PRESENT.:
TRAUMATIC BRAIN INJURY ACT UPDATE

Brain Injury Association of Alaska

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JUNEAU PRESENTATION
February 17-18, 1998

Presenters:
Debra M. Russell, Ph.D. Candidate, CRC, President
Richard Warrington, Vice President, Foundation Affairs

The Brain Injury Association (BIA) was founded in 1980 as a national advocacy organization to help individuals, and their families, who have experienced a brain injury. Although most individuals associate brain injuries with traumatic injuries, our organization has evolved into a nationwide awareness of all types of brain impairments.

Brain injury is a disorder that is seen as "the silent epidemic." This disorder has no boundaries when it comes to socioeconomics, sex, age, or ethnicity. Millions of individuals, children and adults alike, experience this injury every year, leading to death and permanent disabilities. For example, individuals such as President Ronald Reagan (Alzheimers Disease), Katherine Hepburn (Parkinsons Disease), Mohammed Ali (Dementia due to multiple traumatic brain injuries), Kirk Douglas (Stroke), Press Secretary Jim Brady (TBI from a bullet to his head), or recently Congressman Sonny Bono (Singer of Sonny and Cher, died from a brain injury associated with a skiing accident), all have experienced a brain injury. These individuals are a small fraction of the millions who experience a brain injury every day.

FACTS AND FIGURES

Nationwide, we have over 9.5 million brain injuries each year. During the last decade, the sustaining rates of surviving a brain injury has grown from 50% to 90%. For youths, traumatic brain injury is the most frequent cause of disability and death among children and adolescents in the United States. Each year, more than one million children sustain brain injuries ranging from mild to severe trauma (National Pediatric Trauma Registry). According to this registry, about one-third (334,000) of injury cases are related to brain trauma that leads to residual deficits. Unfortunately, a large percentage of this injury is due to physical abuse for new infants, followed by additional abuse for 64% of children under the age of one. Falls are the next major source of brain injury for children under 5 years of age (50%), followed by pedestrian-motor vehicle and bicycle crashes among school-age children and adolescents (National Pediatric Trauma Registry).

In Alaska, the death rate of young adults is extremely higher than other states. The comparison death rates were:

15-19 years of age at death - the U.S. rate was 69.6 compared to Alaskan death rates at 108.4:

20-24 years of age at death - the U.S. rate was 82.5 compared to Alaskan death rates at 117.26:

25-29 years of age at death - the U.S. rate was 68.8 compared to Alaska death rates at 104.18.

Even the combined rate in the U.S. was 58 compared to Alaskans at 81 for death. In contrast, the next highest cause of death in children is leukemia, at a rate of 1.9 per 100,000 population. In addition, concerning brain trauma for the adolescent, the annual prevalence rate jumps from 129.5 to 600 per 100,000 (other statistics record it at 930). For those who survive, a large percentage will suffer some transient cognitive, motor, or sensory irregularities and between 40% to 80% will have physical, intellectual or behavioral deficits. At least 10% will have deficits that result in total and permanent incapacitating disabilities.

Adult survivors also present alarming information and statistics. During the first few hours following a brain injury, more than 100,000 individuals with TBI alone usually die and over 2,000 will remain in a persistent vegetative state. For stroke victims, which affect 500,000 each year, 150,000 of these individuals will also die. Only 20% of stroke victims receive rehabilitation and only 5% for TBI survivors. 70,000 to 90,000 TBI survivors require long-term rehabilitation for basic restoration. In addition, these statistics do not reflect the rate of injury associated with snowmobile accidents; a significant problem unique to Alaska. These disturbing statistics justify the title of "silent epidemic" for these individuals. In summary, people experience brain injuries every 10 to 15 seconds (Brain Injury Association, Inc.), and this statement is why our organization exists.

In Alaska, we believe that our state experiences at least 5,000 to 6,000 brain injuries each year due to multiple causes. According to statistics from the Dept. Of Health Services in Alaska, injuries from unintentional and intentional causes are the leading cause of death, accounting for 29% of deaths and 53% of potential years lost in all ages. Brain injury accounts for 2% of all deaths and 26% of all injury deaths and 12% of hospitalizations due to injury. According to the Alaska Trauma Registry and Public Health, between 1991 to 1993, we had 2178 cases of hospitalized individuals just with TBI. Although this is alarming, these statistics are misleading. Although these facts identify thousands of survivors, the majority of people with brain injury are not hospitalized as their injury is considered mild (75%), yet they still endure deficits.

