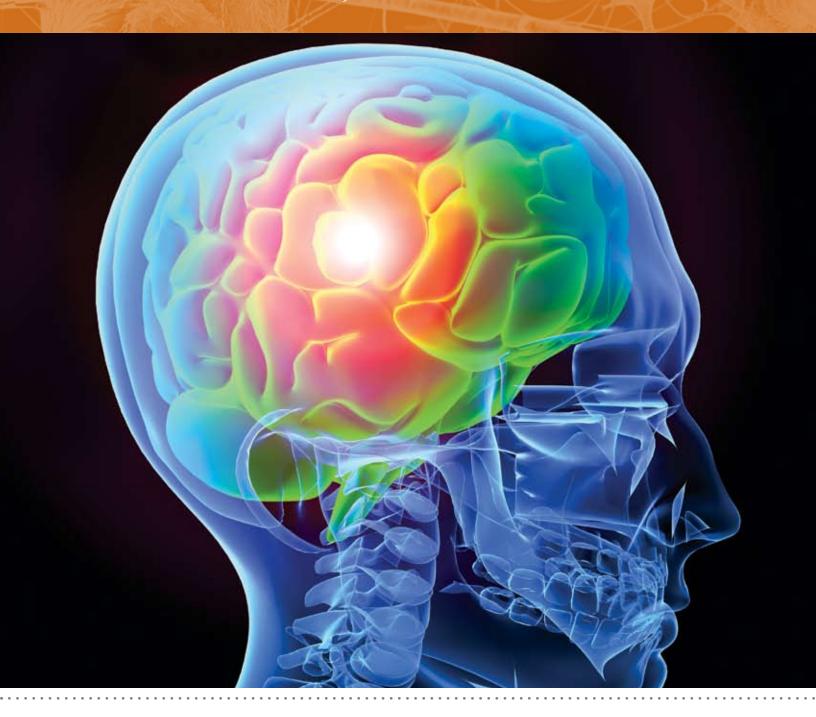
BRAIN INJURIES IN ALASKA



10 year tbi alaska state plan

OCTOBER 2008

ALASKA DEPARTMENT OF HEALTH AND SOCIAL SERVICES , BEHAVIORAL HEALTH , SENIOR AND DISABILITY SERVICES ALASKA MENTAL HEALTH TRUST AUTHORITY , ALASKA BRAIN INJURY NETWORK, INC.

ACKNOWLEDGEMENTS

The Alaska Brain Injury Network (ABIN), Inc. thanks the many people who have been involved over the years with conducting needs assessments and holding public forums to gain input to help Alaska state government to envision a service delivery model for persons with brain injury. This includes the Alaska Brain Injury Network, Inc. committee members who met diligently to discuss, review and provide input. The ABIN appreciates its partners and other organizations that have contributed their knowledge and expertise. Thank you to the Alaska Legislature which provided funding for the development of this plan.

The Alaska Brain Injury Network, Inc. (ABIN), a non-profit organization established in 2003, serves as the TBI Advisory Board to the Department of Health and Social Services and the Alaska Mental Health Trust Authority. The ABIN has embarked on developing this State Plan for improving, developing, and expanding services and supports that reflect the needs of individuals and their families. State program and agency staff have provided invaluable expertise in order to develop a comprehensive approach to capture strengths in Alaska's state service programs, as well as gaps that need to be addressed.

In February 2008, the Alaska Brain Injury Network (ABIN), contracted with S.L. Vaughn & Associates, LLC, to assist the ABIN in developing a comprehensive state plan. These recommendations will be forwarded to the Governor, the Alaska State Legislature, Department of Health and Social Services and the Alaska Mental Health Trust Authority.

On the website you will find the full report: www.alaskabraininjury.net

We invite your comments and suggestions which you can submit to the ABIN at contact@alaskabraininjury.net

PREFACE



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<u>contact@alaskabraininjury.net</u> www.alaskabraininjury.net Every day someone is involved in a car crash, a fall, a sports injury or other incident that results in a traumatic brain injury which alters the way he or she may live over a lifetime.

Alaska has one of the highest TBI rates in the nation. Of recent concern is a significant, but as yet unknown, number of Alaskan service members returning with diagnosed and undiagnosed brain injury.

With appropriate and available care, rehabilitation, community and family supports, even the individual who is most severely injured can live at home, return to school or work, or engage in meaningful and productive life activities.

The Alaska Brain Injury Network and its partners have embarked on developing this 10 year state plan for the purpose of reducing the incidence of brain injury and minimizing the disabling conditions through the expansion of services and supports for TBI survivors and their families.

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WHAT IS A TBI?

TBI DEFINITION

The Centers for Disease Control and Prevention (CDC) defines traumatic brain injury (TBI) as: caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain.

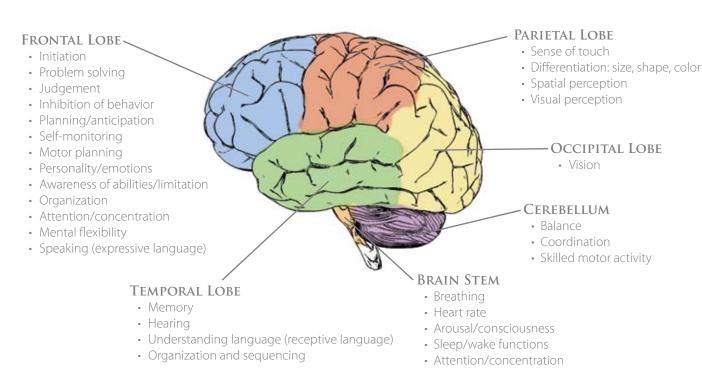
A traumatic brain injury (TBI) is an injury caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI.

Individuals who have TBI-related disabilities may have physical, cognitive or emotional difficulties, or a combination of difficulties that may affect the individual's ability to return to home, school or work, and to live independently. The cognitive difficulties often have more impact on an individual's recovery and independence than his or her physical limitations.

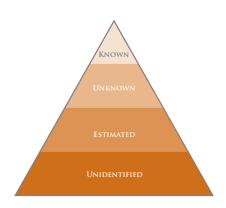
No two brain injuries are alike, which makes developing services for individuals with TBI and their families even more challenging. TBI differs from person to person, depending on the location of the injury, severity, age, pre-injury functioning, substance abuse, education and other factors. While rehabilitation and service needs may be similar, the type of service and duration, as well as when the services are needed, may vary from person to person.

Traumatic brain injury is a significant public health problem resulting in medical costs, lost time from work and life long disabilities, particularly for those who sustain moderate to severe injuries.

