

# BARRIERS and RECOMMENDATIONS



**Addressing the Challenge of Brain Injury in America**

**2008**

*A report provided by the*  
**Brain Injury Consensus Conference**

# Executive Summary

## Introduction

## History

**Brain injury has created serious challenges for both the Department of Defense and the Department of Veterans Affairs; these challenges exist because brain injury has been, and continues to be, a critical healthcare problem in America.**

Survivors, family members, and professionals all meet with a number of barriers that impede best practices in brain injury treatment and create debilitating hardships.

This report addresses those barriers, and calls for unified efforts between civilian and military systems, agencies, and organizations. Today, more than 5.3 million American civilians face challenges resulting from a brain injury. Additionally, 19.5 % of US servicemembers who have returned from Afghanistan and Iraq report experiencing a traumatic brain injury during deployment.<sup>1</sup>

As recently as 2006, an Institute of Medicine report stated:

"...many people with TBI experience persistent, lifelong disabilities. For these individuals, and their caregivers, finding needed services is, far too often, an overwhelming logistical, financial, and psychological challenge. Individuals with TBI-related disabilities, their family members, and caregivers report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation, and respite for caregivers. Yet efforts to address these issues are stymied by inadequate data systems, insufficient resources, and lack of coordination. TBI services are rarely coordinated across programs except in some service sites. Furthermore, in most states, there is no single entry point into TBI systems of care."

Brain injury is also a leading cause of death and disability among Americans. Data indicates that approximately 1.6 million Americans sustain a brain injury each year, and 125,000 are permanently disabled.<sup>2,3</sup> Economically, the total impact of direct and indirect medical and other costs in 1995 dollars is reported to exceed \$56 billion.<sup>4</sup> Despite the prominence of affects of brain injury in the United States, it remains one of the least understood and recognized healthcare issues in our nation.

**Addressing the Challenge of Brain Injury in America**

On November 2, 2007, more than one hundred of the nation's most respected authorities on brain injury convened in Washington D.C. to highlight accomplishments in brain injury treatment and to provide recommendations where barriers to care exist. Called the Brain Injury Consensus Conference, the two-day workgroup produced the groundwork for **Barriers and Recommendations: Addressing the Challenge of Brain Injury in America**.

Participants included members from:

- Department of Defense** (DOD),
- Department of Veterans Affairs** (VA)
- Defense and Veterans Brain Injury Center** (DVBIC)
- Brain Injury Association of America** (BIAA)
- North American Brain Injury Society** (NABIS)
- National Association of State Head Injury Administrators** (NASHIA)
- American Neuropsychiatric Association** (ANPA)
- Over 30 other civilian public and private organizations**

*This report represents the results of an authoritative, cross-systems assessment on the state of brain injury in America. It addresses the treatment of all survivors across the continuum of care, from the point of injury through lifelong needs. It also includes the input of a number of other brain injury professionals who were unable to attend the conference.*

**This report is a free, publicly available document** intended for multiple applications. It can be used as an advocacy tool, an informational resource, and a call to action. It was created to draw attention to the challenges that face Americans with brain injury, for the ultimate purpose of creating better identification of brain injury, access to care and overall bettering of their lives.

The civilian sector, the military, and the VA have made considerable strides in dealing with brain injury, and their focus and energies are to be applauded. However, brain injury in America remains a larger problem than any one entity can manage alone; it is only through a renewed spirit of collaboration that the following barriers can be managed effectively.

# Barriers & Recommendations

## BARRIER ONE

**Screening protocols for brain injury are not consistent across military, civilian, and public systems, and each system poses the risk for various gaps in the identification and assessment of brain injury. Currently, no initiatives have been put forward to remedy this disparity in injury screening.**

### *Recommendation*

The screening of brain injury to date is based on a detailed account of the injury event and the resultant alteration in consciousness. To accurately assess brain injury, this screening should offer a standardized, thorough, historical account of the injury event. This is particularly important because the individual involved may have altered perception, and lack insight into the injury sustained. A neurocognitive assessment such as the Standardized Assessment of Concussion is helpful in determining the extent of injury at the point of injury, but limited thereafter.

