

**Native Americans with Traumatic Brain Injury
and the First National Native American Summit on TBI**

**Bismarck, North Dakota
May 3-5, 2003**



The Federal TBI Program of the Department of Health and Human Services (DHHS) Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) supported the First National Native American Summit. The conference and its proceedings do not necessarily represent the official views of DHHS. The Summit was planned jointly between the Federal TBI Program and the Indigenous People's Brain Injury Association. Contract Number: HRSA-20-MCHB-59A-AB.

Foreword

In May of 2003, the First National Native American Summit on Traumatic Brain Injury (TBI) was held in Bismarck, North Dakota. The Summit was an outgrowth of a relationship forged over a year's time between the Federal TBI program and members of the Indigenous People's Brain Injury Association (IP-BIA). Through this year-long planning process, it became clear that Native Americans with traumatic brain injury and their families have many needs to be addressed.

The Native American Summit on TBI, which included the annual meeting of the IP-BIA, was a first step in getting perspective and direction from American Indians and Alaska Natives affected by TBI along with professionals working in the Native American community. Funding for the meeting was provided by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) Federal TBI Program.

The Summit has opened some eyes and doors. Many State agencies involved with the Federal TBI Program are prepared to use the recommendations of the meeting to adapt and move forward with the development of TBI systems of services and supports for American Indians and Alaska Natives in their States.

When drafting this report the authors were asked to consider the two audiences, the Native American community and State policy makers. This report couples policy issues identified after the meeting with illustrative stories from the participants of the Native American Summit. In this fashion, the document will prove most helpful in improving services for Indigenous people with TBI and their families.

Preface

The Indigenous People's Brain Injury Association (IP-BIA) is the only group in the United States that assists in tracking, educating, advocating, and providing support to the Indigenous population with traumatic brain injury (TBI). Alta M. Bruce (Turtle Mountain Band of the Chippewa), chairwoman of the organization, serves as a lifeline for a large segment of the Native American community in the United States. The IP-BIA hosts an annual conference for professionals, as well as for Indigenous people with traumatic brain injury and their families. Because the spiritual lives of those with TBI and their families is a primary consideration in planning the conference, culturally appropriate information, activities, and speakers are incorporated throughout the meeting.

In 2003, the First National Native American Summit on Traumatic Brain Injury, sponsored by the Health Resources Services Administration (HRSA) of the U.S. Department of Health and Human Services, was organized by the IP-BIA as an expansion of its regular conference. The BIA of America's Geoffrey Lauer served as the facilitator. Through HRSA's support, the IP-BIA not only was able to attract its usual membership to the Summit, but also was able to invite Indigenous people from the Plains, Woodlands, Northwest, and Southwest cultural regions of the Nation. In addition, policymakers; medical, research and service agencies; and caregivers were all in attendance. Stories were shared, gaps and overlaps in services were discussed, policymakers were informed, and the diverse needs of Indigenous people with brain injury were identified. Feedback from Summit participants was used to develop this report.

The Summit opened with a customary Ojibwa language prayer and other traditional spiritually-based presentations, such as passing of the pipe and smudging. Throughout the Summit, other activities indicative to the Native American culture, such as the opportunity to sweat and a talking circle to conclude the conference, were incorporated. Gifts of time-honored Indian crafts, such as quilts and woven bags, were distributed to honor Summit participants. True to Native American custom, the concept of time was respected, creating an unhurried, easy pace for all Summit activities.

The IP-BIA and the First National Native American Summit on Traumatic Brain Injury has the potential to bring Indigenous people's issues surrounding TBI to the forefront. Currently, the literature is silent in this area except for a few reports on isolated tribes or clusters of tribes. Participants repeatedly spoke of the Summit as a promising, positive beginning and hoped to see the continuation of such efforts.

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Executive Summary

This report summarizes the stories and recommendations of the participants of the First National Native American Summit on Traumatic Brain Injury (TBI) as well as policy issues identified after the meeting. It is intended for the Native American community, State policy makers, and others interested in improving services for Indigenous people with TBI and their families.

Often described as a “silent epidemic,” traumatic brain injury can have disastrous effects on individuals and their families. Every 21 seconds someone in the United States sustains a brain injury, resulting in 1.5 million people annually (Centers for Disease Control and Prevention, 1999). A cumulative total of at least 5.3 million Americans live with disabilities as a result of brain injury. Nationally, TBI is the leading cause of death and disability for young adults (CDC, 1999).

TBI hospitalization rates in the United States among minority groups are greatest for Native Americans/Alaska Natives (Langlois, Rutland-Brown & Wallace, 2003). The Native American/Alaska Native age group with the highest hospitalization rate is 15-24, followed by 25-34 years of age, 35-44, over 44, and 0-14. When compared to other populations, TBI death rates are greatest among Native Americans/Alaska Natives at any age. The CDC statistics reveal that Indigenous people are over-represented in the category of TBI.

On May 3-5, 2003, the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS) sponsored the First National Native American Summit on Traumatic Brain Injury as the first step in learning about the special circumstances and needs of Indigenous people with brain injury. Members of the Indigenous People’s Brain Injury Association; Indigenous people from the Plains, Woodlands, Northwest, and Southwest cultural regions of the Nation; policymakers; medical, research, and service agency representatives; as well as caregivers came together to:

- 1) Identify the unique challenges related to Indigenous people with brain injury;
- 2) Ascertain what services are currently available;
- 3) Determine the gaps in services; and
- 4) Provide information to agencies that work with Indigenous people with TBI and their families.

Summit participants provided program and policy recommendations around the issues of funding, prevention, the Indian Health Services, visibility of government agencies on reservations, the cultural and spiritual needs of Indigenous people with brain injury, as well as conferences and potential areas of focus.

Introduction

Traumatic Brain Injury Overview

Traumatic brain injury (TBI) is defined as “an occurrence of injury to the head (arising from blunt or penetrating trauma or from acceleration-deceleration forces) that is associated with any of these symptoms or signs attributed to the injury: decreased level of consciousness, amnesia, other neurological or neuropsychological abnormalities, skull fracture, diagnosed intracranial lesions, or death” (Thurman, Snieszek, Johnson, Greenspan & Smith, 1994).

Often described as a “silent epidemic,” traumatic brain injury can have disastrous effects on individuals and their families. Every 21 seconds someone in the United States sustains a brain injury, resulting in 1.5 million people annually (Centers for Disease Control and Prevention, 1999), 200,000 to 270,000 (cited in Kegler, Coronado, Annett, & Thurman, 2003) of whom are hospitalized and 80,000 to 90,000 of whom will sustain life-long disability. A cumulative total of at least 5.3 million Americans live with disabilities as a result of brain injury. Nationally, TBI is the leading cause of death and disability for young adults (CDC, 1999).

The effects of even a mild brain injury can cause cognitive, physical, emotional, behavioral, and social problems. Brain injuries usually affect memory, concentration, and the ability to focus. Physical consequences range from paralysis, seizures, and fatigue to coordination and balance difficulties. Agitation, mood swings, depression, impulsive behavior, and impaired judgment are common. Brain injuries can result in functional limitation where activities of daily living are difficult to complete.

The types of TBI are many: closed brain injuries, acceleration/deceleration injuries, and penetrating brain injuries to name a few. Closed brain injuries are so commonplace that many people are unaware they have even been sustained. Often there are no visible, outside injuries, as the damage occurs inside the skull. Automobile crashes, sports injuries, assaults, and falls are common causes of closed brain injuries. In general, for individuals 65 years or older, falls are the leading cause of brain injury; 11 percent result in fatalities.

Acceleration/deceleration injuries result from rapid change of movement, causing the brain to stretch and bounce back and forth within the skull. Scraping (lacerations) or impacting (contusions) may occur. Blunt trauma to the skull, resulting in pressure on the brain from bone or bleeding, can cause depressed skull fractures.

Penetrating brain injuries can result from flying objects that pierce the skull. Many introductions to psychology courses include the story of Phineas Gage, a railroad supervisor in the 1800s, as the first documented case of penetrating brain injury. One day an explosion went awry on the job and an iron shaft penetrated Gage’s skull at one angle,

exiting on the other side. Gage, no longer possessing the skills to be a supervisor, became an inexplicable enigma -- no one could understand what happened to him because at that time, a definition of traumatic brain injury did not exist. Today, firearms account for most penetrating brain injuries; in fact, 91 percent of firearm-related TBIs result in death and two-thirds of firearm-related TBIs are classified as suicidal (CDC, 2001).

Brain injury survival rates and resulting life expectancy have improved greatly within the last 10-20 years due to advances in technology and health care. Due to the increasing numbers of people living with a TBI, the need for services and supports have increased.

According to Dr. Glen Johnson (2001), Clinical Neuropsychologist and Clinical Director of the Neuro-Recovery Head Injury Program, diagnosing a brain injury is not simple. Neuropsychological testing is one of the best vehicles for diagnosing brain injury. For those who receive appropriate assessment, TBI diagnosis is 90-95 percent accurate. However, neuropsychology services are not easily accessible for all. Some people live in rural areas, where there is not enough population to support a neuropsychologist, or others may not have insurance to cover neuropsychologist visits, even if a professional was readily available.

TBI: A Brief Snapshot of the Native American Experience

Indigenous people are defined in this report as those of American Indian and/or Native Alaskan descent. TBI hospitalization rates in the United States among minority groups are greatest for Native Americans/Alaska Natives (Langlois, Rutland-Brown & Wallace, 2003). The Native American/Alaska Native age group with the highest hospitalization rate is 15-24, followed by 25-34 years of age, 35-44, over 44, and 0-14. When compared to other populations, TBI death rates are greatest among Native Americans/Alaska Natives at any age.

The CDC statistics reveal that Indigenous people are over-represented in the category of TBI. This is especially true of Northern Plains Indians, who have the largest number of Indigenous people sustaining brain injury. The Northern Plains area consists of the Aberdeen, Bemidji, and Billings Indian Health Services (IHS) Area Offices. The next largest Indigenous groups are in Alaska and in the Southwest (Albuquerque, Navajo, Phoenix, and Tucson Area Offices), respectively.

This report is focused on the special circumstances and needs of Indigenous people with brain injury. TBI is affecting the quality of life, vitality and health status of Indigenous people at a far greater rate than non-Indigenous people in the United States. Society can no longer afford to ignore the loss of perspective of America's Indigenous people through death and limitation caused by brain injury.

