Traumatic Brain Injury in the United States: A Call for Public/Private Cooperation

Executive Summary

Traumatic Brain Injury (TBI) is a growing public health problem in U.S. military and civilian populations.

The standard of care is early, intensive acute treatment and rehabilitation followed by timely post acute rehabilitation of sufficient scope, duration and intensity to restore maximum function and accommodate residual disability. To optimize their independence and maintain good health throughout their lives, individuals with brain injury need access to a full continuum of care as well as intermittent or lifelong community-based information, resources, services and supports.

The complex nature of TBI necessitates treatment by an interdisciplinary team of highly experienced and specialized clinicians. In the past, the Department of Defense and the Department of Veterans Affairs have contracted with private sector clinicians rather than attempt to replicate the many and varied programs and services that make up the TBI continuum of care.

Now is the time to expand those cooperative relationships to avoid treatment delays, unnecessarily high levels of disability, and greater taxpayer burden in the years to come.

The Brain Injury Association of America urges Congress to facilitate greater public and private cooperation in all aspects of brain injury: awareness, education, treatment and research. America's service members with TBI and the millions of children and adults who are injured in the U.S. each year deserve no less.

Acknowledgements

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The American Congress of Rehabilitation Medicine has endorsed this position statement.

A Growing Public Health Crisis

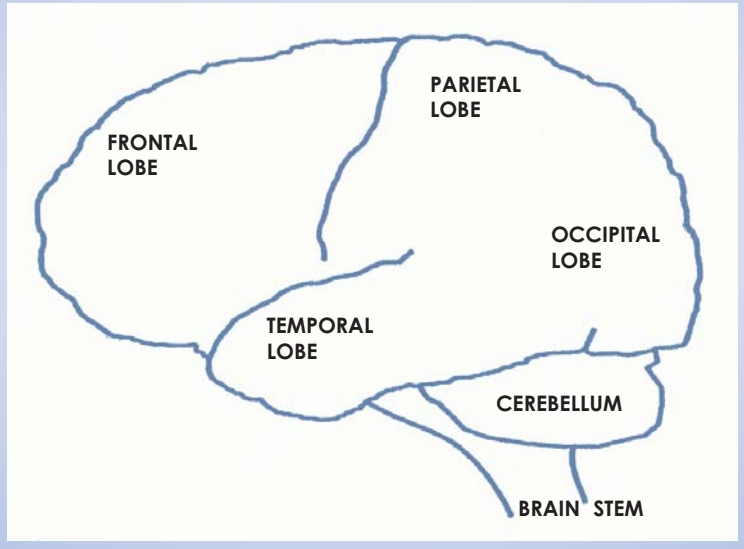
The human brain controls physical, cognitive and behavioral functions. A traumatic brain injury (TBI), which is a blow or jolt to the head or a penetrating head injury, can impact one or more parts of the brain, thereby temporarily or permanently disrupting normal function.

Simplified Brain Behavior Relationships

(Adapted from D. Brooks & L. Meinert, American Academy for the Certification of Brain Injury Specialists, Level I Training Manual, 2nd Ed. 1998)

Frontal Lobe
Initiation
Problem Solving
Judgment
Planning
Behavior
Self-monitoring
Personality
Emotions
Awareness of abilities
Organization
Concentration
Mental Flexibility
Expressive Language

Temporal Lobe
Memory
Hearing
Receptive Language
Organization
Sequencing



Parietal Lobe
Sense of touch
Differentiation in size, shape and color
Spatial perception
Visual perception

Occipital Lobe
Vision

Cerebellum
Balance
Coordination
Skilled motor activity

Brain Stem
Breathing
Heart rate
Arousal/Consciousness
Sleep/Wake Functions
Attention
Concentration

TBIs are caused by falls, motor vehicle crashes, assaults and other incidents. Shock wave blasts from improvised explosive devices, rocket propelled grenades and land mines are the leading cause of TBI for active duty military personnel in combat zones.