People with multiple injuries usually have the brain as the most commonly injured part and in fatal car accidents, injury to the brain is seen in as many as 75% of victims at autopsies

(p. 5). In addition, many studies have shown that brain injury predisposes the individual to the biologic development of other symptoms, such as depression and latent personality disorders (e.g., dependency, impatience, depression, decreased initiative, irritability, temper outbursts, decreased self-control, inappropriate public behavior). Furthermore, studies have shown that many individuals who are in the criminal justice system had significant brain injuries prior to their act of committing a crime. But even this information is not the complete picture. The Center for Disease Control and the Wonder Injury Data of 1994 recognized that suicide rates among Alaska's brain injury survivors and homicide are conjectured to be closely correlated with brain injury prevalence. Thus, these statistics are deceptive. Research has also shown that a large percentage of the homelessness, abuse of alcohol and drugs, and suicide rates following a brain injury is extremely elevated, e.g., nationwide statistics report that the average range of alcohol use of 23% increases to 75% when the person has a brain injury (Federoff et al., 1992; Hales et al., 1991; Lehr, 1990; Sells, 1992; Sladk, 1991, Shordone, 1987, 1988, 1990). If these statistics do not break your heart, it should affect your intellect:

> *the economic burden for treating these individuals is in the billions (economic losses of productivity, wages, health maintenance, and long-term care, which is recognized at 25 to 45 billion dollars yearly.*

In 1996, a study was done on Organic Brain Syndrome (OBS) for Alaska, which identified many factors that contribute to crime, poverty, and low rates of successful vocational rehabilitation for this population (a copy of this study can be obtained from the Center for Disability Policy and Research, University of Washington or from David Maltman, Governor's Committee on Disability and Special Education, Alaska). When reviewing this report, one must begin with the fact that the researchers recognized a difference between mental illness and brain injury. According to this report, which we (BIA) concurs, a large percentage of clinicians working in this state are not schooled in the diagnosis or treatment of OBS. There is some services for children through the support system of the state for developmental disabilities, but this is only for children before the age of 22, and the services are more toward the learning disabled or mentally impaired. Medicaid only provides short-term treatment for situational conditions; they do not affectively address the long-term need (case management, rehabilitation services, independent living supports, etc.). People with OBS have a 60% to 80% rate of unemployment, a high divorce rate, ostracism, homelessness, financial difficulties, victimization, dependence, increased drug and alcohol abuse, secondary disabilities, and suicidal tendencies. In the Alaska Native population, the increase of brain injury is two to one compared to non-natives and services are minimal to none.

The mission of the Brain Injury Association of Alaska is to not only advocate for and assist these survivors, but to help them return to the world of work and independence. Our purpose is to reach thousands of survivors and provide education, prevention, rehabilitation, and support (advocacy). This can be accomplished by:

Educational training and workshops about this disorder;

Full rehabilitation counseling for survivors and families;

Obtainment of assistive technology for the individual;

Collaboration with the school districts (programs such as the HeadSmart program that focuses on reducing violence for children in the school districts);

Violence and Brain Injury Projects (addresses the root causes of violent criminal behavior);

The BIRDS program, for children ages birth to 21 (rehabilitation psychology strategies in the development of training to other professionals, e.g., medical doctors, nurses, school administrators, therapists, etc.);

Public Awareness - prevention program (State Ambassadors Program for traveling across the state, especially villages) to provide information about brain injury as well as prevention strategies for the development of support groups for each area, and;

Counseling and assistance with families, organizations, or companies.

BIA of Alaska is willing to train employees in every city of our state concerning our programs. Our approach promotes exchange of ideas, family needs, current brain injury research, epidemiology, new models of treatment, as well as national training. We are also global as we promote international awareness of brain injury across the world. We even have a program for training the military (Defense and Veterans Head Injury) and training for police officers in identification of brain injuries.