The goals of the Summit and consequently this report, are four-fold:

- 1) Identify the unique challenges related to Indigenous people with brain injury;

- 2) Ascertain what services are currently available;
- 3) Determine the gaps in services; and
- 4) Provide information to agencies that work with Indigenous people with TBI and their families.

Who are the Individuals with Traumatic Brain Injury in the Native American Community?

Individuals with TBI in the Native American community are people with needs, desires, and plans. They are also often hidden, ignored, and lonely. Indigenous people comprise over four million of the United States population (United States Census Bureau, 2000) and yet their numbers become less and less significant as they filter through various groups. There are over 550 Indigenous tribes and several major urban areas where Indigenous people reside. When considering Indigenous people with brain injury in these individual groups, the numbers become “insignificant” to the outside world.

Unfortunately, to Native Americans living with brain injury, the significance of not being recognized is staggering. Although predominantly male, most were children, teens, or young men/women at the point of injury. They experienced car crashes, attempted suicide, or were victims of brutal beatings. Drugs and alcohol often played a role in their injuries.

Following the custom of oral cultures, the following stories will provide a human portrayal of the “who” in the Native American brain injury community, before statistics and numbers are analyzed or compared.

The Human Portrayal – Harold

Harold was a tall, handsome, 18-year-old Shoshone man. He was graduating from high school and had college ambitions, complete with committed scholarships, when one day, his life changed forever. Like his father before him, he decided to end the pain of living in a country and in circumstances that did not recognize him most of the time, and viewed him with disdain when they did. He shot himself in the face with a gun, hoping to die; instead, he sustained a brain injury.

Harold is blind, has trouble hearing, lost all but a few teeth, and has had extensive surgeries and grafts. He walks with a cane. But Harold is at peace. Since the shooting, he has earned a Master’s degree in social work, is employed, has married and started a family. Harold is someone with a traumatic brain injury within the Native American community.

Harold explains that Indigenous people everywhere, and particularly those dealing with traumatic brain injury, need to return to traditional teachings. He conveys that air, fire, water, and earth must figure into daily practices. He reminds us that, “The elders ‘know.’ We don’t ask anything of her [the earth], but she continues to give to us.” Harold reminds us to give thanks.

These beliefs are fundamental and essential for the Native American with brain injury to remember, for the caregiver to understand, and for the policymaker to incorporate into care and education programs. Harold reminds us that to be stoic like a rock, not wanting emotions to rule, is counterproductive.

“Living takes a lot of energy,” Harold warns. “[We must] find the story that was given us” and must not “terrorize ourselves with our thoughts.” These words are significant. Each Indigenous person with TBI must find his or her individual path after brain injury. This is counter to most system-provided programs where the consumer must fit into a pre-prescribed pathway.

Harold gives further insight by connecting natural elements (water, air, fire, and earth) with the person -- intellectually, emotionally, physically, and spiritually. Harold believes that attention must be paid not only to the body and to the intellect, but also to the spiritual and emotional aspects of the life of an Indigenous person with TBI.

Trust is also a seminal need for the Indigenous person with brain injury, his or her family, and caregivers. Trust should be most instructive for policy and programs. Harold reminds us that Native Americans need to continue with ceremonies, interact inter-tribally, and give thanks – all in an environment of trust.

Harold ends by saying, “We weren’t lost, we knew where we were, we know where we are going.” He advises Native Americans with brain injury to “lay on the earth” when feeling discouraged to regain Indigenous strength. This is not a usual activity incorporated into most care programs. Harold inquires, “What is an [Indigenous] person without prayer?” And by inference, “What is an [Indigenous] person with brain injury without prayer?” Prayer, ceremonies, the earth, and elements must all be incorporated into the care of an Indigenous person with brain injury. Harold offers a living picture of one Indigenous person with traumatic brain injury.

The Human Portrayal -- Anna

Anna is a young woman who was in a car crash. She and a friend were driving in North Dakota in the horrendous cold when the car slid off the road. Anna was thrown far from the car and lay face down in the snow for hours. The driver saw light in a Catholic church down the road and ran for help. The priest was there and came to the crash site to help. Anna was in a coma for three months. She is her parents’ only child.

When Anna woke up and came home, she had a different personality. She became rebellious -- smoking, drinking wine coolers, and trying to take the car and leave. Eleven years have passed since the car crash. Anna is in community college. She takes awhile to grasp new ideas, but when she does, she DOES. She is smart.

Anna looks typical. The college professors and other students do not understand her problems. She does not “wear” them as visibly as Harold does. A problematic and

incorrect assessment results; Anna is not offered appropriate services. Her community college is not prepared for students with traumatic brain injury.

Anna likely survived because the tremendous cold kept her brain from swelling too fast. “She came out of the shell – was never supposed to walk or talk,” her mother explains. A vocational rehabilitation program coordinated through welfare services helped her -- not Indian Health Services.

Anna left home to attempt an independent living program in Rapid City, South Dakota. Unfortunately, Anna did not know anyone there. She did not socialize or drive. It was no kind of life for her. She was lonely.

Anna now lives with her parents on a North Dakota reservation. She is able to use a computer and the Internet. Her mother knows she should try to let her go again. “I want her to get her own life; it hurts her to be dependent even though I am the reason.” A lot of tension surrounds this issue.

Other Indigenous People with Brain Injury Speak

“I am looking for resources.”

“I have knowledge [about traumatic brain injury]! Ask me, use me, learn from me.” This person also states that living with a traumatic brain injury is a struggle, but that he is literally a “survivor.” This is important for him to stress. This man suffered a traumatic brain injury as a result of racism. He was beaten and left for dead in an urban area. Often, brain injury professionals and others do not look to people with brain injury themselves for input and suggestions, feeling that due to the nature of their problems, they are incapable of contributing. But, they can and they are.

“[This is the] best thing that ever happened to me because a lot of great people help me.” This man had been on the road to destruction, completely out of control. He had been a young male with alcohol and drug problems. His traumatic brain injury ended that path abruptly. Now he is in a relationship, but struggling to maintain a job and handle financial matters.

From a Navajo tribe, a man with a traumatic brain injury stated, “I am glad to be here,” and “life is good.” In the Navajo way, people with disabilities are viewed as “precious;” they have been given another chance. This is not the usual way the dominant culture characterizes people with disabilities.

Another man states, “Do not call me handicapped.” He feels this is an insult.

What the Data Portrays: Underestimation, Age and Race Are All Factors

From a recent report from the Centers for Disease Control and Prevention, 30/100,000 Indigenous people suffer death by traumatic brain injury. In an older report

issued by the Indian Health Services, tribal or contract-care hospitals recorded 4,491 TBI-related hospitalizations in 1992-1996. Unfortunately, this data has inherent dilemmas: IHS cares for only slightly more than 50 percent of all Indigenous people, data from emergency department visits was not included, and only 14 of 50 States were represented in the report.

The problem of brain injury in the Native American community is severely underestimated due to these limitations, in addition to misidentification outside of the Indian Health Services system. Within the IHS system, the Northern Plains people are identified as having the highest numbers. Again, this may be misleading since the Gallup, New Mexico area, for instance, is known to have the highest rates of motor vehicle crashes, gang and assault activity – all top TBI risk factors.

Two additional studies point to some differences to consider when identifying individuals with traumatic brain injury in the Native American community as compared to the broader population. A bimodal age distribution exists in the dominant culture for traumatic brain injury, the first occurring in the teens and early 20s and the second in the elderly. Studies have *not* shown this to be true in Indigenous populations (Blackmer & Marshall, 1999; *Morbidity and Mortality Weekly Report*, 2003).

The elderly (over 65 years) is not a predominant age bracket for traumatic brain injury within Indigenous populations. Perhaps Indigenous seniors are not surviving falls, auto crashes, or initial trauma care. And, as one study (Moss, 2000) indicates, for mostly cultural and religious reasons, Indigenous elders attempt suicide far less often than elders in the dominant population.

However, one study in California, the State with the highest numbers of Indigenous people, looked at nonfatal fall-related TBI and discovered not only interesting age, but also racial, dynamics. Indigenous people over 65 represented negligible numbers for initial injury. Native Americans in the 0-64 age group represented 8 percent of patients with traumatic brain injury on first time admissions, as compared to 14 percent for Whites and yet, Indigenous people only represent 1 percent of the population as compared to 50 percent for Whites (MMWR, 2003). Figure 1 clearly shows how traumatic brain injury far outpaces population percentages for both Indigenous people and Blacks, although the widest gap is for Indigenous people.

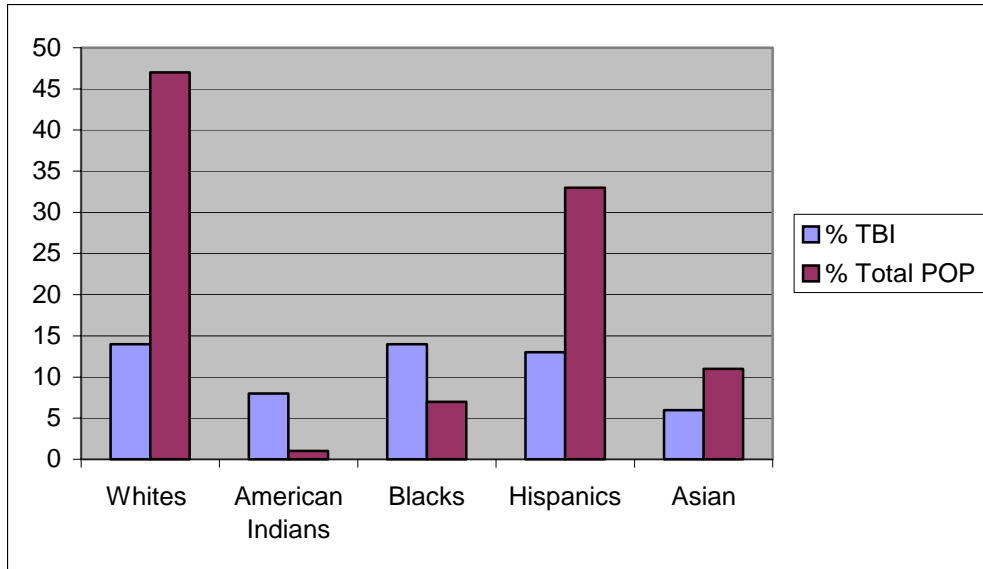


Figure 1: Percent TBI Compared with Percent of Total Population in California. (Data from MMWR, 2003)

Another report covering several urban areas from the Center on Emergent Disability at the University of Illinois at Chicago further demonstrates the racial imbalance in TBI rates for Indigenous people (Figure 2). Note that if the rate for Minneapolis was consistent across the State of Minnesota, 3,000 Indigenous people could, in reality, be the extrapolated number.

