



Covering the Treatment Continuum for Persons with Brain Injury As Part of National Health Care Reform

Introduction

Brain injury is the last thing on your mind until it's the only thing.TM Just ask the millions of children and adults who sustain brain injuries in the U.S. each year. News reports of returning veterans and recent high profile brain injury stories indicate what researchers have been reporting for years—brain injury is a leading public health problem in U.S. military and civilian populations.

In the coming months, Congress will be considering health care reform. The Brain Injury Association of America (BIAA) believes that national health care reform initiatives (including reforms to private sector insurance and public programs) should address the unique health care needs of persons who sustain brain injuries.

Evidence-based literature and individual testimonials demonstrate that when people who sustain brain injuries can access a continuum of appropriate medical treatment, including rehabilitation, their health and quality of life are substantially improved and both patients and taxpayers save hundreds of millions of dollars in future health care costs.

The consequences of inadequate medical treatment for individuals with brain injuries and society are also 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.

BIAA believes national health care reform should address the unique health care needs of individuals with brain injury by recognizing that brain injury is the start of a lifelong disease process requiring access to a full continuum of medically necessary treatment, including rehabilitation, furnished by accredited programs in the most appropriate treatment setting as determined in accordance with the choices and aspirations of the patient and family in concert with an interdisciplinary team of qualified and specialized clinicians.

TM Brain Injury Association of Florida, Inc.

Understanding Brain Injury

Awareness of brain injury has increased substantially because of the estimated 360,000 service members returning from Iraq and Afghanistan with blast injuries. Yet, brain injury is common in the civilian population too.

According to the CDC, each year 1.4 million American children and adults seek treatment for identifiable traumatic brain injuries (TBIs) from falls, car crashes and other external blows to the head. An estimated 1.6 to 3.8 million individuals annually incur sports-related concussions but do not seek immediate treatment. Additionally, each year nearly 1 million Americans sustain acquired brain injuries (ABIs) from strokes, infections, tumors, toxins and metabolic causes.

No two brains are alike so no two injuries are alike. Any brain injury—regardless of cause, type or severity—can temporarily or permanently impact brain and body functions resulting in difficulties in physical, communicative, cognitive, social, emotional, and psychological performance that undermine health, function, community integration, and productive living.

Brain injury is also a disease causative and a disease accelerative in that it predisposes individuals to re-injury and the onset of other conditions. For example, brain injury impacts neurologic disorders such as epilepsy, vision and hearing impairments, psychiatric disorders, and orthopedic, gastrointestinal, urologic, sexual, neuroendocrine, cardiovascular and musculoskeletal dysfunction.

For many individuals who sustain brain injury, the effects may be minimal and when properly treated, full recovery or nearly full recovery is possible. However, the CDC estimates that each year, at least 125,000 brain injury survivors will develop a permanent disability, and therefore, the onset of chronic disease.

Treating and Managing Brain Injury

For many people, brain injury is not an event or an outcome but rather the beginning of a lifelong disease process. These patients need access to a continuum of medically necessary treatment (including rehabilitation) furnished by accredited programs in the most appropriate treatment setting as determined in accordance with the choices and aspirations of the patient and family in concert with an interdisciplinary team of qualified and specialized clinicians.

Treatment Continuum

The treatment continuum for patients with brain injury begins with acute medical treatment, which is necessary to save lives and arrest disease progression in the early minutes and hours after injury. Acute treatment may be provided in the emergency room, trauma unit, intensive care unit, medical/surgical floor or similar hospital-based location.

Acute and post-acute 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, duration and intensity. 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. Some individuals with brain injury are able to return home directly from the hospital, but many patients need the clinically effective and cost efficient medical treatment that is primarily available from specialty rehabilitation hospitals or residential/transitional rehabilitation facilities. Depending on the individual's needs, treatment also may be provided in an outpatient setting, such as a clinic, day treatment program or at home.

Ongoing medical management is also required to achieve durable outcomes, mitigate disease progression and optimize health. These services are offered in community-based settings such as medical offices but can also be provided in group homes, supported apartments, or similar living arrangements.

It is critical to recognize that recovery from brain injury is not a linear event. Brain injury is similar to other chronic conditions (i.e., cancer, asthma, and diabetes) in that the disease may be stable for a period of time and then may become unstable. In fact, it is well documented that individuals with brain injury may attain a plateau in functional restoration prior to entering a secondary recovery phase. For this reason, individuals with brain injury may need renewed access at any point along the treatment continuum throughout their lives.

Medical Necessity

Goals and treatment strategies including duration, scope, intensity, and interval of treatment should be determined based on appropriate diagnosis and prognosis, the individual functional needs (including long-term scope and changing needs), need for treatment settings that ensure safety to self and others, and reasonable expectation of continued progress with treatment. An individualized plan of medical treatment should document specific diagnosis-related goals for a patient who has reasonable expectation of achieving measurable functional improvements in a predictable period of time through the provision of medically necessary services.¹ Such judgments should be developed by a highly specialized and experienced interdisciplinary team in concert with the patient and family.