PARTNERSHIP

We are sure that the mention of funding sends chills down your spines but we have a proposal that may interest you in the area of service provision. There are funds available through many organizations that could support part or all of these programs. For example, Mr. Warrington will present information about the TBI Act of 1996 that addresses some funding possibilities. As we receive calls daily requesting assistance and information, I believe that we must begin with education to our service providers and governing bodies, such as the Alaska Mental Health Trust Authority, the Governor's Council on Disabilities and Special Education, the Alaska Mental Health Board, the Alaska Commission on Aging, the State Independent Living Council, the Alaska Department of Health and Human Services, the Alaska Department of Education, the Alaska Division of Medical Assistance, Division of Vocational Rehabilitation, Workers' Compensation, and Alcohol and Drug Abuse, to name a

few (OBS, 1996). Our association receives phone calls every day from many of these organizations asking for assistance as well as calls from organizations such as P.A.R.E.N.T.S., Access Alaska, School Districts, Division of Vocational Rehabilitation (DVR), private individuals, and a variety of companies. All of these individuals request information and services, which we often cannot provide due to inadequate funding.

BIA of Alaska believes that with proper support, we can provide a large percentage of services for children and adults who have sustained a brain injury. For example, many survivors are directed to DVR for services. This organization attempts to provide rehabilitation services, yet they have a high rate of failure. I am not directing fault at DVR, as many of these counselors are excellent with good intentions. The problem is these individuals never received proper rehabilitation for their cognitive deficits; dooming this service to failure. They are missing the critical component of successful rehabilitation - lack of education for rehabilitating these individuals BEFORE they enter the maze of welfare to work programs. How can a person sustain employment when their cognitive abilities are at a 3rd grade level?

Although our plan does incorporate prevention and education as a major component, we can offer the development and implementation of a rehabilitation program. BIA of Alaska believes that we could provide, alone or in conjunction with other programs, a one-stop-shop for persons with brain injuries. For example, lets assume that this individual was hospitalized for their brain injury. This program would begin once the individual has completed their acute rehabilitation in the hospital. Their records would be transferred to our office and a review would be completed. In the meantime, this individual, and their family, would begin our program as the psychological trauma of this injury is usually extremely distressing. At this point, we would begin with assessments (e.g., neuroevaluations or assistive technology) that have not been provided, for identification of deficits. At this same building, a program will be developed for each client based on history, assessment results, psychological needs, psychopharmacology management, cognitive restoration strategies, and review of the medical diagnosis for each survivor.

Once deficits are identified and a program is developed, clients would be very involved in a holistic method of rehabilitation. Professionals, such as cognitive therapists, speech-language pathologists, occupational therapists, physical therapists, rehabilitation specialists, educational counselors, etc., would provide services at this facility. These individuals will be contracted on an hourly basis, overseen by a case manager(s). Rehabilitation may include memory strategies or training, assistive technology, cognitive restructuring, behavior management, substance abuse education, counseling (group or individual), family support, independent living training, employer training, social skill training, job training and development, etc., all administered by BIA of Alaska. Concentration on restoring language, attention, information processing, problem-solving, organization & planning, sequencing, judgment, executive functioning, etc., will be a segment of the rehabilitation plan.

Trained volunteers will be involved to assist in some services, reducing staff support. By merging these services toward a complete program, most individuals recover more quickly while reducing the chance of inappropriateness or regressive behaviors. Although the program will not focus on rapid recovery as the major goal, our intent is complete rehabilitation so we do not have a return rate (additional rehabilitation services) into this program. Additionally, as this is a nonprofit association, tax benefits for companies will be attractive and can provide additional funding. Financial support could also come from areas such as fines from driving while impaired (DWI) convictions, insurance companies, Workmans' Compensation, private donations, fund raisers, etc. We suspect that within 5 years, this majority of this program will be self-supporting.

Statistically, the State of Alaska will save a large amount of money by providing this program. We will not repeat services in our state: we will work with other organizations to provide the foremost services without duplication. In addition, listed above are some statistics concerning the average lifespan of persons with brain injury (15-29), which means 40 to 50 years of welfare or Social Security benefits for thousands of Alaskans. We will also reduce the costs of Medicare and Medicaid by returning these individuals back into the workforce. The graduates of this approach will become tax-paying citizens. This program would invest quality rehabilitation in the embryonic stages of recovery, reducing decisions that lead to expensive trial & errors. Everyone will win from this program, especially the individuals, and their families, who have survived one of the most traumatic experiences in their life - a brain injury.