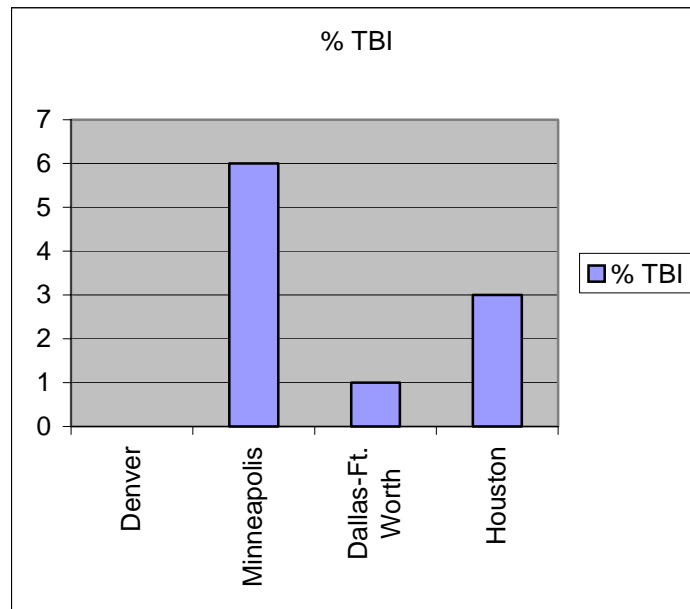


Figure 2: TBI Rates for [Indigenous] People Across Four Urban Areas. (Data from UIC)

Although racial disparity is key to the issue, statistics detailing age at the point of injury are somewhat misleading. Although the Indigenous elderly are not sustaining brain injury in large numbers, the younger generations who did (15-24 year olds) are aging themselves. Large numbers of 40- and 50-year old Native Americans living with

brain injury today (injured decades ago when they were in the prime demographic) are now desperately in need of services within the Native American community. These people are in jeopardy of losing their caregivers -- usually aging parents. In the face of an almost total lack of 24-hour services in reservation settings, a crisis is looming. Those beyond teen/young adult years are in desperate need of work, housing, and training.

These statistics lead to the realization that differences also likely exist in conception, cause, and outcome for Indigenous people in the TBI cycle as compared to those in the dominant culture. Prevention evolves as a major goal for younger people; but, rehabilitation, job opportunities, and caregiving become paramount concerns for older people with traumatic brain injury.

Accurately characterizing the “who” behind the numbers of Indigenous people with traumatic brain injury is difficult. Gross misidentification of Indigenous people as they present to emergency departments and ultimately to in-house hospital admission is the norm. Frequently, if a person does not “pass out” or look or act abnormal, medicine hesitates to identify brain injury, leaving many individuals misdiagnosed from the beginning. The invisible nature of TBI compounds the problem for untold numbers of individuals with brain injury in the Native American community where crashes and incidents of all kinds, as well as suicide attempts, rank higher than for any other ethnic group in the Nation (IHS, 1997).

Women and Children Cannot Be Overlooked

“We must not forget about the women and children,” one Summit participant reminds. Women and children are often forgotten, as they are not represented in the higher numbers for brain injury. However, domestic violence remains one of the most under-reported epidemics in the country. Violent assaults are usually perpetrated against women and children.

According to Locker (2002), the incidence of domestic violence is as high as 75 percent. Women who have experienced domestic violence often do not have a voice. Their cries go unheard. They usually do not seek medical treatment, or file a police report. Their injuries are compounded with each violent incident. Outreach to shelters is needed to educate victims about the causes and effects of brain injury.

Children with brain injury are often mislabeled. Misidentification can occur due to a need for diagnosis. Funding within the school system is dependent on a specific diagnosis (such as mental retardation or developmental delay), which qualifies students for special education services. Since brain injury is not a common or widely known diagnosis, many children with brain injury are mistakenly placed in special education.

What Is the Health Status and Well-Being of Indigenous People with Brain Injury?

Impact of Alcohol and Drugs Pre-Injury

One Summit participant raised a noteworthy point, mentioning that people with disabilities are “hidden,” but that alcoholics are “visible.” He spoke of driving around his area in New Mexico and literally seeing Indigenous people that quite obviously had substance abuse issues. The irony is that although alcohol and drugs are major players in acquiring traumatic brain injury, once brain injury occurs, the Indigenous person is no longer visible. Hidden from society, they are not privy to programs, policy formation, funding streams, or other avenues to improved quality of life. Conversely, there are numerous substance abuse treatment facilities, many which target Indigenous people.

In a study between non-Indigenous North Americans and Indigenous North Americans, there were significant differences between the two groups in the areas of drug and alcohol involvement at the time of brain injury (Blackmer & Marshall, 1999). Summit participants overwhelmingly had stories of substance abuse prior to injury.

Violence/Suicide/Accidents at the Root of Injury

One Summit attendee told of her son being “crazy” with alcohol and methamphetamine use. He was out of control, even once holding a gun to her head. Following his traumatic brain injury, she became his caregiver. Harold and Anna, mentioned in the previous section, are also examples: Harold tried to commit suicide and Anna was in an automobile crash. Others at the Summit were beaten into comas due to racism -- some in the city, some on the reservation.

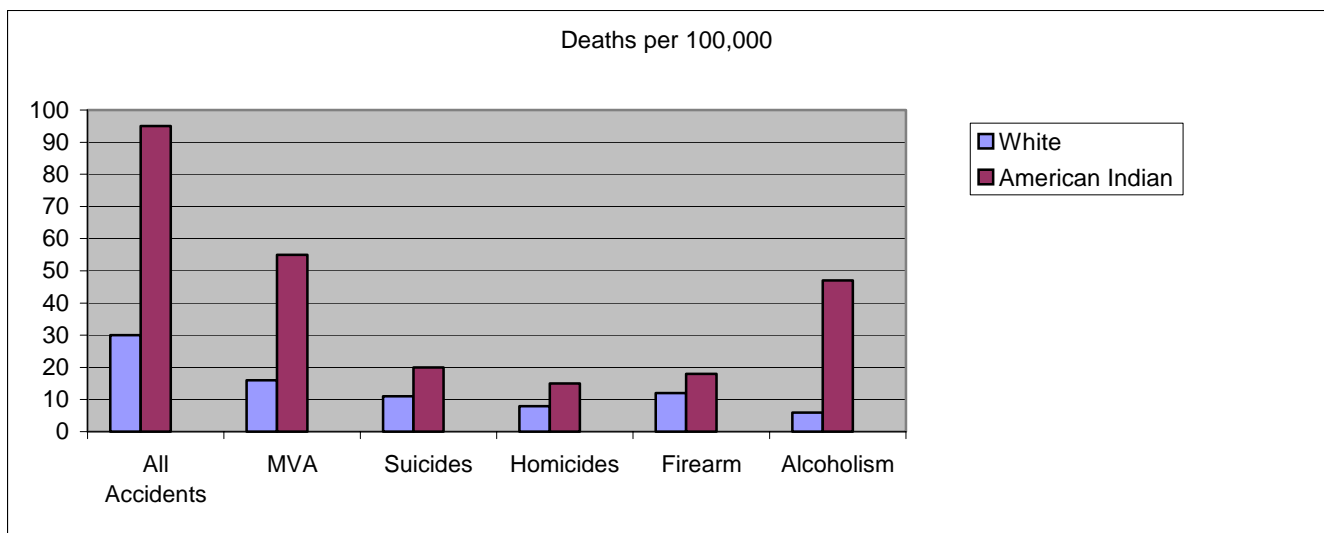


Figure 3: Age-adjusted Death Rates for Indigenous People in all IHS Areas as Compared to All Races. (Data from IHS)

The Indian Health Service reports in *Trends in Indian Health* (1998) that accidents and suicide are higher for Indigenous people under 65 than for any other group in the Nation. In Figure 3 above, violence, accidents, and suicide rank in the top five causes for death in Indigenous populations. Anecdotal speculation suggests that many of the car crashes within the Native American community were actually suicides or attempted suicides. Unfortunately, more is known about death-related brain injury cases in the Native American community than about the individuals who survive.

From Hospitalization to Rehabilitation

Many Summit participants reported being in comatose or sleeping states immediately after injury. One participant described the transition from the hospital to rehabilitation—“it wasn’t a good experience!” Again, a loss of numbers is present if the Indigenous person with traumatic brain injury was seen in an Indian Health Services hospital emergency department and then transferred elsewhere. If the person with a brain injury presented to an outside hospital (out of the Indian Health Services system), racial misidentification often occurred, in addition to possible misdiagnosis. Emergency department data within the IHS needs to be corrected and more complete, as does demographic and diagnostic hospitalization data in both systems. Until the *who* in the brain injury equation are identified, in addition to *what* the definitive diagnoses are, and to *where* individuals are discharged, tracking health status is virtually impossible.

In a Canadian study authored by Blackmer & Marshall (1999), significant differences were noted between the discharge planning and post-discharge follow-up of Indigenous and non-Indigenous patients with traumatic brain injury. Indigenous North American patients were less likely to be offered post-discharge resources and they most often returned to their local hospitals. Although the study did not identify where each Indigenous patient originated, if some were U.S. citizens and returned home, their destination would have been Indian Health Service hospitals, whose services end at the acute phase without offering rehabilitation or long-term care assistance.

For anyone who has sustained a brain injury, after-care is a primary issue; however, in the Indigenous community, this concern is even more pressing. The IHS may hospitalize individuals with TBI for stabilization but soon discharge them to family care, or the individuals with TBI leave against medical advice. No education protocol exists to explain expectations once the hospital is left behind. Many people with brain injury and their families believe there will be no change in individual abilities.

Access to Formal Rehabilitation Limited: Financial and Family Concerns

“TBI changed the whole family; we are now in the phases of healing.” Many Summit participants told of being uncertain and uninformed, not knowing where to turn after the hospitalization of their loved one and upon his/her return home. Blackmer & Marshall’s study (1999) shows that there are fewer family care conferences for Indigenous people than for other segments of the general population.

