

Testimony of Mark J. Ashley, Sc.D., CCC-SLP, CCM
Chairman Emeritus, Brain Injury Association of America

On

A Review of Efforts to Prevent and Treat Traumatic Brain Injury

Prepared for the Subcommittee on Health
Committee on Energy and Commerce

March 19, 2012

Good afternoon, Chairman Pitts, Ranking Member Pallone, and members of the health subcommittee. My name is Dr. Mark Ashley. I am honored to testify today about a topic that has been my life's work: Traumatic Brain Injury (TBI).

I am the President/CEO of the Centre for Neuro Skills, which operates brain injury rehabilitation programs in California and Texas. I am an adjunct professor in the Department of Communication Disorders and Sciences in the College of Education at Southern Illinois University and serve on the clinical practice committee of the American Congress of Rehabilitation Medicine. My textbook, *Traumatic Brain Injury Rehabilitation*,¹ which has been in continuous print for more than 17 years, is now in its third edition.

I'm here today in my volunteer capacity as Chairman Emeritus of the Brain Injury Association of America (BIAA). Founded in 1980, BIAA is the nation's oldest and largest brain injury advocacy organization, serving and representing the 5.3 million children and adults in the U.S. who have sustained TBIs, their families and the professionals who advance research and provide treatment. BIAA advocates for timely access to expert trauma care, specialized rehabilitation and long-term services and supports so that people like my brother, your neighbor, parent, or spouse, and our children can live healthy, independent and satisfying lives.

My work in brain injury stems from personal experiences. In 1972, my brother, Stephen Ashley, sustained a catastrophic brain injury while serving in the United States Navy. Neither he, nor the rest of my family, ever fully recovered. My medical career began as a graduate student treating patients with brain injury. Following graduation, I co-founded the Centre for Neuro Skills (CNS) in 1980 and admitted my brother, eight years after his injury. For those eight years, he laid incontinent, unable to move, unable to speak, communicating through eye blinks only. After 18 months of intensive rehabilitation, he regained continence, movement in all extremities, regained speech, was able to feed himself. He married and fathered a child. Stephen is deceased now but his legacy lives on.

I hope to provide you with several key points today about Traumatic Brain Injury (TBI):

1. TBI is more prevalent than new diagnoses of all cancers and affects people of all ages.
2. TBI is a disease, is disease causative and is disease accelerative. It is immensely complex and requires highly specialized treatment.
3. There is significant variability in access to medically necessary health care interventions for individuals sustaining brain injuries due to factors such as state or residency, type of coverage, particular provider and advocacy skills of family members.
4. TBI treatment is clinically effective and cost efficacious.
5. Research funding is not adequate to match the significance of this public health threat.

¹ Ashley, M.J., ed. *Traumatic Brain Injury: Rehabilitation, Treatment and Case Management*. Third Edition ed., ed. M.J. Ashley. 2010, CRC Press: Boca Raton.

Prevalence

The CDC reports 1.7 million Americans are diagnosed with a TBI in the U.S. each year.² Additionally, the CDC estimates that between 1.6 and 3.2 million concussions are sustained through sporting events.³ By comparison, NIH reports 1.6 million new diagnoses of all types of cancer each year in the U.S.

The annual incidence of TBI is up from 1.4 million just two years ago and does not reflect TBIs sustained in Iraq and Afghanistan. Of the civilians currently injured, 52,000 die and 275,000 are hospitalized.² Seniors and children are at greatest risk for injury. Almost half a million (475,000) children age 0 to 14 visit emergency departments for TBI each year.²

Let me put these numbers in perspective. Today, more than 4,000 people in the U.S. will sustain a TBI. Recall the horror of 9/11, when the death toll was 2,752 lives or Pearl Harbor where the toll was 1,178 lives. In the latter examples, lives were lost. In brain injury, many whose lives are saved say they are not worth living. And unthinkable, parents pray they will outlive their children.

Disease

No two brain injuries are alike. The same force applied to the brains of different individuals can result in different levels of injury severity and vastly different outcomes. An injury to the brain causes changes that can temporarily or permanently diminish a person's physical or communicative abilities, impair cognitive skills and interfere with emotional and behavioral well-being. In other words, a TBI can affect how we move, talk, think and feel.

Physical challenges may include balance or coordination difficulty, fatigue, weakness, hearing or vision impairment, sensory loss and seizures. Speech language can be severely impaired or lost altogether. Cognitive challenges may involve memory loss, difficulty with planning, organization, problem solving, decision making or judgment, slowed processing speed and reduced attention or concentration. Psychosocial challenges may include depression, stress, anxiety, aggression, frustration or mood swings, difficulty relating to others and reduced self-esteem. Simply put, every skill we possess can be at risk following a brain injury.