In prior military conflicts, TBI was present in 14-20 percent of surviving casualties.[1] Reports indicate 12,274 service members have sustained a TBI in Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) as of March 24, 2007,[2] but that number could grow as high as 150,000[3]. In peacetime, more than 7,000 persons are admitted to military and Veterans hospitals for TBI each year.[1]

The Centers for Disease Control and Prevention (CDC) estimates that 1.4 million TBIs annually occur among civilians. Of these, TBI results in 50,000 deaths and leaves 80,000 to 90,000 citizens with a disability.[4] At least 5.3 million children and adults live with a long-term disability resulting from TBI.[5]

The effects of brain injury are cumulative, and individuals with TBI may be predisposed to re-injury and the onset of disability with subsequent injury. In the civilian population the re-injury rate is 14 percent and the severity increases with recurrent injury.[6] Given the added risks for military personnel, it is estimated that the re-injury rate is higher.

For civilians, direct medical expenses and indirect costs such as lost earning potential and caregiver burden annually exceed $60 billion in 2001 dollars.[7] Although costs for OIF and OEF Veterans with TBI are unknown, the medical and disability expenses for all Iraq and Afghanistan War casualties are estimated at $349 to $662 billion.[8]

Cost estimates may under-represent the true burden on society. TBI has been linked to respiratory, circulatory, digestive, and neurological diseases such as epilepsy, Alzheimer's and Parkinson's disease, but awareness of brain injury as a disease, disease-causative and disease-accelerative is only slowly emerging.[9]

Heterogeneity in TBI Diagnosis and Treatment

No two brains are alike; therefore, no two brain injuries are alike. The same force applied to the brains of different individuals will result in different injury severity. The impairments caused by TBI are heterogeneous and are not predictable. This makes TBI unlike other medical diagnoses. In addition, some symptoms or impairments may emerge soon after the injury while others manifest after weeks or months.

In a 2005 descriptive analysis of 433 patients with TBI seen at the Walter Reed Army Medical Center, moderate and severe injuries accounted for 56 percent of those diagnosed with TBI.[10] In the civilian population, up to 20 percent of all TBIs are moderate to severe. Thus, although each year more civilians are injured, the injuries sustained by service members are more severe.

Mild TBI, sometimes called Hidden TBI, is often undiagnosed or misdiagnosed because patients present with what appear to be more critical physical injuries or may have co-occurring disorders such as depression, substance abuse or post traumatic stress disorder. Any brain injury -- whether mild, moderate or severe -- can temporarily or permanently diminish a person's physical abilities, impair cognitive skills, and interfere with emotional and behavioral well-being.

Common Changes After TBI

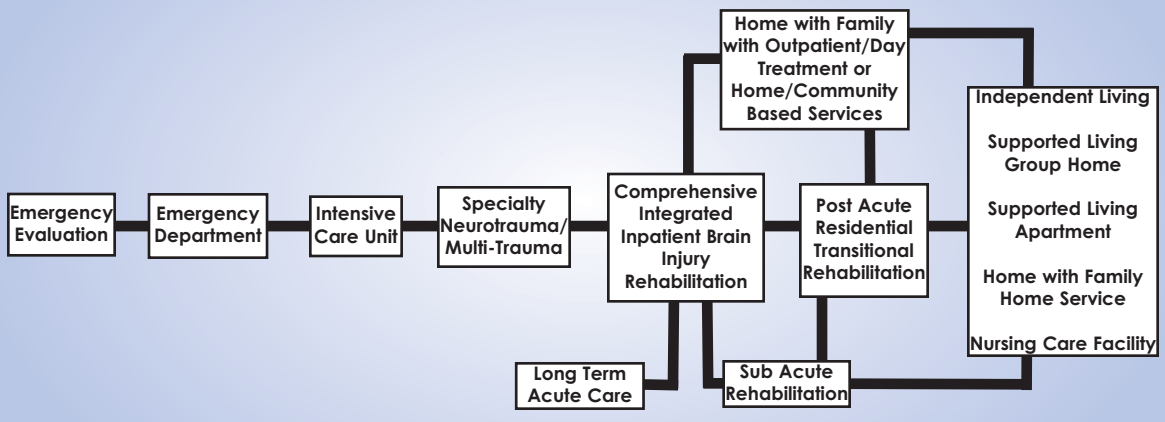
Physical Challenges	Cognitive Challenges	Behavior Challenges
Balance, Mobility	Memory	Depression
Motor Coordination	Problem Solving, Sequencing	Anxiety, Stress
Persistent Headaches	Decision Making, Judgment	Disinhibition, Aggression
Fatigue or Weakness	Processing Speed	Failed Response to Social Cueing
Hearing or Vision Impairment	Planning, Organization	Lack of Emotional Control
Sensory Loss	Attention, Concentration	Frustration, Mood Swings
Seizures	Initiation	Difficulty Relating to Others
Sexual Dysfunction	Speech, Language	Reduced Self-Esteem