Sometimes family denial is a challenge, as some Summit attendees reported. Families may be devastated upon the realization of their loved ones' injuries. Families see what's happened, look at themselves, and feel scared by the situation. They realize it could happen to them, prompting their own insecurities to surface.

At the outset, however, appearances can be deceiving to providers, family, and friends. People with brain injury appear to be intact physically, so they are sent home. Since immediate assessments are generally not completed in the emergency department or hospital, no benchmark exists for post-injury comparison assessments at 3-, 6-, 9-, or 12-month intervals. If an initial assessment was completed at an urban hospital, follow-up assessments become costly given travel considerations and the IHS reimbursement and payment structure.

Indigenous people with TBI themselves have identified the following as top struggles post-injury: 1) completing tasks; 2) gaining acceptance; 3) game playing (child to parent); 4) being institutionalized; 5) coping with a lack of understanding from hospital workers and police officials; 6) "putting up with me"; 7) overprotective family; 8) letting go, and; 9) no family support.

Typically, these struggles are dealt with and handled during the brain injury rehabilitation process; but unfortunately, in HIS' limited budget, some types of services are not available. Specialty services such as brain injury rehabilitation are usually contracted with outside providers and Indigenous people are often only eligible for these contract services when they reside on reservations. IHS contracted providers are generally available once a month and appointments fill rapidly – waiting lists can reach a year in length.

In addition, some contract services are subject to an IHS coding system to categorize the priority of services needed. A Priority I classification requires urgent, life or death care. Both neuropsychological evaluations and cognitive rehabilitation programs are not labeled with Priority I classification. It has been estimated that only 25 percent of patients with TBI have insurance to cover a brain injury recovery program.

Post-Injury Life: Precious Yet Perilous

Amazingly, Summit participants more than once commented that brain injury was ultimately a "good thing" since it changed the direction of lives that were not on course. This new, "precious" life is highly regarded and valued; however, the changes come with many challenges.

Functional disability within the Summit group varied. Some were blind, others deaf; most had difficulty walking and used assistive devices or dealt with gait challenges. Re-injury from fall was a top concern. Many had difficulty eating and chewing, or had choking issues. Dressing, bathing, and other activities of daily living were often challenges. Summit participants were mostly from reservations or rural areas where not being able to chop wood amounts to a significant limitation on daily living. Most

Summit attendees were no longer driving and needed help with physician visits and medications.

Much success had been achieved among Summit attendees in learning vocational rehabilitation jobs. Paul made boxes and Robert also worked for “voc rehab” until he lost his funding. Anna held a position as a nurse’s aide and reportedly the nurses applauded her timeliness and the quality of her work. However, that opportunity was in another State; Anna has since returned to her home State.

Meeting these challenges can at times bring frustrations. Some of the Indigenous people with TBI experienced bouts of violence. More often however, these Indigenous people with TBI yearned for some semblance of normal life. They wanted to work, they wanted relationships, and they aspired to go to college.

Although cognitive difficulties certainly existed with most, great strides were also visible. Attendees had learned to talk and walk again against the predictions of professionals. One even went back to tribal community college. Several found success in using computers. Opportunity exists for computer use in rehabilitation, learning, and perhaps employment. However, most attendees had functional disabilities that required some form of supervision or assistance when using computers. Ultimately, this type of informal caregiving lays squarely at the feet of long-suffering parents who have spent anywhere from 10 to almost 30 years meeting the needs of their sons and daughters with brain injury.

Time is abundant for the Indigenous person with TBI. Since most are unable to work, leisure activities such as dancing, sports, casino, and hiking/walking are encouraged. However, even these activities can prove too difficult or expensive for many.

Since long-term care is nonexistent, resources are limited, and the unemployment rate is as high as 75 percent, alcohol and drug use is common. Often, 1 or 2 years after a TBI, alcohol and drug problems reappear. Sixty percent of people in the general population with TBI may experience major depression after injury (Langlois, Rutland-Brown & Wallace, 2003). However, within the Indigenous community, 60 percent is the depression rate for the general population **pre-TBI**. Depression is overwhelmingly common on reservations whether brain injury is a contributing factor or not. Those without brain injury are faced with overwhelming obstacles to attain employment and to cross over the poverty line. Given the additional obstacles of brain injury, the socioeconomic picture for those with TBI is even more bleak.

What Array of Services Should be Available for Indigenous People with Brain Injury?

Summit Participants Express Their Desires and Opinions

The array of services that should be available for Indigenous people with brain injury spans various systems: Medication Assistance, Preventive Care, Acute/Chronic Care, Rehabilitation, Mental Health, Respite/Support Groups, Long-Term Care, Transportation, Communication/Information, Housing, Employment/Education, Legal/Advocacy, and Cultural/Spiritual Care. Summit participants had thoughts and suggestions regarding nearly all of these areas and expressed those in detail.

Family members especially wanted more education in the care of Indigenous people with TBI. They voiced need for more group homes, medication assistance, changes in the Indian Health Service System, private insurance for tribes, and adult day cares. Anna's father suggested that there should be notetakers at his daughter's college. One mother wanted a support group.

Employment was a predominant topic for many Summit participants. Indigenous people with brain injury would like to work and make their own money, reducing their reliance and dependence on others. However, jobs are scarce and unemployment is high on the reservations. Many stated they become frustrated when they go to a job interview and the employer asks if they are on medications, or if they have seizures. One person asked, "Isn't that discrimination?". Others reported layoffs and the availability of some semi-permanent, part-time work. Overall, employment varies after TBI in the hometowns and villages of Indigenous people with brain injury. As previously mentioned, employment opportunities for Indigenous people without TBI are doubtful and prospects even worsen for Indigenous people with TBI. In the words of one Summit attendee, "If we were rich professionals, we would still be in our jobs. There would be people to help us keep our jobs."

Robert told of being enrolled in a vocational rehabilitation program. He liked to work and yet, after 9 months, he was no longer eligible. No further successful job placement was secured for Robert and he remains unemployed. Such "band-aid" situations are unacceptable.

One promising model for self-sustaining employment was shared at the Summit. A store in the Southwest that sold artists' paintings, jewelry, pottery, and other crafts was run by and for individuals with disabilities.

One area of unanimous agreement among Summit attendees was the need for more focus on cultural and spiritual integration in the lives of Indigenous people with brain injury. At the Summit, special attention was paid to the spirituality of Indigenous people with brain injury and the success of this effort should be a model for application

into the delivery of brain injury services and supports within the Native American population. For instance, Summit participants were given the opportunity to sweat in the traditional Indian way, led by an Ojibwa man who had learned under a spiritual elder. By using Indigenous language and customs throughout the Summit, comfort was offered and healing was provided to Indigenous people with brain injury in a way they have never before experienced.

Most rehabilitation programs are not run by Indigenous people and, therefore, some specific traditions and mores that might particularly benefit the Indigenous population are simply not available. Indigenous people with brain injury are not often able to hear their language, practice their religion, eat their foods, burn offerings, fast or “find the story that was given to them” within the rehabilitation setting. For Indigenous people with brain injury, these are all necessary components to healing.

Current Vocational Rehabilitation Programs in Place, but in Jeopardy

The U.S. Department of Education (DOE) funds some vocational rehabilitation programs across the country for Indigenous people. North Dakota has four such programs—more than most other States in the U.S. However, according to information in the Federal Register, these programs may not be renewed.

The Northern Plains people have been identified as having the highest rates of TBI for Indigenous people. Figure 4 offers insight into the distribution of Indigenous people and vocational rehabilitation sites in North Dakota.

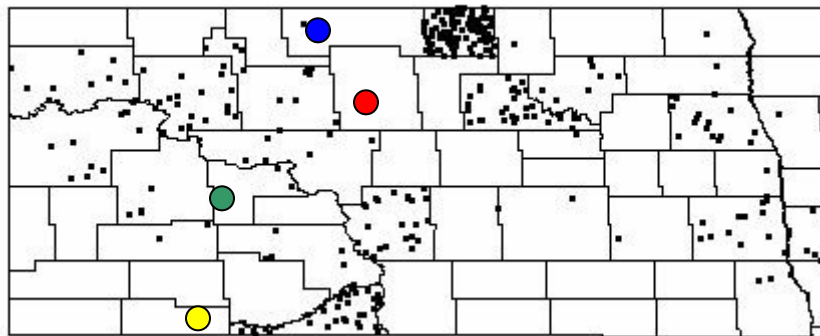


Figure 4: Distribution of Indigenous People in North Dakota and Vocational Rehabilitation Sites. (Data from author)

Indigenous people with brain injury found outside the central corridor of vocational rehabilitation sites represent hundreds of unserved individuals who need these services. For funding reasons, these services are likely to disappear unless operation is assumed by the tribes themselves. Since the 1998 inception of the Spirit Lake, ND vocational rehabilitation site, an estimated 120 people have been served, 10 of whom were Indigenous people with brain injury. With the high rates of traumatic brain injury for Indigenous people around the country and even more in this geographic area, that number translates to about two a year.

Funding and Access Stumbling Blocks for Other Services

Other services funded through Federal sources are assumed to be available to Indigenous people with brain injury in the State where they reside. More often than not, this is not the case. As Indigenous people nationally represent only about 1 percent of the total population, State money often misses this group since funding is based on population numbers representing need. When programs do exist, they are often located in urban or border towns and Indigenous people with brain injury are expected to travel to those venues for assistance or care. But, as discussed, Indigenous prayer, culture, practices, and beliefs often cannot be comfortably practiced outside of their own lands. The situation becomes an unavoidable “Catch 22” -- take care of the body and forget the spirit or vice versa.

Additionally, employment again is a factor. When Indigenous people with TBI earn too much money, they lose their Social Security Insurance (SSI) and therefore, their medication assistance. Some individuals with brain injury are “trapped” into not working.

Do Native Americans with Brain Injury Have an Array of Needed Services?

In a word, “NO”! One Summit participant reported that, “Indigenous people with TBI have a harder time accessing health care.” Another Summit attendee explained that, “There isn’t a fit with specific services for TBI.” In fact, reality dictates an even inferior fit for Indigenous people with TBI.

Limited success has been seen in the areas of medication assistance, preventive care, acute/chronic care and rehabilitation. Beyond these fields, however, huge gaps are present and much work needs to be done to improve service offerings.

Medication Assistance

Indigenous people can get help with medications if they are enrolled members of a Federally-recognized tribe and have access to an Indian Health Service hospital. Otherwise, they may get help – based on income – through welfare and SSI. Many are lost if they do not neatly fit into one of these categories. Since the bulk of U.S. health insurance is otherwise employer-based, an Indigenous person with brain injury who is privately insured is rare. Patients often go without, as they cannot afford the out-of-pocket expense.

