether the life care planner is indeed doing the right things. Notice that this definition focuses on the life care planner, not on the individual who has the brain injury.

Health care professionals are familiar with standards that define the care someone should receive, which are referred to as standards of care. Standards of care do focus on the individual with the brain injury, offering a guide for what care might be rendered. Sometimes, the terms standards of practice and standards of care are used interchangeably, but they are not synonymous. Practice standards define how the professional should prepare and conduct himself/herself in doing the work. Care standards define what the injured individual can expect to have done and the type of care to be received. For example, a person with a brain injury arriving in the emergency department will be seen and treated. The treating physicians and nurses are expected to know a broad base of medical information, gather assessment data, interpret findings, and choose appropriate treatments. These are part of the standards of practice, reflecting the knowledge, skills, and behaviors that are expected from competent practitioners. The patient, on the other hand, can expect that a Glasgow Coma Scale score or other assessments will be conducted, radiology and other diagnostics will occur, certain medications may be administered, and other treatment will be rendered. These are part of the standards of care, which are focused on the patient. Because life care planners do not provide direct patient care, they adhere to standards of practice, but not standards of care.

Another important consideration is that life care planners are covered by more than one set of practice standards. Each life care planner comes from a health care profession, such as registered nurse, physical therapist, or another professional field. For example, a nurse is covered by standards of practice for nurses, and each other kind of practitioner has a similar set of practice standards. In addition to the profession standards, there may also be specialty standards. A nurse who specializes in neurology has
Creating Standards of Practice

There are common themes in how standards of practice are created. The Internet provides excellent access to standards for dozens of professions and roles. There are also many articles published that describe how particular sets of standards of practice were created. These are some of the common themes:

**Standards of practice are created by professionals in the field**

Typically, the standards are created under the auspices of a professional society that has a mission to advance that professional field. By acting as a collective, weight is given to the standards as reflecting the will of people who practice in that field. This reflects exercising internal control of practice, rather than having external entities (such as legislation and regulation) control the field. Every professional field from which life care planners come has standards of practice created by that field.

**Standards of practice are a tool for measuring practitioners**

Examples of how standards are intended to be used are reflected in these statements:

“Standards are authoritative statements that articulate minimal, acceptable or excellent levels of performance. . . . (U.S. National Library of Medicine, National Institutes of Health, 2004)

“. . . people, families, communities, and populations using healthcare and nursing services can use this document to better understand what constitutes nursing. . . .” (American Nurses Association, 2010)

“. . . it is critical that we examine ourselves and set standards by which we must be held accountable.” (Frater, J. & Leonard, M. 2010)

**Standards of practice are created via a thorough and lengthy process**

While there is not a single process that all fields use, there are similarities in the approaches. Steps that are described include:

- Review of literature, evidence, and existing standards
- Inclusion of many participants
- Inclusion of many backgrounds, areas of expertise, and stakeholders
- Writing new material, field testing and getting feedback, re-writing, and finally publication
- Building consensus, obtaining expert opinions, reliance on evidence-based research, and meta-analysis
- Approval by committees or boards
- Use of structured processes, such as modified cooperative inquiry and modified Delphi method

**Process for Creating Standards of Practice for Life Care Planners**

First published in 2000, the 3rd edition of the Standards of Practice for Life Care Planners was published in 2015 and took nearly two years to complete. For each edition, a similar process was used. A revision committee and a separate advisory group, comprising 34 people were appointed by the International Academy of Life Care Planners (IALCP), a section of the International Association of Rehabilitation Professionals (IARP). The IALCP/IARP is the only professional association that represents life care planners in all professional fields. Initial tasks included review of standards from the various professions and roles (to look for potential conflicts), review of literature and research, review of published consensus statements, and design of methodology for reviewing existing standards and eliciting input from as many participants as possible. Two surveys were conducted; first to obtain detailed comments on existing standards, and later to obtain detailed comments on proposed revisions. Practicing life care planners, people who use life care plans, and anyone with an interest in life care planning were invited to participate. Over 100 respondents provided opinions. The revision committee proposed changes incorporating information in research, literature, and consensus of field practitioners. The advisory group provided valuable input throughout the entire process to help clarify ideas and provide other points of view. After a final field review period, the new standards of practice were sent to the IALCP board of directors for approval and publication. A detailed description of the process was published in the Journal of Life Care Planning (Preston & Reid, 2015).

Analyzing the evolution of the standards, one can see the increasing development and sophistication of the field. Figure 1 shows that the first standards were not formalized and were based on personal experiences, sharing, and early training programs. There were limited publications and professional societies were emerging. The shaded box in the center denotes the knowledge, skills, and behaviors (rudimentary standards) that were derived from the early sources.

![FIGURE 1](image)

Figure 2 reflects increased resources in shaping the knowledge, skills and behaviors that comprise standards. There are now mechanisms for professional self-determination, dissemination of core knowledge, new and expanded training and publications, and greater clarity in defining accepted standards.

Figure 3 illustrates the current state of the field and the influence on standards of practice. Now, there is a complex interdependence of training, professional-self-determination,
measurement and validation, dissemination of information, and field-wide agreement on standards of practice. All of these contribute to the ability to offer credentials that validate the life care planner’s knowledge, skills, and behaviors.

**Credentials as a Way to Validate Adherence to Standards of Practice**

Once the knowledge, skills, and behaviors deemed necessary are defined in standards of practice, it becomes possible to measure and display these accomplishments with credentials. There are three different credentials available for life care planners. Two certifications and one Fellow credential are offered.

The Certified Life Care Planner (CLCP) is available to all life care planners through the International Commission for Health Care Certifications (ICHCC). The Certified Nurse Life Care Planner (CNLCP) is available only to registered nurses through the American Association of Nurse Life Care Planners (AANLCP). Both require completion of a minimum set of courses in defined subjects related to life care planning. Once eligible, the life care planner must successfully pass a written examination. These certifications measure knowledge obtained through the course work.