There is no single pathway or course of recovery from TBI. Advances in emergency medicine and improvements in diagnostic procedures, monitoring devices and treatment methods have evolved into a complex continuum of TBI care that includes acute hospitalization, acute rehabilitation, post acute rehabilitation, and community support services.

In the private sector, the TBI continuum of care is comprised of specific facility and specialty program types, many of which have earned accreditation by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and/or the Commission on Accreditation of Rehabilitation Facilities (CARF). Every level of the TBI continuum of care in the private sector is enriched by clinical experience, protocols, and extensive operational management knowledge acquired during the last 30 years.

Traumatic Brain Injury Continuum of Care

(Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI. See Appendix A for a description of each component.)



A patient's length of stay at any level of the TBI continuum of care should be based on the nature of the neurological injuries and the degree to which additional, measurable functional improvement within specific time frames is anticipated. Such judgments, and the scope, intensity and duration of medical, rehabilitative and long-term treatment and service plans should be developed by a highly specialized and experienced interdisciplinary team[†] in concert with the patient and family.

As Douglas Gentlemen aptly noted in a 2001 article,

> **"Clinical and political responses to the worldwide epidemic of traumatic brain injury need to recognize that the quality of outcome depends on both phases of treatment: acute care and rehabilitation."** [11]

The value of effective rehabilitative treatment is demonstrated through peer-reviewed scientific research.[11-16] A 2005 Cochrane review of multi-disciplinary rehabilitation for acquired brain injury in adults of working age examining all relevant studies meeting rigorous methodological criteria published since 1966 found:

> **For individuals with moderate to severe brain injury, there is 'strong evidence' of benefit from formal intervention… for individuals with moderate to severe brain injury who are already in rehabilitation, there is 'strong evidence' that more intensive programs are associated with earlier functional gains.**[17]

Research demonstrates the relationships among provision of rehabilitation therapies, increased functioning, improved test scores and changes in cortical organization on fMRI, as well as an improved rate of recovery and functional independence from more intensive therapies.[15, 16]

Barriers to Accessing Treatment

Americans mistakenly believe Veterans benefits, employer health plans, or individual insurance policies will provide for all needed services when serious injuries or illnesses

[†]The interdisciplinary brain injury team is comprised of medical and allied health professionals with specialized experience in TBI including: behavioral specialist, case manager, clinical psychologist, neurologist, neuro-ophthalmologist, neuropsychologist, neuroscience nurse, neurosurgeon, nurse, occupational therapist, neuro-optometrist, physical therapist, physiatrist, psychiatrist, rehabilitation counselor, social worker, speech/language pathologist, therapeutic recreation specialist, vocational rehabilitation counselor, and paraprofessional support staff such as medical technician, rehabilitation technician, rehabilitation assistant, life skills trainer, job coach and certified nursing assistant.

occur. In reality, most insurance polices are geared toward wellness and routine care with very few supporting best practices in acute and post acute care and rehabilitation.

Some insurance policies still allow patients to substitute skilled nursing benefits for rehabilitative care, but many insurance companies have eliminated this option. One insurance company eliminated rehabilitation benefits altogether.