We recommend the further development of screening tools to be used to screen for TBI in diverse populations. Individuals who screen positive should then undergo further diagnostic testing including: neuroimaging studies, neuropsychological evaluation and neurophysiologic studies.

Furthermore, for populations who are occupationally at increased risk, having a regular baseline cognitive test(s) is of benefit for comparison if risk of injury is present or sustained. Finally, we recommend an evaluation for assistive technologies and compensatory aids and strategies.

## BARRIER TWO

**The current classification of brain injury as Mild, Moderate, and Severe are inadequate to describe various and complex sequelae resulting from a brain injury.**

### *Recommendation*

There is much confusion as to the extent of the actual injury severity. Various cognitive impairments can improve or diminish over a period of time. Although gradual improvements can follow the injury event, impairments can manifest even after other symptoms of brain injury have resolved. Confusion is introduced by the fact that years later, debilitating life-long residual effects may exist, yet the results of that injury may be mistakenly diagnosed based on initial trauma.

[Addressing the Challenge of Brain Injury in America](#)

Repetitive concussions are dangerous and result in cumulative brain injury. The classification of traumatic brain injury should sufficiently demonstrate residual functionality at various periods of time beyond the initial injury, and incorporate the understanding of brain injury as a disease process.<sup>5</sup>

## BARRIER THREE

**Persons accessing mental health services, special education services or imprisoned may have undiagnosed brain injury and the identification/screening for such would help identify effective treatment or placement alternatives. "Unidentified TBI is a major unrecognized cause of social failure: in educational, vocational and economic arenas. Complex barriers often prevent people with mild TBI from: (a) self-identifying as having a brain injury that is seen as the cause of the disabling symptoms they experience, (b) gaining access to help and (c) addressing long-term, TBI-related problems that affect their quality of life." (Gordon & Brown, 2008).**

### *Recommendation*

All mental health organizations that offer screening services should also screen for brain injury.

## BARRIER FOUR

**While a variety of best practices and evidence-based guidelines exist for the treatment of brain injury, there remain no comprehensive national guidelines for best practices in brain injury treatment.**

### *Recommendation*

Currently, the guidelines for best practices in brain injury treatment vary widely. It is recommended that a national guideline for best practices in brain injury treatment be created in order to ensure consistent, quality treatment across all systems.<sup>6</sup> We acknowledge the excellent work toward this goal achieved by the Brain Trauma Foundation (BTF), in which an independent analysis of their guidelines on TBI outcomes and cost savings by the Centers for Disease Control and Prevention (CDC) found that "if the BTF guidelines were used more routinely, there would be a 50% decrease in deaths, improved quality of life, and a savings of \$288 million a year in medical and rehabilitation costs."<sup>7</sup> We also call for the identification, development and refinement of additional best practices in brain injury disease management.

# Barriers & Recommendations

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## BARRIER FIVE

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**Persons with brain injury often have difficulty accessing the necessary type of services needed due to finances, geography or a failure to provide best practices.**

### *Recommendation*

We recommend the development of system-wide access to treatment and support protocols to ensure the right treatment at the right time. This includes entitlement to post-acute active rehabilitation incorporating best practices including cognitive rehabilitation, independent living skills training, vocational rehabilitation and leisure therapy. This also includes access to graduated levels of support in the community, in-home, or 24-hr. supported living, allowing for efficient episodes of treatment across the lifespan in order to ensure retention of skills and enhanced quality of life. Until comprehensive guidelines in brain injury disease management are available, we recommend adherence to the Brain Injury Medical Treatment Guidelines of Colorado.<sup>8</sup>

Treatment and supports are needed to address the complexity of individuals with brain injury including substance issues, Post Traumatic Stress Disorder, psychiatric and significant behavioral issues.

Development of geographically disperse rehabilitation and support options are necessary to address the needs of persons in rural settings. Collaboration with civilian and public partners may be needed for servicemen and women to access timely, appropriate levels of care closer to home.

Benefits packages provided by TRICARE, the VA and Medicaid must be reviewed in order to ensure optimum uniform coverage including providing same payment for same services, access to levels of care including post-acute and cognitive rehabilitation and extension of active duty benefits to reimburse necessary after-hospital treatment.