Preventive Care

As young people are more likely to be brain injury patients than their older counterparts, and males are more likely than females to sustain traumatic brain injuries, the need exists for targeted age and gender TBI prevention and education programs. Few programs designed for Indigenous people exist today.

When an Indigenous person has a TBI, he/she is eligible for IHS services and may be able to access a certain amount of prevention care, not only for TBI-related illness and re-injury, but also for the wide range of preventable illnesses that are commonplace. However, telephone, transportation, education, and comprehension deficits often cause Indigenous people with TBI to fall through the cracks. Outside of the IHS (i.e., outside reservation rural or urban areas) the numbers seeking prevention health care decrease.

Acute/Chronic Care

Acute/chronic care encounters the same IHS/non-IHS problems as before. If the person is eligible and nearby, IHS hospital acute care services can be accessed. Provisions for contract care also exist, again based on eligibility. Chronic care is a bit more difficult. Beyond certain high-profile problems such as diabetes, few chronic care programs are offered within the Indian Health Service System; and outside the IHS, few programs are available.

Rehabilitation

A loose system of vocational rehabilitation programs is available within the Indigenous community, but these programs do not reach everyone, nor do they continue long enough. Permanent placement rates out of the programs are not on par with the norm either.

Physical rehabilitation programs do not exist within the Indigenous community; rather, Indigenous people with brain injury must leave their homes, reservations, and often their States to go into physical rehabilitation. A study on cultural identity, disability status, and rehabilitation needs of Indigenous people brought to light some important points. Pichette, Berven, Menz & La Fromboise (1997) found that in those participants answering a survey regarding identification, disability status and needs, those with American Indian cultural identification were less satisfied with services than either bicultural or other groups. The authors purport that due to the substantial differences in accident, injury, and death rates between races, the American Indian group has much greater need for services and yet service numbers and levels do not even match those for the dominant culture.

Citing further work by White (1987), the authors quote, "...cultural differences become barriers to service unless rehabilitation agencies make a concerted effort to understand cultural differences and to provide services within the context of those differences." By further citing White, another salient point is made in the report that seeking services within State-Federal vocational rehabilitation programs "requires self-initiative and a commitment to long-term planning" – a concept that is counterintuitive to the Indigenous outlook on life.

For instance, Indigenous people with TBI frequently elaborate on the inordinate amount of energy required just to live. One individual even asked, "Do you know how much energy it takes to interrupt?". When Native Americans with brain injury feel as if events are not in accordance with their expectations, they become confused. Although they wish to adopt new ideas or solutions beyond traditional Indigenous attitudes, they are unable due to stress. Many traditional Indigenous people still hold to the viewpoint of living in the present; they are not future-oriented. Complicating matters further still, Indigenous cultural ethics dictate that they should not assert themselves as being "special" or in unique need of specific services.

Mental Health

Mental health is a specialty health service that Indigenous people with TBI have difficulty accessing. Specialty services of this type are often limited on the reservation. In addition, since there is often a 3- or 4-month wait for health clinic appointments, the wait for mental health appointments is even more daunting. Many Indigenous people still view mental health as a taboo topic; going to a mental health provider may invoke a stigma. Thus, Indigenous people with brain injury do not access mental health resources. Home visits would be more beneficial for Indigenous people with TBI.

Respite/Support Groups

Stable, culturally-relevant respite programs would be of enormous help within the Native American community with TBI and their families. Spouses, parents and families as a whole are overwhelmingly the identified caregivers for Indigenous people with brain injury. Respite programs could provide a few hours, a weekend or even a week of care that families could use to nurture their own spiritual, health, and emotional needs. Current literature contains little if any information regarding family caregivers of Indigenous people with brain injury. Experience at the Summit illustrated that family caregivers “clung” to this conference as a valued support group. Others were present to assist their loved ones with meals and entertainment, even for a few moments. Additionally, others were there to share stories. Lifting and sharing the burden even for a few hours at the Summit brought many to tears as family members shared their feelings around the conference’s closing talking circle.

The caregivers who stand by their family members with TBI are shouldering an indefinite term of insurmountable burden – sometimes alone. The needs of these individuals should be addressed.

Long-Term Care

Formal long-term care within the Native American community is dismal at best. There are only a few adult day care centers, assisted living centers, or nursing homes actually on the reservations. Most services are targeted at elders and consist of senior centers that deliver meals and offer a place to congregate and socialize. The facilities that do exist do not come close to serving the needs of 550+ Indian tribes and urban hubs.

Although some caregiving grants are active, funding some worthwhile programs, they are few and far between. The lack of formalized care for Indigenous people widely affects the elders and does not even meaningfully touch the disabled population. Many States with high numbers of Indigenous people have moratoriums on building nursing facilities. For cultural reasons, most do not seek to leave their reservations for care.

Therefore, with the Indigenous population with brain injury, an informal caregiver system is the norm, one in which there are no second shifts, little information or therapy, and certainly no days off.

Transportation

In the study on rehabilitation needs cited previously, two of the highest community rehabilitation needs within the Native American community were: 1) safe, accessible, and available public and tribal transit systems; and, 2) routed/regularly scheduled transportation systems to and from school for people with disabilities (Pichette et al., 1997). As Figure 4 illustrates, Indigenous people are often spread out across hundreds of miles, further compounded by the problematic and varying distances between

rehabilitation centers, respite programs, long-term care, employment, and general healthcare services for people with brain injury. Indigenous people with TBI and their families would have to be extremely motivated and forward-thinking to access these services. Summit feedback unearthed a high level of fatigue and frustration.

Communication/Information

Some Indigenous people with TBI are deaf or have speech impediments. Others have cognitive language deficits. Language barriers are often significant, multiplied by a need to reconcile the Indigenous oral world with one that is more literal.

Additionally, not all Native American families have telephones; in fact, on some reservations, less than half have phones. For written communication, many locations are serviced only by post office boxes, which require trips “into town” to retrieve mail. Communication, information, and transportation are integrally intertwined. Most of the Native American community do not drive; cars and public transportation services are rare.

Some States fund programs that provide telephonic assistive devices for people who cannot get to a phone quickly, or who cannot see or hear well. Summit participants were not aware of these programs and did not have these types of phones.

And finally, although the Internet on some reservations and in rural areas is either not available or inconsistent, more than one Indigenous person with TBI spoke at the Summit of being able to use and enjoy the computer. For people with fine motor problems, typing is often easier than writing with a pen. Certain assistive devices, such as speech recognition software, can also be attached to computers to facilitate use by individuals with disabilities. However, current literature, as well as Indigenous people with brain injury themselves, are silent on these innovations and potential application in their lives.

Housing

For Native Americans with brain injury, paperwork, qualification criteria, transportation concerns, and other barriers to housing exist both on and off the reservation. Some have tried to live independently, but feel socially isolated, while others cannot find housing with appropriate services or trained care. Some even cannot afford housing at all. Eventually, most Indigenous people with brain injury return to their families, even if they have initially ventured on their own immediately after injury. Urban Native Americans face unique challenges, often becoming lost in the shuffle.

Indigenous families need to be able to rely on group homes, shelter care, assisted living, and at times, 24-hour nursing facilities. Almost none of these programs are available on reservation lands.

Employment/Education

The study by Pichette et al. (1997) identified numerous “high priority” community rehabilitation needs on Midwest reservations. The number one need centered on employed individuals with disabilities earning enough salary to offset losses in benefits. Adequate job training programs for individuals with disabilities was the second highest priority. Several Summit participants reported limited success in securing jobs following vocational rehabilitation – disappointing information especially since people with brain injury are often highly motivated, reliable employees. The fear of inadequate earning power to compensate for benefit loss was pervasive among Summit participants.

Also in the top five in the Pichette et al. study (1997) was the need for public and tribal schools to recognize and accommodate the needs of students with disabilities. Services are severely limited on reservations for the special education of Indigenous children with TBI. Schools frequently have the funding for positions and actively recruit professionals, but the positions remain vacant or have high turnover rates, making services sporadic and sparse. Professionals that are available may be unaware that educational interventions for children with TBI are different than those used for other special education children.

Legal/Advocacy

The Native American community does have some protection and advocacy programs; however, not enough exist. The number three high priority community rehabilitation need in the Pichette et al. study (1997) was that people with disabilities should know their rights as citizens.

Beyond the individual needs of people with brain injury and caregivers, legal concerns are often ignored. Policies and laws now in place, such as the funding of States instead of tribes for rehabilitation programs, moratoriums on care beds, medication assistance rules, and other system-level problems impact the health, safety, and welfare of Indigenous people with TBI.

Cultural/Spiritual

The spiritual practices and beliefs of Indigenous people are as numerous as the Native American tribes themselves. However, enough similarities do exist to support certain assumptions. As Harold asked us, “What is an Indian without prayer?” How, why, where, and with whom they pray may vary, but provisions for prayer must be incorporated into the programs/housing/education for Indigenous people with brain injury.

Indigenous people with brain injury must be allowed to burn things (such as sage and tobacco), make food offerings, fast, go outside, participate in sweats, and live in buildings where windows open. Many long-term care facilities will not allow burning, have sealed windows, and highly schedule residents’ outdoor access. The views of

Indigenous people on how to maintain optimum health are greatly disconnected from what Western models of care say are necessary. Therefore, Indigenous people are reluctant to seek out “White Man’s” programs or facilities.

The Anglo world has little understanding of how Native Americans approach “finding the story that was given them” and strides in this area are virtually nonexistent. As one Summit participant from the Southwest said, “We are invisible.”

Complicating matters even further is the need to understand Christian Indigenous people who have roots in two worlds. One nurse tells of providing a comatose Lumbee man with a dreamcatcher over his bed and later arranging for him to be “saved,” per his request prior to necessary brain surgery following his accident (Holland, 2000).

Is an Array of Services Accessible to Indigenous People with Brain Injury and their Families?

An array of services is not available and therefore not accessible to Indigenous people with brain injury and their families. Policies, cultural disconnects, misunderstandings, geographical distances, funding streams and mechanisms, societal inequity issues, and other barriers such as language and world views all impede service accessibility. Not only are America's Indigenous people stereotyped due to their ancestry and race (LaRocque, 1999), but Indigenous people with TBI face additional stigmatization due to their injuries.

