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*Stan Hubbard*

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*5-29-2009*

Date

**2/5/08**

**PRESENTA-**

**TION:**

**TRAUMATIC**

**BRAIN INJURY**

**& MILITARY**

**VETERANS**



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To: House HESS Committee Members  
From: Jill Hodges, Executive Director, Alaska Brain Injury Network, Inc.  
Date: Tuesday, February 5, 2008  
Subject: Traumatic Brain Injury Presentation

Thank you for the opportunity to share Alaska-related TBI issues and highlighting the needs of Alaskans and returning service members experiencing traumatic brain injury.

There is a solution to 'a long-forgotten blow to the head.' The solution is the same for those who recently experienced a brain injury including children, civilian adults, and soldiers. And the solution lies in Alaska's ability to recognize the "common thread running through many cases of seemingly unrelated social problems." Brain Injury.

A coordinated system of care here in Alaska is possible, research shows it is essential, and the time is now. The many thousands of Alaskans who live with this disability (and their family members) will tell you that everyday living is WORK. Alaska can create the essential brain injury services that allow these same individuals the opportunity to redirect their energy...AWAY from the frustrating forgetful behavior, the substance abuse, and the suicidal thoughts...and TOWARDS providing for their families, paying taxes, and improving their communities.

We can all agree that it is very possible for any of us to 'hit our head'; that in an instant, our life or a family member's success in life will be dependent on our knowledge of brain injury.

Alaska has one of the highest rates of brain injury in the Nation. This is currently being compounded by the number of Alaskans returning from the OIF/OEF wars with brain injury due to improvised explosive devices and trauma.

There are standard services for brain injury, let's continue to develop them in Alaska. Let's create a system that supports Alaskans living with brain injury and their families as they relearn life and create identities that are manageable, productive, and meaningful.

Presentation messages:

- Brain Injury in Alaska is epidemic
- The epidemic is being compounded by soldiers and veterans returning to Alaska from OIF/OEF wars.
- TBI has higher incidence rates relative to other disabilities; however, there are comparatively fewer services

- TBI infrastructure is standard in other states, Alaskans are asking for services close to home.
- The disjointed TBI system is putting excess pressure on other resources by producing high numbers of TBI survivors that are abusing alcohol, creating violence, practicing unlawful behavior, destroying family infrastructure, and committing suicide.
- Need support and funding to create a continuum of care for survivors of brain injury and their families to live manageable, productive, and meaningful lives.

Recommendations:

- A coordinated rehabilitation system between community providers, military, and state services.
- A multi-disciplinary approach where all treatment providers are talking to each other regularly.
- TBI educational materials to be distributed to families and the individual regarding what is traumatic brain injury, symptoms and behaviors related to the injury, and the role treatment plays in the individual's recovery.
- A liaison between the military and the community providers to communicate to both parties and the individual accessing the services.
- Case management for the survivor to organize the treatment teams; provide access to financial supports, family supports, and community programs; and to follow up with the individual, confirming that he/she is making it to their appointments.
- Clubhouses/Day Programs for survivors who are not yet able to work to be in a productive/social environment; encourages vocational and volunteer activities, and appropriate social skills.
- Specialized vocational rehabilitation and employment services for person with traumatic brain injury.
- Workforce development and training to increase the number of providers in Alaska that can serve people with brain injury using evidence-based brain injury practices.
- Develop brain injury screening requirements among various State Departments and Divisions. In addition, create volunteer screening opportunities for military service members that may not have been identified in the system.

I hope you find the presentations informative and useful. I have included a packet of materials and articles for education and reference. The Alaska Brain Injury Network looks forward to working with the Alaska legislature in continuing to plan for Alaska's traumatic brain injury survivors and their families.

For more information on the Traumatic Brain Injury Task Force Report to the Army Surgeon General: (123 pages)

<http://www.armymedicine.army.mil/news/reports/TBITaskForecReportJanuary2008.pdf>

Alaska Brain Injury Network, Inc. mission to educate, plan, coordinate, and advocate for a comprehensive service delivery system for survivors of traumatic brain injury and their families.

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Alaska Brain Injury Network, Inc. mission to educate, plan, coordinate, and advocate for a comprehensive service delivery system for survivors of traumatic brain injury and their families.



Traumatic brain injury (TBI) has been described as the signature injury of the Iraq and Afghanistan wars. It has been an Alaska public health issue for several decades, with surveillance beginning in 1991. The Alaska Brain Injury Network has identified several fiscal and policy recommendations that will help solve the issues facing Alaskans with traumatic brain injury.

**Please support:**

1. Legislative Resolution  
Traumatic Brain Injury Awareness Month, March 2008
2. FY09 GF/MH Governor's Budget  
\$100.0 Brain injury training for providers  
\$10 million Housing Trust

**Recommendations for additions to the FY09 GF/MH Legislative Budget**  
Priorities in the FY09 GF/MH Alaska Mental Health Trust Authority budget included:

\$200.0	Brain injury services development: LT rehab support
\$175.0	Brain injury training for providers (not fully funded)
\$25.0	Brain injury outreach

ABIN recommends that there be increased funding for brain injury prevention and brain injury services. We are working with the Department of Health and Social Services on the implementation and prioritization of successful brain injury state-funded programs.

ABIN GF/MH Budget recommendations include:

\$200.0	Brain injury prevention
\$2 million	Brain injury services (to serve 1000 Alaskans)

**Brain Injury Program Recommendations**

1. In-State Brain Injury Post-Acute Rehabilitation
2. Targeted Case Management
3. Clubhouse and Day Programs
4. Vocational Rehabilitation Services for Person with TBI
5. Workforce Development and Training
6. Brain injury Screening, Referral, Assessment, and Treatment Protocol

**The budget and program recommendations will benefit both the Civilian and Military populations. The issues we are working to solve are: quality of life, health, and safety for the TBI survivor, family, and community. Every recommendation is based on improving the lives of Alaskans and reducing fiscal and indirect costs.**

*Alaska Brain Injury Network, Inc., mission is to educate, plan, coordinate, and advocate for a comprehensive service delivery system for Alaskans with brain injury and their families.*

**For contact information visit [www.alaskabraininjury.net](http://www.alaskabraininjury.net)**



## alaska brain injury network

**Every 15 seconds** someone sustains a traumatic brain injury (TBI) in the U.S.

Thirty years ago, only half of all people with brain injury survived; now 78% survive. This means that many individuals now live with significant disability requiring a full range of services.

Every year the Alaska Department of Health & Social Services reports about 800 traumatic brain injury (TBI) cases resulting in hospitalization or fatality. The Alaska TBI rate is 28% higher than the national average. The TBI rate in rural Alaska is one of the highest in the nation.

It is estimated that at least 10,000 Alaskans are living with brain injury today. The number keeps accumulating. Brain Injury can be a life-long disability

**The Alaska Brain Injury Network, Inc. (ABIN)** is a non-profit organization dedicated to Alaskans whose lives have been changed by brain injury.

ABIN's Board of Directors represent all regions of Alaska and the extended brain injury community – survivors, family members, service providers, health educators, researchers and those who write laws and policy.

ABIN works with the Alaska Mental Health Trust Authority, Department of Health and Social Services, and partner boards to advocate for policy changes, programs, and facilities to better serve the brain injury population.

ABIN connects survivors and family members with others. Please contact us to learn about brain injury programs in your region.

**The goal for every brain injury survivor is the best possible recovery for a fulfilling and productive life. Achieving that goal requires full range of services close to home. This includes...**

- Prevention
- Early identification and intervention
- Access to skilled specialists
- Community-based post injury services
- Continuing rehabilitation
- Brain injury support groups and in-state resources

### What you can do...

- **Be aware of the fiscal and social burden of brain injury nationally and to the state of Alaska**
- **Become familiar with ABIN Priorities in the Governor's FY09 GF/MH Budget: Brain Injury Training for Providers.**
- **Support the Housing Trust, [www.akhousingtrust.com](http://www.akhousingtrust.com)**
- **Join Alaska Brain Matters listserv to meet Alaskans who have been touched by traumatic brain injury.**

### ABIN Priorities

**In-state rehab facility** – many Alaskans are left in a hospital setting because there is no post-acute rehabilitation option in the State. Others are sent out of State. It is time for Alaskans to have treatment for their brain injury. Research shows outcomes improve with quality rehabilitation.

**Brain Injury Waiver** - recommendations for the current Medicaid waiver system to accommodate the services needed by brain injury survivors: neuropsychological assessment, cognitive and functional therapy, case management, counseling, home modifications, transportation, respite care, and more.



brain injury  
network

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*Alaska Brain Injury Network, Inc. helps identify, develop, implement, and sustain needed programs and resources that promote prevention and expand treatment and service delivery to Alaskans who experience TBI and their families.*

# You KNOW us ...



## ***The Public Health Burden of Brain Injury (prevalence)***

### **5.3 million Brain Injuries**

5 million persistent Mental Illness

4 million Alzheimer's

3 million Stroke

2 million Epilepsy

900,000 HIV/AIDS

500,000 Cerebral Palsy

400,000 Spinal Cord Injury

***Brain injury accounts for more years of lost productivity than any other injury.***

## ***The Financial Burden of Brain Injury***

- It is estimated that over a lifetime, it can cost between \$600,000 and \$1,875,000 to care for a survivor of severe TBI.
- Direct medical costs and indirect costs of TBI such as lost productivity totaled an estimated 60 billion dollars in the United States in 2000. (*Centers for Disease Control and Prevention*)
- Every dollar used for brain injury rehabilitation saves up to \$35 in future medical costs. (Rhode Island Brain Injury Association)

## ***Prevention is the only cure for Brain Injury***

- The three leading causes of brain injury nationally and in Alaska are:  
1) motor vehicle crashes 2) falls and 3) assaults.
- One-third of all TBIs recorded in the Alaska Trauma Registry were alcohol related.
- The use of safety belts is the single most effective measure to prevent traumatic brain injuries.
- Helmets are estimated to be 37% effective in preventing fatal injuries to motorcyclists. (*National Highway Traffic Safety Administration*)
- Bicycle helmets are 85-88 percent effective in mitigating head and brain injuries. Every dollar spent on a bike helmet saves \$40 in direct medical costs and other costs to society. (*National Highway Traffic Safety Administration*)
- 60-67% of injured U.S. soldiers sent from Iraq to Walter Reed Army Medical Center have a TBI from blasts, severe falls and motor vehicle accidents. (*United Press International, July 2004*). These soldiers are now returning home to Alaska for continuing treatment and rehabilitation.