The Fellow (FIALCP) credential is offered through the IALCP, the life care planning section of IARP. Life care planners who have completed a minimum of 50 plans can submit two for blind peer reviews to have their work evaluated for adherence to published standards of practice. In addition, the life care planner must have demonstrated contribution to the field through publishing, teaching, research, or mentoring, and must be active in professional associations. This credential demonstrates application of knowledge and demonstrates the skills and behaviors deemed necessary.

All life care planning credentials are voluntary. As a role, not a profession in itself, life care planning is not subject to regulations or licensing. Some people representing themselves as life care planners may not have any specialized training or do not come from a health care related profession. Other life care planners may complete training courses but choose not to obtain a life care planning credential, instead relying on other means, such as academic degrees and credentials in related relevant fields, to show competence. Life care planners who obtain credentials can offer consumers of life care plans an additional level of specialty competence. This variability among practitioners means that care must be taken when hiring or retaining a life care planner to ensure competence.

**Standards of Practice for Life Care Planners**

There are 14 standards that have been identified for professionals practicing in the specialty role of life care planner. Complete information for each standard, including measurement criteria to determine compliance, can be obtained through the published booklet available through the IARP website: www.rehabpro.org (IALCP, 2015). The standards address the following:

- **Educational background and professional preparation**
  Maintains licensure, registration, or board certification to practice in a professional rehabilitation or health care field. Obtains continuing education in life care planning.

- **Ethical practice**
  Follows the Code of Ethics for profession, roles, certifications, and credentials.

- **Use of scientific principles of medicine and health care**
  Uses research-based practices and findings in developing life care plans.

- **Cultural competence**
  Considers cultural and linguistic factors in assessment, development, and implementation of life care plans.

- **Practices within a professional scope of practice**
  Remains within scope of practice in performing all aspects of life care plan development.

- **Understands health care needs**
  Understands health care needs and locates resources regarding unfamiliar needs to incorporate state-of-the-art knowledge and recommendations.

- **Comprehensive assessment**
  Collects data from multiple sources that holistically assess the evaluée.
Use of a consistent, valid, and reliable approach
Follows accepted methodology consistently, using valid and reliable practices.

Analysis of data
Critically thinks about the meaning of data to determine needs, recommendations, and gaps in information.

Use of a planning process
Organizes and documents data, analysis, and recommendations.

Collaboration
Seeks information and expert opinions.

Facilitates others’ understanding of the life care planning process
Objectively provides information and assistance to resolve disagreements and ensure understanding of the life care planning process.

Evaluation
Ensures completeness and internal consistency of the life care plan. Provides consultation for proper interpretation of the completed life care plan.

Engages in forensic applications
May act as a consultant and/or expert in legal proceedings. May provide sworn testimony.

Taken in total, these standards provide a framework for competent practice by life care planners through a description of the critical knowledge, skills, and behaviors required.

Summary
Standards of practice are a familiar and dynamic tool used both by those in a professional practice and by those who want to understand and evaluate professional practitioners. Standards provide a useful benchmark for measuring knowledge, skills, and behaviors. By their nature, standards evolve over time. It is expected that standards are periodically reviewed and updated, ideally by those who are practicing in the field.

REFERENCES

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The Affordable Care Act – What Effect Does It Have on Life Care Plans?

The United States Congress, in 2010, enacted the Patient Protection and Affordable Care Act (ACA), whose aim was to increase the number of Americans covered by health insurance and decrease the cost of healthcare. In *Federated Business*, the United States Supreme Court upheld the “individual mandate” which required most Americans to maintain “minimum essential” health insurance coverage. While too many Americans are still uninsured, the ACA significantly increased the number of Americans who now have health insurance.

Shortly after passing the ACA, the Department of Health and Human Services (HHS) promulgated regulations requiring employers with fifty or more full-time employees to offer “a group health plan or group health insurance coverage” that provides “minimal essential coverage.”

When the ACA was found to be constitutional, commentators wrote articles discussing the potential effects that the ACA would have on claims for future medical expenses in personal injury lawsuits. The commentators discussed the anticipated effects that the ACA will have in personal injury actions and how the Act will affect claims for future medical expenses.

With the presidential election of Donald Trump, the viability of the ACA remains in doubt. Throughout the election campaign, he vowed to repeal and replace it, which could leave the 20 million Americans currently so covered, uninsured. Regardless of what specifically happens to the ACA, the issue of insurance coverage and its effect on life care plans will remain.

Traditionally, a plaintiff in a personal injury action is entitled to make a claim for past, present and future medical expenses, even though the past medical expenses may already have been covered by health insurance and future medical expenses could also be covered by health insurance. This rule is called the Collateral Source Rule, which is the “doctrine that if an injured party receives compensation for its injuries from a source independent of the tortfeasor [wrongdoer], the payment should not be deducted from the damages that the tortfeasor must pay.” The Rule is designed to prevent the wrongdoer from benefitting from third-party payments. As between an injured plaintiff and a defendant-wrongdoer, the policy of the Collateral Source Rule is the plaintiff is the appropriate party to receive any windfall of private health insurance.

Starting in the 1990’s, some states enacted legislation overturning the Collateral Source Rule, finding that a plaintiff is not entitled to recover past or future medical expenses which have been paid or will be paid by an outside source. For instance, in New Jersey, under N.J.S.A. 2A:15-97, Deduction of Duplicate Benefits:

Expiration of insurance coverage or the lapse of an insured status

In interpreting N.J.S.A. 2A:15-97, a New Jersey Appellate Court held that “future collateral benefits are deductible only to the extent that they can be determined with reasonable
certainty. … The phrase ‘if a plaintiff … is entitled to receive benefits’ refers only to those benefits to be paid post-judgment to which plaintiff has an established, enforceable legal right when judgment is entered and which are not subject to modification based on future unpredictable events or conditions. Future collateral benefits are deductible only if ‘they can be determined with a reasonable degree of certainty.’”7

**Life Care Planning**

In many catastrophic personal injury cases, a plaintiff’s counsel will retain a life care planner to prepare a life care plan. The concept of life care plans has been utilized in a variety of healthcare and legal settings to provide information and documentation regarding the types and costs of services related to life-long care.8 In personal injury litigation, life care plans have been utilized as a measure of future economic loss. Since the ACA mandates that every individual obtain health insurance, what effect will the ACA have on a plaintiff’s ability to recover economic damages for future medical expenses and costs if some, most, or all of those medical expenses will be now covered by health insurance?