¹ Medically necessary services include services that a physician, exercising prudent clinical judgment, would provide or prescribe to a patient for the purpose of preventing, evaluating, diagnosing or treating an illness, injury, disability, disease or its symptoms, and that are: a) in accordance with generally accepted standards of medical practice; b) clinically appropriate, in terms of type, frequency, extent, site and duration, and considered effective for the patient's illness, injury, disability or disease; and c) not primarily for the convenience of the patient, physician or other health care provider, and not more costly than an alternative service or sequence of services at least as likely to produce equivalent therapeutic or diagnostic results as to the diagnosis or treatment of that patient's illness, injury, disability or disease. For these purposes, "generally accepted standards of medical practice" means standards that are based on credible scientific evidence published in peer-reviewed medical literature generally recognized by the relevant medical community or otherwise consistent with the standards set forth in policy issues involving clinical judgment.

Interdisciplinary Team of Qualified Professionals

Due to the complex nature of the brain, individuals with brain injury require coordinated, interdisciplinary treatment involving specialists from more than one therapeutic discipline. The team may be comprised of medical and allied health professionals including a behavioral specialist, case manager, clinical psychologist, neurologist, neuropsychologist, occupational therapist, physical therapist, speech/language pathologist, and recreational therapist. Diagnosis and treatment of individuals with brain injury should be undertaken by clinicians who have fulfilled the requirements for professional training and certification in their respective medical or allied health disciplines.

Variety of Settings; Accredited Agencies and Organizations

For individuals with brain injury, the treatment continuum is comprised of specific facility and specialty programs types, many of which have earned accreditation by the Joint Commission on Accreditation of Healthcare Facilities (JCAHO) and/or the Commission on Accreditation of Rehabilitation Facilities (CARF). Program types include acute care hospitals, inpatient rehabilitation facilities, residential rehabilitation facilities, day treatment programs, outpatient clinics and home health agencies. Every level of the brain injury treatment continuum is enriched by clinical experience, protocols, and extensive operational management knowledge acquired during the last 30 years.

The Dollars and Sense of Rehabilitation

It is important to recognize that the brain is the only organ that responds to and relies on external stimulation for physiological remodeling of the neural structures that allow humans to function—to walk, talk, eat, think and feel. No pharmacologic or surgical intervention exists that will repair or replace the neural structures. Instead, they must be re-modeled through structured and consistent rehabilitation interventions.

Brain injury rehabilitation works because it provides a measured application of scientifically-designed therapies that facilitate the genetic, biochemical and structural changes needed for recovery of function. These neurophysiological changes, known as remodeling, require time to occur. Evidence shows early access to intense rehabilitation, such as that available in rehabilitation hospitals and inpatient residential/transitional programs, improves the rate and extent of recovery. Conversely, delaying rehabilitation increases the cost of achieving similar levels of recovery, and withholding rehabilitation diminishes the extent of possible recovery.

Appropriate access to the treatment continuum is exemplified in the stories of people like Trisha Meili, the Central Park Jogger who was accosted and left for dead, and ABC News Journalist Bob Woodruff, who was injured by an IED blast in Iraq. With treatment of sufficient scope, duration and intensity, both were able to regain their independence and resume their roles within their families and as working professionals. Bob H, who was injured in a workplace explosion, accessed the treatment continuum and recovered from severe neurobehavioral and orthopedic disability. Without treatment, Bob faced institutionalization and a lifetime of pharmacological

sedation. With treatment, he was able to return to life with his family and is able to walk, talk, and care for himself.

Others were not so fortunate.

- Dr. J, a dentist who was severely injured in a motor vehicle accident, received a total of 6 weeks of rehabilitation before being sent home severely disabled in a wheelchair, requiring full care from his wife of more than 30 years. As his disease progressed, he became delusional and extremely violent toward his wife and family. He was psychiatrically hospitalized and sedated with medications known to cause permanent neurologic damage.
- A 17-year-old girl received a total of 2 weeks of rehabilitation after a severe brain injury she sustained skateboarding behind a car in a parking lot. The medical director of the insurance company refused to authorize continued inpatient rehabilitation and she was forced into outpatient treatment in her small hometown, limited to 20 outpatient visits. When asked to authorize an internal appeal, the medical director declined and advised that the applicant “talk to somebody who cares.” She will not go on to college as was her potential with effective treatment.
- Ms. O, injured by a fall, received 5 years of diagnostic evaluations following her brain injury before being allowed to receive inpatient rehabilitation services. Her treatment was stopped 30 days early. She did not return to work as intended, but regressed significantly upon her return home.
- Mrs. M sought treatment for her husband, a Veteran who was injured while serving in Vietnam. An evaluation in the first year after injury indicated he would be able to return to and maintain independent living with his wife after treatment. After waiting 5 years for authorization for treatment, his potential dramatically declined and he now will require institutional care away from his family for the rest of his life.