Insurance companies' reimbursement policies have driven down the average length of stay for acute hospitalization and rehabilitation of TBI patients from 77 days in 1990 to a current average of only 46 days.[18, 19] Nearly two-thirds of all individuals hospitalized with brain injury return to their homes with no further medical rehabilitative treatment.[20]

Public funding sources, such as Medicare and Medicaid, support only minimal medical rehabilitation in acute hospitals and post acute rehabilitation settings. The long-held institutional bias among public payers often consigns individuals with brain injury to inappropriate placements such as nursing homes and psychiatric facilities. Depending on the state in which the civilian lives, access to publicly funded services may be limited by age, cause of injury, or injury severity.

Barriers to Accessing Treatment	Military		Civilian	
	DoD Medicine	Veterans Hospitals	Insurance Policies	Public Funding
Limitations on service scope, duration and intensity	X		X	X
Shortage of TBI specialty personnel		X		
Age restrictions				X
Injury severity restrictions				X
Cause of injury restrictions				X
Institutional bias toward nursing homes		X		X
Shortage of community-based options	X	X		
Lack of information, resources, advocacy and support	X	X	X	X
Lack of federally-funded basic and applied research	X	X	X	X
Bureaucracy and/or paperwork burdens		X	X	X

The Armed Forces Epidemiological Board acknowledged the Department of Defense lacks "a system-wide approach for proper identification, management and surveillance of individuals who sustain a TBI."[21] Servicemen and women with severe brain injuries are treated at military hospitals where they are covered by an active duty military insurance policy that in some cases pays for private care, if needed. After acute treatment, the Department of Defense shifts service member healthcare to the Department of Veterans Affairs.

The needs of individuals with TBI are urgent and the complexity of the injury is not conducive to accelerated training of heath care providers. Personnel shortages are a substantial barrier to appropriate care for our Armed Forces.

Service member access to the full TBI continuum of care is also limited by extended travel distances to centralized Veterans hospitals. Just like other payers, TriCare limits access to comprehensive rehabilitation by negotiating contracts that only allow for minimal service provision.

Payers of all types point to the need for additional evidence-based research on health outcomes as a reason for denial of medically-necessary inpatient and outpatient rehabilitative treatment for individuals with TBI, particularly for those who require behavioral health services and cognitive rehabilitation.

The federal government has made a modest investment in applied TBI research within the Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The agency awards a total of $6 million to 16 geographically disbursed TBI Model Systems of Care Centers to develop and test practice parameters, innovative treatment interventions, and novel diagnostic procedures as well as identify adverse outcomes and associated risk factors of TBI.

The Model Systems are a vital component of quality TBI care and a national resource. They furnish technical assistance to local Veterans hospitals and prepare private sector researchers and clinicians for TBI specialty care. NIDRR's Model Systems maintain the only non-proprietary longitudinal database on the recovery and outcomes of patients with TBI.

As has been identified by Model Systems investigators and other leaders in the brain injury field, comprehensive, validated outcome measures applicable to both military and civilian populations must be developed. To that end, treatment must be accurately characterized for therapeutic intensity, duration and content, and measures must encompass immediate, short-term and long-term gains from admission to discharge. The stability of achieved outcomes and the cost/benefit relationship between dollars expended for treatment and lifetime dollars saved by disability reduction must be documented.

The influx of TBI survivors returning home from war emphasizes the need to leverage the existing civilian TBI research and treatment capacity to address the outcomes measurement issue and to augment the care systems being developed at both the Department of Defense and the Department of Veterans Affairs. The public and private sectors must come together to meet this mutual need.

In both the military and civilian populations, there is a nationwide shortage of TBI information, resources, advocacy and support for patients and family caregivers. Information requests to the Brain Injury Association's National Brain Injury Information Center indicate the areas in which help is needed most.

Information & Resource Needs		
Information/Resource Topic	**Military Requests**	**All Requests**
Basic Packet	27%	32%
Medical	20%	11%
Behavior	20%	3%
Programs/Providers	12%	20%
Concussion	10%	7%
Finance	4%	7%
Specific Publication	2%	7%
Support Group	2%	6%
Legal	2%	3%
Rehabilitation	<1%	3%
Coma	<1%	2%

Data From the Brain Injury Association of America's National Brain Injury Information Center Database of callers, Oct 2004 to Mar 2007.