UNDERSTANDING THE AMAZING BRAIN



TBI PYRAMID



Known

800 hospitalized or fatal TBI/year

Unknown

About 3,000 emergency visits with mild TBI/year

Estimated

10,000+ Alaskans living with TBI

Unidentified

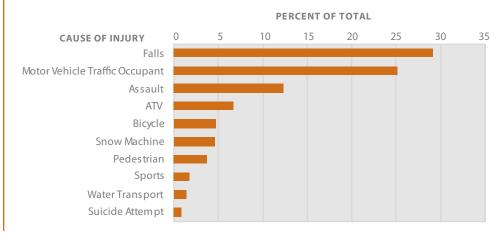
Symptoms not recognized as TBI

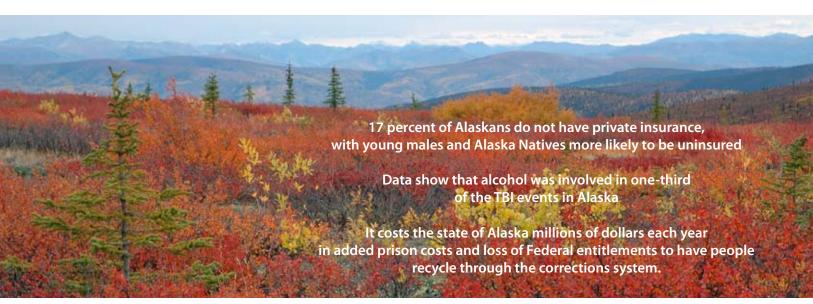
Every year the Alaska Department of Health & Social Services reports about 800 TBI cases resulting in hospitalization or death. The CDC estimates that almost 3,000 Alaskans visit the emergency department each year with a mild TBI. There are an estimated 10,000 plus Alaskans currently living with a disability due to their TBI.

The three top causes of TBI among those admitted to a hospital from 2001-2005 were falls, motor vehicle traffic crashes and assaults. Off-road motor vehicle crashes, snow machine and ATV combined, ranks a close fourth.

The highest rates of TBI are among Alaska Natives, residents of rural Alaska, youth ages 15-19 in motor vehicle crashes, and elders who fall.

TOP TEN CAUSES OF NON-FATAL TBI HOSPITALIZATIONS OF ALASKA RESIDENTS, 2001-2005





GETTING THE RIGHT SERVICES AT THE RIGHT TIME

CREATING ABIN

The Alaska Brain Injury Network, formerly the Alaska Traumatic Brain Injury Advisory Board, organized in 2000 to fulfill the requirements of the US Health Resources and Services Administration (HRSA) Federal TBI Act. The ABIN now serves as an advisory board to the Department of Health and Social Services and the Alaska Mental Health Trust Authority.

ABIN MISSION

To educate, plan, coordinate and advocate for a comprehensive service delivery system for survivors of TBI and their families. The ABIN and participating partners have developed this comprehensive plan to address the challenges of this disability.



Treatment and care begins from the time of injury and may span a lifetime for many individuals with resulting disabilities from their TBI. An effective service delivery system is one with a coordinated and integrated multi-disciplinary approach. The components include: emergency medical services; early intensive and acute medical care; comprehensive rehabilitation services; community integration; and psychosocial, vocational, community and long-term services and support.

Alaskans with moderate to severe injuries generally enter the health care system through emergency departments. Individuals with mild TBI, or concussion, are most likely to access services through emergency departments, clinics, physician's offices or not at all. These individuals may experience problems later and warrant follow-up assessment, counseling and other assistance.

Screening special populations often results in identifying individuals with TBI who have not been previously identified, but may have associated problems. These populations are often found in schools, correctional facilities, behavioral health programs, and domestic violence and homeless shelters. The Alaska Division of Behavioral Health providers routinely screen for TBI and find that one third of those who approach their agencies for behavioral health services are identified as having history of TBI.

Patients with moderate to severe TBI who receive rehabilitation immediately following their medical stabilization, also known as post-acute rehabilitation, have better outcomes than patients who don't receive prompt rehabilitation. Post-acute rehabilitation may be provided in a free-standing rehabilitation program within a hospital, in a separate rehabilitation facility, or offered in the home.

Transition and follow up services in the individual's home following rehabilitation is critical. Individuals with traumatic brain injury generally have trouble transferring learned behavior from one setting to another setting. It is important, therefore, to teach functional skills in context and in an established routine.

Individuals with traumatic brain injury may need specialized vocational training and supported employment. Others may need assistance obtaining housing, or supports such as personal assistance or help with managing finances. And, others may require more intense care, especially those with significant medical, behavior or substance abuse issues.

Children and youth who are injured require similar acute and rehabilitation services as adults, but these rehabilitative services need to be tailored to the needs of children. Rehabilitation for adults focuses on relearning skills already acquired, while children, depending on their age at the time of injury, may not have acquired certain skills. Since most children return to school, rehabilitation

staff should create transition plans to help educators develop education and learning strategies that accommodate the disabilities of the child. It is not uncommon for TBI related disabilities to become more apparent when a child enters middle school or high school.

Children with more severe injuries may require medical assistance or structured behavioral settings. They may be placed in residential programs, receive services in out-of-state programs or the family may need extensive help in their homes to care for the injured child.

With such a variety of circumstances and needs, the challenge for service delivery systems is to offer the right services at the right time – to be responsive to when the problems arise or are presented. One strategy for ensuring that individuals receive timely services and supports is through service coordination.

Service coordination is a critical element in helping individuals who have multiple needs to access multiple resources. A service coordinator may facilitate the:

- Evaluation and assessment of needs;
- Information and education about the cause and effects of TBI and preventing secondary conditions;
- Development of a service plan to meet the identified needs; and
- Provision of assistance in locating and accessing resources and services such as medical care, housing, counseling, transportation, rehabilitation, vocational training, and cognitive/behavioral training.

Services Available for Alaskans with TBI

Since 1992, Alaska has focused attention on how best to serve individuals with TBI and their families through existing systems. The Alaska Division of Behavioral Health has required its providers to screen Alaskans seeking behavioral health services. The data show approximately one third of those applying for behavioral health services have history of TBI. There are other State agencies directly serving Alaskan adults and children with TBI, such as Senior and Disability Services, Vocational Rehabilitation, and Education and Early Development. There are other State agencies indirectly serving Alaskans with TBI, such as Juvenile Justice, Corrections, Public Health, and the Alaska Native Tribal Health Consortium. Because they do not screen for TBI, data collection is not possible. More importantly, the services may not fully address the needs of the TBI survivors. The military has increased TBI services in the years 2007-08. Screening for those deployed is mandatory through the Post Deployment Health Reassessment. In addition, there is a mild TBI clinic at Elmendorf Hospital.