With respect to cognitive rehabilitation, the effectiveness of cognitive rehabilitation has unfortunately proven difficult to study due to several factors, including the heterogeneity of subjects, interventions and outcomes studied, as well as the difficulty involved in attempting to control for spontaneous recovery.

Clinical consensus, along with widespread professional opinion, must be taken into account, in addition to the research evidence attesting to the efficacy of cognitive rehabilitation.<sup>9</sup>

Civilian and military coverage plans must be sufficient to rehabilitate patients and return them to productivity. Moreover, cognitive therapy is an essential component of the rehabilitation process for persons with brain injury and should also be a covered therapy.

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## BARRIER SIX

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**Advances in brain injury care are implemented too slowly between systems. Currently, any current cross-system coordination efforts do not include strategies for effectively supporting person with brain injury over the lifespan. Additionally, case managers/care coordinators are commonly unfamiliar with protocols and practices outside their respective system, causing unnecessary complexity for the survivor who moves between systems. No formal body exists which coordinates an effective communication between systems.**

### *Recommendation*

As the military continues to make advances in the area of brain injury treatment, a vehicle for sharing of information must occur between systems. The advances learned from the resultant military experience from the effects of blast, particularly primary blast, from helmet sensors to balance tables, from screening with standardized assessment tools at point of injury to post deployment health assessment (PDHA), must be shared with other systems in order to allow for more effective brain injury trauma care for all Americans.

Veteran's Administration and Department of Defense hospital data are not included in the states' trauma system data. We recommend coordination and communication between Department of Defense, Veteran's Administration, and civilian agencies, allowing the civilian system to accurately anticipate the impact of wounded veterans as they return to their communities. Seamless coordination should not only occur between military systems, but between military, public, and private systems as well.

Military and civilian case managers must have opportunities to learn each other's systems of care, funding mechanisms, treatment programs, community resources, and communicate with one another. We encourage the DoD, the VA, and the public/private sector to jointly engage in educational and training seminars that allows each entity to benefit from the other's successes and to learn from their challenges.

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# Barriers & Recommendations

We also recommend the formation of a Federal Brain Injury Council, established in statute for the purpose of communication and system coordination. Members may include representatives from Federal agencies, advocacy organizations, professional associations/societies, and others.

The Council may be an effective mechanism to foster successful collaborations such as those currently in place between the Centers for Disease Control and the Social Security Administration as well as formal Memoranda of Understanding as are in place between DoD and VHA for the Office of Seamless Transition and for spinal cord injury care and neuro-optometric rehabilitation. The proposed Federal Brain Injury Council will use a variety of mechanisms to facilitate and foster ongoing communication, collaboration, and system coordination among its members. Since the Commission on Accreditation of Rehabilitation Facilities (CARF) is actively engaged with many of the members of the proposed Council, the standards that address the use of feedback from stakeholders for program development, strategic planning, resource planning and performance improvement can be used as innovative practice tools for members to foster these relationships.

In the interim, it is suggested that civilian sector advisors be added to the Senior Oversight Committee for DoD/VA Wounded, Ill and Injured. Further, it is recommended that VHA conduct a formal gap analysis, publicize its needs, as appropriate, and outreach to private sector to obtain assistance in meeting those needs.

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## BARRIER SEVEN

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**Brain injury care does not receive research funding on parity with other disease processes.**

### *Recommendation*

In 2007, the Federal AIDS budget was \$22.8 billion dollars. Parkinson's disease received \$250 million dollars. The HRSA Traumatic Brain Injury Program was allotted \$8.5 million dollars in 2007, and in 2008 President Bush proposed eliminating the funding. We recommend that brain injury treatment receive funding on parity with other disease processes

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## BARRIER EIGHT

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**Following brain injury, family members and case managers (care coordinators) are not effectively incorporated into treatment, particularly in the acute phase of care. The family often becomes the primary support unit. Families are typically ill-equipped to respond to the complexity of issues a person with brain injury may experience.**

[Addressing the Challenge of Brain Injury in America](#)

### *Recommendation*

Encouraging family members to participate in educational programs and follow-up appointments is important to ensure an accurate account of the patient.