Consequences of Inadequate Treatment

Barriers to accessing the TBI continuum of care result in enormous medical, social and economic consequences for the individual who is injured, his or her family members, and the nation as a whole.

Delayed treatment results in higher levels of disability, an increased reliance on pharmacological interventions, greater durable medical equipment needs, and higher long-term care costs.

People who experience a TBI report poorer physical and emotional health as compared to those with other disabilities and those without disabilities.[22] Individuals with brain injury who live with residual disability often fail when they attempt to return to active military duty, productive work, previous social roles, familial responsibilities and pre-injury lifestyles.[22] People with TBI are 66 percent more likely to receive welfare or disability payments and are four times more likely to attempt suicide than people without disabilities.[22]

Depression, substance abuse, and family dysfunction are just a few of the personal consequences of inadequate access to the TBI continuum of care. Societal costs for both military and civilian populations include transference of burden to federal, state and municipal taxpayers through homelessness, psychiatric placements and correctional sentences.

The Right Treatment, Right Now

America's Armed Forces and millions of children and adults with TBI are harmed when they cannot access immediate medical treatment, comprehensive rehabilitation, and community-based information, resources, services and supports.

The system of care and expertise that is needed to deliver TBI services to all exists in the private sector. Replicating such a system in the Department of Defense or the Department of Veterans Affairs for an unknown number of service members with brain injury would be cost prohibitive and delays in treatment would result in higher levels of disability and poorer health outcomes.

The Brain Injury Association of America urges Congress to improve the systems of care for all Americans with brain injury by adopting the following recommendations:

1. Require all allied health professionals, including case managers and support staff, working with service members with TBI to obtain brain injury specialty training and certification.

2. Provide confidential information, resources and service system navigation to assist individuals with TBI and military families to understand brain injury, cope with its aftermath, and access the many and varied program types within the TBI continuum of care.

3. Revise Department of Defense and Department of Veterans Affairs policies and procedures to ensure records are transferred from the operational environment to Germany and then U.S. facilities without a loss of information.

4. Revise Department of Defense and Department of Veterans Affairs policies to broaden the number of eligible private sector rehabilitation providers by:

    (a) ensuring access to hospital and less costly non-hospital facilities for comprehensive post acute inpatient and outpatient rehabilitation. Current requirements for Medicare certification and Comprehensive Outpatient Rehabilitation Facility accreditation are not appropriate for non-hospital-based rehabilitation programs and should be substituted with requirements for JCAHO and/or CARF accreditation, which are appropriate to the provision of outpatient rehabilitation for TBI;

    (b) evaluating the benefits of a one-year moratorium on medical retirement so that service members can remain on active duty status with insurance coverage allowing for care in the private sector. If this approach is adopted, military families should be fully informed of the retirement moratorium; and

(c) accelerating the pace at which contracts are negotiated and executed.

5. Enact and fully fund the Heroes At Home Act of 2007 and provide full funding for the Heroes At Home Act of 2006, which together provide for:

   (a) implementation of an objective assessment protocol to measure cognitive functioning both prior to and after deployment to improve the screening process for TBI in service members;

   (b) establishment of a Traumatic Brain Injury Family Caregiver Personal Care Attendant Training and Certification Program to train, certify and compensate family caregivers as personal care attendants for service members with TBI; and

   (c) grant awards to community-based organizations to meet employment and emotional adjustment needs of members of the National Guard and Reserve with TBI.

6. Reauthorize the Traumatic Brain Injury Act and fund the measure at $30 million in FY 2008. The TBI Act charges agencies within the Department of Health and Human Services with epidemiological research, public awareness, and administration of grants to state agencies and protection and advocacy organizations to improve coordination of and access to public services.