Children who experience a TBI at an early age may or may not exhibit some of the behavioral and cognitive problems associated with the TBI until they reach adolescence.

Schools often misclassify children with brain injury as having a learning disability, an emotional disability or developmental disability.

DEFINING CORE SERVICES

GUIDING PRINCIPLES ADOPTED FOR SELECTING TBI SERVICES AND SUPPORT

Person-Centered

Individualized and self-determined

Easy to access

No "wrong door" for services

Timely

Right services at the right time

Effective

Evidence and outcome based

Appropriate

Based on individual strengths, needs, age, and least restrictive environment

Efficient

Maximizes resources; avoids duplication

Seamless

Transitions through continuum of care and across systems

Equitable

Access to services and quality of care are provided regardless of gender, ethnicity, age, geographic location and ability to pay

Safe

Provides a safe and healthy environment, yet supports dignity of risk

The Alaska Brain Injury Network, Inc. and their collaborators have defined the services and resources needed to support individuals with TBI and promote independence and success. These services aim to be in the least restrictive environment with the highest quality care.

The core services selected are organized under two major headings:

I. SERVICES AND SUPPORTS

- Information and Referral
- Service Coordination
- Acute and Post-Acute Rehabilitation
- Children and Youth: Education and Related Services
- · Vocational Rehabilitation and Employment
- Long-Term Care and On-Going Support

II. SYSTEMS INFRASTRUCTURE

- Public Awareness, Prevention and Advocacy
- Outreach and Identification
- Training and Workforce Development
- Statewide Planning and Policy Coordination

The ABIN and partners recognize that a strong system of services that are timely and efficient will be dependent on interagency collaboration, common goals and defined outcomes. Data across systems will be needed to assess progress toward the overall goal of this plan, which is to improve existing systems and expand services.

Anticipated results of improving existing systems and expanding services:

- · Fewer number of Alaskans sustaining a TBI.
- Efficient and coordinated TBI services that result in seamless transitions along a continuum from scene of injury to home and community supports.
- Maximize recovery through community integration and support services to enable individuals with TBI and their families to return to home, work or school.
- Improved health, safety, social, educational and employment outcomes for individuals with TBI.

RECOMMENDATIONS



William B. Anchorage, AK. Motorcross crash, May 26, 2007, resulting in traumatic brain injury.



Received acute and post-acute rehabilitation. 46 days in the hospital.



Today William lives at home. His day includes school, appointments, and ongoing rehabilitation efforts.

The ABIN has set forth the following recommendations to implement, improve or expand programs to offer a seamless system of these services and supports. These recommendations have emerged from defining service requirements, assessing current capacity, and then identifying gaps. Implementing these recommendations may require funding, which may include federal grants, federal programs (i.e. Medicaid), state funding or other sources, as well as coordination with existing resources among state and local agencies and partners. Chapter 3 of this plan provides a description of the services and detailed recommendations over a 10 year time frame. The following are prioritized recommendations.

Information and Referral

- Continue Resource Navigator(s), supporting materials, web site and phone line (toll free) beyond 2009.
- Expand the United Way 2-1-1 capabilities to include TBI resource and services information.
- Expand Aging and Disability Resource Center capabilities to include TBI resource and services information.
- Develop and provide educational packets for TBI patients in emergency departments, clinics, doctor's offices, and other health care settings.

Service Coordination (Care Coordination or Case Management)

- Two (2) positions for TBI Service Coordination as a Demonstration Project in FY 2010, with the goal of expanding to cover either (1) additional persons with TBI and/or (2) to cover additional regions of the state in subsequent years.
- Expand care coordinator capacity in other agencies that may serve TBI through training on brain injury and available resources. Develop and continue protocols with hospitals for linking individuals to services following TBI.
- Develop Memorandum of Understanding with agencies to help coordinate case management services across agencies (establish primary, secondary TBI service coordinators; facilitate team planning).

Acute and Post-Acute Rehabilitation

- Develop funding options through general revenue, federal grant, Medicaid and private insurance to pay for post-acute rehabilitation and therapies.
- Identify and develop community providers for rehabilitation services.
- Pilot program models for delivery of rehabilitation services (i.e. in-state rehabilitation facility, telerehab, mobile rehab clinic, in-home therapies).
- Pool resources for rehabilitation service system (i.e. Veteran Affairs, Department of Defense, Indian Health Services, and Worker's Compensation).



Parent and educator training.



Independent living skills training.

Children and Youth: Education and Related Services

- Support the Bring the Kids Home initiative.
- Expand capacity for helping families with children with TBI under the Alaska Parent Training Initiative at Stone Soup Group and other parent training programs.
- Provide training to educators and paraprofessionals on brain injuries, identify resources to help educators work with students who have TBI on academic and behavior.
- Utilize Special Education Service Agency (SESA) and Stone Soup Group as resources and as trainers to school districts.
- Collaborate with Vocational Rehabilitation and Tribal Vocational Rehabilitation to increase employment opportunities for students with TBI who are transitioning from school into adult life.

Vocational Rehabilitation and Employment

- Increase long-term supported employment programs (job coaching).
- Expand Mental Health Customized Employment Grant to include TBI.
- Provide training to VR counselors, community VR providers, and employers on TBI.
- Develop pre-vocational options to prepare people for vocational rehabilitation services.

Long-term Care and On-Going Support

- Apply for and fund a Home and Community-Based Services (HCBS)
 Medicaid Waiver for individuals with TBI who need long-term care,
 but are not eligible for community-based services as offered in other
 HCBS waiver programs.
- Expand existing waivers to serve TBI.
- Fund similar services for non-Medicaid eligible individuals.
- Obtain state or AMHTA funds as seed money to start Club House/day programs for TBI.
- Include TBI in Senior and Disability Services efforts to develop person-centered hospital discharge planning model to help transition to community services.

RECOMMENDATIONS



Prevention is the only cure for brain injury.

Post-injury employment rates for individuals with TBI range from 22 percent to 55 percent, and wage levels for those who returned to work post-injury have also been low.

Research has demonstrated favorable employment outcomes following participation in supported employment, while other studies have indicated that college, counseling and job placement result in successful employment.

Public Awareness, Prevention, and Advocacy

- Continue public awareness campaigns that inform Alaskans about TBI.
- Enact booster seat legislation.
- Develop and implement an elder fall prevention program.
- Support local helmet use ordinances.
- Adopt ImPACT concussion management system for school sports and expand to semi-professional leagues.
- Recruit and train TBI self-advocates.