Case Managers are helpful in tracking and supporting those requiring follow up care. We recommend that all brain injury care providers provide educational and case management services from the moment of injury. When home placement is advised, family members should be trained in maintaining quality care at home.

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## BARRIER NINE

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**There are few or no support systems that consistently monitor care and patient satisfaction throughout the continuum of care.**

### *Recommendation*

Programs should be a collaborative effort; as much as possible, the program should be directed by the person with the brain injury, but there must also be an adequate support system that monitors, advocates, and intervenes on that person's behalf as necessary.

Moreover, mental health supports are also needed, with personnel trained in and knowledgeable about the effects of brain injuries. This level of support should include a continuum of care from a brief counseling session, to an ongoing, in-depth counseling program, to an intensive crisis intervention by a mobile crisis response team. Police departments, the criminal justice system, and emergency health care providers must be trained to prevent the inappropriate placement of an individual with brain injury in psychiatric hospitals or jail.

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## BARRIER TEN

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**Across the lifespan, brain injury programs do not address all aspects of treatment. Instead, only specific symptoms receive care.**

### *Recommendation*

Brain injury programs must address every area of the person's life, including physical, financial, emotional, intellectual, vocational, recreational, and spiritual. The effect of holistic treatment is synergistic, with small efforts in many areas combining to have a large impact on overall success. We recommend adherence to the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, as supported by the World Health Organization.<sup>10</sup> These rules govern areas that span Medical Care, Rehabilitation, Support Services, Accessibility, Education, Employment, Income Maintenance and Social Security, Family Life and Personal Integrity, Culture, Recreation and Sport, and Religion.<sup>11</sup>



# Barriers & Recommendations

## BARRIER ELEVEN

**Respite care services are difficult for most family members and caregivers to access, leading to caregiver burnout, compassion fatigue, and overall lack of quality of care.**

### *Recommendation*

Respite care should be a regular and accessible service for family members and caregivers.

For mentors and life coaches, a delicate balance is required to provide necessary daily structure to ensure health and safety, while simultaneously fostering independence.

## BARRIER TWELVE

**Over the lifespan, offers of independent living and life-skills training are arbitrary, and sometimes unsupported.**

### *Recommendation*

Independent living and life skills training must be offered on a regular basis. As the person with a brain injury works to re-enter the community and rebuild his or her life, he or she will need to be trained in independent living and life skills.<sup>12</sup>

## BARRIER THIRTEEN

**Treatment plans for brain injury do not include strategies for dealing with aging-related issues, nor do they anticipate that brain injury is disease-causative and disease-accelerative.**

### *Recommendation*

Aging issues must be addressed by case managers/care coordinators in the treatment plan. As the person's condition changes, he or she may need additional care including physical, occupational, speech, or recreational therapies, cognitive remediation, psychiatric interventions, or pre-vocational services. We recommend new treatment plans that allow for brain injury disease management.

## BARRIER FOURTEEN

**Long-term, supervised housing and other residential programs for persons with brain injury are regularly denied services under most funding systems.**

### *Recommendation*

Access to affordable housing with associated services, physical access, and support must be financially attainable. Individuals may need long-term, supervised residential programs with related support care sensitive to their specific needs. Others may require a day-treatment program, where they can participate in supervised, meaningful activities. In conjunction with such programs, we recommend the provision of life care planning services such as financial resource management, legal arrangements for durable power of attorney and healthcare, wills, family and/or personal estate planning, health insurance purchase and availability, life insurance purchase and availability, and family member life insurance as a financial planning tool.

Moreover, we recommend a coordinated approach to state and federal assistance programs that are available for housing, food stamps, maternal assistance programs, child nutrition programs, Meals on Wheels, independent living programs, caregiver resources programs, public transportation assistance options, Social Security, aid to dependent families assistance, public utility relief programs, Medicare and Medicaid eligibility and pharmaceutical assistance programs.