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Hello Senator Wilken,

January 13th 1998

Hapy New Year,

The three Ambassadors of the National Brain Injury Assocation and the President of the Brain Injury Assocation of Alaska are looking to have a meeting with you and Commitee Members on Febraury 13th 1998.

We want Alaska to "Qualify" for Grants that are aviable under the TBI Act (public Law 104-166) that was passed thru the "Congress in July 1996.

We will give you detail on how the 5,000 Brain Injuries happen in Alaska each year and its impact on people with Brain Injuries and their families.

Brain Injury is the leading cause of death and disability among people under 24 years of age.

A Brain Injury occurs every 15 seconds, every five minutes one of these people will die and another will be permanently disabled.

Brain Injury is not acts of fate.

Injuries, like diseases, occur in highly predictable patterns and are often preventable. They are not "Accidents". Injuries can be either unintentional or intentional.

Alaska needs to set up Emergency Centers to help the survivors instead of losing time and money to out of State Treatments and the follow thru Rehabilitation.

I'm a SURVIVOR OF TBI THAT HAPPENED 20 YEARS AGO IN COLORADO.

I have lived in Alaska twelve years.

Please let me now when you get this letter. Please share this letter with Senator, Mike Miller and Representive, Con Bundie and House Speaker Gail Phillips.

The Governer's Council on Disability and Special Education likes what I'm trying to do for the Brain Injured in the State.

" We need funding for this trip"

SINCERELY,

Richard A. Warrington

RICHARD A. WARRINGTON
Kenai, Alaska

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January 23, 1998

Senator Gary Wilken
State Capitol
Room 510
Juneau, Alaska 99801-1182

Dear Senator Miller,

The Brain Injury Association of Alaska is scheduled to meet in Juneau on February 17th and 18th of 1998 concerning public issues such as the TBI Act of 1996, the HeadSmart School Program, prevention, rehabilitation, and other programs associated with the topic of brain injuries. In our state, we have thousands of brain injuries every year that often lead to permanent deficits in living, learning, and working. These individuals desperately need rehabilitation and training to work around their disabilities. In fact, it was this need that evolve into the TBI Act of 1996 (Public Law 104-166).

The Traumatic Brain Injury Act (TBI) authorized the federal government to disburse funds for this population in areas such as advancement, prevention, rehabilitation, treatment, and education. The initial appropriation of funds was to the study of this malady as well as funding education and prevention, with the goal to be disseminated at state levels. The consensus of the study included identification, accountability, therapeutic interventions in rehabilitation, and adequacy of appraising outcomes. According to Section 4, paragraph (a)(2), a report describing the findings made as a result of carrying out paragraph (1)(A) must be generated. I believe we have reached this date, according to this Act, and we wait patiently for the results.

The purpose of our attention to this law is rooted in the suffering that people with brain injuries experience daily with minimal or no services in rehabilitation. Although the Vocational Rehabilitation Acts were initiated in the early 1900's to protect and assist veterans with disabilities, additional Acts were developed but none were associated with brain injury restoration. These Rehabilitation Acts were geared more for sheltered workshops for persons with discriminating disabilities. Although this law was for the most "severely" disabled, many survivors with TBI were too severe for most services. Many survivors of TBI were ignored, considered "nonrehabilitatable," or for the less severe, were given menial (often token) positions for training or employment. Rehabilitation for this population in the past and present is considered "two costly" as sometimes it requires some long term restoration services. Instead, these individuals are often provided unacceptable, but cheaper, alternatives in place of rehabilitation. In Alaska, there is no long-term rehabilitation program(s) for persons with brain injuries, outside of the private rehabilitation specialists, who do exist.

However, most of the survivors cannot afford their services. As the majority of these individuals do not have funding for even basic needs, they usually fall through the cracks into destitution without a chance of rehabilitation. In fact, only 5% of these individuals receive proper rehabilitation and secondary problems usually develop, e.g., increased rates in suicide, substance abuse, poverty, etc., all associated with the brain injury (specific data will be provided at the presentation). However, additional statistics show that when survivors are rehabilitated, these individuals are harder workers than the nondisabled, have fewer sick days, and are considered committed employees.