Brain injuries are heterogeneous and unpredictable, treatment is complex and outcomes are variable. The Brain Injury Association of America recognizes TBI is the start of disease-causative

² Faul M, Xu L, Wald MM, Coronado VG. Traumatic brain injury in the United States: emergency department visits, hospitalizations and deaths 2002–2006. Atlanta: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.

³ Langlois JA, Rutland-Brown W, Wald MM. The epidemiology and impact of traumatic brain injury: a brief overview. *J Head Trauma Rehabil* 2006;21(5): 375–8.

and disease-accelerative processes involving the central nervous, autonomic nervous, endocrine and immune systems that result in chronic respiratory conditions, widespread infections, neurologic disorders and psychiatric diseases as well as musculoskeletal, bowel, bladder and sexual dysfunction. We are just beginning to understand the impact of brain injury on diseases such as Parkinson's disease, Alzheimer's disease, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, and, as we are learning from retired athletes, Chronic Traumatic Encephalopathy.

The consequences of inadequate medical treatment for individuals with brain injuries and society are well known. Inadequate treatment often results in higher levels of medical complications, permanent disability, family dysfunction, job loss, homelessness, impoverishment, medical indigence, suicide and involvement with the criminal or juvenile justice system. Inadequate treatment also leads to lost productivity and greater utilization of publically-funded income maintenance programs (such as SSI and SSDI), medication, durable medical equipment, long-term care and institutionalization. Thus, the burden of care for brain injury is systematically transferred from private insurance companies to families and then to taxpayers at the federal, state and local levels.

The consequences of adequate medical treatment are also well known. Acute and postacute treatment include disease management, mitigation and prevention as well as treatment to promote neurophysiological remodeling and reorganization through physical, occupational and speech therapies and other rehabilitative interventions of sufficient scope, timing, intensity and duration. These treatments restore maximum levels of function and reduce long-term disability and pain, rather than merely accommodating for disability through durable medical equipment or medication. More specifically, medically necessary rehabilitative services:

- Prevent, mitigate, reverse or arrest neurophysiological disease processes;
- Speed recovery (better outcomes and enhanced likelihood of discharge to one's home, living longer and retaining a higher level of function post injury or illness);
- Improve long-term cognitive and physical function, improve overall health status and improve the likelihood of independent living and quality of life;
- Decrease the likelihood of homelessness, joblessness, impoverishment, family system disintegration, incarceration, and medical indigence;
- Decrease reliance on various public health and assistance programs;
- Halt or slow the progression of primary and secondary disabilities (maintain functioning and prevent further deterioration); and
- Facilitate return to work in appropriate circumstances.

Yet, this disease and the benefits of treatment are not well understood in the general medical and allied health communities. Further, treatment requires specialized settings designed to maximize patient outcomes. Just as you would not expect surgery to be conducted outside an operating theatre, each phase of treatment following brain injury requires specially designed settings.

In the early weeks after injury, recovery is dependent upon the brain's metabolism which stabilizes and improves. Recovery of function occurs as the brain finds and uses available undamaged, alternate pathways to perform tasks. This process is a little like using side streets instead of the beltway. In order to maximize recovery, the brain must grow new neurons, glial cells, synapses and vascular structures—in short, new brain. This process is demand-induced, meaning that it occurs only when there is sufficient environmental demand for new structures. Demand must be controlled, properly timed, of sufficient intensity and duration and expertly applied. This is what proper rehabilitation induces.

The process of growing new structures is rate-limited: it only can occur so quickly. This has bearing on how long the process can be expected to take, contrasted with how long most patients are given for treatment. Interestingly, TBI-related hospitalizations increased by 19.5% from 2002 to 2006¹ while lengths of stay decreased sharply. When my brother was injured 40 years ago, his initial hospital stay was over 12 months; today, patients with moderate to severe TBI spend just 19 days in the hospital.⁴

In part, reduced lengths of stay are due to advances in diagnosis through CT (computed tomography) scans and MRI (magnetic resonance imaging), life-sustaining technologies such as ventilators and NG (nasogastric) tubes, and improved monitoring of oxygen, heart rate, blood flow and intracranial pressure. Neurosurgeons are perfecting procedures to accommodate for the brain's natural bruising and swelling after injury and can administer nutrition, pharmacological agents and electrical stimulation to save the patient's life, reduce secondary injury and speed recovery. Nevertheless, there is enormous pressure by both public and private payers for acute care hospitals to discharge patients "sicker and quicker."