*Traumatic Brain Injury is a beneficiary group participating in the Alaska Mental Health Trust Authority "You Know Me" Anti-Stigma Campaign.*



## **SUCCESS STORY:**

### **Mr. L**

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#### **Injury**

Mr. L was working as a reserve deputy sheriff when he and his partner became involved in a high-speed chase. Their cruiser overturned on some loose gravel, ejecting Mr. L. He suffered a traumatic brain injury in addition to numerous fractures and lacerations as he slid approximately 200 feet along the asphalt and was then run over by his own vehicle. Paramedics flew him to a local trauma center where doctors told his wife he might not live another hour.

#### **Medical Care**

After 2 months in a coma, and 6 months on life-support, Mr. L was discharged home to 24-hour attendant care, unable to perform self-care activities. He was confined to a wheelchair, unable to stand even with a walker. He was unable to drive and required extensive home and vehicle modifications. At the age of 52 Mr. L had a reasonable life expectancy of 22 years.

#### **Cost/Benefit Analysis**

At the request of the insurance representative, a cost/benefit analysis was done to evaluate the decision to invest in further rehabilitation. Centre For Neuro Skills (CNS) in Dallas, Texas was contacted to assist in this analysis. CNS has specialized in the rehabilitation of persons suffering from traumatic brain injury for over 25 years. Both the insurance carrier and CNS determined that without an investment in further rehabilitation services, Mr. L's annual lifecare costs would exceed \$200,000. (See Appendix A)

#### **Rehabilitation**

Mr. L was admitted to CNS - Dallas in February, 2001. He participated in an intensive, interdisciplinary rehabilitation program for approximately eight months. The treatment goals were to improve coordination, overall strength and endurance and range of motion. His therapy team addressed ongoing depression and psychological issues as well as improving cognitive functioning. The focus was to improve his ability to live independently and participate in work activities.

#### **Outcome**

In October, 2001, Mr. L was discharged home with his wife completely independent in all activities of daily living. He regained functional ambulation with a straight cane and is now able to operate a motor vehicle. He began a volunteer position with the local sheriff's department and is enrolled in an Associate Degree program at a local college. No attendant care or nursing is necessary. Discharge recommendations were for continued physical therapy, 3 times a week for 3 to 6 months, and counseling twice a week for 6 weeks.

**Table 1**

<u>Annual Lifecare Costs</u>	
Prior to CNS Admission	\$207,267
Following CNS Discharge	\$8,452
Savings per year:	<b>\$198,815</b>
\$198,815 X 22 years = \$4,373,930	
<b>Total Lifetime Dollars Savings =</b>	<b>\$4,373,930</b>

## Appendix A

### Annual Lifecare Costs without a Postacute Admission

Attendant Care (24/hr)	\$157,248
Additional Hospitalizations	19,272
Allied Health Consultations	10,858
Medications	2,000
Van Modifications	4,350
Home Modifications	2,727
Medical Specialists	2,220
Case Management	5,000
Equipment	3,592

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Total: **\$207,267**

### Annual Lifecare Costs with a Postacute Admission

Re-evaluation (continued therapy)	\$1,250
Medications/Supplies	1,702
Equipment	2,500
Additional Surgery	2,000
Physician Visits	1,000

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Total: **\$8,452**

## ***HIDDEN TRAUMA***

# **Studies Cite Head Injuries As Factor in Some Social Ills**

Brain Researchers Link  
Mental Woes, Alcoholism  
To Long-Ago Blows  
By THOMAS M. BURTON  
January 29, 2008; Page A1

Researchers studying brain injury believe they've found a common thread running through many cases of seemingly unrelated social problems: a long-forgotten blow to the head.

They've found that providing therapy for an underlying brain injury often helps people with a variety of ill effects ranging from learning disabilities to chronic homelessness and alcoholism. If broadly verified, the findings could have a significant impact in dealing with such intractable difficulties.

That severe head injuries can lead to cognitive and behavioral problems is widely accepted. The U.S. Centers for Disease Control and Prevention estimates 5.3 million Americans suffer from mental or physical disability that is due to brain injury.

What's new is the contention of some researchers that there are many other cases where a severe past blow to the head, resulting in unconsciousness or confusion, is the unrecognized source of such problems. "Unidentified traumatic brain injury is an unrecognized major source of social and vocational failure," says Wayne A. Gordon, director of the Brain Injury Research Center at Mount Sinai School of Medicine in New York, where much of the research is being done.

Research by his team has consistently found high rates of "hidden" head trauma when screening various populations in New York schools, addiction programs and the general population. The CDC acknowledges its 5.3 million estimate is an undercount based on hospital admissions; it doesn't include people who sought no treatment for a severe blow to the head or who were sent home from a doctor's office or emergency room with little treatment.

### **UNDERLYING CAUSE**

- **New Findings:** Researchers say a blow to the head years earlier may be linked to problems later in life, such as learning disabilities, homelessness and alcoholism.
- **Early Identification:** Some schools are trying to identify children who may have had head injuries to provide special help in education.
- **The Impact:** The findings are offering new hope to adults coping with the onset of disorders such as losing the ability to read or concentrate.

Causes of brain injury can include bike and car accidents, sports concussions such as those suffered by professional football players, and abuse and falls that can date back to childhood.

Doctors say about 85% of common falls in infancy don't produce long-term deficits, but that some do.

To be sure, it's difficult to connect with any certainty a long-ago blow to the head to memory and cognition problems years later. Other researchers point out that many people do recover completely from severe head injury, and mental problems arise from other causes. Moreover, Mount Sinai's findings haven't all been published, nor have they been widely evaluated at other institutions.

### **Lost Ability to Read**

Mount Sinai's research involves people like Kate Gleason, a business-college instructor who over the course of a year lost her ability to read, keep her home orderly and even maintain friendships.

In 1998, Ms. Gleason tried to open a window in her New York apartment building's hallway, but the heavy top window fell and bashed her on the head. She was treated by doctors at a local hospital, who she says let her walk home and told her she'd be fine. But on the way back, she was still so confused she had to hang onto lampposts and buildings to keep from losing her way.

A slim, auburn-haired woman then in her mid-40s, Ms. Gleason kept teaching, but found that the bright lights and hectic office were overwhelming. She says she confided in a boss about her troubles and soon lost her job. After that, she made ends meet by returning to proofreading work, but she slowly withdrew socially.

She didn't pay bills on time. Her house was a mess. "Years and years went by, and I had lots of problems," she says. "I didn't know it was from the head injury. I just thought I had a clutter problem." By 1999, Ms. Gleason, who has a master's from Columbia University, was "so bad on the level of functioning as a college grad that I wanted to die." She had no idea why.

Then about two years ago, she got a strange letter from Mount Sinai: It asked if she was having trouble thinking or solving problems or if she became easily overwhelmed. It turned out Mount Sinai doctors were reaching out to people whose medical records showed a blow to the head. Ms. Gleason responded, and when researchers interviewed her, she began to sob, saying, "Life is just so hard."

On what was to be the first day of an attention and memory program, Ms. Gleason got lost in the maze of hospital hallways and began crying again. Once she found the site, she discovered she wasn't the only patient who got lost a lot, or who cried.

For five days a week for six months, she worked through five hours of attention exercises, reading articles to explain the main idea, interpreting charts and graphs, taking classes on how to take apart a problem and reduce it to smaller steps, writing mock "advice columns" on how to handle life issues.

At first, she found the work so intense she needed a break every 15 minutes. By a week later, she could concentrate a little longer. She completed the program in August 2006, eight years after

the window struck her. Now she's studying to be a church-based counselor. "That program gave me my life back," she says.

A group for whom the research on undiagnosed head injuries could be especially relevant is the homeless. Assessments by Mount Sinai researchers of about 100 homeless men in New York found that 82% had suffered brain injury in childhood, primarily as a result of parental abuse.

An epidemiological study in 2000 was larger. Researchers went door-to-door in New Haven, Conn., interviewing 5,000 people, 7.2% of whom recalled a past blow to the head that was followed by unconsciousness or a period of confusion. In follow-up testing, the researchers found that those who reported such injuries had more than twice the rate of depression and of alcohol and drug abuse as others.

They also had sharply elevated rates of panic disorder, obsessive-compulsive disorder and suicide attempts, say the researchers, led by Jonathan Silver of New York University.

Such research began in the late 1980s with Mount Sinai's Dr. Gordon and Mary Hibbard, both Ph.D. psychologists specializing in rehabilitation and neuropsychology. In questioning patients referred to them, they were struck by how often they turned up a history of a brain injury that wasn't in the patients' medical records.



**Wayne A Gordon**

Using a questionnaire they devised, they tried to determine how many children in the city school system had head injuries that were followed by cognitive difficulties. At one school, 10% of students told of having once had a significant head injury. Later testing of these children frequently "was suggestive of impairments," Dr. Hibbard says.



**Mary Hibbard**

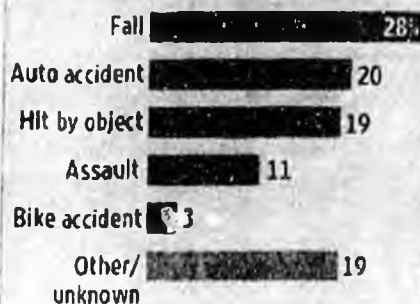
Next, with a grant from the U.S. Department of Education, they set out to determine how many pupils enrolled in programs for children with learning disabilities had ever suffered a hard blow to the head. The results were startling: About 50% had.

"The accident can be three months ago, but by the time the symptoms happen, the accident is forgotten. Nobody puts it together," says Tamar Martin, a psychologist in the program. The team worked with about 400 children, finding that many children who'd had brain injuries were lost in regular learning-disabilities classrooms.

They have trouble with their memory from day to day, and teachers can assume they're not trying hard, Dr. Martin says. They need more breaks between topics. But their performance varies greatly from day to day, and a teacher can also erroneously perceive this fluctuation as lack of initiative.

## A Pervasive Problem

### Causes of traumatic brain injuries



### Groups at risk

- Children ages 0 to 4 and 15 to 19: greatest risk of brain injury
- Adults 75 and older: highest rates of hospitalization and death

Note: 'Hit by object' includes sports injuries

Source: Centers for Disease Control and Prevention

Just giving such children more time often helps, she says, as do special prompts from teachers. For instance, Dr. Martin says, a teacher may say, "In a couple of minutes, I am going to ask you about problem No. 10," and give the child time to prepare before officially asking.