## BARRIER FIFTEEN

**Transportation issues plague survivors of brain injury the duration of their lives.**

### *Recommendation*

While some individuals will be completely independent in their transportation needs, others will require assistance with accessing public transportation. Still others will be unable to access or deal with public transportation. Life care planners, case managers, and long-term care providers are encouraged to advocate within the community for supportive transportation services.

## BARRIER SIXTEEN

**Across all systems, case management services are not consistent. In military and VA settings, case management and care coordination services may be complicated, confusing survivors and family members; in the private sector they are either difficult to access or unavailable.**

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# Barriers & Recommendations

## *(Barrier 16 Cont'd) Recommendation*

We encourage all case managers, care coordinators, and case management organizations who are experienced, trained and certified in disease management of brain injury to participate in collaborative initiatives to form guidelines that ensure care that offers a particular focus on the many personal needs of survivors of brain injury.

Where services are absent, we call on state healthcare officials to conduct an assessment of needs report detailing the challenges that face their respective population of survivors. We encourage the National Association of State Head Injury Administrators to facilitate dialogue and actions that promote the use of case management services where needed, and programs which help individuals access the service.

## **BARRIER SEVENTEEN**

**Despite the complexity of brain injury, there is no national certification or training for brain injury case management. Few organizations outside direct care providers encourage personnel to receive certification as a brain injury specialist (CBIS).**

### *Recommendation*

We encourage the Case Management Society of America, the Commission for Case Management Certification, and the American Academy of Certified Brain Injury Specialists to collaborate and create an effective credential that educates and empowers case managers involved in the treatment of brain injury.

Furthermore, we recommend that institutions such as mental health centers, community colleges, veterans centers, the criminal justice system, and social service systems all designate individuals who can serve in the capacity of a certified brain injury specialist.

## **BARRIER EIGHTEEN**

**For brain injury survivors under 21, case managers are underutilized or uninvolved in the creation and development of Individualized Education Plans (IEPs).**

### *Recommendation*

In the case of individuals with TBI under the age of 21, case managers should provide input to school districts

to develop Individualized Education Plans (IEP) specific to brain injury issues and educational goals.<sup>13</sup>

The 1975 Federal Public Law 94-142 (Disabilities Education Act- IDEA) maintains that states and school districts must develop and implement annual Individual Educational Plans (IEP) on all individuals with disabilities. Community case managers are an asset to the patient's school district in this process.

## **BARRIER NINETEEN**

**Survivors of brain injury do not typically receive special accommodations for their cognitive deficits in state and federal courts.**

### *Recommendation*

Self-advocacy and self-representation in court are basic needs that can be thwarted by cognitive deficits. Most courts currently accommodate language and physical disabilities with the necessary supports. We recommend additional cognitive deficit accommodation by the court system, particularly in matters involving the social agency interactions and medical decision-making transactions.

## **BARRIER TWENTY**

**Throughout all systems, there is a well-documented personnel shortage of healthcare professionals that provide valuable services to survivors of brain injury.<sup>14</sup>**

### *Recommendation*

We recommend that university health science programs incorporate brain injury treatment into their curricula and actively recruit healthcare professionals for the purpose of specialization in brain injury. We also suggest that community-based organizations, professional societies, and schools of higher education provide continuing education opportunities on the topic of brain injury.

# Barriers & Recommendations

## CONCLUSION

The Department of Defense, the Department of Veterans Affairs, and numerous organizations in the public and private sector have made tremendous strides in the treatment and care of brain injury, and they have demonstrated outstanding abilities to meet their responsibilities.

By addressing the barriers to brain injury care, we hope to encourage these different systems to renew their efforts to form collaborations, and to address gaps in service where they exist.

With respect to TBI survivors from Operation Iraqi Freedom and Operation Enduring Freedom, members of the media have been an extremely positive influence in raising public awareness and understanding of TBI and in garnering altruistic feelings for survivors, especially service members, and their families.

The efforts of military, veteran and civilian advocacy organizations are currently synergized into a political will for TBI care that is unmatched in U.S. history. It is incumbent upon the leaders in civilian, military and veterans' systems to work cooperatively to build on strengths and minimize weaknesses to improve the quality of research, treatment and life-long living for all individuals with brain injury.

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