7. Intensify and accelerate research efforts research by:

   (a) supporting specialized research on the mechanisms and recovery pathways for blast injury survivors as well as other treatment and education initiatives of the Defense and Veterans Brain Injury Center with funding of $19.5 million in FY 2008;

   (b) augmenting existing research programs of the National Institute on Disability and Rehabilitation Research TBI Model Systems and allocating line-item funding of $30 million in FY 2008 to continue and expand NIDRR's applied research results;

   (c) elevating the National Center for Medical Rehabilitation Research to full Institute status within NIH; and

   (d) enhancing collaboration between military and civillian trauma entities to conduct clinical research and establish a National Trauma Institute that will benefit both the military and civilian populations.

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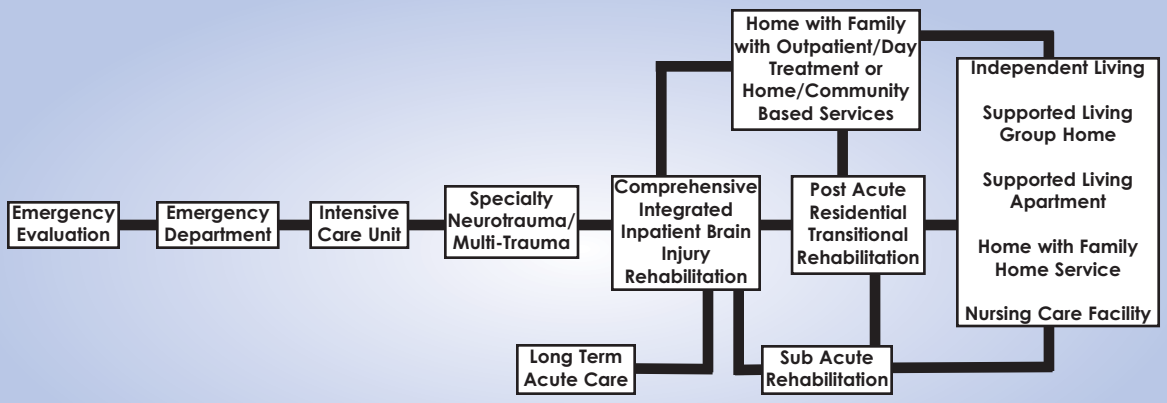
Appendix A
TBI Continuum of Care



(Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI.)

Acute Care

Established Emergency Medical Services (EMS) triage guidelines and organized pre-hospital trauma systems improve the delivery of trauma care and should be utilized. Trauma systems with identified regionally-designated neuro-trauma centers (preferably Level I or Level II Trauma Centers) should be utilized for the acute care of individuals with traumatic brain injury. Neuro-trauma centers should have a multidisciplinary trauma team, an in-house trauma surgeon, promptly available neurosurgeon, a continuously staffed operating room, neuroscience nurses, neuro-intensive care unit, lab, and a CT immediately available at all times. Other team members should include orthopedists, radiologists and anesthesiologists. Rehabilitation therapies should be initiated in this phase of care as soon as the patient is stable.

Acute Rehabilitation

Following medical stability, individuals with moderate/severe brain injury should be transferred from acute hospital care to a comprehensive integrated inpatient brain injury rehabilitation program. Acute brain injury rehabilitation hospitals should have a designated specialty program, with therapy programs, equipment, and a sufficient number of individuals with TBI to constitute a peer and family milieu. Acute rehabilitation hospitals should be accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and have components consistent with the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF certification implies that programs meet specific care standards of design and efficacy.

Long-Term Acute Care (LTAC)

Some individuals will be unable to participate in a full inpatient program immediately following acute care and may need long-term acute care for a period of time prior to entering a comprehensive program. LTAC is a recognized designation (by the Centers for Medicare and Medicaid Services) for acute care hospitals whose average length of stay is at least 25 days. LTAC hospitals provide specialized care services, including skilled nursing care to manage medical conditions so that individuals with catastrophic or acute illnesses/injuries may progress toward entry into comprehensive brain injury inpatient rehabilitation. LTAC programs should be accredited by the JCAHO. LTAC rehabilitation is generally accepted, but should not be used in lieu of categorical inpatient rehabilitation.