Our organization desperately needs funding and we believe that we can offer you a great barter. We receive approximately 5 phone calls a day just at our Anchorage office requesting assistance, and many others for information, and we do the best we can with our limited funding (last year cash donations were $425). During this time, we provided information to organizations such as the Division of Vocational Rehabilitation, ACCESS Alaska, P.A.R.E.N.T.S., School Districts, private organizations, etc., as well as parents and survivors - all without funding. Obviously, we were only able to offer basic information. We suspect that our organization, with proper financial support, could incorporate the full gamete of rehabilitation services at offices that would encompass rehabilitation counseling, vocational training, assistive technology, prevention, employer/employee education as well as family education, and training to the school districts. This program could encompass neuroevaluations, occupational therapy, speech therapy, physical therapy, community integration and social training, rehabilitation counseling, cognitive restructuring, etc., all in one office, which could reduce costs. Furthermore, additional studies have shown that proper rehabilitation could even reduce crime rates as many incarcerated individuals have sustained a significant brain injury that altered their cognitive abilities, e.g., poor problem solving due to cerebral injury. In summation, it could be a one-stop-shop for persons with brain injuries once they leave the hospital. In addition, once we have completed the non-profit requirements, there will be tax benefits for any contributors and supporters. Our goal is to assist any individual who has a brain impairment to reach their highest level of potential with a major goal of independence and reemployment for most individuals. For the children, we can "teach the teachers."

Another major goal of the Brain Injury Association is prevention, such as methods to reduce violence and injury (HeadSmart Program) or the Headie Hurtle Program for young children and educate the public about this often disabling injury, e.g., the importance of helmets for bicyclists, motorcyclists, and all ATVs (All Terrain Vehicles). We also want to visit hospitals where we can disseminate information to the families of the survivors and obtain a 1-800 number for the state. We are willing to travel to villages through our Ambassador Program, which distributes information about prevention and rehabilitation statewide. It would be during this time that support groups and chapters could be developed, with an emphasis in respecting cultures. Our intent is to incorporate education, support, rehabilitation, and prevention for the public, children and adults. We are also working on a registered program developed by professionals called B.I.R.D.S. (Brain Injury Rehabilitation Developmental Systems), which is specifically geared for professionals, e.g., teachers, counselors, medical community, etc. for treating children from birth to 21 years of age. Obtaining services has been done in other states where funding was provided, e.g., Florida, Arizona, Washington,

etc. Furthermore, this could be funded by several grants associated with the TBI Act, donations by organizations and companies, monies from insurance companies, or dollars added to traffic fines. With time, funding from multiple resources could be identified, which would reduce funding from the state. We believe that BIA of Alaska could be self-supporting after five years.

We know this is a simplistic explanation of our goals, but we believe that this is attainable. We would appreciate an opportunity to meet with the Senators and Legislators to discuss the possibilities. I hope you will support and attend our meeting in Juneau in February

Respectfully,

Debra M. Russell

Brain Injury Association of Alaska

Debra M. Russell, Ph.D. Candidate, CRC, President
Rick Warrington, Vice President
Mary Warrington, Vice President

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What is the Brain Injury Association?

Founded in 1980, the Brain Injury Association (BIA) is a national advocacy organization, providing services to millions of Americans with traumatic brain injury (TBI) and their families. BIA works to increase public awareness of TBI through our network of state associations and support groups, and provides support programs directly to individuals who have sustained a brain injury and their families. BIA also provides a toll-free Family Helpline which offers information about brain injury, available services and resources. The Brain Injury Association is here to provide the help and information people need.

The BIA Mission Statement:

The mission of the Brain Injury Association is to advocate for and with people who have survived brain injury, to secure and develop community based services for people with traumatic brain injury and their families, to support research leading to better outcomes that enhance the life of people who sustain a brain injury, and to promote prevention of brain injury through public awareness, education and legislation.

What can the BIA offer you?

The following is a sample of BIA programs supported in part by membership dues:

The BIA Information and Resource Network:

BIA's toll-free Family Helpline responds to over 20,000 queries each year, concerning every aspect of brain injury, including rehabilitation facilities, state associations, and much more. Individuals with brain injury, their families and professionals can turn to the Helpline for information and support.

Public Awareness:

Through BIA's national education and public awareness campaigns, The organization promotes awareness and educates the public about the causes and consequences of TBI, and the means and benefits of TBI prevention.