Shortly after the ACA was upheld by the U.S. Supreme Court, Congdon-Hohman and Matheson argued:

> We argue that the ‘guaranteed issue’ and ‘individual mandate’ requirements of the recently passed Affordable Care Act (ACA) will allow victims to address a large portion of their health needs through the purchase of a simple health insurance plan rather than direct compensation for an itemized list of healthcare needs. As such, damage awards for many health expenditures should be capped at a maximum of $6,250.00 per year. Therefore, the role of a life care planner should evolve into determining which life care expenses are covered under the minimum insurance requirements mandated by the ACA and which entail additional expenditures beyond those covered by health insurance.

Since the adoption of the ACA, courts throughout the United States have begun to address this thorny issue. To understand the various “rulings,” the following discussion is divided into two parts: (a) decisions from states that permit “double recovery” under the Collateral Source Rule and (b) those states which have enacted legislation to prevent plaintiffs from recovering past and future medical expenses that have been paid or will be paid by health insurance.

**A. STATES THAT PERMIT DUPLICATION OF BENEFITS**

In **Haughton v. Blackships**,9 the defendants moved to limit a plaintiff’s future medical expense damages to projected payments of premiums and deductibles under the ACA. The plaintiffs asserted a medical negligence claim against the defendants due to their failure to set forth certain labor and delivery policies which resulted in injuries on the birth of their son. The plaintiff asserted claims for future medical expenses. The defendants argued that such damages should be limited because the plaintiff is not required to pay the full price of the projected medical services and refusing to do so would grant the plaintiff a windfall. The plaintiff objected, asserting that medical damages should not be limited in light of the Minnesota Collateral Source statute10 and general principals of tort recovery. The plaintiff argued that the ACA did not change the plaintiff’s right to recover medical expenses and there was uncertainty about the implementation and survival of the Affordable Care Act.

The Federal District Court concluded that “any benefits received through the Affordable Care Act do not provide a basis for reducing the potential award to a plaintiff.”11

In **Alexander v. U.S.A.**,13 the plaintiffs alleged harm, including the infant plaintiff’s permanent neurologic impairment caused by the defendant’s negligence in the medical care of their son at Madigan Army Medical Center. The plaintiffs moved to preclude the defendant from offering evidence of future collateral source benefits for the payment of future medical care which would have been paid by the plaintiff’s TRICARE policy. All of the plaintiff’s medical expenses since birth had been paid by TRICARE and all future expenses would be paid by TRICARE as long as his father was enlisted in the United States Army. While this case was governed by the Federal Tort Claims Act, the defendants were to be treated like a private party and the Court had to apply the “nature of the benefits” test to consider whether evidence of future TRICARE benefits should be excluded under Washington’s Collateral Source Rule. Courts have limited the abrogation of the common law collateral source rule where the covered disability benefits have been paid on “account of the injury.”14 The policy considerations underlying this distinction are aptly expressed in **Haughton v. Blackships**, a maritime action applying the collateral source rule:

> On the one hand, an employer-tortfeasor who voluntarily undertakes to indemnify itself against liability by payment into a fund for that purpose, should not be penalized by permitting the plaintiff a double recovery of his benefits under the fund as well as his full measure of damages. On the other hand, where the employer-tortfeasor makes payment directly or indirectly into a fund established for an independent reason, or where such payment by the employer should be considered in the nature of a fringe benefit or deferred compensation, the employer should not be entitled to benefit by setting off such income in mitigation of his responsibility as a tortfeasor.

The Alexander defendant also argued that the rationale for applying the Collateral Source Doctrine had been eliminated by the ACA and that future ACA benefits should be admissible. The Court declined “the invitation to modify Washington's Collateral Source Doctrine in light of the ACA because the same justification for denying an offset for future TRICARE benefits applied to projected ACA benefits.” The Court granted the plaintiff’s motion, finding future TRICARE benefits and future ACA benefits would be excluded.

**Benavidez v. ERMC II, L.P.**15 involved a case where the plaintiff...
slipped and fell due to a patch of black ice adjacent to a pile of snow near where she had parked her car in the defendant's parking lot. The defendant moved for summary judgment on the plaintiff's claim for medical expenses, asserting that under the ACA, the plaintiff's duty to mitigate her damages eliminates the Collateral Source Rule. In response, the plaintiff argued that the defendants were not entitled to receive the benefit of plaintiff's decision to purchase insurance, regardless of the ACA. Kentucky's Collateral Source Rule provided that "benefits received by an injured party for his injuries from a source wholly independent of and collateral to, the tortfeasor will not be deducted from or diminish the damages otherwise recoverable from the tortfeasor." The Court denied the defendant's motion on that issue.

**B. STATES WHERE COLLATERAL SOURCE HAS BEEN ABROGATED**

In states where the collateral source rule has been modified or eliminated by legislative action, courts have been cautious in striking claims for future medical expenses under the ACA.

A New Jersey trial court was asked to address the effect of the ACA regarding a plaintiff's claim for and presentation of evidence of medical costs. This case arose out of the delivery and birth of an infant plaintiff who suffered from cerebral palsy. The plaintiff alleged that because of the defendant's negligence, the plaintiff's medical expenses through the Affordable Care Act, the plaintiff's $2.3 million. The defendants contended that since the infant plaintiff would receive contribution or reimbursement of a majority of her medical expenses through the Affordable Care Act, the plaintiff's claim for medical costs should be limited to consider the potential contribution and reimbursement afforded by the ACA. The New Jersey trial court, relying on the decisions in *Parker v. Esposito,* and *Puzio v. Mimms,* which held that "future collateral source benefits are deductible only to the extent that they can be determined with reasonable certainty," found that the plaintiff's "right to receive such benefits [under the ACA] is likely subject to policy changes, as Congress has sought to repeal and/or undermine the ACA over fifty times. Longevity of the ACA is overwhelmingly called into question by the upcoming government election. Even if arguendo, the ACA remains in effect for thirty plus years, [infant plaintiff's] entitlement to receive such benefits and the amount she may be entitled to receive is merely speculative."