Sub-acute Rehabilitation Programs

These programs are located on separate and specially licensed units of hospitals or nursing homes. Individuals who are appropriate for sub-acute care typically are medically stable, require skilled nursing care, and have ether completed comprehensive inpatient rehabilitation or are judged to not be able to benefit from inpatient rehabilitation. Sub-acute rehabilitation is generally accepted, but should not be used in lieu of categorical inpatient rehabilitation for individuals who may benefit from a comprehensive inpatient rehabilitation program. Sub-acute rehabilitation programs should be accredited by the JCAHO.

Post Acute Rehabilitation

Post acute rehabilitation describes programs following inpatient rehabilitation, including outpatient or day treatment rehabilitation, residential transitional rehabilitation, or home-based programs. The most appropriate post acute rehabilitation depends on the individual's needs following inpatient rehabilitation, as well as proximity and availability of services, family dynamics, and projected long-term outcomes. Individuals with significant deficits or who require behavioral treatment or supervision for safety may require brain injury residential transitional rehabilitation. Other individuals may be able to use a combination of home and community-based rehabilitation and outpatient or day treatment rehabilitation. Post acute rehabilitation programs should be accredited by CARF. CARF certification implies that programs meet specific care standards of design and efficacy.

Long-Term Care

The range of long-term outcomes following TBI is diverse from virtually complete independence and function to severe and permanent disability. Therefore, the range of needed services is complex and individualized. Some individuals with moderate/severe brain injury will require significant care and supervision, either at home by family or attendant care, in a nursing care facility, or in a long-term assisted or supported living program. Individuals may benefit from periodic re-evaluations, based on condition and needs. Long-term care programs should be accredited by the JCAHO or CARF. CARF eligibility or certification implies that programs meet specific care standards of design and efficacy.

Appendix B
TBI Resource Facilitation

Military personnel and their families have difficulty understanding traumatic brain injury (TBI), coping with the changes following TBI, and accessing appropriate and local information, resources, services and supports. The Brain Injury Association of America, which has more than 25 years of experience in the field and a nationwide network of chartered state affiliates, is uniquely positioned to meet service members' care coordination needs through Resource Facilitation.

Resource Facilitation is a person-centered, community-based initiative linking individuals with TBI and their families to local information, resources, service providers and natural supports. It is a collaborative process that respects and encourages the involvement and choices of individuals with brain injury and their family members. The model includes: 1) identifying needs, problem-solving, planning, negotiating, referral to services and monitoring; 2) on-going assessment of goals, emotional support and self-advocacy training; and 3) education and awareness, outreach to service professionals and support providers within the community, and resource development. The outcome of Resource Facilitation is timely and appropriate receipt of services and support that meets the unique needs of participants and their families to ensure a seamless transition back to their communities, family responsibilities, and social roles.

The Brain Injury Association of America (BIAA) is ready to provide Resource Facilitation for returning service members using its existing infrastructure. Working cooperatively with the VA's polytrauma centers, network sites, and the Defense and Veterans Brain Injury Center, the Association can adapt data-driven outreach initiatives, intake procedures, data collection and analysis methods, and program models for the military population. The Association can also create a national standardized outcome assessment to evaluate access and linkage to services and supports in the community, monitor lifespan changes, family supports, natural supports and customer satisfaction. The Brain Injury Association of America can implement TBI Resource Facilitation on a nationwide basis for all service members.

The Brain Injury Association of America was founded in 1980 to improve the quality of life for individuals with brain injury and their family members. Today, the Association is headquartered near Washington, D.C., and encompasses a nationwide network of state affiliates that offer resource facilitation programs, support groups, peer mentoring activities, family caregiver training and more.

Annually, the Brain Injury Association of America and its affiliates respond to 100,000 individual requests for help through toll-free information centers that include Spanish language services. The Association's comprehensive website receives more than 2 million hits per year. The Brain Injury Association of America publishes the only National Directory of Brain Injury Service Providers and has expanded the number of certified professional and paraprofessional brain injury specialists/trainers to nearly 2,000. The Association is administering the newly created Bob Woodruff Family Fund for TBI to assist service members and their families affected by the war in Iraq and Afghanistan.

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