Outreach and Identification

- Develop outreach materials and disseminate.
- Develop materials that are culturally appropriate.
- Increase TBI screening among high risk populations in these settings:
 - Schools to better identify children and youth with TBI, as defined by IDEA;
 - Correctional facilities;
 - Long-term care facilities to identify older adults who may have an undiagnosed TBI;
 - Health clinics, emergency departments and other health care settings;
 - Post-deployment to identify returning service members who may be undiagnosed or misdiagnosed.

Training and Workforce Development

- Develop distance delivered TBI curriculum.
- Conduct training through existing educational certificate and endorsement programs.
- Conduct training through agency sponsored workshops/conferences for direct care providers, educators and other professionals/ paraprofessionals.
- Expand core competencies for the workforce to address TBI.
- Expand telehealth for training providers and families, particularly in rural areas.

Statewide Planning and Policy Coordination

- Continue TBI Advisory Board role as the planning board for the Department of Health and Social Services and the Trust, maintaining funding eligibility under HRSA TBI ACT.
- Continue to provide a venue for consumer input on the TBI service delivery system.
- Expand data capacity across pertinent programs to evaluate the TBI service delivery system; i.e individuals served, services provided, expenditures and outcomes.
- Continue TBI participation among the 4 statutory advisory boards.
- Develop Memorandum of Understanding to coordinate program data; individual service planning, including TBI documentation/evaluations, subject to confidentiality release of information.
- Evaluate post consumer satisfaction surveys every 2 years.

IMPLEMENTATION OF RECOMMENDATIONS





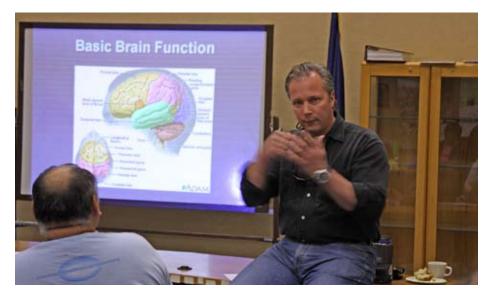
TBI Survivor and Family Member Panel. ABIN workshop in Barrow, Alaska.



Dr. Heather Macomber, ABIN Board Member and Neuropsychologist, answering questions from Tok resident. ABIN workshop in Tok, Alaska.

To promote this plan, ABIN will coordinate the participation of partner agencies, policy makers, community providers and advocates in developing strategies for implementation. The ABIN Board of Directors invites public comment on the plan's recommendations, as well as public participation in growing a system in Alaska where TBI survivors thrive and are well served. Progress will be reported to the ABIN Board and key partners annually.

To learn more about the 10 Year TBI State Plan and find out how you can get involved, please visit the Alaska Brain Injury Network website: www.alaskabraininjury.net



Dr. Russell Cherry, ABIN Board Member and Neuropsychologist.

ABIN Board and staff listening to public comment in Kodiak, Alaska.



TRAUMATIC BRAIN INJURY (TBI): IN AN INSTANT, FOR A LIFETIME

TBI DEFINITION

The Centers for Disease Control and Prevention (CDC) defines traumatic brain injury (TBI) as: caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury.

Holly is a 24-year-old woman who was injured in a car crash. She was diagnosed as having a traumatic brain injury. She didn't recognize anybody – not even her parents. Her mother says that her main concern is that her daughter is forgetful, moody and sometimes very emotional, not like she used to be.

Her mother wants to get Holly into some kind of program, but she doesn't have the resources. She was unsuccessful in qualifying Holly for Medicaid. Her parents are frustrated about not being able to help their daughter resume her life after traumatic brain injury.

Had Holly received the right services at the right time her story could read:

Holly was in a car crash; she was wearing her seat belt. She had physical injuries as well as injuries to her head, resulting in traumatic brain injury. She received medical care at the hospital. After acute care where she became medically stable, she received post-acute rehabilitation (i.e. physical, speech and language, and occupational therapies) where she was taught coping skills for her emotions and compensatory strategies for her memory.

Upon discharge from rehabilitation, a service coordinator was instrumental in helping her develop short and long-term goals, helping access appropriate services to reach those goals, and providing education and supports to the family about TBI. Holly sees a behavioral health specialist who is trained in TBI to help her and her family with her emotional issues. Holly is also in vocational rehabilitation. As a result of these coordinated services, Holly is able to learn how to function independently.

Her mother is able to return to work while Holly begins a journey of discovering how to best live with her brain injury and pursue educational and vocational goals.

MANY ALASKANS WOULD BENEFIT FROM THE RIGHT SERVICES AT THE RIGHT TIME







INTRODUCTION

TRAUMATIC BRAIN INJURY (TBI): IN AN INSTANT, FOR A LIFETIME

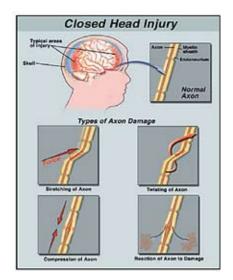
Symptoms of "mild" brain injury include headache, dizziness, vertigo (a sensation of spinning around or of objects spinning around the patient), memory problems, trouble concentrating, sleeping problems, restlessness, irritability, apathy, depression and anxiety. These symptoms may last for a few weeks after the brain injury.

Traumatic brain injuries are classified as "mild," moderate or severe. Mild Traumatic Brain Injury (MTBI), or concussion, is one of the most common neurologic disorders. According to the CDC, Emergency Department visits account for about 80 percent of TBIs and include a large number of mild TBIs. Most people recover from a mild TBI, but some have serious long-term consequences. In the CDC findings very young children ages 0 to 4 years had the highest rate of TBI-related ED visits (1,035.0 per 100,000 population), followed by older adolescents ages 15 to 19 years (661.1 per 100,000). Mild is a medical term associated with loss of consciousness, not necessarily associated with functional outcomes.

CDC estimates that the likelihood of an athlete in a contact sport experiencing a concussion may be as high as 19 percent per season. Although the majority of athletes who experience a concussion are likely to recover, an unknown number of these individuals may experience chronic cognitive and neurobehavioral difficulties related to recurrent injury. Symptoms following a mild TBI are referred to as "Post-Concussion Syndrome." A repetitive injury while recovering from an initial concussion can have catastrophic consequences, as in the case of "Second Impact Syndrome," which has led to approximately 30-40 deaths over the past decade.