### High Intellect

One 14-year-old girl had a high intellect, but after she was hit by a car, she suddenly couldn't do outlines or organize her time, her mother says in an interview. "Her processing was slower," adds Michelle Kornbleuth, another psychologist in the Mount Sinai program. "She was frustrated, and her scores came out in the average range."

With Dr. Kornbleuth's help, the girl was allowed to take exams privately in an office and could concentrate better. With such accommodations, she completed high school and went on to graduate from prestigious Smith College.

Kansas systematically tries to identify brain injuries among the "learning disabled." School social workers and teachers with special training across the state show other teachers how to recognize and work with the brain-injured, says Janet Tyler, director of a neurologic-disabilities project in the state education department.

"When you look at children with learning disabilities or behavior problems, there's often an underlying high percentage of children with traumatic brain injury. We're looking at about 20%," she says.

In Mulvane, Kan., Sandy Baca's son Timothy, who was hit by a car at age 2, struggled in school for years. Ms. Baca says that once teachers understood the difference between brain injury and other disability, "they found ways for him to be successful. If he couldn't do the work one day, they would lower expectations for the day." Ultimately, he finished high school.

The Mount Sinai team evaluates people via a battery of "neuropsych" tests lasting up to nine hours. They are shown pictures of objects, then asked minutes later what they saw. They see a complex geometric design with triangles, lines and circles and are asked to draw it from memory. They're shown a series of multiple random letters and asked to cross out, say, the "c" and "e" every time they see one.

On a recent morning, a 44-year-old manager at a New York investment firm was working on attention training with a postdoctoral fellow. He had sustained several sports concussions as a younger man and then in recent years twice banged his head hard. Lately, he had been feeling confused. Commuting between New York City and Long Island, he boarded the wrong train three days in a row.

In the first of several exercises, the patient was asked to read a page of text while crossing out all words ending in "ing," and then to answer questions about what he'd read. The first time through, he caught only seven of 12 "ing" words. A second test asked him to choose a word that didn't

belong in a group of five, while listening to other words and pressing a buzzer when he heard words with four letters.

About five years ago, the Mount Sinai team began looking at residents of New York centers for alcoholism and drug abuse. They evaluated 845 patients and determined that 54% had once suffered a hard blow to the head. Of course, some had injuries after they began drinking, so there is a certain chicken-and-egg problem with that number.

### **Link to Addiction**

Steven Kipnis, medical director of a New York state agency for alcoholism and addiction, says his work with counselors convinces him that many of the patients became alcoholic or addicted in part because of a head injury, and knowing about it helps in treatment.

"Someone can get hit in the head with a softball and still be working. They tend to be in denial. They get mood swings, they yell at a spouse. It's a slow downward spiral, and that's when alcohol and drugs" become an option, he says.

The agency has a program specifically for the brain-injured at the R.E. Blaisdell Addiction Treatment Center in Orangeburg, N.Y. A counselor there, Steve Oswald, tells of one patient who dropped out of a general alcoholism program three times before the program for the brain-injured began, and then successfully completed the program.

In 2006, Mount Sinai's Dr. Gordon began to work with Common Ground, a New York nonprofit that builds housing for the homeless. About 70% of 100 homeless people they tested came out in the 10th percentile or lower for memory, language or attention, says the group's director of psychiatric services, Jennifer Highley. Questioning uncovered that 82% had a significant blow to the head prior to becoming homeless, usually from severe parental abuse during childhood.

"People get abused as kids, making them inattentive in school and sometimes unable to learn," says Ms. Highley. She says head injury and the emotional fallout from abuse can lead to alcoholism and addiction, and "that combination creates the inability to function and often leads to homelessness."

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## Mild Traumatic Brain Injury in U.S. Soldiers Returning from Iraq

Charles W. Hoge, M.D., Dennis McGurk, Ph.D., Jeffrey L. Thomas, Ph.D., Anthony L. Cox, M.S.W.,  
Charles C. Engel, M.D., M.P.H., and Carl A. Castro, Ph.D.

### ABSTRACT

#### BACKGROUND

An important medical concern of the Iraq war is the potential long-term effect of mild traumatic brain injury, or concussion, particularly from blast explosions. However, the epidemiology of combat-related mild traumatic brain injury is poorly understood.

#### METHODS

We surveyed 2525 U.S. Army infantry soldiers 3 to 4 months after their return from a year-long deployment to Iraq. Validated clinical instruments were used to compare soldiers reporting mild traumatic brain injury, defined as an injury with loss of consciousness or altered mental status (e.g., dazed or confused), with soldiers who reported other injuries.

#### RESULTS

Of 2525 soldiers, 124 (4.9%) reported injuries with loss of consciousness, 260 (10.3%) reported injuries with altered mental status, and 435 (17.2%) reported other injuries during deployment. Of those reporting loss of consciousness, 43.9% met criteria for post-traumatic stress disorder (PTSD), as compared with 27.3% of those reporting altered mental status, 16.2% with other injuries, and 9.1% with no injury. Soldiers with mild traumatic brain injury, primarily those who had loss of consciousness, were significantly more likely to report poor general health, missed workdays, medical visits, and a high number of somatic and postconcussive symptoms than were soldiers with other injuries. However, after adjustment for PTSD and depression, mild traumatic brain injury was no longer significantly associated with these physical health outcomes or symptoms, except for headache.

#### CONCLUSIONS

Mild traumatic brain injury (i.e., concussion) occurring among soldiers deployed in Iraq is strongly associated with PTSD and physical health problems 3 to 4 months after the soldiers return home. PTSD and depression are important mediators of the relationship between mild traumatic brain injury and physical health problems.

From the Division of Psychiatry and Neuroscience, Walter Reed Army Institute of Research, U.S. Army Medical Research and Materiel Command, Silver Spring, MD (C.W.H., D.M., J.L.T., A.L.C., C.A.C.); and the Deployment Health Clinical Center and Uniformed Services University of Health Sciences, Washington, DC (C.C.E.). Address reprint requests to Dr. Hoge at the Division of Psychiatry and Neuroscience, Walter Reed Army Institute of Research, 503 Robert Grant Ave., Silver Spring, MD 20910, or at charles.hoge@us.army.mil.

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**M**ORE THAN 1.5 MILLION U.S. MILITARY personnel have deployed to Iraq or Afghanistan since the start of military operations in 2001. Because of improved protective equipment, a higher percentage of soldiers are surviving injuries that would have been fatal in previous wars.<sup>1</sup> Head and neck injuries, including severe brain trauma, have been reported in one quarter of service members who have been evacuated from Iraq and Afghanistan.<sup>1,2</sup> Concern has been emerging about the possible long-term effect of mild traumatic brain injury, or concussion, characterized by brief loss of consciousness or altered mental status, as a result of deployment-related head injuries, particularly those resulting from proximity to blast explosions.<sup>3-5</sup> Traumatic brain injury has been labeled a signature injury of the wars in Iraq and Afghanistan.<sup>4,5</sup>

The exact proportion of troops who have mild traumatic brain injury is not known, although it has been reported to be as high as 18% in news articles citing army medical officials.<sup>6</sup> Many troops reportedly have persistent postconcussive symptoms, such as irritability, memory problems, headache, and difficulty concentrating. As a result, the Department of Defense and the Department of Veterans Affairs are implementing new population-screening procedures for mild traumatic brain injury.<sup>7-9</sup>

Despite these steps, little is known about the epidemiology of mild traumatic brain injury during deployment and its association with adverse health outcomes after deployment. The bulk of the literature on mild traumatic brain injury has been based on civilian patients treated in clinics or hospitals, has not been population-based, and has lacked adequate comparison groups, such as persons with other types of injuries.<sup>10,11</sup> It is not known whether population screening for mild traumatic brain injury could improve health outcomes,<sup>12</sup> and there are conflicting guidelines for treating mild traumatic brain injury.<sup>13,14</sup>

The case definition of mild traumatic brain injury that is being adopted by the new Department of Defense and Department of Veterans Affairs screening programs<sup>8,9</sup> is consistent with national surveillance definitions.<sup>11,15</sup> However, the use of this definition for clinical screening weeks or months after concussive events, such as during the period after deployment, has not been evaluated. The definition may not be sufficiently

specific for the combat environment, where acute signs of concussion, such as alteration of mental status (e.g., being dazed or confused), may overlap with dissociative symptoms of acute stress disorder, or for the postcombat period, during which postconcussive symptoms may overlap with symptoms of post-traumatic stress disorder (PTSD) and other disorders.<sup>16</sup>

This epidemiologic study assesses the prevalence and significance of a self-reported history of combat-related mild traumatic brain injury, based on the accepted case definition, among soldiers after a yearlong deployment to Iraq. The purpose is to provide information to advance prevention and treatment strategies and inform public health policies.

## METHODS

In 2006, we conducted an anonymous survey of 2714 soldiers from two U.S. Army combat infantry brigades — one Active Component and one Reserve Component (Army National Guard) — 3 to 4 months after their return from a yearlong deployment in Iraq. The units saw high levels of combat, similar to those of other infantry units.<sup>17-19</sup> The 3-to-4-month time point was chosen to minimize recall bias and for its appropriateness for assessing persistent postconcussive symptoms.<sup>20,21</sup>

### RECRUITMENT

Unit leaders provided time for all their soldiers who had deployed to Iraq and were on duty to attend a recruitment briefing by study investigators. Written informed consent was obtained under a protocol approved by the institutional review board of the Walter Reed Army Institute of Research. Of 4618 soldiers in the two brigades, 2714 (59%) completed the questionnaire. Lack of availability of soldiers to complete the questionnaire was mostly due to normal transfers to other units, training, or attendance at military schools. More than 98% of soldiers who attended the recruitment briefings agreed to participate. However, up to 7% of the values for some variables were missing.