In *Brewington v. U.S.A. *, the plaintiff went to the Department of Veterans Affairs for treatment of a branch retinal vein occlusion that affected the vision in his left eye. At the VA, the plaintiff's left eye was injected with the wrong medication, resulting in irreversible blindness. The defendant asserted an affirmative defense of offset for collateral source payments under California's Medical Injury Compensation Reform Act of 1975 ("MICRA"). The defendant sought to introduce evidence of ACA coverage as a collateral source for future medical expenses. Under California law, medical malpractice defendants may introduce evidence of "any amount payable as a benefit to the plaintiff as a result of the personal injury" under "any health, sickness or income-disability insurance, accident insurance that provides health benefits or income-disability coverage, and any contract or agreement of any group, organization, partnership, or corporation to provide, pay for, or reimburse the cost of medical, hospital, dental, or other health care services." Section 3333.1 does not preclude recovery of such damages, but rather, it allows the trier of fact to decide how to apply the evidence in calculating damages. The Court found it "appropriate to take insurance benefits available under the ACA into consideration in calculating reasonable future life care plan needs."

On appeal, the appellate court essentially upheld the trial court's determination, that the defendants were entitled to an offset for future medical expenses that would be covered under the ACA. The Court rejected the plaintiff's argument that Medicare and the ACA are political targets subject to privatization, budget cuts, and even repeal and that any offset would be speculative.
SUMMARY
Whether the ACA will have an effect on precluding claims for future medical expenses in states that have abrogated the collateral source rule, is still an undecided issue, especially in light of the recent presidential election. Attorneys representing plaintiffs should follow New Jersey’s case law arguing that any credit due to the ACA is uncertain and speculative at best. Defense attorneys should press for an offset, relying on the Jones decision. If a court permits an offset, the life care planner will have to determine what future medical benefits would be covered under a medical insurance policy. It is important to keep in mind that the ACA is a federal statute which requires people to carry private medical insurance or be taxed. The ACA is not an insurance policy. Life care planners will have to demonstrate within a “reasonable degree of certainty” what benefits would be included in a policy of insurance that the plaintiff does not currently have. This will prove to be difficult burden to overcome. There are still many issues that need to be resolved before this becomes settled.

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ABOUT THE AUTHOR
Bruce H. Stern, Esq., is a Shareholder and member of the Accident & Personal Injury Group of Stark & Stark, where he concentrates his practice in the areas of traumatic brain and spinal cord injuries and wrongful death. Mr. Stern has been listed in Best Lawyers in America 2003-2016. Presently he is the Secretary of the American Association for Justice and also serves as the Treasurer of the North America Brain Injury Society and the International Brain Injury Association. Mr. Stern is a fellow of the International Academy of Trial Attorneys, the International Society of Barristers and a past president of the Belli Society.

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Hospital and Centers for Healthcare
BrainLine—our website about preventing, treating, and living with TBI—has been part of my life for almost ten years. We’ve tried from the start to provide authoritative information about diagnosis and treatment. We’ve tried to speak in plain English, so the information will be accessible to everyone. We’ve tried to use every tool at our disposal—articles, video, infographics and social media—to convey the story clearly. But like most ambitious projects, BrainLine has been shaped and improved by the people we’ve met and the things we’ve learned. This is the story of how it started and how it changed.

When I first starting learning about brain injury, it struck me as the most under-diagnosed, under-treated, under-reported, and underfunded public health problem in the U.S. The continuum of care seemed fragile, the professional training often sparse, and the funding for treatment and research very scarce.

In 1998, I was working at WETA-TV, the PBS station in Washington, and producing a series called “Exploring Your Brain” about the brain and mental health. We had produced programs about fear and anxiety, depression, and memory—topics that touched the lives of millions of people. But all I knew about concussions was that football players sometimes got them. TV announcers would laugh about a player “getting his bell rung” and then praise the player for “shaking it off” and staying in the game. And if a player was sidelined by a concussion, it was soon forgotten. There was always someone else to take his place.

EYES WIDE SHUT

I’d never heard the term “traumatic brain injury” but when we decided to do a show called “Stress, Trauma and the Brain,” my long-time colleague, Christian Lindstrom, remembered a conversation she’d had with a woman named Theresa Rankin. At the age of 21, Theresa had been an honors student at San Diego State University. Then her life was turned upside down—literally—when she and her boyfriend Steve were out in his sports car and he drove the car off a cliff. Steve broke his ribs and punctured a lung but he recovered in three months. Theresa sustained a significant brain injury and spent the next thirteen years on a long, scary journey around the country—hoping to heal her injured brain and searching for doctors who could help. Theresa’s story was compelling, Christian said. Three months later, Theresa was in her kitchen telling that story again...this time on camera, to Garrick Utley, the host of “Exploring Your Brain.” By then, Theresa had given us a master class in TBI—what the research showed, what the government was doing, and which experts were on top of it.

In the same program, we profiled Pat LaFontaine, the great American hockey player, whose career had been cut short by concussions. I saw one video of Pat getting injured, and it was no joke: a 235-pound defenseman had slammed Pat’s head into the ice at Madison Square Garden. Pat’s next—and last—concussion was less violent but the consequences were even worse. “I was wiped out physically,” Pat said. “I was emotionally depressed...a total personality change.” It was hard to concentrate on anything. “At one point,” Pat recalled, “I was reading a story to my daughters and had trouble focusing on the words. And then I had to look at my daughters and say ‘Daddy’s just going to have to read this story another time’.”

We heard other stories, too, and came to understand that there was a whole army of people whose lives had been changed forever by TBI. Their families had been upended too, but among the general public, TBI remained an almost invisible epidemic.