Educational Symposia and Workshops:

Through its annual national symposium, regional and state association conferences, BIA promotes the exchange of ideas and information about TBI. Topics run the full spectrum of issues, including: family needs, trends in current brain injury research, new models for treatment and the effectiveness of rehabilitation methods. Regional training workshops are conducted in conjunction with our state chapters, and a series of acute neurotrauma conferences will take place at five strategic locations throughout 1996.

Educational Materials:

BIA maintains an extensive library about TBI research, epidemiology, rehabilitation, and information about brain injury. In addition, BIA's *Catalogue of Educational Materials* includes over 100 books, brochures, tapes and videos on a wide range of subjects related to brain injury. These materials can be purchased through our publications department.

Prevention Campaigns:

Prevention education is a high priority for BIA. Educating the public about prevention of traumatic brain injury is a major focus of BIA. Through the Be HeadSmart™ Campaign, BIA is reducing the incidence of TBI. In addition, the Violence and the Brain Injury Project addresses the root causes of violent criminal behavior and examines the efficacy of model treatment and violence prevention.

Defense and Veterans Head Injury Program (DVHIP):

The DVHIP is a unique collaboration among the Department of Defense, Department of Veterans Affairs and BIA. This project ensures that all military and DVA personnel with TBI receive specific evaluation and follow-up to assist in their treatment.

Advocacy and Public Policy:

The Paul Spanbock Fund for Public Policy was created in 1993, to ensure adequate representation of people with TBI before the Congress, Administration and Executive branch. Advocacy is the reason BIA is in Washington, DC. Because of BIA's continued presence and activity here, your concerns have a strong voice and impact on the public policies and laws developed and enacted by our government. Significant changes are occurring in Washington by the moment, as a result, BIA remains vigilant in its mission to advocate for and with persons with TBI, their families, and the people who serve them.

State Associations:

Through BIA's national network of state associations, chapters, and support groups, individuals can identify and reach local resources who understand the needs and problems associated with TBI. Social reinforcement is an integral aspect in rehabilitation both for the person with brain injury and family members. Through this network, you can become involved in local activities and find the social support you may need.

The Brain Injury Resource Center (BIRC):

The Brain Injury Resource Center is an interactive multimedia touch-screen computer system. A combination of video, graphics, text, and sound delivers educational information about brain injury, rehabilitation and prevention. The system provides information which meets the needs of a family member whose relative has sustained an injury. At the same time, it will provide education and information of a more technical nature for medical professionals with varying degrees of knowledge of TBI. And, because the person using the BIA's Brain Injury Resource Center controls the rate at which it is explored, they can learn at their own pace.

TBI Challenge!

All members receive TBI Challenge! BIA's quarterly magazine. This magazine addresses issues of importance to people with TBI and updates members on the activities of BIA and its state Associations.

International Brain Injury Foundation (IBIA)

IBIA ia a multi-disciplinary organization dedicated to promoting international awareness of brain injury through grassroots advocacy programs, education concerning the latest innovative medical treatment and subjects related to brain injury. IBIA is composed of individuals with brain injury, their families, professionals and other concerned individuals from all over the world.

The Library

The BIA library houses a collection of approximately 10,000 volumes on issues related to brain injury and disabilities. It consists of print as well as audio/video materials and has an extensive assortment of serials, conference proceedings and reference literature. (Rev. 7/95)

WHO SUSTAINS TRAUMATIC BRAIN INJURIES

Males aged 14 to 24 years are at highest risk, followed by infants and the elderly.[7]

Males are twice as likely as females to sustain TBI due to differences in risk exposure and lifestyle.

According to the National Pediatric Trauma Registry, more than 30,000 children sustain permanent disabilities as a result of brain injuries.[8]

WHEN TRAUMATIC BRAIN INJURY OCCURS

Mid-afternoons to early evenings, weekends and the summer months are critical times during which TBI is most likely to occur.[9]

Children are especially at risk in the afternoon hours after they are dismissed from school. 42.6% of children's injuries occur on roads, 34.3% at home and 6.6% in recreation areas.[10]

CONSEQUENCES

Cognitive: may include short and long term memory loss; difficulties with concentration, judgment, communication and planning; spatial disorientation.

Physical: may include seizures; muscle spasticity; vision, hearing, smell and taste loss; speech impairment; headaches; reduced endurance.