There are two types of traumatic brain injuries: open and closed. An open brain or head injury is when a penetrating injury occurs as the result of an object piercing the skull and entering the brain tissue, such as a gunshot injury. A closed brain injury is when the head suddenly and violently hits an object but the object does not break through the skull, such as when a head hits the windshield of a car. An injury can also occur when a head is shaken so violently that the brain is damaged from inside the skull, which is what causes Shaken Baby Syndrome.

Primary blast waves can also cause concussions or MTBI without a direct blow to the head. Blast injuries are an emerging cause of TBI experienced in combat as part of the Global War on Terrorism. The brain is vulnerable to both secondary and tertiary blast injury. A still unresolved controversy is whether primary blast forces directly injure the brain. Shear and stress waves from the primary blast could potentially cause TBI directly (e.g., concussion, hemorrhage, edema, diffuse axonal injury). The symptoms of concussion and post traumatic stress disorder can be similar. However, the clinical data for brain injury due to primary blast forces is quite limited. The Department of Defense is still conducting research on blast injuries, brain injuries and related disorders.



INTRODUCTION

BRAIN INJURY AND RESULTING PROBLEMS



Alaska service members are returning from war with difficulties caused by brain injury.

The cognitive difficulties often have more impact on individuals' recovery and outcome than their physical limitations.

Individuals with a traumatic brain injury may have physical, cognitive or emotional difficulties or a combination of difficulties that may affect their ability to return to home, school or work, and to live independently. In general, problems associated with TBI include:

- Cognition or "thinking," changes referring to the ability to problem solve, concentrate, organize thoughts, plan, remember, and make good decisions.
- Personality and behavior changes that may result in lack of motivation, depression, anxiety, or irritability.
- Physical changes that affect mobility, balance, fatigue, weakness, or cause sleep disturbance.

The cognitive difficulties often have more impact on individuals' recovery and outcome than their physical limitations. Within a year, 90 percent of individuals with traumatic brain injury are getting around independently and are physically able to care for themselves. It is, however, the cognitive difficulties and behavioral problems that have the most significant impact in terms of one's independence (Novack, 1999). For example, problems with short-term memory make it difficult for individuals to remember to engage in activities of daily living that are critical to survival, such as remembering to eat, to take medications, to pay bills, and so forth. It also impairs a person's ability to learn new information, or sometimes to be able to retrieve old information previously learned.

Cognitive abilities are also needed to engage in appropriate speech and language. To communicate effectively requires being able to organize thoughts and to deliver speech that makes sense. Individuals with TBI often have difficulty picking up cues from others that are involved in the conversation or shifting with the focus of the conversation as others change topics. The person may have difficulty finding the correct words and will often talk around the topic. These problems may contribute to the inability to obtain and maintain employment, maintain a social network and to integrate fully into the community.

Individuals with TBI often have diminished insight and may not have a very good understanding of their deficits or the impact of those deficits on daily life. Individuals may continue to drive when they are unaware that their deficits may put them at risk, or they may make poor choices in social situations. Impulsivity and socially inappropriate behavior result from both diminished reasoning and lack of inhibition. For example, if working, an individual may say or do something inappropriate to other employees or to customers, which may affect his or her ability to keep the job.

Individuals with TBI may have "co-morbidity" or co-occurring conditions, meaning that there may be other conditions, such as substance abuse or psychiatric conditions, along with the brain injury. Substance abuse and psychiatric conditions associated with impulsive behaviors and attention-deficit disorders are often risk factors for TBI. Alcohol is frequently a contributing cause to the injury.

MEDICAL CONSEQUENCES OF TBI







MEDICAL CONSEQUENCES OF TBI INCLUDE PHYSICAL, COGNITIVE AND BEHAVIORAL IMPAIRMENTS

Impairment Description

Physical

- Physical disabilities such as loss of limb functioning and diminished range of motion
- Limited ability to perform daily activities such as eating, dressing, bathing, shopping, and managing finances
- Hydrocephalus, or fluid around the brain that causes intracranial pressure

Neurological

- Post-concussion syndrome, which includes headaches, dizziness, vertigo, sleeping problems, restlessness, and apathy
- Additional complications such as vascular and nerve injuries, chronic pain, seizures, and blood clots in the brain

Cognitive

- Difficulty with short-term memory, reasoning, decision-making, information processing, problem-solving, and concentration
- Post-traumatic amnesia, or permanent memory loss of events before and after the trauma
- Speech-language problems affecting written and verbal communication
- Difficulty interpreting subtle social cues and other non-verbal forms of communication

Communication

• Impaired vision, smell, taste, and hearing and limited hand-eye coordination

Behavioral

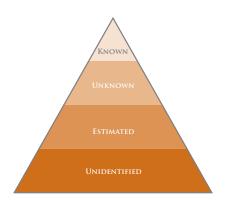
- Psychiatric conditions such as depression, anxiety disorders, eating disorders, substance abuse, and borderline personality disorder
- Behavioral problems such as physical aggression, disinhibition, mood swings, impulsivity, and socially inappropriate comments or actions
- Personality changes, including changed interests and apathy

Source: Evaluating the HRSA Traumatic Brain Injury Program, Institute of Medicine, 2006, pp. 43-50.

INTRODUCTION

TBI IN ALASKA

TBI PYRAMID



Known

800 hospitalized or fatal TBI/year

Unknown

About 3,000 emergency visits with mild TBI/year

Estimated

10,000+ Alaskans living with TBI

Unidentified

Symptoms not recognized as TBI

Those at highest risk for TBI are described below based on age and sex. (2001-2005)

NON-FATAL TBI HOSPITALIZATION RATE PER 100,000

All Alaskans	98.6
Males age 80+	301.3
Females 80+	217.2
Males age 15-19	215.7
Males age 70-79	200.9

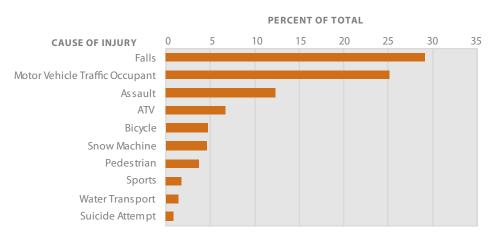
Every 15 seconds someone sustains a traumatic brain injury (TBI) in the U.S.

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

Every year the Alaska Department of Health & Social Services reports about 800 traumatic brain injury (TBI) cases resulting in hospitalization or death. Besides the approximately 640 seriously injured TBI patients that survive their injuries and are discharged from Alaska hospitals each year, an estimated three times as many individuals suffer a mild TBI. This adds up to upwards of 2,500 new TBI survivors in Alaska each year, joining an estimated 10,000 Alaskans currently living with brain injury. Of recent significance and currently unknown, is the number of Alaskan service members returning with diagnosed and undiagnosed TBI.