A recent analysis of three archival datasets (CDC's Central Nervous System Injury Surveillance database; National Trauma Data Bank; and National Study on the Costs and Outcomes of Trauma) encompassing 68,000 patient records indicates that among people age 16 and older with moderate to severe injuries, only one in four is referred to rehabilitation. The investigation showed that the decision to discharge a patient directly home from the hospital is due to severity-related factors, while the decision to discharge to rehabilitation is driven by sociobiologic and socioeconomic factors.⁵

We all witnessed the incredible recoveries of ABC News journalist Bob Woodruff and Congresswoman Gabrielle Giffords following TBI. What you don't see is the thousands of people who are desperate because they can't access similar treatment. Peter King, father of four adult children, married, and in business with one of his sons in a small plastering company

⁴ TBI Model Systems, 2011. Retrieved on March 14, 2012 from <https://www.tbindsc.org/Documents/2011%20TBIMS%20National%20Database%20Update.pdf>.

⁵ Cuthbert JP, Corrigan JD, Harrison-Felix C, Coronado V, Dijkers MP, Heinemann AW, Whiteneck GG. Factors that predict acute hospitalization discharge disposition for adults with moderate to severe traumatic brain injury. Arch Phys Med Rehabil 2011;92:721-30.

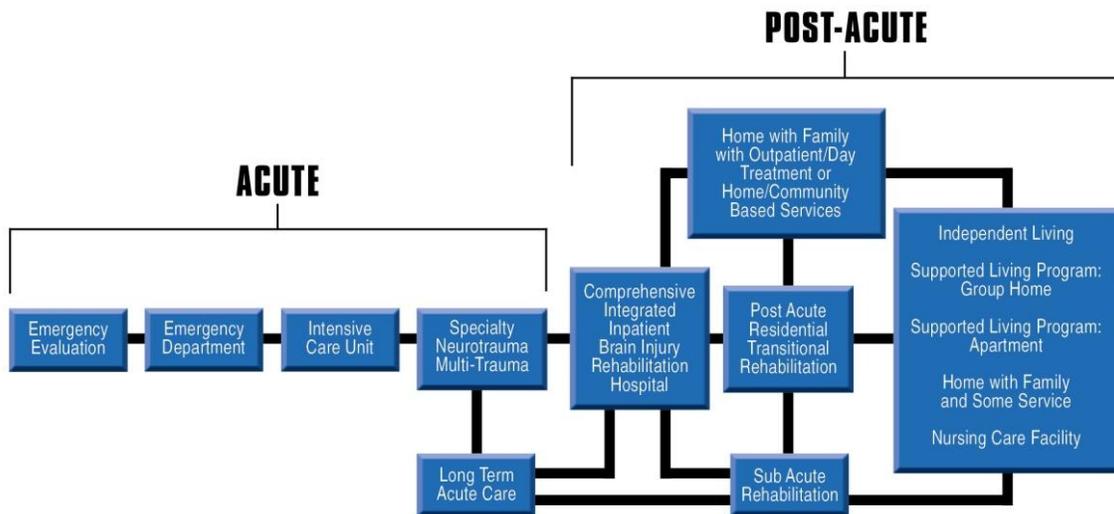
was struck by a drunk driver while riding his motorcycle. His adult daughter, a passenger, was killed. Mr. King struggled with his brain injury for 14 months until his insurer finally authorized 47 days of postacute rehabilitation. While awaiting treatment, he buried his daughter, was jailed, lost his wife to separation and lost his business. Two weeks after discharge, despondent and frustrated, he took his own life.

Spectrum of Care

Unlike most medical conditions, there is not a single pathway or course of treatment for catastrophic TBI. The continuum of care spans emergency evaluation, medical/surgical services, rehabilitation and long-term disease management. Care is provided in a variety of treatment settings that decrease in medical acuity from hospital-based trauma centers and intensive care units, to acute, subacute and postacute rehabilitation facilities, and home and community-based placements where the primary focus moves from medical stabilization to recovery-inducing treatments.

CONTINUUM OF CARE

(adapted from the Rocky Mountain Regional Brain Injury Systems)



Progression along the continuum is not linear—many patients make gains quickly while some may regress backwards. Access to the entire continuum is not uniform. Reasons for inconsistent access include scarcity of beds, inconsistent payer coverage, poor awareness of the need for highly specialized treatment in the general medical, allied health and lay communities and a lack of understanding of the long-term health and cost benefits to maximizing disability reduction immediately proximal to onset of this disease.