### INJURIES AND COMBAT EXPERIENCE

The questionnaire asked soldiers whether they had been injured during their deployment by a blast or explosion, a bullet, a fragment or shrap-

nel, a fall, a vehicle accident, or other means and whether the injury involved the head. A soldier was considered to have had a mild traumatic brain injury if any of three questions — regarding “losing consciousness (knocked out),” “being dazed, confused, or ‘seeing stars,’” or “not remembering the injury” — elicited a positive response. These questions were based on definitions from the Centers for Disease Control and Prevention and the World Health Organization that were adapted by the Defense and Veterans Brain Injury Center working group for military-wide use.<sup>9,11</sup> The question regarding loss of consciousness was analyzed separately to determine whether it was a stronger predictor than the two other questions pertaining to altered mental status, the results of which were combined. Soldiers who reported any injury that did not involve altered mental status or losing consciousness served as the reference group for all analyses.

Combat intensity was measured with the use of 17 of the 18 questions from the Combat Experiences Scale<sup>17</sup> (range, 0 to 17, with higher scores indicating a greater number of different combat experiences on one or more occasions). The 18th question, concerning being wounded, was excluded because it was covered in the questions about injuries. Of the 17 experiences, soldiers had a median of 9 (interquartile range, 6 to 11) during the deployment. The Cronbach alpha for the 17 dichotomized questions was 0.85.

#### MEASURES OF PHYSICAL HEALTH

Soldiers were asked how they rated their overall health (from “poor” to “excellent”), how many primary care (“sick call”) appointments they had attended, and how many days of work they had missed in the past month because of illness. Physical symptoms were measured by the Patient Health Questionnaire 15-item somatic symptom severity scale (PHQ-15).<sup>22</sup> This scale normally has a range of 0 to 30, with higher numbers indicating a greater number and severity of symptoms. For this study, the range was 0 to 28 because a question on menstrual cramps was excluded owing to the low number of women. High severity of symptoms was defined as a score of at least 15.<sup>22,23</sup> Five additional questions, which were not part of the PHQ-15, were asked regarding important post-concussive symptoms that concerned memory, balance, concentration, ringing in the ears, and irritability.

#### MEASURES OF DEPRESSION AND PTSD

Current symptoms (i.e., symptoms during the past month) of major depressive disorder and PTSD were assessed by the 9-question depression-assessment module of the Patient Health Questionnaire<sup>24</sup> and the 17-item National Center for PTSD Checklist, respectively, which are based on well-validated case definitions used in veteran and military populations.<sup>17,25,40</sup> For major depression, subjects had to meet the criteria of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV), and report impairment in work, home, or interpersonal functioning at the “very difficult” level.<sup>17,24</sup> For PTSD, subjects had to meet the DSM-IV criteria (one intrusion symptom, three avoidance symptoms, and two hyperarousal symptoms) and have substantial distress, as measured by a total score of at least 50 (range, 17 to 85, with higher scores indicating a greater number and severity of symptoms).<sup>17,26</sup>

#### STATISTICAL ANALYSIS

Surveys were scanned with the use of ScanTools (National Computer Systems), with quality control verifying error rates below 0.25%. SPSS software (version 12.0) was used for data analysis, including chi-square and analysis-of-variance testing for univariate analyses. Multivariate analyses were conducted with the use of multiple logistic regression with SPSS software (version 12.0), including goodness-of-fit testing of all models.

## RESULTS

#### SUBJECTS

Of 2714 soldiers, 149 (5.5%) were excluded because of missing data from the questions about injuries, and 40 (1.5%) were excluded because they reported having had a head injury without loss of consciousness or altered mental status. The demographics of the study population were similar to those of infantry soldiers deployed to Iraq<sup>17,19</sup>: 95.5% were male, 55.5% were under the age of 30 years, and 47.5% were of junior enlisted rank.

#### INJURIES

Of the 2525 soldiers included in the study, 124 (4.9%) reported an injury with loss of consciousness (most often lasting between a few seconds and 2 or 3 minutes), and 260 (10.3%) reported an injury with altered mental status not involving

Table 1. Characteristics of the Study Population.\*

Characteristic	Injury with Loss of Consciousness (N = 124)	Injury with Altered Mental Status (N = 260)	Other Injury (N = 435)	No Injury (N = 1706)	P Value for Loss of Consciousness vs. Other Injury	P Value for Altered Mental Status vs. Other Injury
Female sex — no./total no. (%)	1/123 (0.8)	3/258 (1.2)	21/431 (4.9)	88/1692 (5.2)	0.04	0.01
Age <30 yr — no./total no. (%)	79/123 (64.2)	149/257 (58.0)	206/431 (47.8)	958/1698 (56.4)	0.001	0.01
High-school education or less — no./total no. (%)	53/122 (43.4)	103/253 (40.7)	172/429 (40.1)	719/1683 (42.7)	0.51	0.87
Rank — no./total no. (%)					0.04	0.86
Junior enlisted (E1–E4)	73/122 (59.8)	127/256 (49.6)	202/426 (47.4)	780/1684 (46.3)		
Midlevel enlisted (E5–E6)	40/122 (32.8)	97/256 (37.9)	168/426 (39.4)	615/1684 (36.5)		
Senior enlisted and officers	9/122 (7.4)	32/256 (12.5)	56/426 (13.1)	289/1684 (17.2)		
Marital status — no./total no. (%)					0.30	0.06
Single	32/108 (29.6)	76/245 (31.0)	100/403 (24.8)	528/1595 (33.1)		
Married	67/108 (62.0)	149/245 (60.8)	250/403 (62.0)	933/1595 (58.5)		
Divorced, separated, or other	9/108 (8.3)	20/245 (8.2)	53/403 (13.2)	134/1595 (8.4)		
Mechanism of injury — no. (%) †					<0.001	<0.001
Blast or explosion	98 (79.0)	189 (72.7)	101 (23.2)			
Bullet	6 (4.8)	2 (0.8)	7 (1.6)			
Fragment or shrapnel	31 (25.0)	48 (18.5)	35 (8.0)			
Fall	38 (30.6)	73 (28.1)	190 (43.7)			
Vehicle accident	38 (30.6)	47 (18.1)	58 (13.3)			
Other	16 (12.9)	23 (8.8)	147 (33.8)			
Improvised explosive device exploded near soldier on ≥2 occasions (with or without injury) — no./total no. (%)	106/122 (86.9)	231/258 (89.5)	281/434 (64.7)	938/1690 (55.5)	<0.001	<0.001
Hospitalized while deployed — no./total no. (%)	50/124 (40.3)	44/259 (17.0)	59/433 (13.6)	89/1701 (5.2)	<0.001	0.23
Quartile of combat intensity — no./total no. (%) ‡					<0.001	<0.001
1	2/124 (1.6)	8/259 (3.1)	74/435 (17.0)	452/1705 (26.5)		
2	15/124 (12.1)	29/259 (11.2)	95/435 (21.8)	467/1705 (27.4)		
3	21/124 (16.9)	53/259 (20.5)	97/435 (22.3)	376/1705 (22.1)		
4	86/124 (69.4)	169/259 (65.3)	169/435 (38.9)	410/1705 (24.0)		

Mental health problems	54/123 (43.9%)	71/260 (27.3%)	70/433 (16.2%)	155/1701 (9.1%)	<0.001
PTSD — no./total no. (%)					
Major depression — no./total no. (%)	27/118 (22.9%)	21/250 (8.4%)	28/423 (6.6%)	55/1673 (3.3%)	<0.001
Score on Post-Traumatic Stress Disorder Checklist†	46.8±19.0	39.8±16.3	35.0±15.0	29.1±13.2	<0.001

Complete data regarding some of the characteristics were not available for all subjects. P values were calculated with the use of the chi-square test except where indicated. PTSD denotes post-traumatic stress disorder.

† Mechanisms of injury are not mutually exclusive.

\* Combat intensity was measured with a 17-question scale representing the number of different combat experiences. Scores range from 0 to 17, with higher values indicating a greater number of experiences. Scores of 0 to 5 constitute quartile 1, 6 to 8 quartile 2, 9 and 10 quartile 3, and 11 to 17 quartile 4.

† PTSD was measured with the Post-Traumatic Stress Disorder Checklist, which has a range from 17 to 85, with higher scores indicating a greater number and severity of symptoms. All subjects who met the psychiatric-symptom criteria of the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV)*, and who had a total score on the Post-Traumatic Stress Disorder Checklist of at least 50 were classified as having PTSD. Plus-minus values are means ±SD. P values for the score on the Post-Traumatic Stress Disorder Checklist were calculated with the use of analysis of variance.

\* Major depression was measured with the Patient Health Questionnaire. Subjects who were classified as having major depression had to meet the psychiatric criteria according to DSM-IV and report functional impairment at the "very difficult" level.

loss of consciousness (253 said they had been "dazed, confused, or seeing stars"). Four soldiers reported loss of consciousness lasting longer than 30 minutes. Although technically they were considered to have had moderate traumatic brain injury, they were not excluded because the number was low and it was not possible to verify the self-reported data from any of the subjects. An additional 435 soldiers (17.2%) reported some other injury during the deployment with no loss of consciousness or altered mental status, most commonly resulting from a fall or other incident (e.g., handling heavy equipment or injuring oneself during training) (Table 1). This was the reference group for all analyses (Tables 1, 2, and 3). Also shown in Tables 1 and 2, for comparison purposes, are the characteristics of the remaining 1706 soldiers who reported no injury.

As compared with soldiers who had other injuries, soldiers who reported mild traumatic brain injuries were significantly more likely to report high combat intensity, a blast mechanism of injury, more than one exposure to an explosion, and hospitalization during deployment (Table 1). Soldiers who reported mild traumatic brain injuries were also significantly younger, more likely to be junior in rank, and more likely to be male than were soldiers who had other injuries.