TBI's among Alaska Natives and rural Alaskans are overrepresented. The Alaska Native population comprises about 16 percent of the population however the TBI population is 34 percent Alaska Native. Similarly the highest rates of TBI occur to the residents of the regions of the Northwest , North Slope, Norton Sound, and the rural Interior Region.

TOP TEN CAUSES OF NON-FATAL TBI HOSPITALIZATIONS OF ALASKA RESIDENTS, 2001-2005



INTRODUCTION

IN SUMMARY



Traumatic brain injury (TBI) is a significant public health issue to all Alaskans and Alaskan Natives, whether it is a "mild", moderate or severe brain injury. Brain injury can occur to anyone at any time and at any age. Falls, motor vehicle crashes, assault, sporting and recreational injuries, and occupational injuries – including war-related injuries – are the primary causes of TBI. Alcohol is often a contributing factor. In many instances, the brain injuries are preventable.

Individuals experiencing a TBI encounter short-term and long-term problems, ranging from fatigue, headaches, loss of memory, and emotional problems to injuries so severe that the person is in a vegetative state. These resulting problems affect a person's ability to:

- · Perform activities of daily living.
- Return to school or work or engage in productive activities.
- Develop or maintain relationships.

Services and supports that address these short-term and long-term problems will improve the lives of Alaskans who survive a traumatic brain injury and their families.

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GETTING THE RIGHT SERVICES AT THE RIGHT TIME



Acute care.



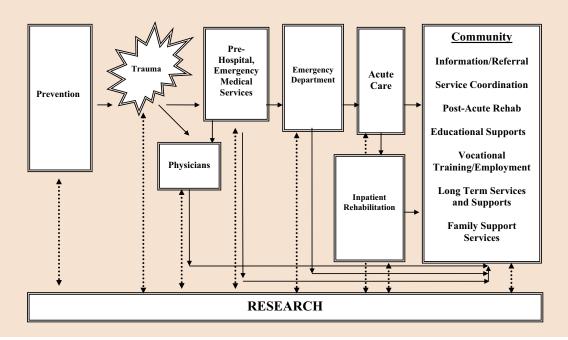
Returning home.

Treatment and care begins from the time of injury and may span the lifetime for many individuals with disabilities resulting from their brain injury. An effective service delivery system coordinates and integrates a multi-disciplinary approach. The components include emergency medical services; early intensive and acute medical care; comprehensive rehabilitation services; community integration, psychosocial, vocational, community and long-term services and support. Many of these services can be delivered at a rehabilitation center, in the person's community or at home.

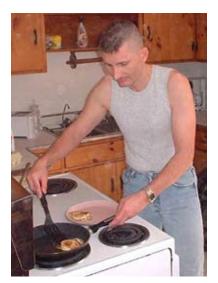
Alaskans with moderate to severe injuries are treated in acute inpatient hospitals. They generally enter the health care system through emergency departments, often after being attended to and transported by an emergency medical services (EMS) organization. Once medically stable, they may receive rehabilitation therapies to learn basic functions, such as walking or dressing.

Following acute rehabilitation, individuals may continue to receive post-acute rehabilitation which includes physical therapy, occupational therapy, and speech and language therapy. Individuals will learn how to compensate for deficits, including memory problems. Social skills training and counseling services may be provided to address the emotional and adjustment needs of the individual and family. Post-acute rehabilitation may be provided in a free-standing rehabilitation program within a hospital or in a separate rehabilitation facility, or therapies may be offered in the home.

MAPPING TBI SYSTEMS AND PROCESS



GETTING THE RIGHT SERVICES AT THE RIGHT TIME



Independent living skills training.



Physical therapy.



Speech therapy.

Transition and follow-up services with the individual in his or her home setting is of utmost importance following rehabilitation. Individuals with traumatic brain injury generally have trouble with transferring behavior learned in one setting to another setting. Because of their memory problems, they may not be able to remember "the rules," and so may have difficulty linking consequences with their behavior. It is important, therefore, to teach functional skills in context and in an established routine, repetitiously. These strategies differ from traditional approaches often used to help individuals with other disabilities to improve their behavior. Rather than trying to employ these techniques to "shape" behavior, the focus should be on structuring the environment to help the individual to manage his or her behavior.

Generally, insurance, Workers' Compensation programs, Medicaid, private pay or other third party payor programs will cover emergency department, acute care and acute rehabilitation services. However, many of these payors limit the amount, type and duration of post-acute rehabilitation and transition services. Private insurers rarely pay for community and long-term care and supports.

Research in brain injury rehabilitation is limited, but research that has been conducted has concluded that patients who received inpatient rehabilitation after brain injury had better outcomes than patients who received only acute care. Outcomes were measured in the areas of functional status, daily care requirements, ability to return home and vocational status.

Individuals with "mild" TBI, or concussions, are most likely to access services through emergency departments, physician's offices or not at all. Yet, these individuals may also experience problems later that warrant follow-up, assessment, counseling and other assistance. Screening special populations often results in identifying individuals with TBI who have not been previously identified but may have associated problems. These populations include schoolaged children, correctional facilities, behavioral health programs, domestic violence providers and individuals residing in homeless shelters. Behavioral Health providers routinely screen for TBI and find one third that approach their agencies for services are identified as having a TBI (AKAIMS).

The Brain Injury Research Center at Mount Sinai School of Medicine in New York City through its research has consistently found high rates of "hidden" head trauma when screening various populations in New York schools and substance abuse programs, as well as the general population. These "hidden" injuries are often the result of falls and other injuries that occurred many years before and were not identified or treated. Their research in small populations of homeless persons also found high incidence of TBI. Through these screenings, the clinical program at Mount Sinai provided counseling, compensatory strategies for memory and behavior issues, and other accommodations to help individuals resume a more normal life routine.

GETTING THE RIGHT SERVICES AT THE RIGHT TIME



Vocational training.

One strategy for ensuring that individuals receive timely services and supports is through service coordination.

Individuals with TBI may need specialized vocational training and supported employment. The Vocational Rehabilitation (VR) program is a federal/state-funded program providing services to help individuals with disabilities enter or return to employment. Studies have found that college, counseling and job placement were significantly and positively related to vocational rehabilitation closure status. Research has also demonstrated favorable employment outcomes following participation in supported employment (Kruetzer et. al 2003).

Some may need assistance with obtaining housing or supports, such as personal assistance or help with managing finances. Others may require more intense care, especially those with significant medical, behavior or substance abuse issues.