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We finished our program, but the stories we’d heard about TBI stuck with me. We were determined to get back inside that world and to develop a website that could address TBI full-time. Theresa again was indispensable—reaching out tirelessly to her extensive network and letting people know that WETA was ready to build a new website if someone would help fund it.

WITH THE MILITARY

A few years later, we had the chance. The wars in Iraq and Afghanistan were escalating and the military was just starting to acknowledge the mounting toll of TBI and PTSD. Dr. Deborah Warden, director of the Defense and Veterans Brain Injury Center, spoke out courageously at a time when many in the military wouldn’t openly address TBI. She and her successor at DVBIC, Col. Michael Jaffee, came to believe that a PBS station like WETA might be the best source of information about TBI, because on a subject that was so sensitive inside the military, many service members would prefer
to rely--anonymously--on an outside, independent website.

Dr. Warden and Col. Jaffee stuck their necks out to provide the financial support we needed to develop BrainLine. Then they and their colleagues patiently educated us about the impact of TBI, the available treatments, and the effects of TBI on service members, veterans, and their families.

We launched BrainLine in 2008, with the goal of providing practical information about treating and living with brain injury and the most common co-morbid conditions, including headaches, insomnia, chronic pain, substance abuse, and PTSD. We now offer more than 700 articles and we regularly add more. We sought to serve anyone whose life was touched by TBI--people with brain injuries and their families, along with researchers, clinicians, social workers, case managers, rehab specialists and more. We knew that it was hard for people with TBI to find high-quality professional help, and so we used BrainLine to provide expert advice. We now offer more than 100 video interviews with top professionals, and we have invited users to “Ask the Expert” by posing questions that our advisers answer online.

We were also mindful of something that Dr. Randall Chesnut told us early on: “What people really talk about--five, six, ten years out--is social isolation. What they really want is friendship [and love].” The problem seemed especially acute for military families, who were losing the camaraderie they had known inside the military and returning to communities where it often seemed that nobody understood what they had been through.

We actively sought out first person stories: people with TBI and caregivers talking frankly about their own experiences. Those people range from retired Army Sergeant Adam Anicich, talking on his video blog about his long road back from a TBI; to the spouses and parents of soldiers injured in battle; to civilian caregivers like Abby Maslin and Rosemary Rawlins, whose powerful blogs describe the countless adjustments they have made to care for their injured husbands and to reinvent their family life.

We invited user comments and soon received a strong, sustained response to articles like “Lost and Found: What Brain Injury Survivors Want You To Know,” “Traumatic Brain Injury Is…..” and “9 Things NOT To Say to Someone with a Brain Injury,” all of which addressed the social and emotional components of TBI. We set up BrainLine channels on Facebook and Twitter, hoping to build an online community where users could support each other.

A year after we launched BrainLine, our audience was growing but still modest. Then two things gave us a jolt...and upended the entire field of TBI. The first was a radical change in the military's approach to TBI. Almost overnight, with new leaders in place, the military got more serious about addressing brain injury. Admiral Michael Mullen (Chairman of the Joint Chiefs of Staff), General Peter Chiarelli (Vice Chief of Staff of the Army), and a few other top officials declared that military had to acknowledge the prevalence of TBI and PTSD, de-stigmatize those conditions, and vastly improve diagnosis and treatment. In the midst of two wars, Adm. Mullen, Gen. Chiarelli and Deborah Mullen (a tireless advocate for families wrestling with TBI and PTSD) made time to explore and then actively support our efforts to address TBI head-on.

That gave us a chance to produce extensive content about military-related TBI and PTSD, including three online courses for professionals.

The second major development was the extraordinary campaign to expose the prevalence of TBI and CTE in the National Football League. At first, just a handful of people were involved: researchers like Bennet Omalu, Julian Bailes, Ann McKee, Robert Stern and Robert Cantu; Chris Nowinski, the Harvard football player who became a star professional wrestler using the name “Chris Harvard”; and Alan Schwarz, a New York Times reporter, who eventually wrote more than 100 pieces showcasing the NFL's concussion crisis. We interviewed Nowinski back in 2010, followed by Drs. Bailes, McKee and Cantu. BrainLine wound up riding a wave, as Schwarz and other reporters wrote articles after article documenting the risks to NFL players and telling the poignant stories of former players such as Junior Seau, Andre Waters, and Dave Duerson. Concussions and CTE were taking their toll elsewhere too: in lacrosse, hockey, soccer and any other sport with frequent collisions.

We interviewed Thomas Jones, a top NFL running back, and he was blunt about what players go through: “I've seen countless guys get knocked out right in front of me...a contact lens lying on the side of their face, bleeding from the nose, bleeding from the ear. We're trained like warriors to keep playing, keep playing, keep fighting. But you've got to choose life over football.” It doesn't matter how much money you have. You only get one brain.”

As a result of the military's growing openness, the new spotlight on sports concussions, and the tireless advocacy of groups like the Brain Injury Association of America and the United States Brain Injury Alliance, TBI has become a much more visible problem. That's especially evident among the parents of young athletes. About three years ago, Michael Singer, CEO of the medical device company BrainScope, organized a forum about concussions at a high school in Bethesda, Maryland that our sons attended. In the past, a dozen parents might have shown up for a meeting like that. This time, the auditorium was full, mostly with parents whose children had gotten hurt playing sports. One after another, the parents told us the same story: our pediatrician says my son is fine, but he's not the same kid. He's more irritable now, or less focused, and he never sleeps through the night.

Those worried parents are at the heart of a growing public unease about sports concussions. Participation in youth tackle football has declined by 28% since 2010 (though there was a small increase in 2015). Several NFL players have walked away from the game, fearing the toll of concussions. “I just want to do what's best for my health,” said linebacker Chris Borland, who retired at age 24. “I don't think [football is] worth the risk.”
Given the high incidence of TBI, maybe it was inevitable that TBI would eventually hit close to home. Last year, one of my colleagues was involved in what seemed to be a minor car crash. She reported to work that day seemingly unhurt, with just a nagging headache. Her symptoms soon worsened, however, and she spent the next six months struggling with vision problems, headaches, and pain. Then my son Aaron, an ultra-competitive athlete, incurred his own concussion when a soccer ball smashed into his face at point-blank range. Despite what we’d learned from working on BrainLine, we faced the same perplexing path as most patients with TBI—the lack of a clear diagnosis, the challenge of finding effective care, the uncertainty about long-term effects. Those injuries brought home the fear and confusion that many of our users experience every day.