#### PTSD AND MILD TRAUMATIC BRAIN INJURY

PTSD was strongly associated with mild traumatic brain injury. Overall, 43.9% of soldiers who reported loss of consciousness met the criteria for PTSD, as compared with 27.3% of those with altered mental status, 16.2% of those with other injuries, and 9.1% of those with no injuries (Table 1). In a logistic-regression model that included age, military rank, sex, hospitalization or no hospitalization, mechanism of injury (blast or other mechanisms), level of combat intensity, exposure or nonexposure to multiple blasts from improvised explosive devices, and type of injury (loss of consciousness vs. other injuries), only loss of consciousness and combat intensity remained significantly associated with PTSD (odds ratio for loss of consciousness, 2.98; 95% confidence interval [CI], 1.70 to 5.24; odds ratio for top quartile of combat intensity vs. lowest quartile, 11.58; 95% CI, 2.99 to 44.83) (see Supplementary Appendix 1, available with the full text of this article at [www.nejm.org](http://www.nejm.org)). Injury with loss of consciousness was also independently associated with ma-

Table 2. Physical Health Status after Deployment According to Type of Injury during Deployment.<sup>a</sup>

Physical Health during the Past Month	Injury with Loss of Consciousness (N = 124)	Injury with Altered Mental Status (N = 260)	Other Injury (N = 435)	No Injury (N = 1706)	P Value for Loss of Consciousness vs. Other Injury	P Value for Altered Mental Status vs. Other Injury
	<i>no./total no. (%)</i>					
Poor overall health	15/119 (12.6)	17/257 (6.6)	29/422 (6.9)	38/1665 (2.3)	0.04	0.90
≥2 Missed workdays due to illness	28/120 (23.3)	40/256 (15.6)	61/419 (14.6)	122/1671 (7.3)	0.02	0.71
≥2 medical visits for physical condition	51/120 (42.5)	84/256 (32.8)	123/426 (28.9)	331/1678 (19.7)	0.005	0.28
PHQ-15 score of ≥15 <sup>†</sup>	30/121 (24.8)	41/254 (16.1)	48/426 (11.3)	85/1683 (5.1)	<0.001	0.07
Physical symptoms included in PHQ-15 <sup>‡</sup>						
Stomach pain	14/120 (11.7)	20/249 (8.0)	37/421 (8.8)	71/1674 (4.2)	0.34	0.73
Back pain	40/121 (33.1)	78/253 (30.8)	122/424 (28.8)	311/1678 (18.5)	0.36	0.57
Arm, leg, or joint pain	45/121 (37.2)	105/252 (41.7)	168/423 (39.7)	387/1673 (23.1)	0.62	0.62
Headache	39/121 (32.2)	45/254 (17.7)	51/421 (12.1)	141/1674 (8.4)	<0.001	0.04
Chest pain	17/121 (14.0)	7/253 (2.8)	20/425 (4.7)	40/1675 (2.4)	<0.001	0.21
Dizziness	10/120 (8.3)	15/254 (5.9)	13/425 (3.1)	31/1680 (1.8)	0.01	0.07
Fainting spells	5/120 (4.2)	2/253 (0.8)	8/423 (1.9)	7/1678 (0.4)	0.17	0.34
Heart pounding or racing	23/120 (19.2)	25/253 (9.9)	21/425 (4.9)	62/1679 (3.7)	<0.001	0.01
Shortness of breath	17/120 (14.2)	19/254 (7.5)	30/421 (7.1)	54/1675 (3.2)	0.02	0.86
Constipation, loose bowels, or diarrhea	26/120 (21.7)	31/253 (12.3)	50/424 (11.8)	115/1681 (6.8)	0.006	0.86
Nausea, gas, or indigestion	22/120 (18.3)	34/253 (13.4)	65/423 (15.4)	132/1677 (7.9)	0.43	0.49
Pain or problems during sexual intercourse	10/120 (8.3)	8/253 (3.2)	16/425 (3.8)	16/1673 (1.0)	0.04	0.68
Fatigue	59/111 (53.2)	92/232 (39.7)	136/393 (34.6)	388/1542 (25.2)	<0.001	0.21
Sleep disturbance	63/117 (53.8)	111/247 (44.9)	157/422 (37.2)	402/1666 (24.1)	0.001	0.05
Other postconcussive symptoms <sup>§</sup>						
Memory problems	29/118 (24.6)	41/253 (16.2)	58/422 (13.7)	124/1680 (7.4)	0.005	0.38
Balance problems	10/120 (8.3)	17/254 (6.7)	12/424 (2.8)	26/1677 (1.6)	0.02	0.02
ringing in the ears	28/119 (23.5)	45/251 (17.9)	59/422 (14.0)	99/1675 (5.9)	0.01	0.17
Concentration problems	37/118 (31.4)	65/250 (26.0)	76/420 (18.1)	170/1667 (10.2)	0.002	0.02
Irritability	67/118 (56.8)	118/248 (47.6)	154/419 (36.8)	409/1659 (24.7)	<0.001	0.006

<sup>a</sup> Complete data regarding the physical health categories were not available for all subjects.

<sup>†</sup> PHQ-15 refers to the Patient Health Questionnaire 15-item somatic symptom scale (range in this study, 0 to 28, with higher numbers indicating a greater number and severity of symptoms).

<sup>‡</sup> The numbers and percentages of persons reporting "bothered a lot" (for all symptoms except fatigue or sleep disturbance) or "more than half the days" (for fatigue and sleep disturbance) are shown. One symptom from the PHQ-15 pertaining to menstrual cramps was not included, since there were so few women in the study.

<sup>§</sup> The numbers and percentages of persons reporting "bothered a lot" (for memory problems, balance problems, and ringing in the ears) or "more than half the days" (for concentration problems and irritability) are shown.

for depression (odds ratio, 3.67; 95% CI, 1.65 to 8.16). Similarly, injuries associated with altered mental status (as compared with other injuries) and combat intensity were significantly associated with PTSD (but not with depression) (odds ratio for injuries with altered mental status, 1.78; 95% CI, 1.13 to 2.81; odds ratio for combat intensity, 6.63; 95% CI, 2.23 to 19.76).

#### ADJUSTED AND UNADJUSTED ANALYSES OF PHYSICAL HEALTH

Tables 2 and 3 show the association of the type of injury with measures of physical health. Soldiers who had lost consciousness were significantly more likely to report poor general health, more missed workdays, and a higher number of medical visits in the past month than were soldiers with other injuries. Soldiers who had lost consciousness also had significantly higher scores on the PHQ-15 and significantly higher rates of nine of the PHQ-15 physical symptoms and all five of the other postconcussive symptoms (Table 2). Multivariate logistic-regression analysis was then conducted to assess whether PTSD and major depression mediated the relationship between loss of consciousness and physical health outcomes (Table 3).<sup>27</sup> When PTSD and depression were included in the analyses, the associations between loss of consciousness and the multiple physical health outcomes disappeared, except for two symptoms (headache and heart pounding). For example, when loss of consciousness was compared with other injuries, the odds ratio for having a high PHQ-15 score fell from 2.60 (95% CI, 1.56 to 4.33) in the unadjusted comparison to 0.92 (95% CI, 0.46 to 1.82) after adjustment for PTSD and depression (Table 3). In contrast, the odds ratio for having a high PHQ-15 score in this adjusted equation for PTSD was 7.86 (95% CI, 4.09 to 15.10), and the odds ratio for major depression was 7.47 (95% CI, 3.53 to 15.78) (see Supplementary Appendix 2). Further adjustment to include all significant variables from Table 1 did not change the results appreciably; the odds ratio for having a high PHQ-15 score dropped to 0.76 (95% CI, 0.31 to 1.84), and the association with heart pounding became nonsignificant (Table 3). Of all physical health outcomes associated with loss of consciousness in the unadjusted analysis, only headache remained significant after adjusting for PTSD and depression. In contrast, PTSD, depression, or both were strongly associated with all the physical health outcomes in these adjusted models.

A similar analysis compared altered-mental-status injuries with other injuries (Tables 2 and 3). Initially, altered mental status was associated with only three of the physical symptoms and three of the other postconcussive symptoms. The associations disappeared when PTSD was included in the analyses, and there was no change with

further adjustment for demographic and combat variables. Depression was not included, since there was no association between altered mental status and depression (Table 1).

The following example illustrates how cases were distributed and why the association between mild traumatic brain injury and high symptom-severity scores did not persist after adjustment for PTSD. The high PHQ-15 scores occurred almost exclusively in soldiers who had PTSD. Of soldiers with PTSD, there were no significant differences in the proportion with a high PHQ-15 score according to type of injury: 27 of 53 with loss of consciousness (50.9%), 28 of 67 with altered mental status (41.8%), and 29 of 69 with other injuries (42.0%) had a high PHQ-15 score. Of soldiers without PTSD, the proportion with a high PHQ-15 score was much lower and also showed no significant differences according to type of injury: 3 of 67 with loss of consciousness (4.5%), 13 of 187 with altered mental status (7.0%), and 19 of 356 with other injuries (5.3%). (The denominators differ slightly from those in the tables because of missing values.)

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#### DISCUSSION

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In this study, nearly 15% of soldiers reported an injury during deployment that involved loss of consciousness or altered mental status. These soldiers, defined as having mild traumatic brain injury, were significantly more likely to report high combat exposure and a blast mechanism of injury than were the 17% of soldiers who reported other injuries. Soldiers with mild traumatic brain injury reported significantly higher rates of physical and mental health problems than did soldiers with other injuries. Injuries associated with loss of consciousness carried a much greater risk of health problems than did injuries associated with altered mental status.

Although this study was based on a nonrandom sample from two brigades, the sample is likely to be representative of soldiers serving in ground-combat units in Iraq. The demographic characteristics and rates of combat experience of the subjects are consistent with those in other studies.<sup>17-19</sup> The unavailability of soldiers was mostly due to work schedules, which would be unlikely to introduce bias. One bias is that on the survey days, soldiers who were ill, at medical appointments, or more seriously injured did

Table 3. Unadjusted and Adjusted Odds Ratios for Each Postdeployment Physical Health Outcome According to Type of Injury during Deployment.\*