Psychosocial/Behavioral/Emotional: may include anxiety and depression; mood swings; denial: sexual difficulties; emotional lability; egocentricity; impulsivity and disinhibition; agitation; isolation.

COST

The cost of traumatic brain injuries in the United States is estimated to be $48.3 billion annually. Hospitalization accounts for $31.7 billion, whereas fatal brain injuries cost the nation $16.6 billion.[11]

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TRAUMATIC BRAIN INJURY ACT BECAME LAW IN 1996

Congress Passes Traumatic Brain Injury Act

On July 12, 1996, the Senate passed language identical to the House passed version of the Traumatic Brain Injury Act. The House of Representatives had passed the bill on July 9. The TBI Act authorizes the federal government to spend $24.5 million over the next three years on:

- Grants to states to develop model treatment programs.
- Funds for the Centers for Disease Control and Prevention to study the incidence of brain injury.
- Funds for agencies in the Department of Health and Human Services to research into prevention, treatment and rehabilitation of brain injury.
- Funds for the National Institutes of Health to host a national conference, gathering all the experts in the field of brain injury.

After a 5 -year process, not a single legislator voted against the Traumatic Brain Injury Act in 1996. In fact, a number of legislators were instrumental in passing the TBI Act. Jim Greenwood of Pennsylvania ushered this legislation through the House and consistently worked with the Senate to keep that chamber on track. Other legislators who played pivotal roles include Senators Orrin Hatch of Utah and Ted Kennedy of Massachusetts, and Congressman Frank Pallone of New Jersey.

President Hosts Signing Ceremony For The Traumatic Brain Injury Act

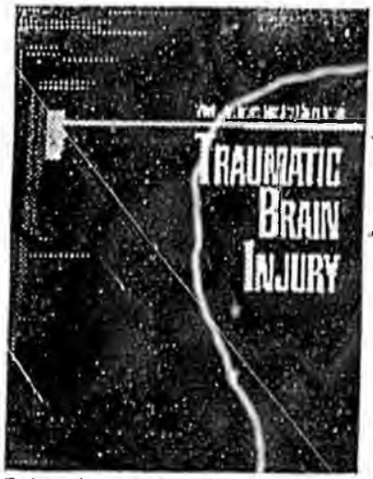
On July 29, President Clinton hosted a signing ceremony, recognizing the importance of people with brain injury and their families. By passing and signing this legislation, the federal government has taken proactive efforts to resolve problems associated with brain injury. Christopher Reeve, Gary Busey, Jim Brady and Frank Gifford made phone calls to the White House to convince the President that this signing ceremony was important to millions of Americans -- individuals with brain injury and their family members. In addition to BIA President Dr. George Zitnay, Vice Chairman Jim Brady and Chairman Martin Foil, top federal agency officials and ranking members of Congress were present at the ceremony.

Congress Appropriates Funds for the Traumatic Brain Injury Act

On September 30, 1996, Congress appropriated funds to support the Traumatic Brain Injury Act for fiscal year 1997:

- $2,600,000 for the Centers for Disease Control to study the incidence of brain injury and fund education/prevention initiatives
- $2,857,000 for the Health Resources and Services Administration to implement model demonstration projects at the state level
- A directive to the National Institutes of Health to organize a national consensus conference and produce a white paper on brain injury in the United States

http://www.ncsl.org/public/catalog/6639ex.htm



What Legislator's Need To know About Traumatic Brain Injury

Executive Summary

Each year, 2 million Americans sustain traumatic brain injuries from automobile crashes, falls, recreation injuries, assaults and violence. These injuries are the leading cause of death and disability in children and young adults in the United States. Of those who suffer traumatic brain injuries, 75,000 to 100,000 will die, and 70,000 to 90,000 must live the remainder of their lives with severe disabilities. The highest rate of injury is suffered by young males.

Brain injury has dramatic repercussions for the injured and their families. People with brain injuries have trouble with short-term memory, concentration, judgment and organization. Many have substance abuse problems that may have existed before the injury or were acquired afterwards as a way to escape the difficulties of their lives. Divorce is common among married people who sustain brain injuries, and many lose their friends. People with serious brain injuries may need constant supervision and help in managing money, doing household chores, and sometimes bathing and dressing. Because the injuries are not always visible, people with brain injuries may have trouble qualifying for federal and state programs.