And yet, nine years after starting BrainLine, there is reason for hope as well. The treatment guidelines developed by the CDC, the Brain Trauma Foundation, the American Association of Neurological Surgeons and others appear to be more broadly understood and more widely used. Organizations like Cohen Veterans Bioscience and the Broad Institute are mounting a coordinated research effort that will draw on neuroscience, genetics, computer science and neuro-imaging. As Dr. Magali Haas, President of Cohen Veterans Bioscience, recently observed, scientific papers on PTSD and TBI appeared last year at a rate of more than 10 a day. “According to ClinicalTrials.gov…117 trials are underway on PTSD and TBI and almost 400 more are currently recruiting participants,” Dr. Haas wrote. “Promising research...must be scaled up and repeated to be sure that leads are worth pursuing into the costly and lengthy process of drug development.”

The sharply higher level of public awareness makes it more likely that an ambitious research effort can be sustained. The greater availability of information about TBI—on BrainLine and elsewhere—makes it easier for families to find help and for professionals to stay up-to-date. And hopefully BrainLine, along with many others, can help ensure that TBI will never again be the neglected outlier of American public health but rather an issue that we care about, report on, and at some point, learn to treat more effectively.

ABOUT THE AUTHOR
Noel Gunther, BA, JD, oversees national education projects, including BrainLine, at WETA-TV in Washington, D.C. He is co-author of Beyond Boardwalk and Park Place (Bantam Books) and has written for The New York Times, The Washington Post, and many other publications. He is a graduate of Yale University and Harvard Law School. You can reach him at: ngunther@weta.org
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**NORTH AMERICAN BRAIN INJURY SOCIETY**

Co-chairs, Stewart Casper, Simon Forgette, Kenneth Kolpan, and Bruce Stern have been hard at work organizing the 30th Annual Legal Conference on Brain Injury, which is scheduled to take place March 30-April 1, 2017, at the Sheraton New Orleans Hotel in New Orleans, Louisiana. The full program is now on the NABIS website. 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. As a special feature of the Legal Conference, Erin Bigler will deliver an in-depth four-hour lecture that will review the current applications of neuroimaging methods in the study of TBI, and provide a glimpse into future applications in the diagnostic, treatment and outcome predictions in TBI. Optional pre-conference sessions will cover Trial Strategies for TBI Cases and Current Diagnostic Techniques and their Admissibility. The NABIS legal conference will be held concurrently with the 12th World Congress on Brain Injury, providing attendees unrivaled access to both legal and medical education. As an official affiliate of IBIA, NABIS has organized a Pre-Congress Session at the Congress entitled Evidence Based Assessment and Treatment of Concussion, and a keynote presentation by Jonathan Silver entitled Persistent Symptoms after Concussion: A Neuropsychiatric Perspective. See you at the World Congress! For more details and to register, visit nabis.org

**BRAND INJURY ASSOCIATION OF AMERICA**

Brain Injury advocates from every corner of the nation will come together in Washington, D.C. on March 22, 2017 for Brain Injury Awareness Day. The annual Hill visit is an exciting opportunity to network with Members of Congress and congressional staff while learning about the brain injury community and field.

With changes to the Affordable Care Act looming ahead, advocates have a unique and important opportunity to educate lawmakers on brain injury and its impact on the individual, their family, employers, treatment providers, and the community at large. Talking points, printed collateral, and public service announcements are available for use during Brain Injury Awareness Month at www.biausa.org/Awareness.

**DEFENSE CENTERS OF EXCELLENCE FOR PSYCHOLOGICAL HEALTH AND TRAUMATIC BRAIN INJURY**

Traumatic brain injury (TBI) impacts both patients and their caregivers. The Defense and Veterans Brain Injury Center (DVBIC) has clinical tools to help providers treat patients with TBI.

DVBIC’s clinical recommendation suites are designed to help frontline providers implement clinical practice guidelines. Suites contain clinical support tools, training materials as well as a patient fact sheet with tips for recovery after a mild TBI.

DVBIC also offers resources for TBI patients and their caregivers. Patients experiencing long-term TBI effects need to develop life care plans. DVBIC products such as TBI: A Guide for Caregivers of Service Members and Veterans provide moderate and severe TBI patients with a full spectrum of treatment and rehabilitation options. Patients and caregivers use the guide to work with their health care provider and learn about assessing and managing TBI symptoms.

For more information about DVBIC’s clinical recommendation product suites, visit dvbic.dcoe.mil or access the DCoE Resource Catalog at http://www.dcoe.mil/About_DCoE/Resources.aspx

**INTERNATIONAL BRAIN INJURY ASSOCIATION**

The program for the 12th World Congress on Brain Injury is now online! Congratulations to the scientific committee members Drs. Lisa Brenner, David Arciniegas, Risa Nakase-Richardson, Angelle Sander and Nathan Zasler, for assembling a rich and varied program. State of the art research will be presented on every aspect of brain injury from coma to community. In addition to over 200 oral presentations, panels, workshops and keynote lectures will be delivered by Fiona Lecky, Jeffrey Kreutzer, Jonathan Silver, Nathan Zasler, Lucia Braga, and Martin Monti. IBIA is also pleased to present a special Post-Congress session focused on female brain injury including concussion from sports, violence, accidents, and military service. Organized by Pink Concussions, during this six-hour session an expert faculty will provide cutting edge research and training for medical providers while stimulating conversation and collaboration among researchers working in the field. Also new this year, on Friday evening, IBIA will host an Unmasking Brain Injury Reception that will feature masks painted by persons with brain injury from around North America. All professionals working in the field of brain injury are encouraged to register for the Congress as soon as possible to ensure their space -- the IBIA block of rooms at the Sheraton is already nearly full. Organizations seeking to be an exhibitor or sponsor of the Congress should note that only a handful of exhibit spaces remain! For complete details on the World Congress, including the program, speaker list, and exhibitor information, visit our dedicated Congress website, www.ibia2017.org