Physical Health during the Past Month†	Injury with Loss of Consciousness vs. Other Injury‡			Injury with Altered Mental Status vs. Other Injury§		
	Unadjusted	Adjusted for PTSD and Depression	Adjusted for PTSD, Depression, and Other Variables <i>odds ratio (95% confidence interval)</i>	Unadjusted	Adjusted for PTSD	Adjusted for PTSD and Other Variables
Poor overall health	1.96 (1.01-3.78)¶	0.92 (0.43-1.99)	1.43 (0.50-4.07)	0.96 (0.52-1.78)	0.76 (0.40-1.44)	0.97 (0.44-2.16)
≥2 Missed workdays due to illness	1.79 (1.08-2.95)¶	1.31 (0.75-2.27)	1.76 (0.85-3.65)	1.09 (0.71-1.68)	1.00 (0.64-1.55)	0.93 (0.54-1.60)
≥2 Medical visits for physical condition	1.82 (1.19-2.77)¶	1.31 (0.82-2.07)	1.28 (0.72-2.28)	1.20 (0.86-1.68)	1.11 (0.79-1.57)	1.08 (0.71-1.63)
PHQ-15 score of ≥15**	2.60 (1.56-4.33)¶†	0.92 (0.46-1.82)	0.76 (0.31-1.84)	1.52 (0.97-2.38)	1.13 (0.69-1.87)	1.31 (0.71-2.41)
Physical symptoms included in PHQ-15**						
Stomach pain	1.37 (0.72-2.63)	0.70 (0.32-1.50)	0.67 (0.25-1.82)	0.91 (0.51-1.60)	0.75 (0.43-1.40)	1.21 (0.58-2.51)
Back pain	1.22 (0.79-1.89)	0.84 (0.52-1.36)	0.87 (0.48-1.57)	1.10 (0.79-1.55)	0.96 (0.68-1.37)	0.97 (0.64-1.47)
Arm, leg, or joint pain	0.90 (0.59-1.36)	0.62 (0.39-0.98)	0.79 (0.44-1.39)	1.08 (0.79-1.49)	0.97 (0.70-1.35)	1.28 (0.86-1.92)
Headache	3.45 (2.13-5.58)¶†	2.10 (1.22-3.61)†	2.38 (1.12-5.07)¶	1.56 (1.01-2.41)¶	1.34 (0.85-2.10)	1.63 (0.92-2.90)
Chest pain	3.31 (1.67-6.54)¶†	1.58 (0.72-3.49)	1.84 (0.61-5.52)	0.58 (0.24-1.38)	0.48 (0.20-1.17)	0.52 (0.18-1.54)
Dizziness	2.88 (1.23-6.75)¶	1.19 (0.45-3.15)	4.00 (0.96-16.62)	1.99 (0.93-4.25)	1.54 (0.70-3.38)	2.15 (0.83-5.56)
Fainting spells	2.26 (0.72-7.03)	1.02 (0.30-3.52)	1.11 (0.22-5.60)	0.41 (0.09-1.96)	0.31 (0.06-1.50)	0.27 (0.05-1.62)
Heart pounding or racing	4.56 (2.43-8.58)¶†	2.14 (1.04-4.41)¶	1.90 (0.71-5.09)	2.11 (1.56-3.85)¶	1.64 (0.87-3.10)	1.75 (0.79-3.84)
Shortness of breath	2.15 (1.14-4.05)¶	1.02 (0.49-2.13)	0.77 (0.30-1.99)	1.05 (0.58-1.91)	0.82 (0.44-1.53)	0.72 (0.34-1.54)
Constipation, loose bowels, or diarrhea	2.07 (1.22-3.49)¶	1.42 (0.80-2.53)	1.55 (0.74-3.24)	1.05 (0.65-1.68)	0.88 (0.53-1.44)	1.20 (0.67-2.17)
Nausea, gas, or indigestion	1.24 (0.73-2.11)	0.74 (0.40-1.36)	0.65 (0.31-1.38)	0.86 (0.55-1.34)	0.75 (0.47-1.18)	1.06 (0.60-1.85)
Pain or problems during sexual intercourse	2.32 (1.03-5.26)¶	0.80 (0.31-2.07)	0.98 (0.27-3.51)	0.84 (0.35-1.98)	0.58 (0.24-1.42)	0.81 (0.26-2.54)
Fatigue	2.14 (1.40-3.29)¶†	1.15 (0.68-1.94)	1.24 (0.66-2.34)	1.24 (0.89-1.74)	1.03 (0.72-1.49)	1.25 (0.79-1.96)
Sleep disturbance	1.97 (1.30-2.98)¶	1.14 (0.70-1.85)	1.13 (0.63-2.03)	1.38 (1.00-1.90)¶	1.19 (0.84-1.67)	1.23 (0.81-1.85)
Other postconcussive symptoms						
Memory problems	2.05 (1.24-3.38)¶	1.06 (0.59-1.90)	1.79 (0.85-3.79)	1.21 (0.79-1.87)	0.97 (0.61-1.54)	1.23 (0.70-2.15)
Balance problems	3.12 (1.31-7.41)¶	1.66 (0.63-4.36)	1.58 (0.41-6.08)	2.46 (1.16-5.25)¶	2.07 (0.96-4.48)	1.40 (0.51-3.82)
ringing in the ears	1.89 (1.14-3.14)¶	1.30 (0.75-2.26)	0.78 (0.39-1.55)	1.34 (0.88-2.05)	1.19 (0.77-1.83)	0.76 (0.45-1.27)
Concentration problems	2.07 (1.30-3.28)¶	0.83 (0.45-1.55)	0.92 (0.42-2.00)	1.59 (1.09-2.32)¶	1.29 (0.84-1.96)	1.59 (0.94-2.69)
Irritability	2.26 (1.49-3.42)¶†	1.33 (0.82-2.16)	1.17 (0.65-2.11)	1.56 (1.14-2.15)¶	1.32 (0.93-1.89)	1.46 (0.95-2.24)

\* PTSD denotes post traumatic stress disorder

† All dependent variables (physical health problems or symptoms 3 to 4 months after deployment) are shown.

‡ Two adjusted analyses were conducted by logistic regression. The first was adjusted for PTSD and depression, and the second was adjusted for PTSD, depression, sex, age, rank, mechanism of injury, exposure or nonexposure to multiple blasts from improvised explosive devices, hospitalization or no hospitalization, and combat intensity.

§ Two adjusted analyses were conducted by logistic regression. The first was adjusted for PTSD, and the second was adjusted for PTSD, sex, age, rank, mechanism of injury, exposure or nonexposure to multiple blasts from improvised explosive devices, hospitalization or no hospitalization, and combat intensity.

¶ P=0.01 to &lt;0.05.

‡ P=0.001 to 0.009

\*\* PHQ-15 denotes the Patient Health Questionnaire 15-item somatic symptom severity scale (range in this study, 0 to 28, with higher numbers indicating a greater number and severity of symptoms).

†† P&lt;0.001.

not have the opportunity to participate, possibly resulting in an underestimate of prevalence rates.

In this study, mild traumatic brain injury was significantly associated with psychiatric symptoms, notably PTSD, and the association remained significant after combat experiences had been controlled for. More than 40% of soldiers with injuries associated with loss of consciousness met the criteria for PTSD. The data indicate that a history of mild traumatic brain injury in the combat environment, particularly when associated with loss of consciousness, reflects exposure to a very intense traumatic event that threatens loss of life and significantly increases the risk of PTSD.<sup>28</sup>

The principal limitation of the study is the cross-sectional design based on self-reported data, and thus causality can only be inferred and recall bias is possible. However, the consistency of the results obtained with the use of validated clinical instruments supports the validity of the methods. The analyses suggest that the high rates of physical health problems reported by soldiers with mild traumatic brain injury 3 to 4 months after deployment are mediated largely by PTSD or depression. When these mental disorders were included in the analyses, mild traumatic brain injury was no longer associated with any of the physical health problems, except for headache among those who had lost consciousness. Both PTSD and depression have been associated with a wide range of physical health problems,<sup>23,29,30</sup> including persistence of postconcussive symptoms.<sup>31,32</sup>

The mechanisms of these relationships are complex. Studies have not confirmed any direct link between PTSD and injury to brain tissue from the concussion itself, although this is an important area of research that makes use of new technology, such as diffusion tensor imaging.<sup>33,34</sup> There is evidence that implicit processing of traumatic memories and fear conditioning, both mechanisms for the development of PTSD, occur even in persons with severe traumatic brain injury who are amnesic for the traumatic event.<sup>35</sup> Mechanisms that are likely to underlie both the onset of PTSD after traumatic brain injury and the physical symptoms related to PTSD and depression include biologic processes associated with exposure to extreme stress, activation of the hypothalamic-pituitary-adrenal axis,

autonomic reactivity, reactive cell-mediated immune responses, disturbed sleep physiology, and altered perception of symptoms.<sup>16,28,29,35</sup>

Despite the complexity associated with attribution of physical health symptoms in the post-deployment period, these data should not be construed as suggesting that mild traumatic brain injury is not a serious medical concern. Soldiers who reported mild traumatic brain injury events, particularly loss of consciousness, were at very high risk for physical and mental health problems. Multiple concussions are associated with a longer recovery period,<sup>36</sup> which increases the risk for soldiers who have more than one episode during deployment. However, the relationship between concussion and persistent postconcussive symptoms is poorly understood. Postconcussive symptoms, which usually resolve rapidly (within several days or weeks),<sup>20,21</sup> are not specific to traumatic brain injury.<sup>37</sup> One recent study showed that the prevalence of postconcussive symptoms after injury was identical among patients with mild traumatic brain injury and patients with non-head traumas.<sup>37</sup> There is a theoretical concern about the neurologic effects of primary-blast overpressure (as distinct from the mechanical injuries caused by secondary or tertiary blast effects).<sup>3,38</sup> However, there is no evidence that a brief period of unconsciousness from a blast explosion is different clinically from an equivalent duration of unconsciousness caused by any other mechanism. With the absence of meaningful data on the effects of primary blast exposure on the brain, speculation by clinicians and the surrounding publicity<sup>39</sup> may unnecessarily increase patients' anxieties about the nature of their symptoms.<sup>40</sup>

From a diagnostic and treatment perspective, postconcussive symptoms are indistinguishable from symptoms of various disorders, including other symptom-based conditions described by soldiers returning from war.<sup>40-42</sup> The persistence of postconcussive symptoms has also been shown to be associated with medical disability and compensation processing, as well as the expectations and beliefs that patients have about their injuries.<sup>10,43</sup> Evidence-based interventions for the treatment of persistent postconcussive symptoms are lacking,<sup>11,14</sup> and the results of diagnostic procedures (neuroimaging or neuropsychological testing) for mild traumatic brain injury or deployment-related cognitive effects are often inconclu-

sive and difficult to interpret.<sup>15,19,44</sup> Management focuses largely on alleviating symptoms, yet the most compelling efficacy data highlight the importance of education to normalize symptoms and provide expectation of rapid recovery.<sup>13,14,43,45</sup> Toward this goal, the use of the term "concussion" is encouraged instead of "mild traumatic brain injury." Validated risk-communication approaches, education strategies, and evaluation procedures are needed.