Families provide the majority of care for people with brain injuries. Many exhaust their family resources or have to give up jobs to care for a family member full time. The psychological and financial stress is overwhelming as families struggle to provide care with little or no help from existing state service systems.

Today, more and more people survive brain injuries, thanks to advances in medicine and trauma care. The for-profit brain injury rehabilitation industry has grown rapidly in the last 10 years until it is now generating an estimated $10 billion a year in gross revenues.

However, state services have lagged far behind for people with brain injuries who are not insured, have exhausted their benefits, or have left the rehabilitation centers to live with their families or in the community. Today, only one in 20 people with traumatic brain injuries receives the rehabilitation services needed.

People with brain injuries, like everyone else, want good relationships with friends and family, respect and dignity, opportunities to develop and exercise competence, and opportunities to contribute to community life and make choices about their futures. The growing advocacy movement is demanding that people with traumatic brain injuries be able to control their lives and the services they receive. Increasingly, legislators will be asked to set polices based on these values and create cost-effective systems of care.

Though some forward-looking states are providing services targeted at the special needs of people with brain injuries, in other states services are fragmented and inefficient. Many state bureaucracies

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have no central home for people with traumatic brain injuries. Services are spread over many departments, including health, mental health, education and social services, to name a few. This causes problems for the people with brain injuries and their families who have to go from department to department, trying to patch together services. It also causes problems for states as they look to developing policies that would more appropriately meet the needs of people with traumatic brain injuries.

States are trying to improve service delivery by establishing state councils, creating a lead agency for people with traumatic brain injuries, and offering case management to control costs by ensuring that people get the most appropriate services. States are paying for services through traditional sources of financing such as Medicaid, vocational rehabilitation funds and state general revenues. States are also making use of more innovative financing ideas, such as dedicated funding streams drawn from fees on motor vehicle violations, including speeding, drunk driving and seat belt violations. Other states are writing Medicaid home- and community-based waivers targeted at people with traumatic brain injuries.

States can reduce the catastrophic costs of brain injury through prevention programs. Brain injury, unlike other illnesses, can be prevented in many instances. States can help prevent the incidence and severity of brain injury by passing and rigorously enforcing laws requiring seat belts, child restraints and helmets for motorcycle riders. States and localities can also launch educational campaigns to increase the use of helmets by bicycle riders and in other sports.

This publication is intended to provide legislators with the background information to help them make informed public policy decisions about systems of care for people with traumatic brain injuries in their states. The booklet is in a question and answer format and is organized as follows:

- The first two questions define traumatic brain injury and its impact on people with brain injuries and their families. They raise issues of interest to legislators, including the high cost to society, the high cost of inappropriate care, the inability of existing service systems to meet the needs, aging caregivers, the growth of advocacy movements, federal legislation that will elevate brain injury to the national agenda, and the availability of data.
- Questions 3 and 4 outline services needed by people with brain injuries and available federal assistance.
- Questions 5 and 6 look at private insurance coverage for people with traumatic brain injuries and public/private options that might be used to support services, including publicly subsidized health insurance, state-financed catastrophic health insurance, catastrophic riders to insurance policies, preferred provider organizations targeted at people with disabilities, state high-risk pools and self-sufficiency trusts.
- Questions 7 and 8 look at state service delivery and financing of services for people with traumatic brain injuries.
- Prevention efforts are addressed in Question 9, including mandatory seat belt laws, mandatory helmet laws for motorcycle riders and other strategies.
- Question 10 presents innovative approaches by state and nonprofit agencies, including statewide programs, home- and community-based services, housing, jobs education, and central registries.

TONY KNOWLES, GOVERNOR

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May 29, 1997

Jean Athey, Director
Emergency Medical Services for Children
Maternal and Child Health Bureau
Health Resources and Services Administration
Room 1812, Parklawn Building
5600 Fishers Lane
Rockville, Maryland 20857

Dear Ms. Athey:

It is with pleasure that I submit the attached application for a Traumatic Brain Injury Demononstration Grant. This request is for a Planning Grant for one year.This application was completed by the Section of Community Health and Emergency Medical Services, within the Division of Public Health, Department of Health and Social Services.

Within the application package you will find all signed assurances and certifications required by the program announcement.

Thank you for the opportunity to focus efforts on traumatic brain injuries.

Sincerely,

Karen Perdue
Commissioner

enclosure