Paperwork obstacles, poverty, and disparate educational levels all heighten the discouragement of Indigenous people with brain injury who daily confront the tremendous amount of energy required just to live. One Indigenous person with TBI at the Summit relayed that Northern Plains Indians are more represented. Others reported that cultural activities are missing on their reservations. Most Summit participants reiterated the desire for tribes to unite in support of one goal – brain injury awareness and prevention. With over 550 federally recognized tribes and no funding source to gather tribes together, this feat is not easily accomplished.

A paucity of resources for Native Americans with brain injury is a stark reality. In general, many Indigenous people with TBI are not aware of resources that are available. If awareness does exist, the resources are usually in an urban area that is hundreds of miles away. Until resources are universally accessible, the quality of life for Indigenous people with TBI will be less than that of non-Indigenous people with brain injury. Indigenous people with TBI are not on an equal playing field with the rest of the Nation in regard to resources and services.

A lack of resources leads to inaccurate diagnoses and subsequent gaps in treatment. Access to basic health care, much less to a neuropsychologist, is not always available. Many times Native Americans with brain injury are seen for a number of complaints and they are unable to discuss “real” problems. Often, these patients appear to be “somatizing” or trying to get attention. They may overutilize the health care system because of an inability to verbalize what is wrong. Providers often do not know how to proceed with treatment and eventually issue a specialist referral.

When a specialist is requested, the health care provider attends a contract health meeting to ask for a referral for services. A team of providers and contract health personnel meet to determine if the services requested are a priority, and if money is budgeted for such services. However, if the referral is made at the end of a fiscal year, when funds are depleted, the patient may be told to “come back after August.” Many people have to wait until a new fiscal year begins for services to begin.

In summary, Indigenous patients are not usually assessed correctly, nor are they treated for brain injury. They may continue to go in and out of a revolving door of

medical appointments. A lack of awareness regarding brain injury is the primary reason for misdiagnosis. If health care workers and the general population are not aware of TBI, the Indigenous community is even more in the dark about awareness and prevention.

Conclusion

“There are people out there who are not identified...I know there are!” one man from the Plains lamented at the Summit.

The foremost problem is a lack of full understanding of the number or the severity of Indigenous people who survive brain injury today. Best estimates for the age of injury have been made, but not for the prevalence of brain injury in the population. No documented understanding exists of the care Indigenous people with brain injury (or their caregivers) receive. In the United States, numbers are not adequately tracked, primary data have not been collected, and the literature is silent on Native Americans with brain injury and their constellation of problems. Reports on secondary data/chart review and one research study from Canada are simply not enough.

If a rehabilitation program is nearby, it likely serves other disabilities at a greater rate than TBI specifically. Indigenous people with brain injury may not know of the programs or how to access them. If and when programs exist, geographical, environmental, and psychosocial/societal barriers hamper care. Vocational rehabilitation time is limited and successful placement post-program is rare.

Program funding often bypasses tribes by funneling directly to States. Indigenous people are expected to “fit in” outside their culture -- no provisions are currently available in dominant culture models of care. Indigenous people who practice their traditions and religions often are required to do so in specific places at specific times with specific people.

As brain injury is the fastest growing disability with long-term effects, a crisis is looming in the immediate future. The health care system has proven to be unprepared for this unique group of individuals. An immediate call to action, designed to educate not only Native Americans with brain injury, but also their families and policy/program entities, is paramount.

Program and Policy Recommendations for Indigenous People with Brain Injury and Their Families

Funding

National, Federal, and State funding should have dedicated dollar amounts for TBI. Services require financial support and money should be legislated for allocation to Indigenous tribes. In many cases, Indigenous people who live day today with brain injury do so with the help of family and friends. The strain of financial resources on families is overwhelming. Many Indigenous people with TBI either do not, or cannot, receive funding.

Prevention

Prevention legislation for both on and off the reservation needs to be improved. Current State and tribal laws should be enforced and strengthened, including those on seat belt use, child restraints, motorcycle and bike helmet use, and driving under the influence.

Another reason for a lack of prevention programs may be linked to statistics of another kind. Few Indigenous people are employed in the brain injury health care field (as neurosurgeons or neuropsychologists, for example) and therefore, Native American needs and outlooks do not have a professional voice.

IHS Overhaul

IHS needs to broaden its services, especially in the area of rehabilitation, allowing more Indigenous people with brain injury to remain in their communities. A neuropsychologist should be hired, or contracted with, for each area office. Training could be developed for providers, which would increase accurate diagnosis and improve care for Native Americans with brain injury and their families. Cognitive rehabilitation groups could be developed and implemented at each facility.

In addition, IHS could incorporate more training (pre-hospital discharge) and counseling (post-hospital discharge) services designed to help Indigenous people with TBI and their caregivers (e.g., families and friends) with the changes that occur. A contact person in each clinic or hospital (e.g., social worker) could provide the training and the follow-up to offer help and support, including service referral if needed. Money management, recreation assistance, and social skills are services Indigenous people with TBI may need, but might not know how to access.

Agency Visibility

State, Federal, and national agencies need to be more visible on reservations. A representative from major agencies (e.g., Social Security) should visit the reservation on a monthly basis to answer questions or help with paperwork. Additionally, these agencies should be invited to conferences that address Indigenous populations with disabilities.

Culture and Spirit

A final but important focus should be on the cultural and spiritual aspects of care for Indigenous people with brain injury. Activities, venues, and leaders that are appropriate to the spiritual needs of Indigenous people with TBI and their families are needed.

Conferences

More conferences need to be organized for Indigenous people with brain injury, their families, and providers that will: 1) educate the Native American community about TBI; and, 2) bring cultural awareness to outside agencies regarding Indigenous people with brain injury.

Other Potential Focus Issues

1. Attention to the cultural, spiritual and religious aspects of Indigenous care
2. National prevalence of TBI in Indigenous people
3. Partnership programs among Indigenous people with TBI, their families and program providers
4. Research
5. Increased advocacy including the National Indian Health Bureau, the Indian Health Service, the National Congress of American Indians, and other national level involvement
6. Long-term care
7. Information, support, therapy, and respite for people with brain injury
8. Brain injury as an IHS conference theme
9. "Ronald MacDonald House" for families
10. National clearinghouse of culturally specific information
11. Volunteer and peer mentoring
12. Education of healthcare providers both within and outside of the Indian Health Service System
13. Monitoring of alcohol use pre- and post-injury
14. Self-employment opportunities
15. Tutors and college note takers or assistive computer software
16. Community-based jobs
17. Accessible and affordable housing
18. Summer camp

19. Support groups
20. Bi-annual IP-BIA Conference
21. Prayer/Sweats



Bibliography

- J. Blackmer and S.C. Marshall, "A Comparison of Traumatic Brain Injury in the Saskatchewan Native North American and the non-Native North American Populations," *Brain Injury*, 13, 8, pp. 627-35 (1999).
- Centers for Disease Control and Prevention, "Traumatic Brain Injury in the United States: A Report to Congress," (1999).
- Karen F. Flippo, "Our Story, Your Story," Presentation at the First National Indigenous Summit on Traumatic Brain Injury, Bismarck, ND (2003).
- E.C. Holland, "A Dream Awakened," *Rehabilitation Nursing*, 25, 1, pp. 4-5 (2000).
- Indian Health Service. "Trends in Indian Health," (www.ihs.gov/publicinfo/publications/trends98/front.pdf, 1998).
- Glen Johnson, *Traumatic Brain Injury Survival Guide*, (Traverse City, MI: www.tbiguide.com, 2001).
- Scott R. Kegler, Victor G. Coronado, Joseph L. Annest, and David J. Thurman. "Estimating Nonfatal Traumatic Brain Injury Hospitalizations using an Urban/Rural Index," *The Journal of Head Trauma Rehabilitation*, 18, 6, pp 469-478 (2003).
- Jean Langlois, Wesley Rutland-Brown and David Wallace, "Traumatic Brain Injury Among American Indians and Alaska Natives: What Do We Know and Where Do We Go?," Presentation by the Centers for Disease Control and Prevention at the First National Indigenous Summit on Traumatic Brain Injury, Bismarck, ND (2003).
- S. LaRocque, "A Factor Analysis of Caucasian College Students' Perceptions of Native Women," Doctoral Dissertation, University of North Dakota (1999).
- Rachel Locker, "Violence Against Women is a Public Health Problem of Epidemic Proportions," (April 2002), PHS Indian Health Service.
- M.P. Moss, "Zuni Elders: Ethnography of American Indian Aging," Doctoral Dissertation, University of Texas-Houston (2000).
- "Nonfatal Fall-Related Traumatic Brain Injury Among Older Adults-California, 1996-1999," *Morbidity & Mortality Weekly Report*, 52, 13, pp. 276-8 (2003).
- E.F. Pichette, N.L. Berven, F.E. Menz, T.D. La Fromboise, "Effects of Cultural Identification and Disability Status on Perceived Community Rehabilitation Needs of Native American People," *Journal of Rehabilitation*, pp. 38-44, (1997).
- D.J. Thurman, J.E. Sniezel, D. Johnson, A. Greenspan and S.M. Smith, *Guidelines for Surveillance of Central Nervous System Injury*, (Atlanta: Centers for Disease Control and Prevention, 1994).
- United States Census Bureau, "U.S. Census," (2000).