A public health policy implication of this study relates to the sheer number of service members and veterans likely to be referred for further evaluation after being screened under new Department of Defense and Department of Veterans Affairs policies. This study suggests that a self-reported history of mild traumatic brain injury during deployment, particularly when associated with altered mental status without loss of consciousness, lacks specificity in predicting postdeployment physical health problems among injured soldiers. No empirical validation of the screening questions by means of clinical interviews has been done, with the exception of one widely quoted study that had no control group.<sup>9,46</sup> Almost two thirds of the mild traumatic brain injuries in this study sample were identified on the basis of a question that asked soldiers whether they were dazed or confused at the time of the injury. The question proved to have poor correlation to physical health outcomes, even without adjustment for PTSD. Screening for mild traumatic brain injury months after the injury is likely to result in the referral of a large number of persons for evaluation and treatment of non-

specific health symptoms attributed to brain injuries, with potential unintended iatrogenic consequences.<sup>12,40,47,48</sup> Evaluation of the screening programs for traumatic brain injury is needed to ensure that the risks do not outweigh the benefits and that screening is conducted within an effective structure of care.

The strong associations between mild traumatic brain injury, PTSD, depression, and physical health symptoms in combat veterans reinforce the need for a multidisciplinary approach centered in primary care. Evidence-based studies of the management of symptom-based disorders and collaborative care approaches to the evaluation and treatment of coexisting mental disorders in primary care settings are important in designing intervention strategies.<sup>30,40,41,45,48-51</sup>

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DRAFT

# **Promising Practices**

**State Systems of Coordinated  
Services and Supports for  
Individuals with Traumatic Brain  
Injury and Their Families**

## Do I know someone who's had a Traumatic Brain Injury?

**A** four-wheeled Melissas as she was driving her car to work. She moved in and out of consciousness during the ambulance ride, but was coherent when she arrived at the hospital. She was treated for cracked ribs and a ruptured spleen and was given an MRI which showed no apparent brain injury. Several months later she began having memory problems and serious depression. She began drinking heavily to deal with the depression and lost her job as a legal secretary. She is attempting to live off of unemployment insurance.

**A** four-year-old, Shook Abdul when he was 6 months old. He was in a coma for 7 days and diagnosed with Shaken Baby Syndrome. Abdul walked and talked much later than other children his age. He has been evaluated for developmental disability services and currently receives education when he is not asleep.

**R**ickard was diagnosed by a doctor as having a brain injury after a fall. He has all the usual physical conditions resulting in the ongoing difficulties. He has a history of problems completing homework and to grades in school. As a result his parents are concerned about his being admitted to college.

Despite their outward differences, all of these people have experienced a Traumatic Brain Injury (TBI). These examples provide a glimpse into the complex and unique nature of TBI and its effects.

### Chances are ....

It may have been called by a different name: a concussion, Shaken Baby Syndrome, head injury, or anoxia due to trauma. These are just a few of the other names for Traumatic Brain Injury (TBI), but all of them have the potential to kill or leave an individual with life long disabling conditions.

### STATISTICS

One million Americans sustain a TBI and of these, more than 50,000 die and 80,000 experience the onset of long-term disabling conditions following the TBI. Current estimates from the Centers for Disease Control (CDC) state there are 5.3 million Americans living with a disability as a result of TBI. At greatest risk are adolescents, young adults and those older than 75.

TBI occurs 8 ½ times more frequently than breast cancer, 35 times more than HIV/AIDS, 137 times more than spinal cord injury, and 144 times more than multiple sclerosis. The numbers of individuals living with TBI have steadily increased over the past 25-30 years, so to have the challenges of accessing existing systems of supports and services that are available, appropriate, and acceptable.

### COSTS

The annual costs of TBI are estimated to be \$48.3 billion with hospitalization accounting for \$31.7 billion, and fatal brain injuries costing the nation \$16.6 billion. What the long term costs are to provide supports and services is unknown, but it is an issue that needs our attention.

### RISK FACTORS

TBI occurs regardless of age, gender, ethnicity, socio-economic status, or education. Anyone has the potential for being involved in an event resulting in a TBI. TBI is a significant public health issue that must be addressed. HRSA's MCHB grants to the States are helping to address the needs of Individuals with Traumatic Brain Injury and Families by assisting States as they define and build Coordinated State Systems of Services and Supports.

# Promising Practices for State Systems of Coordinated Services and Supports<sup>1</sup> for Individuals with Traumatic Brain Injury and Their Families

## **BACKGROUND**

### **The TBI Act of 1996**

Resulting from uncontrolled costs and inadequate access to services, in July 1996 Congress enacted the Traumatic Brain Injury Act, Public Law 104-166: "to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury (TBI)". Under the Law, the Health Resources and Services Administration (HRSA), is charged with implementing a State Grant Program to improve access to health and other services for individuals with TBI and their families.

All HRSA TBI Grants to States address one or more of the following Healthy People 2010 goals:

1. Improve access to comprehensive, high quality health care services.
2. Increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and improve health and quality of life.
3. Ensure that Federal, Tribal, State, and local health agencies have the infrastructure to provide essential public health services effectively.

The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) were also delegated responsibilities in the areas of research, and prevention and surveillance respectively. CDC has additional public awareness and education responsibilities.

### **Consensus Statement**

In 1998, the NIH convened a consensus conference on TBI Rehabilitation Methods. The panel concluded that individuals with TBI have the best chances for rehabilitation if they have access to individualized treatment programs that combine a wide range of components . . . "the consequences of TBI are rarely limited to one set of symptoms. Rather, they typically affect many facets of a person's life..."

In September 2000, the Brain Injury Association of America (BIA) held a Resource Facilitation Summit. Supported by HRSA/MCHB, the Summit outlined "Principles and Best Practices to Guide Program Development and Operations in Brain Injury" targeted to programs that are administered by State government agencies or contracted to state BIA's. This Summit recognized the great need to build partnerships that help individuals and communities access information, supports, and services.

In October 2000, the CDC convened an Expert Working Group to identify preliminary models of key domains in assessing longer-term outcomes of TBI in Children and Youth. The Work Group

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<sup>1</sup> Services and Supports are defined as any and all of the medical, therapeutic, rehabilitative, community based, psycho-social, economic, educational, vocational, or other needs to necessitate the individual with TBI's ability to function in the community of choice as independently and productively as possible.

recognized that appropriate services for children and youth with TBI are severely lacking. They concluded that an additional dimension to existing models was needed: "Studies of outcomes of TBI in this population should document the needs for services and the barriers to receiving them." Therefore, the Work Group developed a separate Operational Model specifically for these issues.

In April 2001, HRSA's/MCHB's Traumatic Brain Injury Technical Assistance Center (TBI TAC) sponsored a Service Coordination Work Group comprised of individuals from States with TBI grants, including Alabama, Iowa, Minnesota, Michigan, South Carolina, Colorado, Washington, Kentucky, as well as representatives from the BIA, the National Association of State Head Injury Administrators (NASHIA) and TBI TAC Staff. This group was charged with the responsibility of identifying the key elements needed for State Systems of Coordinated Services and Supports. The expertise each State brought to the discussions resulted in the recognition of two key factors: (1) State service delivery systems are fragmented and (2) lack coordination and the points of entry into the States' systems are neither readily identified nor accessible. The States represented in this Work Group have been working to develop mechanisms and methods to coordinate, change, and improve their existing systems of services and supports.

### **STATEMENT OF NEED**

The conclusions from these distinct meetings have recognized: **It is imperative that coordinated, accessible, appropriate, and acceptable TBI services and supports must be available throughout an individual's life as TBI is complex, variable, personal, and can have life-long effects.** TBI is underdiagnosed as it is easily misdiagnosed or goes undiagnosed altogether. Individuals' lives are being saved; we must have systems to support individuals in living their lives after TBI.

This document proposes there are six Critical Indicators every State needs to address as State Systems of Coordinated Services and Supports are developed, enhanced or sustained. The Critical Indicators will be used to measure a State's success in achieving coordinated systems and as the basis for the core outcomes, described later, to be achieved for children, youth, and adults with TBI and their families.

### **PROGRAM DESCRIPTION**

#### **Critical Indicators Needed to Build State Systems of Coordinated Services and Supports**

##### **System Entry or Access**

Service Needs are often not identified until the service system has been entered. Early and correct diagnosis of a TBI is essential as a missed diagnosis or a misdiagnosis leads to absent, inappropriate or denied services and supports. Once a TBI and the ensuing service needs have been identified, it is crucial that families and individuals with traumatic injury have straightforward and readily available information. This information must identify both the point of entry into the State's existing delivery system of services and supports and be user friendly<sup>2</sup>.

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<sup>2</sup>This may include, but not limited to the identification of the physical location, assistance for literacy, language, and cognitive needs, cultural sensitivity, and forms that are easy to use and are not redundant.

Additionally, the assessment tool used by State agencies for in-take, identification of service needs, and/or referral must be consistent or uniform across agency lines.

### **Assistance in Coordination**

Individuals with TBI frequently require a spokesperson or advocate for assistance in navigating State systems and for articulating their service needs. Issues resulting from TBI are often complex and frequently develop or change over time therefore a coordinated State system of services and supports needs to be flexible, creative, and cost effective in the approaches to service delivery. Providers of services<sup>3</sup> must work closely with the individual and family in developing a plan to meet those needs. Providers of services and supports can be instrumental in helping individuals and families develop self-advocacy skills that will be utilized throughout the individual's life.

### **Partnership Approach to Service and Support Provision**

All providers<sup>4</sup> of TBI services and supports must recognize that coordination of services and supports begin at the scene of the injury and may continue indefinitely, as individual needs dictate. There may be a multiplicity of providers, both professional and para-professional, called upon to use their expertise and knowledge with fluctuating levels of involvement and for indeterminate periods of time. A Partnership Approach expects that all providers of services recognize there are many providers working on behalf and with the individual and the family. Therefore, the individual and family are full partners in the decision making and service delivery process. Each participant's contribution is significant as it serves to build the service coordination efforts, document data about TBI issues, provide an environment supportive of the individual and the family within the context of their choices, needs, life roles, and community, as well as raise the awareness of issues stemming from TBI.

### **Education and Training**

Education and training about TBI is the core of a coordinated system of services and supports. Families and individuals with TBI are thrown into the world of TBI with little if any prior knowledge. Information about TBI, its effects, and where to access available services within the State must be readily available. Frequently, families or individuals with TBI seek this information from their medical providers. It cannot be assumed that comprehensive education and training about TBI is included in under-graduate or graduate studies and specialized training such as medical school, teacher preparation, or allied health training. The long term effects and issues resulting from TBI are frequently not included in these curricula. Accurate, comprehensive, and timely educational<sup>5</sup> and training opportunities from multiple sources and perspectives for providers of services, policy makers, families, and individuals with TBI will produce the foundation for Accessible, Available, Appropriate, Acceptable, and Affordable coordinated services and supports for individuals with TBI and their families.