While individuals with traumatic brain injury may have similar rehabilitation and service needs, the extent and duration varies, as well as when services may be needed. The challenge for service delivery systems is to offer the right services at the right time – to be responsive to when the problems arise or are presented. One strategy for ensuring that individuals receive timely services and supports is through service coordination.

Families, caretakers and other circles of support often request counseling, information on brain injury and resources, and assistance in navigating the complex state, insurance, medical and public school systems -- all of which have different eligibility guidelines, different points of entry and different services available.

Service coordination is a critical service in helping individuals who have multiple needs to access multiple resources. A service coordinator may facilitate the:

- Evaluation and assessment of needs.
- Information and education about the cause and effects of TBI and preventing secondary conditions.
- Development of a service plan to meet the identified need.
- Provide assistance in locating and accessing resources and services such as medical care, housing, counseling, transportation, rehabilitation, vocational training, and cognitive/behavioral training.

In some states the TBI service coordination program has developed relationships with trauma centers and rehabilitation programs in order to link and transition individuals with TBI to services following hospital discharge or discharge from a rehabilitation program.

TBI SYSTEMS PLANNING



Most children with TBI return to their own home and school.

Children and Youth

Children and youth who are injured will need similar acute and rehabilitation services as adults, but these rehabilitative services should be tailored specifically to the needs of children. Rehabilitation for adults focuses on relearning skills already acquired, while children, depending on their age at the time of injury, may not have acquired certain skills. Their rehabilitation may also need to focus on accommodations for learning new information and skills.

After recovery, most children with TBI return to their own home and school. Successful readjustment to the school environment depends partly upon the quality of the transition plan. Rehabilitation staff should develop transition plans that will help educators to develop educational and learning strategies that accommodate the disabilities of the child. When children with TBI return to school, their educational, behavioral and emotional needs are often very different from their needs before the injury. Often, children in primary grades will be able to adapt to the structure afforded in the primary school settings, although they may have trouble with new learning. However, it is not uncommon for their TBI related disabilities to be more apparent when they enter middle school or high school and have to negotiate several teachers and differing teaching styles. They may have trouble with organizing their work, initiating and carrying out school assignments and completing essay tests due to their cognitive problems. Support services from counselors, social workers and school psychologists can assist the child's social and emotional needs.

Children with more severe injuries may require medical assistance or structured behavioral settings. They may be placed in residential programs or receive services in out-of-state programs, or the family may need extensive help in their home to care for the injured child.

LEVELS OF SUPPORT AND SERVICES BY AGE

	Age	E	Ac	jency ute Ca abilita	are,	·-,	Home, Community & Family Supports									Structured Programs Long-Term Residential									
	0 to 2		LO		"		School		ite			ses					0	Abuse	s						ent
	3 to 5	Education	oilitati	Outpatient	services	ehab.		ion	Respite			services				Φ	Living	Subst. A	Groups						Placement
CHILDREN AND YOUTH	6 to 13	Educ	Rehabilitation	Outp	ol se	Tele-rehab.	Home,	Coordination	training,			School			동	al care	Independent		oort G	Juvenile Justice		<u>≩</u>			<u>ਰ</u>
	14 to 17	ion &	cute F	pies,	School		ab to		y trai		from				ortatio	personal	lepen	Services,	Support	ync Jus	₹	Facility		Program	ident
	18 to 21	Information	∢	Therapies		Therapies,	ר Rehab	Service	Family	۶	work	ol Ed.	Training	Living	Transportation				amily		Facility	QQ/ 4		e Pro	Home/Residenti
	22 to 50		ent/Po	Individual			n from	ĸ.	eling,	rograi	Plar ol to	Post-School Ed.	al Trai	rted Liv	F	In-home,	Employment,	II Health	and F		tional	Health	Homeless	of State	Hom
ADULTS	51 to 64 65 to end of life	Family	In-Patient/Post-	Indivi		In-home	Transition	<u>∞</u>	Counseling,	Day Program	Transition Schoo	Post-	Vocational	Supporte		_	Empl	Behavioral	Peer		Correctional	Mental	Hom	Outo	Nursing

TBI SYSTEMS PLANNING



Each TBI differs from person to person.

National Association of Head Injury Administrators (NASHIA): Assisting state government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.

No Two Brain Injuries Are Alike

One challenge in developing services for individuals with traumatic brain injury and their families is that no two brain injuries are alike. Each TBI differs from person to person, depending on the location of the injury, severity, age, preinjury functioning, substance abuse, education and other contributing factors. While rehabilitation and service needs may be similar, the extent and duration varies individually, as well as when they may need them in their recovery and reintegration process. The goal for service delivery systems is to offer the right services at the right time – to be responsive to when the problems arise or are presented.

Traumatic brain injury is a complex disability. Individuals and their families may need assistance from several service systems at one time and these systems in themselves are often complex. They may have differing missions, eligibility criteria and organizational structure. These systems include insurance, health care, education, Social Security Disability, Medicare, Medicaid, developmental disabilities, behavioral health, vocational rehabilitation and other state systems. Treatment and care begins from the time of injury and may span the life time for many individuals who have resulting disabilities from their brain injury. An effective service delivery system is one that is coordinated and integrates a multi-disciplinary approach.

Federal and State Funding

To pay for services in Alaska a variety of funding is used including General Fund, General Fund/Mental Health, MHTAAR, and Medicaid, in addition to private pay. Federally, Congress passed the TBI Act of 1996, as amended in 2000 and 2008, that authorizes funding to the US Department of Health and Human Services, Health Resources and Services Administration (HRSA) to fund grants to states to improve access and expand capacity for services and supports for individuals with TBI and their families. The law also authorizes funding to HRSA for state Protection & Advocacy (P&A) Services for TBI advocacy services. The law authorizes appropriations to the CDC for injury prevention, surveillance, and public education. CDC awards grants to state health departments to carry out many of these activities. There are other federal grants available to States to help fund TBI systems and services.

States are eligible to apply for HRSA TBI Systems development grants provided they have a TBI advisory board, lead agency, and have conducted a needs assessment and developed a state action plan.

TBI SYSTEMS PLANNING



Care coordination.



Early Referral from hospital/clinic to service coordination is associated with better functional outcomes.

Cost Benefit

Analyzing cost benefit is tricky when public dollars come from multiple sources, and the billing data does not consistently reflect a TBI diagnosis. Two examples provided to illustrate cost benefit of providing appropriate services come from one other state and a private agency.