**INTERNATIONAL PEDIATRIC BRAIN INJURY SOCIETY**

IPBIS and IBIA are pleased to announce that the Call for Abstracts for the Second International Conference on Pediatric Acquired Brain Injury is now open! The conference will be held in Rome, Italy from September, 20-23, 2017, with the theme New Strategies to Improve Outcome and Quality of Life. IPBIS welcomes the submission of original research on a wide range of pediatric brain injury topics including: clinical outcome measures, family supports/ interventions, robotic rehabilitation, neuropsychological issues, educational transitions, legal issues, and prevention. The conference will take place within the beautiful grounds of the Pontificia Universitá Urbanaiana, which is located directly adjacent to the Vatican. The Urbanaiana is steps away from St. Peter’s Square and the St. Angelo Castle. Complete details on the conference and the abstract submission process, can be found on our website, internationalbrain.org. IPBIS also looks forward to the 12th World Congress on Brain Injury
where Lucia Willadino Braga will deliver IPBIS’s plenary lecture entitled How to Help Preadolescents with TBI Develop Executive Functions to Prevent Later Behavioral Problems. In addition, IPBIS organized a special Pre-Congress Session entitled Transforming TBI Management for Youth: Beyond Acute to Advancing Function in the Long Term. See you at the Congress!

NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

The National Association of State Head Injury Administrators asks that you join us at the Congressional Brain Injury Task Force (CBITF) Brain Injury Awareness Day Wednesday, March 22, 2017. The Awareness Day will be held at the Rayburn Foyer in Washington DC. This is the one day that national attention is focused on brain injury! It is an excellent opportunity to learn about current federal and national research, prevention and rehabilitation/community services initiatives. For a detail agenda of the day’s activities, visit www.nashia.org.

Plans are now underway for our 28th NASHIA State of the States meeting (Sharing the Lessons, Advancing the Learning) to be held in Tempe, Arizona at the Tempe Mission Palms Hotel and Conference Center, September 11 to 14, 2017! Please contact us if you have specific topic areas that you would like considered by our planning committee.

NASHIA Training and Education committee has developed hot topic webinars that are available to our members and the public. Our inventory of webinars include Professional Ethics Series (CEU credited), Falls in the Elder, ICD-10 Codes, Introduction to Brain Injury, as well as a series on TBI Public Funding. All of this and more is readily available for viewing!

Our staff and pool of consultants are ready and available to provide information on state TBI programs, technical assistance and other resources. Join us now at www.nashia.org!

UNITED STATES BRAIN INJURY ALLIANCE

The leadership of USBIA is pleased to announce a new membership category! Starting in December, USBIA welcomes all those with an interest in brain injury to join the Alliance as Advocate Members! This includes persons with brain injury, family members, caregivers, medical professionals, legal professionals and administrators. All those with an interest in brain injury are encouraged to join USBIA and be a part of a nation-wide community of advocates seeking to prevent brain injury and improve lives. Best of all, there is no cost to joining USBIA as an Advocate Member! USBIA is dedicated to affecting positive change through education, collaboration, advocacy, and outreach. By joining USBIA as an Advocate Member, you will be uniting with others around the country in a common mission to prevent brain injury and improve lives. For more information or to join USBIA as an Advocate Member, visit our newly redeveloped website, www.usbia.org.

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).

www.restorehealthgroup.com
800-437-7972 ext 8251
Tell us about what the University of Toronto Acquired Brain Injury Research Lab (www.abiresearch.utoronto.ca) is working on regarding application of technology in brain injury rehabilitation?

Our lab has investigated user preferences over the years with a particular focus on gender. For instance, in a study led by one of my doctoral students, we found that female caregivers were actually more interested in technology use to assist their loved one than were men, controlling for age. Further, although caregivers were interested in technology, they were not using or were not aware of some innovative items that have the potential to assist them.

What do you see as promising new technology on the horizon for individuals with TBI?

I think technology that is ubiquitous and used by everyone (whether smart phones, tablets, computers) are great, so there is no stigma attached to using them. Features related to smart homes are becoming more common and could also be very beneficial to persons living with the effects of brain injury. These smart home features include options such as the ability to remotely monitor home environments and lock doors remotely if needed.

Historically, assistive technology for individuals with disabilities has had high rates of user abandonment or discontinuation. What are some ways to maximize successful adoption and integration of technology for individuals recovering from brain injury?

It is important for devices to be easy to use and also have user support. The appearance of technology can influence use, so design is important. Both of us have had the opportunity of learning from Dr. Marcia Scherer and her foundational working on matching person and technology, including her text published by Springer ‘Assistive Technologies and Other Support for People with Brain Impairment’. For more information specific to this topic, see www.matchingpersonandtechnology.com.

Any devices that maximize community integration whether at home, work or in the community are desirable. For instance, stove top devices with sensors that shut off the oven when a person leaves the area for a specified time, can promote both safety and independence. There certainly are more and more options and devices like this becoming available. It is not clear to me to what extent these items are routinely suggested for home use. Further, GPS devices can promote independence in the community... and are increasingly available through apps and smart phones, accurate for whether walking, driving or using public transportation and with both the on screen and verbal instructions. I believe more apps could be used in the application of best practices in the treatment setting. We just created an app that informs injury prevention for concussions and/or brain injuries and provides education about the injury that can be used in a work setting.