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<sup>3</sup> Includes but not limited to both private and public; e.g., state agency service delivery systems, community based providers, medical and rehabilitative services, schools, managed care.

<sup>4</sup> Examples include but are not limited to: medical, rehabilitative, and other direct care providers, case managers/coordinators, life-skills attendants, family members, individuals with TBI, peer counselors - all providers from every discipline, role, and location

<sup>5</sup> Training that is approved for CEU's, CME's, or other licensing or certification requirements

## **Flexible and Coordinated Long Term Services and Supports**

Individuals with TBI and their families may need life-long services and supports, however the level of intensity at which services are needed varies. The long-term effects of TBI may manifest over time, therefore systems must be designed with the flexibility of allowing individuals to take recesses and then be able re-enter as needs are identified. TBI services may be provided by many agencies within a State's system, but these may not be the appropriate service delivery systems to meet the individual's needs. To increase the efficiency, effectiveness, and cost sharing, agencies must develop a mechanism for case finding<sup>6</sup>, resource identification, tracking the individual's progress, and collaboration in order to maximize existing resources. No one State agency can be expected to shoulder the responsibility of being the sole provider of services and supports within the State. Accessibility, Availability, Appropriateness, Acceptance, and Affordability<sup>7</sup> for individuals with TBI must become the norm as it provides an environment supportive of the individual and the family within the context of their choices, needs, life roles, and their community of choice.

## **Using Data for Policy Development**

Accurate and current data are critical for making informed policy decisions that affect systems change. States should recognize there are multiple potential data sources and build data linkages between agencies and other credible data sources<sup>8</sup> as individuals with TBI frequently are receiving services for secondary conditions resulting from the TBI. Therefore, a comprehensive picture of TBI issues, needs, and resources will be identified as individuals with traumatic injury access services across the spectrum of service delivery systems. The data picture should include incidence, prevalence, costs, cost benefits, and results of case-finding: the "Hard" data. The "Heart" data: are the stories and experiences from the individuals who are living with effects of TBI. Heart data can serve to be a measuring stick of how well the State's systems are functioning. Both types of data are necessary when building an accurate picture to support policy for the coordination of services and supports in the State.

## **ROLES and RESPONSIBILITIES**

All TBI stakeholders need to become collaborative partners in developing a coordinated system of services and supports in every state. As you work towards achieving these outcomes, each partner in this process must contribute to creating or enhancing the existing service systems as well as documenting the results of these efforts.

**Individuals with TBI and their Families** have the best perspective respect to systems' accessibility, availability, appropriateness, acceptability, and affordability. As such, families of all types, cultures, and socioeconomic levels must be able to participate in all aspects and at all levels of coordinating efforts and in the measuring of success of these Promising Practices.

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<sup>6</sup> Many people with TBI access non-TBI services, finding and identifying these individuals for appropriate supports and services is critical. Many people with TBI are not seen in a hospital, but a doctor's office... these individuals need to be identified in the event they are in need of supports and services.

<sup>7</sup> Affordability means affordable by the individual/family with TBI, by service coordinators who looking for affordable options, by funding sources who need to pay for the most cost effective measures to meet the needs, and for providers, be they public or private as to whether they can afford to deliver said services for the amount reimbursed.

<sup>8</sup> Data from the State BIA, ILC, UAP, counties, or other points of entry or service delivery

**Communities**<sup>9</sup> are frequently the entry points into the State's system as well as the point of service delivery, therefore, communities must make entry points and available services and supports known. Because communities are the front line of entry and service delivery, it is essential that they participate in collaborative efforts to build State systems of coordinated services and supports. This includes documenting the efficacy of accessibility, availability, appropriateness, acceptability, and affordability of services and supports and the degree to which individuals with TBI and their families participate at all levels of decision making. Communities must examine the resources available and establish goals to increase their capacity for assisting individuals with integrating into the mainstream of community life. Additionally, communities must collect data on the six key indicators in ways that allow for a common measurement across communities.

**Employers and Educators** need to evaluate and improve their existing systems and to document their efforts in building environments for individuals with TBI and their families as individuals enter or return to work or school post TBI. Employment and educational settings are frequently the front line of community re-entry, therefore it is essential to coordinate needed services and supports and to document costs as well as cost benefits when individuals successfully return to work or school.

**Service Providers**<sup>10</sup> should maximize a Partnership Approach by working to coordinate the systems of delivery of services and supports. Service providers should document and evaluate the systems of identification and referral to promote data systems that are linked and coordinated. This will produce more effective and technologically appropriate methods of identification of TBI. Data systems need to be responsive to the complex issues of confidentiality and privacy while preserving ways to share data. As key stakeholders in the service system, all providers, including those in acute medical, rehabilitation, community based services, education, employment, and long-term supports can provide data for policy development that documents the range, the efficacy, and the coordination of services for individuals with TBI and their families.

**Brain Injury Association of America State Affiliates and other grass roots organizations** play a key role in promoting self-advocacy and representing the experiences and views of individuals with TBI and their families. To do so they must share their information and referral data collection efforts across the country. These organizations have data that is not otherwise available through established systems or registries. The data captures the immediate and life long needs of individuals with TBI as well as their satisfaction with the system's services and supports. Incorporating the data from these sources into policy decisions will facilitate policy development from a real life perspective. BIA's and other grassroots organizations should also build partnerships with other groups representing individuals who share similar needs for services and supports as a way to build a more responsive service delivery system for all people.

**Members of National Association of State Head Injury Administrators (NASHIA)** assist state governments in promoting partnerships and in building systems to meet the needs of individuals with TBI and their families. NASHIA members must exercise their unique opportunity of providing information and data that supports coordinated State system of services and supports and assist in the development of TBI policy as a national body and individually in member States.

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<sup>9</sup> Communities include taxable frameworks e.g., counties, cities, towns, villages, parishes, boroughs

<sup>10</sup> Includes both private and public; e.g., state agency service delivery systems, community based providers, medical and rehabilitative services, schools, managed care

**Funding Sources**<sup>11</sup> are vital players in fostering system coordination efforts and funding appropriate brain injury services and supports that deliver coordinated services and supports. In doing so, this serves as a source of information regarding insurance coverage, costs, and cost benefits - the appropriate utilization and types of services provided to individuals with TBI and their families. It is critical for funding sources to build linkages with other data systems, address confidentiality issues, and assure early and accurate diagnosis or identification of TBI within the variety of delivery systems and examine cost reimbursement mechanisms. This will provide the documentation necessary to capture the real costs of TBI and the efficacy of service coordination that is needed to build accurate funding decisions in states.

**State Governments** should use the four core components<sup>12</sup> as the baseline for building and maintaining coordinated State systems of services and supports for individuals with TBI and their families. States should also be sensitive and responsive to the needs of individuals with TBI and their families when addressing policy and funding decisions as well as establishing measures to address costs, promote cost benefits, establish and oversee standards of care, and to maintain efficacy and customer satisfaction of the State's services and supports. States have the unique opportunity of partnering with a variety of agencies, organizations, associations, individuals, and families all leading to ensure systems that are truly responsive to the needs of individuals with TBI and their families.

**Federal Partners** will help in providing the national picture of TBI and providing the data and information on progress being made in establishing coordinated services and supports in every state. This ongoing process of measuring the state's success in achieving their outcomes will narrow the gap between the vision of coordinated systems and reality. It must be coordinated at the national level.

## EVALUATION

In a Coordinated System in which health care and long-term services and supports are to be provided for individuals with TBI and their families, the stated "Promising Practices" for service coordination builds upon the experiences and successes of the State grantees in the TBI Program. By doing so it will assure that programs and policies are established to guarantee that:

- All individuals with disabilities resulting from TBI and their families have access to relevant information, quality health care, protection and advocacy, and services and supports to meet lifelong needs emanating from the effects of TBI.
- Services are coordinated.
- Providers are adequately trained.
- Individuals with TBI and their families actively participate in how services are chosen and provided.
- Individuals with TBI are prepared to function in the community and to lead productive lives.
- Financing issues are equitably addressed.

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<sup>11</sup> Includes public and private insurance, state service delivery systems funded by Medicaid option dollars, waivers, state general revenue, trusts, agency budgets

<sup>12</sup> State TBI Advisory Board/Council, Lead Agency, Current Needs and Resource Assessment, and State TBI Action Plan

These changes must occur in ways that will provide optimal outcomes for individuals with TBI and their families. As the next step in the implementation of these "Promising Practices", six national outcomes have been selected by the TBI TAC Service Coordination Work Group as critical to guide efforts within States to supporting a coordinated system of services and supports.

**Core Outcomes to be achieved:**

**All individuals with TBI and their families will:**

1. Have the TBI diagnosed or identified in a timely and expeditious manner, with appropriate documentation.
2. Be able to access services through easily identified points of entry that are user friendly.
3. Receive coordinated ongoing services and supports within their community of choice.
4. Have services and supports that are carefully planned, culturally sensitive, cognitively and life-stage appropriate, and necessary for making successful transitions to school, work, and independence as needed throughout the individual's life.
5. Partner in decision making at all levels, and express satisfaction with the services required to achieve the planned outcomes.
6. Have adequate private and/or public funding (including insurance) to pay for the services they need.

**CONCLUSION**

Through collaborative action, we will establish State systems of coordinated services and supports that meet the long-term needs of individuals with TBI and their families. We will be able to communicate the value in developing such systems as we will be focusing our activities on Accessible, Available, Appropriate, Acceptable, and Affordable services and supports while maximizing cost effectiveness and long-term benefits.



**2:30 p.m.      2008 Alaska State Legislature: Health-related Bills under Consideration**

Panel Discussion:      Pat Jackson, State Liaison  
                                 Sherry Hill, DHSS  
                                 Alaska Legislators

**3:30 p.m.      Adjournment**

**4:00 p.m.      ATHS Presentation to Bush Caucus (Capitol Building)**

- ~ Introduction to the ATHS
- ~ ANHB State Priorities
- 1. Medicaid
- 2. Electronic Health Record
- 3. Behavioral Health Grants
- 4. Other Priorities
- 5. Village Safe Water

**5:30 – 8:00 p.m.      Reception: In Honor of Paul Sherry, ANTHC CEO**  
*Home of Myra M. Munson*