Appendix A: First National Native American Summit on Traumatic Brain Injury Agenda

National Native American Summit on Traumatic Brain Injury



**Bismarck, North Dakota
May 3-6, 2003**

AGENDA

Saturday, May 3, 2003

Meeting Room

2:00 p.m.-4:00 p.m.	Registration	East Heritage
4:00p.m.- 8:00 p.m.	Opening Prayer Pipe Ceremony Francis Cree, Old Eagle Heart Honoring Guard Drum Dinner Flute Player, Dan Jerome	

Sunday, May 4, 2003

East Heritage

8:30 a.m.	Opening Prayer, Francis Cree, Old Eagle Heart	
8:40 a.m.	Welcoming remarks: Indigenous Peoples Brain Injury Association Betty Hastings, MSW, Director, Federal TBI Program Geoffrey Lauer, Director of Affiliate Relations Brain Injury Association of America	

Sunday, May 4, 2003 (cont'd)**Meeting Room**

9:15 a.m.	Keynote Speaker Arnold Thomas, Inspirational Speaker	East Heritage
10:30 a.m.	B-R-E-A-K	
11:00 a.m.	Unity of Advocacy Karen Flippo, Vice President Brain Injury Association of America [For PowerPoint Presentation, see Appendix C]	
12:00 p.m.	Lunch	
1:00 p.m.	Centers for Disease Control (CDC) Jean A. Langlois, ScD, MPH Senior Epidemiologist [For PowerPoint Presentation, see Appendix D]	
2:00 p.m.	Introduction to facilitated breakout groups Geoffrey Lauer, Brain Injury Association of America	
3:00 p.m.	B-R-E-A-K	
3:30 p.m.- 5:00 p.m.	Breakout groups	Chamber Congress Senate Suite 114 Suite 106
5:00 p.m.- 6:30 p.m.	Dinner	East Heritage
7:00 p.m.	Ceremony (Sweat Lodge)	

Monday, May 5, 2003

8:00 a.m.	Breakfast	East Heritage
9:00 a.m.	Opening Prayer, Old Eagle Heart	
9:10 a.m.	Opening Remarks	
9:30 a.m.	Brain Injury Association of America: Presentation on Information & Resources	

Monday, May 5, 2003 (cont'd)

Meeting Room

Karen Flippo, Brain Injury Association of America
Geoffrey Lauer, Brain Injury Association of America

10:30 a.m.	B-R-E-A-K	
11:00 a.m.	Breakout Groups	
12:00 p.m.	Lunch	West Heritage
1:00 p.m.	Precious Life, Linah Lilih	
2:00 p.m.	Wrap up and Summary Geoffrey Lauer, Brain Injury Association of America	
2:30 p.m.	B-R-E-A-K	
3:00 p.m.	Talking Circle	Assembly
6:00 p.m.	Dinner, Ceremony/Give- A-Ways	

Tuesday, May 6, 2003

8:00 a.m.	Breakfast Departures	
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Appendix B: First National Native American Summit on Traumatic Brain Injury Participant List

National Native American Summit on Traumatic Brain Injury



**Bismarck, North Dakota
May 3-6, 2003**

PARTICIPANT LIST

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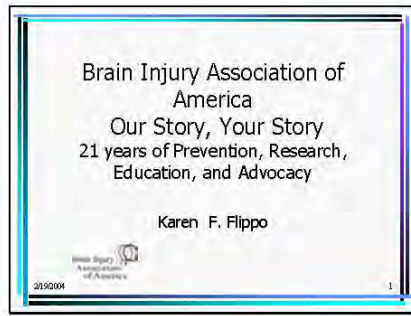
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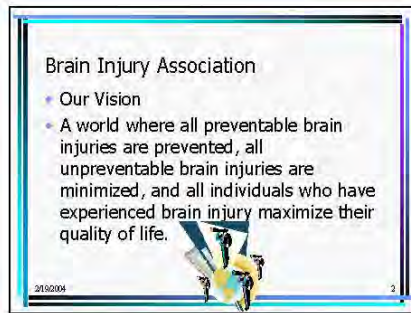
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APPENDIX C: Brain Injury Association of America: Our Story, Your Story

Slide 1



Slide 2



Slide 3

Brain Injury Association

- Our mission:
- Creating a better future through brain injury prevention, research, education and advocacy.

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Brain Injury Association

- Brain Injury Association of America is collectively the largest single voice advocating on behalf individuals who have experienced brain injury.
- Our strength is in our shared experience and the collaborative efforts that we bring in fulfilling our organizational mission.

2192004 4

Slide 5

Brain Injury Association

- Approximately 5.3 million people with brain injuries are living in the U.S.
- 1.5 million people experience brain injuries each year.
- Cost of TBI in the U.S. is estimated at \$48.3 billion annually.
- Each year, 230,000 persons are hospitalized with TBI and survive.

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Slide 6

Just the Facts

- 91% of firearm-related TBIs result in death.
- 11% of fall-related TBIs proved fatal. 22% of persons with TBI die.
- 2/3 of firearm-related TBIs are classified as suicidal in intent.
- Falls are the leading cause of TBI for persons age 65 and older; transportation-related injuries lead among the 5-64 population.

2192004 6

Slide 7

Brain Injury Association

- Strategic thinking allows us to position ourselves in our business to retain a competitive advantage—allows us to allocate resources to remain viable, flexible, and retain leadership.
- Second aspect is managerial—inspire and coordinate collective work to achieve mission and goals (board, BIA staff, state affiliates).

2192004 7

Slide 8

Brain Injury Association

- **Core Purpose**
- Our purpose is to put a name, face and voice on the “silent epidemic”.
- To unify and lead the cause of brain injury with courage and integrity.

2192004 8

Slide 9

Brain Injury Association

- Huge constituency of individuals with brain injury, family members, state and federal policy makers, medical personnel, service providers, educators.
- A task of a national association is to identify highest priorities and allocate resources to achieve goals and objectives.

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Slide 10

Brain Injury Association

- Broad Goals:
- Public Awareness and Public Education
- Public Policy
- External and Internal Collaboration
- Research



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Slide 11

Public Awareness and Prevention

- I. Public Awareness and Public Education
- There will be broad understanding of brain injury, its causes and consequences and recognition of the Association's brand name.

2192004 11

Slide 12

Public Awareness and Prevention

- **Develop and launch national multi-media public awareness campaign.** BVK/McDonald developed creative concepts to raise awareness of the causes of brain injury. Launch in DC and Chicago, Summer 2003, funded by HRSA PIC.

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Public Awareness


- Brain Injury Awareness month kits mailed to 5,000 individuals/organizations that focus on causes and prevention of brain injury. (October 2003)

2192004 13

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Public Awareness


- Communication Products
- TBI Challenge!
- Catalog of Educational Resources
- Web site www.biausa.org (new design launched in November-currently at 500,000 hits per year!).



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Public Policy



- Public Policy
- **The Brain Injury Association will be a key voice in shaping US public policy related to brain injury.**

2192004 15

Slide 16

Topic Three

- During the 106th Congress, the 1996 Traumatic Brain Injury Act was reauthorized for an unprecedented five year period!
- Expanded Congressional Brain Injury Task Force that includes approximately 50 Congressional members. (Co- chairs are James C. Greenwood (R-PA), and Bill Pascrell, Jr. (D-NJ)).
- In 2003, Public Policy staff and grassroots advocates were successful in achieving appropriations increases for TBI Act.

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Slide 17

Public Policy

- Continues to build advocacy networks through state affiliates.
- Train on self-advocacy techniques and provide TBI policy information to Congressional members

2192004 17

Slide 18

Public Policy

- Participate as a member of the Consortium of Citizens with Disabilities, a group of 100 national disability organizations. Member of the following task forces: Rights, Long Term Services and Supports, Housing, Child Abuse, Prevention, Health, Social Security, Education, Employment.

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Public Policy

- At request of Senator Edward Markey (D-MA), convened a Blue Ribbon panel of national medical, research and industry professionals to analyze data on cause and effect of brain injury and roller coaster rides.

2192004 19

Slide 20

Public Policy

- State affiliate staff and volunteers have opportunity to shape policy and best practices through committee and task force participation.
- A weekly electronic newsletter, "Policy Corner" helps keep 600 advocates current with national policy development on TBI legislation and regulation including family support, work incentives, patients' rights, health care, employment and education.

2192004 20

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Public Policy and Advocacy

- Highest priority is TBI Act Appropriations.
- TBI falls far short of other disability groups in federal funding of services and supports.
- Full funding of the TBI Act is essential to continue the activities of the HRSA state grants, P&As, and CDC's surveillance and prevention programs.

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The Numbers



- \$6.5 million for the Health Services Resources Administration (HRSA) grants to states for planning, implementation or post-demonstration grants to improve access to health care and other life improvement services. (increase of \$500,000 over FY 2002).

2192004 22

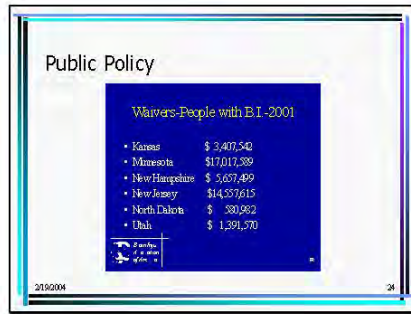
Slide 23

TBI Act Appropriations

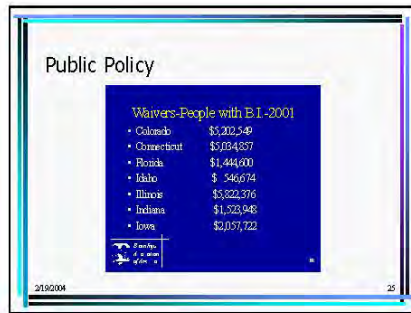
- \$3 million for HRSA Protection and Advocacy Services for persons with TBI (\$1.5 appropriated for 2002).
- **Prevention and Research**
- An additional \$1,000,000 for the Centers on Disease Control and Prevention for surveillance and prevention programs, including funds to phase in a "one stop" information and resource center.

2192004 23

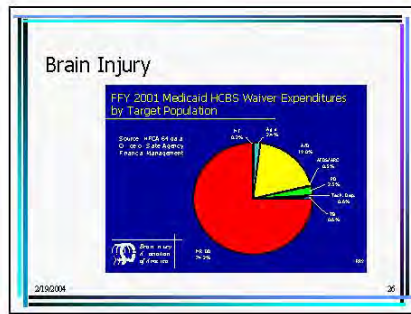
Slide 24



Slide 25



Slide 26



Slide 27

Brain Injury and Long Term Care

States Without Medicaid
Personal Care Option

• Alabama	• Illinois	• North Carolina
• Arizona	• Indiana	• North Dakota
• Arkansas	• Iowa	• Ohio
• California	• Kansas	• Oklahoma
• Colorado	• Kentucky	• Oregon
• Connecticut	• Louisiana	• Pennsylvania
• Delaware	• Maryland	• Rhode Island
• Florida	• Massachusetts	• South Carolina
• Georgia	• Michigan	• South Dakota
• Hawaii	• Minnesota	• Tennessee
• Idaho	• Missouri	• Texas
• Kansas	• Montana	• Virginia
• Kentucky	• Nebraska	• West Virginia
• Louisiana	• New Hampshire	• Wisconsin
• Maine	• New Jersey	• Wyoming
• Maryland	• New Mexico	
• Massachusetts	• New York	
• Michigan	• North Carolina	
• Minnesota	• North Dakota	
• Mississippi	• Ohio	
• Missouri	• Oklahoma	
• Montana	• Oregon	
• Nebraska	• Pennsylvania	
• Nevada	• Rhode Island	
• New Hampshire	• South Carolina	
• New Jersey	• South Dakota	
• New Mexico	• Tennessee	
• New York	• Texas	
• North Carolina	• Utah	
• North Dakota	• Vermont	
• Ohio	• Virginia	
• Oklahoma	• Washington	
• Oregon	• West Virginia	
• Pennsylvania	• Wisconsin	
• Rhode Island	• Wyoming	
• South Carolina		
• South Dakota		
• Tennessee		
• Texas		
• Utah		
• Vermont		
• Virginia		
• Washington		
• West Virginia		
• Wisconsin		
• Wyoming		

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Goals



- III. Funding
- **The Brain Injury Association will have an expanded, stable and diverse funding base to support future growth.**
- Developing a healthy mix of affiliation dues, individual and corporate donations and government grants.