Here are some North American resources for research, advocacy and general information on assistive technology:

- www.resna.org – Rehabilitation Engineering and Assistive Technology Society of North America
- www.atia.org – Assistive Technology Industry Association
- www.atarpg.org – Association of Assistive Technology Act Programs
- www.tetrasociety.org – Tetra Society of North America
- www.aem.cast.org – National Center of Accessible Educational Materials
- www.rehabtool.com – Guide to Assistive Technology
- www.nichd.nih.gov/health/topics/rehabtech - National Institutes of Health Rehabilitation and Assistive Technology
- www.brainline.org – enter ‘technology’ or ‘apps’ in the search box to find easy to read review articles

I have long appreciated your scholarship on our common interests in issues related to gender and aging, which is how we first met. How do these factors of age and gender interact with use of technology in rehabilitation?

Utilization does tend to influence use, with younger age associated with more use, although older adults have been shown to more readily adopt technology. There are a paucity of studies, however, that actually examine technology use and preferences by age and sex. Technology design should be responsive to preferences and features that may vary by age and sex to promote greater adoption. It is also important to recognize comorbidities associated with age, such as arthritis, changes in vision, etc., which may affect the need for larger interfaces, bigger screens, and easy to read font sizes.

Are there technological advances, apps or tools that you feel are underutilized in the brain injury field?

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ABOUT THE INTERVIEWER

Tina M. Trudel, PhD, CBIST is the Chief Executive Officer and Clinical Neuropsychologist for Northeast Evaluation Specialists, providing assessment and rehabilitation at locations throughout New England. She is a NABIS Board member, author of over 50 brain injury publications, and co-editor of the recent Essential Brain Injury Guide 5.0.
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To schedule a Continuing Education Inservice, Facility Tour, or to request additional educational materials please call Ana Aguilar at 1-800-697-5390 ext. 4420
January 2017 kicked off with the new 115th Congress and the inauguration of a new President and Vice President. A new Administration means changes in leadership within the federal agencies. Thus, the Senate began vetting and approving nominees put forth by President Trump for key cabinet positions. After his inauguration, President Trump immediately issued Executive Orders to undo a number of previous Executive Orders issued by President Obama. Among the Executive Orders that followed was the order to undo the Affordable Care Act (ACA) by empowering federal agencies to scale back rules and regulations implementing health care reform.

Congress also began repealing the ACA as its first order of business through a process called budget reconciliation. A replacement bill has yet to be introduced, although several replacement measures are being discussed. These proposals include encouraging the use of health care savings accounts; tax credits for individuals who purchase health insurance; federal grants to assist with state high risk pools, and allowing individuals to purchase insurance across state lines. Lawmakers are also proposing to change the Medicaid program from an entitlement program into a block grant program, which would provide a fixed amount of money to states to implement as states deem fit. The Medicaid program is currently a joint state/federal program with a federal match provided to states based on federal poverty levels (FPL) as determined by the federal government. The majority of Medicaid spending is for long-term services and supports for individuals with disabilities and for older adults. Medicaid pays for care for almost two-thirds of those who reside in nursing homes.

As the current therapy cap exceptions process will expire on December 31, 2017, lawmakers in both the House and Senate have indicated plans to sponsor legislation to repeal therapy caps. In 1997, Congress placed an annual cap on rehabilitation services under Medicare. Since then, Congress has acted several times to prevent implementation of a hard cap. Meanwhile, Congress will need to fund federal government and services beyond April 28, 2017, when the current continuing resolution expires. Although the President’s budget for FY 2018 is due by Feb. 6, it is unclear if that deadline will be met or what will be contained in the budget recommendations. The new President has proposed cutting federal spending throughout agencies, including the federal workforce through attrition by imposing a hiring freeze.

Prior to the 114th Congress adjourning, lawmakers did pass the 21st Century Cures Act, H.R. 34, which provides funding for the National Institutes of Health (NIH) to conduct health research and the Food and Drug Administration (FDA) to speed up the approval process for drugs used in regenerative medicine. The bill includes $1.511 billion over ten years for NIH’s role in the BRAIN Initiative, $53 million less than what was originally included. The intention is that this funding would be in addition to the BRAIN Initiative funding provided by the annual appropriations bill. The bill establishes the Precision Medicine Initiative to help researchers develop medicines tailored to individuals, rather than one-size-fits-all treatments. The bill also includes the rehabilitation research legislation known as the “Enhancing the Stature and Visibility of Medical Rehabilitation Research at the NIH Act.” The provision builds upon recommendations of the NIH Blue Ribbon Panel on Medical Rehabilitation Research.

The U.S. Department of Health and Human Services’ Administration for Community Living (ACL) Federal Traumatic Brain Injury (TBI) Grant Program, authorized by the TBI Act of 1996, as amended, released a report, “As-Is” Assessment, describing the status of the TBI grant programs (State Grant and Protection & Advocacy Grant), as well as some of the recommendations offered by stakeholders for the future administration of these federal funds. The TBI State Implementation Grant Program and the Protection & Advocacy TBI (PATBI) Grants were transferred from Health Resources and Administration (HRSA) to ACL in 2015 and 2016. As such, the ACL began a two-part process to assess the current state of the program and to follow up with a “To-Be” Report that will reflect the goals and strategies for the program moving forward.

March is Brain Injury Awareness Month. As such, the Congressional Brain Injury Task Force will hold its annual Brain Injury Awareness Day on March 22, 2017, with all events to be held in the Rayburn House Office Building. The Brain Injury Awareness Fair will be held in the Rayburn Foyer starting at 10:00 a.m., followed by the briefing, “Faces of Brain Injury: The Invisible Disability Affecting Children and Adults,” to be held in the Rayburn Gold Room 2168. A reception will also be held in the Rayburn Gold Room 2168 from 5:00 p.m. - 7:00 p.m. This is an excellent time for agencies, organizations, individuals with brain injury, families and other professionals to network and to educate policymakers about brain injury.

ABOUT THE AUTHOR

Susan L. Vaughn, S.L. Vaughn & Assoc., is the Director of Public Policy for the National Association of State Head Injury Administrators and consults with the Brain Injury Association of America on state policy issues. She retired from the State of Missouri in 2002, after working nearly 30 years in the field of disabilities and public policy. She served as the first director of the Missouri Head Injury Advisory Council, a position she held for 17 years. She founded NASHIA in 1990, and served as its first president.
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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 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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