Ironically, the latter half of the care spectrum—that which is commonly referred to as postacute—evolved in the 1980s in response to demands to develop less costly, non-hospital-based treatment settings that could address specific TBI-related disability and disease presentations. Today, older patients, minorities and those without insurance or who are covered by Medicare and Medicaid are far less likely to receive postacute rehabilitation.⁵ These patients are at greater risk for re-injury and re-hospitalization due to unresolved physical and cognitive deficits. Family caregivers are rarely equipped or trained to manage the extraordinary burdens placed on them so soon after a loved one's injury.

My company, CNS, provides patients with TBI a broad range of postacute treatments, including physical, occupational, speech language therapies, behavior modification programs, psychological counseling plus family education, home evaluations and case management in residential facilities and day treatment clinics. Care is provided by physicians, licensed therapists and other allied health professionals in real-world settings. We work to restore, not accommodate for lost function, thereby mitigating or slowing disease progression and maximizing health outcomes and personal independence.

Like many other postacute treatment providers, CNS is accredited by CARF (the Commission on Accreditation of Rehabilitation Facilities), my staff is certified by the Academy of Certified Brain Injury Specialists, and we are licensed as an assisted living facility. Because CNS is not a hospital, nursing home, home health agency or doctor's office, we are not eligible to be a Medicare provider. And because we do not have a Medicare provider number, we cannot accept TRICARE patients through our normal admissions process.

Currently, CNS is participating in the Veterans Health Administration's Assisted Living-Traumatic Brain Injury (AL-TBI) pilot project; however, we are voluntarily supplementing the care paid by the VA with more frequent and intensive therapies because after 35 years of clinical practice, I know that's what our service members need and firmly believe they deserve it. Arbitrary limits on the frequency, intensity and duration of rehabilitation treatment are not justified in the scientific literature, disallow patients' attainment of maximal functional outcome and unnecessarily increase societal costs.

Variability in Access to Treatment

A survey conducted by BIAA showed there is significant variability in access to medically necessary health care for individuals sustaining brain injuries. The major factors influencing this variability include: state of residency; type of coverage (accident and health, no-fault auto, workers compensation, Medicare/Medicaid); particular provider (willingness and knowledge and experience of medical director, case management staff); and/or advocacy skills of the family and the experience and sophistication of the provider's staff in their dealings with insurers (e.g., exchange of benefits, extra-contractual services, Letters of Agreement). Importantly, public and private carriers need to be as informed of the latest and best treatment

approaches for people with brain injury as the medical community. When both act are better informed, they can act in concert to achieve better outcomes and better cost savings.

Treatment is Clinically Effective and Cost Efficacious

Over the years, CNS and many other postacute treatment providers have welcomed VA clinicians who wished to observe our treatment protocols and management policies and procedures. In 2010, I was honored to participate in the Blue Ribbon Symposium on Traumatic Brain Injury and Post Traumatic Stress organized for Gen. Peter Chiarelli, then Vice Chief of Staff of the U.S. Army. Appended to this testimony is a compilation of research findings I reported to the General with respect to the efficacy and cost effectiveness of rehabilitation.

In summary, the research demonstrates treatment of appropriate scope, duration, timing and intensity delivered by an interdisciplinary team of experienced and specialized clinicians results in shorter lengths of stay, increased rate of recovery, improved extent of recovery, less overall cost for treatment, less caregiver burden, fewer hours of attendant care per day, and greater lifetime cost savings.⁶

Further, the evidence shows that even late rehabilitation, as in the case of the VA's AL-TBI, is cost-effective and improves function and independence so much so that the lifetime cost savings outweigh the rehabilitation costs. Similarly, ongoing disease management results in fewer difficulties with activities of daily living, significantly reduced morbidity, and significantly reduced severity of symptoms as well as a decreased reliance on pharmacological interventions and durable medical equipment, lower long-term care costs and greater likelihood of return to school and work.⁶

For children and adolescents, the ability to return to school is critical. Following a moderate or severe brain injury, new learning and the development of milestone skills is a challenge. Many postacute facilities include a classroom setting with a curriculum that enhances success. An educational team works with the parents, child and local school district to create an Individualized Education Program (IEP) so the patient, or student, can continue to earn school credit. Most parents prefer to care for their injured child at home. That's true for spouses too, but a postacute residential facility provides a safe, structured, supervised environment that successfully bridges the transition from hospital to home.