2192004 28

Slide 29

Partnerships

- IV. Strategic Partnering, Internal and External
- **All parts of the Brain Injury Association will work collaboratively to achieve the strategic plan**
- **"No man, woman, or organization is an island."**
- Continually work to support and build a national network of 40 affiliates from Hawaii to Maine.

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Slide 30

Support to Affiliates

- Provide "StarSite" Intranet to promote continued networking and internal collaboration.
- Conduct Leadership Conferences.
- Access to I&R listserv.
- Use of Spanish Helpline I&R Manager (funded by CDC) and translation of materials into Spanish.

2192004 30

Slide 31

Support to Affiliates

- I&R Managers are highly trained and informed of latest developments in treatment and practice. Staff field approximately 17,000 calls each year!
- Family Helpline number: 800-444-6443
- Priority access for literature searches from the Association's extensive database and resource library.

2192004 31


Slide 32

Education, Research and Training

- V. Research
- **The Brain Injury Association will develop and disseminate a progressive research agenda.**

2192004 32


Slide 33

Research Projects 

- TBI National Data Center subcontract
- Increase accessibility to and utilization of TBI Model Systems research.
- Articles written in lay language highlight studies and findings then made publicly available via the Internet, our publications and Helpline.
- Materials available in English, Spanish and large print.

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AACBIS 

- American Academy of Certified Brain Injury Specialists.
- Offers a national certification program that improves the quality of care by establishing competencies for education and training of individuals working in brain injury rehabilitation.
- Reorganizing process and curriculum to provide more than one level of training and examination.

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Research Projects

- Self-Employment Project for Individuals with Traumatic Brain Injury:
- Partner-University of Montana
- Work with 20 individuals in Utah and Virginia to develop self-employment options and document results.

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Slide 36

Research Projects

- Assistive Technology Research and Development Collaborative on Cognitive Disabilities
- 5 year project to identify benefits and features of electronic organizers when used by individuals with cognitive disabilities.
- Communicate results to manufacturers and vendors.
- Develop Web Assessment Tool for People with Cognitive Disabilities.



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Slide 37

Strategic Plan

- "The future depends entirely on what EACH of us does every day...a movement is only people moving."
Gloria Steinem, 1992




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Appendix D: Traumatic Brain Injury Among American Indians and Alaska Natives: What Do We Know and Where Do We Go?

Slide 1

Traumatic Brain Injury
among
American Indians and Alaska Natives
What do we know, and
where do we go?


Jean Langlois
Wesley Rutland-Brown
David Wallace
Centers for Disease Control
and Prevention
May 2003



Slide 2

Overview

- What is Traumatic Brain Injury?
- Is TBI a problem for American Indians and Alaska Natives?
- What can we do about TBI among indigenous people?



Slide 3

TBI: One Woman's Story


- Marilyn was injured in a car crash
- She hit her head and was knocked out
- She was taken to the Emergency Department, treated and sent home



Slide 4

TBI: One Woman's Story (cont'd)



- Afterwards, Marilyn had many problems thinking and remembering



Slide 5

TBI: One Woman's Story (cont'd)


- Marilyn had a
Traumatic Brain Injury (TBI)



Slide 6

What is a TBI?

- a blow or jolt to the head that disrupts the normal function of the brain




Slide 7

Is Concussion a TBI?


YES!

Even people with concussion or "mild" TBI can have serious and long-term problems.



Slide 8

Clara's story



Slide 9

What happens after a TBI?

People with TBI often have difficulty


- Thinking and remembering
- Controlling emotions or behavior
- Walking or doing other physical activities



Slide 10

What happens after a TBI?

- “Shopping was a problem for many reasons. I couldn’t decide what to put on my list. I didn’t know where to go or what to buy. I would forget to take the list. I would remember the list but forget money. Decisions involving sizes and brands were most easily solved by buying nothing.” *Claudia Osborne*



Slide 11

What happens after a TBI?

Alcohol problems are common after TBI

- These problems often reappear 1 to 2 years after a TBI
- In a SC study, people with TBI reported alcohol problems more than twice as often as those without TBI

Depression is common after TBI

- As many as 60% of people with TBI may experience major depression post-TBI




Slide 12

What happens after a TBI?

Many people with TBI have difficulty returning to work or to the same level of work


- In a CO study, one in 4 people who were working before their injury were no longer working one year post-TBI



Slide 13

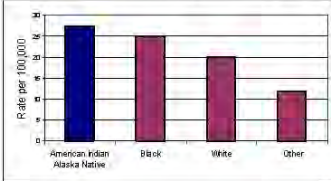
Is TBI a problem for American Indians and Alaska Natives?

YES!




Slide 14

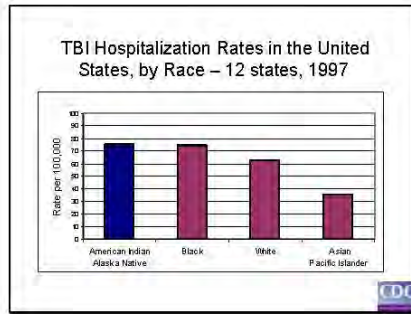
TBI Death Rates in the United States, by Race -- 1989-1998 (Annual Average)



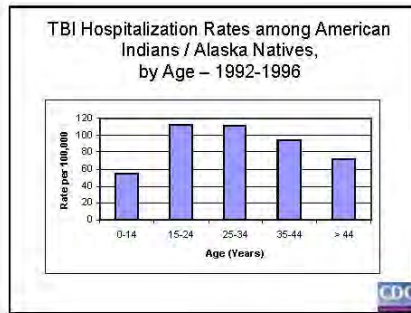
Race	Rate per 100,000
American Indian Alaska Native	~18
Black	~12
White	~10
Other	~6



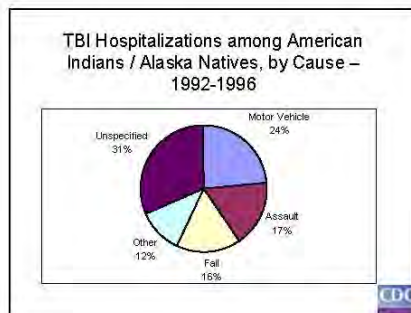
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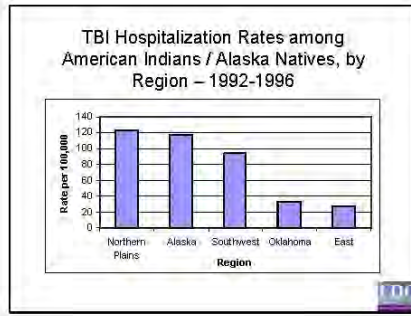
Slide 16



Slide 17



Slide 18



Slide 19

Limitations of the data on TBI in American Indians/Alaska Natives

- Hospitalizations that are not paid for by IHS may not be included in the IHS data, e.g., those paid for by private health insurance, Medicare, or Medicaid.
- CDC TBI surveillance for hospitalizations do not include all states with Native American populations
- No data about Emergency Dept visits was available

CDC

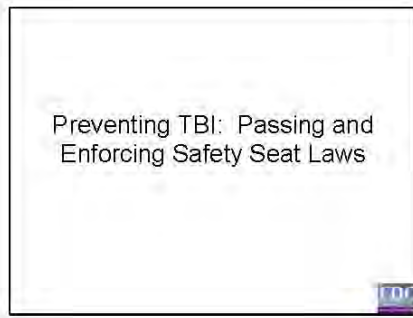
Slide 20

What can we do about TBI?

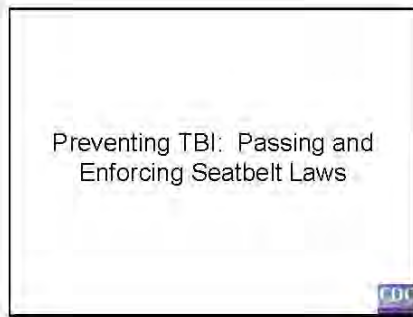
Prevention is the key...

CDC

Slide 21



Slide 22



Slide 23



Slide 24

What can we do after a TBI?

Reduce disability by providing treatment, rehabilitation, services and support




Slide 25

Reducing Disability from TBI

After a TBI, people need


- Treatment
 - to reduce the impact of the injury
- Rehabilitation
 - to regain function
- Services and support
 - to compensate for long-term problems, return to work and live independently



Slide 26

Reducing Disability from TBI

Services and support are the key to reducing disability and improving quality of life




Slide 27

Reducing Disability from TBI

Some of the services needed:

- Information
- Help improving mood and emotions
- Help improving thinking and memory
- Help improving job skills/finding a job
- Transportation
- Personal assistance

From COTBIRFS and SCTBIFR



Slide 28

Reducing Disability from TBI among American Indians and Alaska Natives



We need to collect better information about the problems and service needs of Native Americans living with TBI




Slide 29

Reducing Disability from TBI among American Indians and Alaska Natives

We need to provide better information about

- What a TBI is
- What kinds of problems result
- How to get help



Slide 30


Reducing Disability from TBI
among American Indians and
Alaska Natives



Slide 31


Summary

- TBI is an important problem among Native Americans
- Prevention is the only cure
- For those who survive, we need
 - To obtain better information about TBI-related problems and service needs
 - To provide better information about TBI and how to get help



Slide 32

What can WE do to help
Native Americans with TBI?



Slide 33

A very great vision is needed and the man who has it must follow it as the eagle seeks the deepest blue of the sky.

Crazy Horse