Study after study demonstrates that specialized brain injury rehabilitation not only improves health and quality of life for persons with brain injury but is cost efficient. Rehabilitation is an investment that saves hundreds of millions of dollars for patients and taxpayers. For example:

- A single patient with severe neurobehavioral disorders who received comprehensive rehabilitation realized a savings of \$4.8 million to \$6 million in the lifetime cost of care after subtracting the cost of rehabilitation programming.
- The cost of supporting 76 patients in community settings was reduced by more than \$1.48 million per person after each received six months of neurorehabilitation.
- Post-acute rehabilitation resulted in 20-year cost-of-care reductions ranging from \$1 million to \$4.8 million per person for the majority of 112 patients who had been previously placed in chronic care settings.
- The weekly cost of care for 297 patients with severe brain injury was reduced by one-third following rehabilitation; the cost of rehabilitation was recovered within 16 to 38 months.
- Patients treated in specialized brain injury residential rehabilitation settings demonstrated improvements in levels of care, functional ability and performance of social roles; the costs of rehabilitation were offset within two years and the lifetime savings ranged from \$5.3 thousand to \$1.48 million per patient.

Private Sector Insurance and Public Programs

Some private payers provide access to the full treatment continuum of necessary services. For example, sectors of private insurance that have long-term contractual liability for individuals with injury, such as workers' compensation and liability companies, promote and actively support the development and utilization of the post-acute rehabilitation model and treatment continuum. These entities recognize the need to treat catastrophic injury aggressively and intensively to maximize disability reduction and promote disease mitigation and prevention to achieve long-term cost efficiency.

Unfortunately, many private payers do not provide access to the full continuum of necessary services despite the overwhelming evidence of cost efficiency and benefit to patients with respect to regaining health and function, reintegrating into the community, assuming former social roles, and making productive contributions to society. For example, accident and health carriers often seek to delay or deny treatment until such time that the patient's insurance has run out and the carrier is no longer responsible for him/her. In publicly-financed systems, arbitrary limits are placed on scope, duration and intensity of care despite well-established treatment guidelines. Both systems rely on allied health and administrative personnel who are not experts in brain injury to authorize care plans and both invoke questionable practices with respect to utilization review and post-treatment audits.

National health insurance reform must ensure that private insurance systems do not delay or deny treatment as a means of transferring the burden of brain injury care to taxpayers at federal, state and local levels; ensure that both public and private health insurance systems meet the health care needs of people with brain injury in the same way that such systems meet the needs of persons with other chronic diseases (e.g., heart and lung disease); and avoid using Medicaid and Medicare as the first option for coverage of people with brain injury.

Conclusion –Guiding Principles for Health Care Reform

Based on the foregoing, BIAA offers the following principles to guide national health care reform initiatives from the perspective of persons with brain injury.

BIAA believes that national health care reform initiatives should address the unique health care needs of individuals with brain injury by recognizing that brain injury is the start of a lifelong disease process requiring access to a full continuum of medically necessary treatment (including rehabilitation) furnished by accredited programs in the most appropriate treatment setting as determined by an interdisciplinary team of qualified and specialized clinicians in concert with the patient and his/her family.

More specifically, national health care reform should:

1. Recognize that brain injury is not an event or an outcome but is the beginning of a **lifelong disease process** that **impacts brain and body functions** resulting in difficulties in physical,

communication, cognitive, emotional, and psychological performance that undermines health, function, community integration and productive living. Brain injury is also **disease causative and disease accelerative** in that it predisposes individuals to re-injury and the onset of other conditions because it impacts neurologic disorders such as epilepsy, vision and hearing impairments, psychiatric disorders, and orthopedic, gastrointestinal, urologic, sexual, neuroendocrine, cardiovascular and musculoskeletal dysfunction.

2. Focus on health care that is **medically necessary**. A person with brain injury should have an individualized medical treatment plan that documents specific diagnosis-related goals when the person has a reasonable expectation of achieving measurable functional improvements in a predictable period of time through the provision of treatment of sufficient scope, duration and intensity.
3. Provide access to the full **treatment continuum** to **manage the disease** that includes early, acute treatment to stabilize the condition followed by acute and specialized post-acute brain injury treatment and rehabilitation, including inpatient, outpatient, day treatment and home health programs, to minimize and/or prevent medical complication, recover function and cope with remaining physical or mental disabilities, and achieve durable outcomes that maintain an optimal level of health, function and independence following brain injury.
4. Ensure that treatment is provided in the **most appropriate treatment setting by accredited programs** (including acute care hospitals, inpatient rehabilitation facilities, residential rehabilitation facilities, day treatment programs, outpatient clinics and home health agencies) **as determined in accordance with the choices and aspirations of the patient and family in concert with an interdisciplinary team of qualified and specialized clinicians.**
5. **Prevent private insurance systems from delaying or denying treatment as a means of transferring the burden of brain injury care to taxpayers** at federal, state and local levels; ensure that both public and private health insurance systems meet the health care needs of people with brain injury; and **avoid using Medicaid and Medicare as the first option for coverage** of people with brain injury.

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