

BARRIERS and RECOMMENDATIONS

Addressing the Challenge of Brain Injury in America

2008

A report provided by the
Brain Injury Consensus Conference

Executive Summary

Introduction

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; the Global War on Terror has added to that number.

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 50,000 Americans die from brain injury each year, and 90,000 are permanently disabled. Despite the prominence of effects of brain injury in the United States it remains one of the least understood a recognized healthcare issues in our nation.

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

History

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 represent 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 bettering 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.

For more information on this report, visit:www.nabis.org

Barriers & Recommendations

BARRIER ONE

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 labeled based on initial trauma. When repeated brain injuries of a milder event have occurred, the cumulative effects cause significant damage. 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.

BARRIER TWO

Screening protocols for brain injury are not consistent across 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 diagnosis 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 account should be 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.

Neurophysiological assessments should accompany neuropsychological testing, and be offered in a standardized protocol. Further, for populations who are occupationally at increased risk, having a regular base-

line 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 THREE

No federal guidelines exist 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 federal guideline for best practices in brain injury treatment must be created in order to ensure consistent, quality treatment across all systems.

BARRIER FOUR

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 after-hospital 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.

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.

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Barriers & Recommendations

Barrier Four cont'd

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 and extension of active duty benefits to reimburse necessary after-hospital treatment.

Civilian and military coverage plans must be sufficient to rehabilitate patients and return them to productivity.

BARRIER FIVE

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 is 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.

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 and low vision care. To ensure that truly effective working relationships are developed, it is recommended that all Council members follow best practices for public/private partnerships as adopted by the Commission on Accreditation of Rehabilitation Facilities (CARF).

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.

BARRIER SIX

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.

Recommendations

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

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Barriers & Recommendations

Barrier Six Cont'd

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. This may be provided through an organization such as the American Academy for the Certification for Brain Injury Specialists (AACBIS) program, which could be modified to reflect special needs of servicemen men and women. When home placement is advised, family members should be trained in maintaining quality care at home.

BARRIER SEVEN

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

Recommendation

In 2007, the Federal AIDS budget was \$2.8 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

BARRIER EIGHT

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.

BARRIER NINE

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.

BARRIER TEN

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 ELEVEN

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.

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Barriers & Recommendations

BARRIER TWELVE

Treatment plans for brain injury do not include strategies for dealing with aging-related issues.

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.

BARRIER THIRTEEN

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.

BARRIER FOURTEEN

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 FIFTEEN

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.

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

Recommendation

We encourage all case managers, care coordinators, and case management organizations to participate in collaborative initiatives to form guidelines that ensure person-centered care for 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 SIXTEEN

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 SEVENTEEN

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

Recommendation

In pediatric 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.

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Barriers & Recommendations

Barrier Seventeen Cont'd

Conclusion

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.

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.

BARRIER EIGHTEEN

Screening for brain injury is not mandatory at mental health facilities.

Recommendation

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

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 and 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.

Sources

Evaluating the HRSA Traumatic Brain Injury Program, Committee on Traumatic Brain Injury, Board on Health Care Services, Jill Eden and Rosemary Stevens, Editors, Institute of Medicine of the National Academies, National Academies Press, Washington DC 2006

Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2003.

Signatories

We, the undersigned, acknowledge the aforementioned barriers facing Americans with brain injury, and call upon all related systems and agencies to collaborate in efforts to address these challenges.

Consensus Paper Committee

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Conference Attendees & Paper Contributors

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