Six years ago, the United Kingdom developed a typology for extracting reliable evidence from studies that are not randomized controlled trials (RTCs) and showed that that the findings

⁶Ashley MJ. Maximizing rehabilitation outcomes and cost efficiency following acquired brain injury. Brain Injury Source 2010:10-21.

compared favorably to those derived from RCTs.⁷ Despite these findings and the U.S. Preventive Health Task Force's admonition to use all levels of evidence, we do not do so in brain injury. This was illustrated in a recent comparative effectiveness investigation sponsored by the Agency for Healthcare Research and Quality in which a comprehensive search strategy spanning 30 years of published research on multidisciplinary rehabilitation of moderate to severe TBI of adults yielded 1,616 studies, of which only 16 were deemed usable by the contractor. Consequently, investigators could not draw any conclusions about the effectiveness or comparative effectiveness of TBI rehabilitation.⁸

Conversely, in a report released in October 2011, panelists from the National Academies' Institute of Medicine (IOM), who analyzed the effectiveness of cognitive rehabilitation for patients with TBI determined:⁹

- Despite the scarcity of conclusive high quality evidence, we support the ongoing use of promising practices/approaches while improvements are made in the standardization, design, and conduct of research studies.
- Limitations of the evidence do not rule out meaningful benefit.
- Policy should facilitate the application of techniques based on best available evidence with the proviso that objectively measurable functional goals are articulated and tracked and treatment continues so long as it is medically necessary.

Research Funding

Unlike many other health conditions, such as breast cancer, wherein affected individuals and their loved ones can advocate for and raise funds for research, that is not the case for people with brain injury. They rely on surrogates to advocate for them and for policymakers to invest wisely in prevention, treatment and research.

In 2011, the National Institutes of Health invested only \$81 million in TBI.¹⁰ That includes all investigations funded by the National Institutes on Neurological Disorders and Stroke (NINDS),

⁷ Turner-Stokes L, et al. Generating the evidence base for the national service framework for the long term conditions: a new typology. *Clinical Medicine* 2006;6(1): 91-97.

⁸ Agency for Healthcare Research and Quality. Comparative effectiveness: Multidisciplinary postacute rehabilitation for moderate to severe traumatic brain injury in adults (DRAFT). 2012; Report No. XX. Retrieved on March 10, 2012 from http://www.effectivehealthcare.ahrq.gov/ehc/products/283/930/Rehab-and-TBI_DraftReport_20120112.pdf.

⁹ IOM (Institute of Medicine). 2011. *Cognitive Rehabilitation Therapy for Traumatic Brain Injury: Evaluating the Evidence*. Washington, DC: The National Academies Press.

¹⁰ NIH. 2012. Retrieved on March 13, 2012 from <http://www.report.nih.gov/rcdc/categories/>.

the National Center for Medical Rehabilitation Research (NCMRR) and the National Institute of Child Health and Human Development (NICHD). By contrast, NIH invested \$5.4 billion in cancer research. Even with Congresses' recent infusions into DoD and VA TBI research, the gulf is enormous. As policymakers and advocates, how do we explain this to individuals and families who are suffering so much?

The Brain Injury Association of America supports basic science research as envisioned by the One Mind Campaign, investment in epidemiological research by the Centers for Disease Control and Prevention and recognizes the need for more rehabilitation research, for children and adults, at the National Institute on Disability and Rehabilitation Research, which is housed in the U.S. Department of Education.

BIAA also supports the adoption and widespread use of a more precise system for classifying injury severity and the development of a taxonomy of TBI impairments and interventions that would strengthen research methodology and transparently communicate treatment plans to payers and patients. We believe the taxonomy should be established alongside the development of medical treatment guidelines for postacute rehabilitation of moderate and severe TBI that would be applicable for both civilian and military populations.

We cannot sacrifice care while the field works toward a cure. Therefore, BIAA strongly supports reauthorization of the TBI Act, the only federal law that specifically addresses the development and coordination of systems of care and long-term services and supports at the state level for the civilian population through a grant program administered by the Health Resources and Services Administration. We urge policymakers to move away from time-limited, project-oriented grants to formula funding so that all states and territories can build a sustainable infrastructure to address this growing public health problem.

Conclusion

As your witnesses today have testified, individuals with brain injury are a growing segment of the U.S. population. The injury happens in an instant and exacts a devastating toll on the patient and his or her loved ones. But we know that by administering treatment at the proper time and with the right scope, intensity and duration by a well-skilled workforce yields significant cost savings in both the public and private sectors and vastly improves health outcomes, functional independence and life satisfaction.

Our job as advocates is to identify barriers and opportunities. Your job as a member of Congress is to support prevention, research, and treatment that will lead to better health, enhanced employment and education and more fairness and equality for this vulnerable population. We have made great strides in the last 30 years, but much remains to be accomplished on behalf of individuals with brain injury and their families.

Thank you for giving me the opportunity to testify today. I look forward to answering your questions.