The Missouri Department of Health and Senior Services evaluated its early referral program which is an outgrowth of the service coordination program, linking individuals at the time of hospitalization to Information & Referral Services and to Service Coordination administered by the department. The findings are:

Benefits of Service Coordination and Early Referral

- Medicaid utilization data generally revealed a need for services that was consistent with the functional limitations experienced by program participants.
- Clients in the Early Referral Program had higher rates of and costs for doctor office visits and personal care services in 2004.
- In 2005, clients in the Early Referral Program continued to have more doctor office visits and use more personal care services.
- However, in 2005 clients in the Early Referral Program were significantly less likely to receive emergency room care.
- This may reflect success in addressing medical needs on an ongoing basis rather than in an acute crisis management model, which results in seeking emergency services.

The overall outcome of the TBI Early Referral Program is associated with better functional outcomes in terms of social/emotional functioning and the ability to return to work.

TBI SYSTEMS PLANNING

Rehabilitation Benefits

At the request of an insurance representative a rehabilitation provider analyzed data with regard to rehabilitation benefits.

THE SUCCESS STORY OF MR. L

Injury

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

Medical Care

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

Cost/Benefit Analysis

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

Rehabilitation

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

Outcome

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

Annual Lifecare Costs Without A Post-Acute Admission

Attendant Care (24/hr)	\$157,248
Additional Hospitalizations	\$19,272
Allied Health Consultations	\$10,858
Medications	\$2,000
Van Modifications	\$4,350
Home Modifications	\$2,727
Medical Specialists	\$2,220
Case Management	\$5,000
Equipment	\$3,592
Total	\$207,267

Annual Lifecare Costs With A Post-Acute Admission Re-evaluation (continued therapy)

Total \$8,452	
Physician Visits	\$1,000
Additional Surgery	\$2,000
Equipment	\$2,500
Medications/Supplies	\$1,702

Annual Lifecare Costs

Prior to CNS Admission	\$207, 267
Following CNS Discharge	\$8,452
Savings per year	\$198, 815
\$198,815 x 22 years	\$4,373,930

Total Lifetime Savings... \$4,373,930

Source: Centre for Neuro Skills, Dallas, TX

IN SUMMARY



Jessi C., Ketchikan, AK. Three years post injury. Ongoing TBI supports have led to further recovery and independence.

Rehabilitation, compensatory strategies, services, supports, and accommodations help individuals to resume living as independently as possible. Individuals and their families often look to state and federal governmental programs for assistance with medical, rehabilitation, vocational training and employment, family support, long-term care, and other community services and supports to help individuals with traumatic brain injury to return to work, school, home, and the community. Without this support, these individuals may ultimately be referred to out-of-state programs, nursing homes, or institutional services or worse yet, end up homeless or in correctional facilities.

A challenge in developing services to meet every person's needs is that the range of service needs and supports vary as each TBI differs from person to person, depending on the location of the injury, severity, age, pre-injury functioning, substance abuse, education and other contributing factors.

Another challenge is that TBI is a complex disability, and individuals and their families may need assistance from several service systems at one time. These systems include insurance, health care, education, Social Security Disability, Medicare, Medicaid and other state systems. These systems in themselves are often complex, having differing missions, eligibility criteria, and organizational structure.

There are many states that have a full continuum of care, from trauma to long-term living supports. Developing TBI-specific funding mechanisms and services to address the needs of this complex disability has been the focus of many states; several have recognized this disability for many decades. The Alaska Department of Health and Social Services began recognizing TBI in the 1990s, and is making ongoing efforts to create and improve TBI services.

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CHAPTER 2: HISTORY OF TBI PLANNING AND POLICIES IN ALASKA

LEADERS IN TBI PLANNING AND POLICY COORDINATION

KEY AGENCIES

Alaska Brain Injury Network

Department of Health and Social Services

Senior and Disability Services

Behavioral Health

Public Health, Injury Prevention

Alaska Mental Health Trust Authority

Alaska Commission on Aging

Governor's Council on Disability and Special Education

Alaska Mental Health Board

Advisory Board on Alcoholism and Drug Abuse

Disability Law Center, Protection and Advocacy Public Health received funding from the U.S. Centers for Disease Control and Prevention to initiate traumatic brain injury (TBI) surveillance beginning in 1998. This funding began to systematically quantify what had previously been believed anecdotally to be a significant and growing public health problem. Alaska administers a trauma registry capturing hospitalizations (more than 24 hours) of those who have sustained a traumatic brain injury.

The Alaska Division of Mental Health and Developmental Disabilities, in partnership with the Brain Injury Association of Alaska (BIAA), succeeded in obtaining a US Health Resources and Services Administration Planning Grant in 2000. Unfortunately, the BIAA dissolved, and the initial planning effort was unsuccessful. The Division was able to obtain a new planning grant, and the planning effort continued until March of 2003. As part of the planning effort, the Alaska Traumatic Brain Injury Advisory Board was established. In 2002, the Disability Law Center of Alaska, in collaboration with the Division of Mental Health and Developmental Disabilities and Alaska Traumatic Brain Injury Advisory Board, successfully applied for a HRSA Protection and Advocacy grant. The Center is now also an active member of the Alaska Traumatic Brain Injury Advisory Board.

Lead State Agency

As of 2008, Senior and Disability Services was invited to become the lead agency for the purpose of increasing the scope of the HRSA grant. Senior and Disability Services and Behavioral Health are united in improving the continuum of services for Alaskans with brain injury. The Alaska Department of Health & Social Services, Behavioral Health, was the lead state agency for traumatic brain injury services. The division had assumed responsibility for planning and providing those services that are appropriate division services for individuals with traumatic brain injury. As a result, the department is eligible for federal funding through the US Health Resources and Services Administration (HRSA) Federal TBI State Grant Program.

In 1999, the then Division of Mental Health & Developmental Disabilities, now known as Behavioral Health, obtained a HRSA TBI Planning & Implementation Grant. The HRSA grant required the following:

- Identify a State Lead Agency (Alaska, Department of Health and Social Services, Behavioral Health).
- Establish a Statewide Advisory Board (Alaska Brain Injury Network, Inc., formerly, the Alaska Traumatic Brain Injury Advisory Board).
- Conduct a statewide needs and resources assessment.
- Develop an implementation plan (completed March 2003).

CHAPTER 2: HISTORY OF TBI PLANNING AND POLICIES IN ALASKA

SYSTEMS PLANNING

ABIN TIMELINE

1999

State of Alaska (SOA), Department of Health and Social Services (DHSS) awarded Federal TBI Act Grant.

2000

SOA, DHSS, Division of Mental Health and Developmental Disabilities formed Traumatic Brain Injury Advisory Board.

2003

Alaska Traumatic Brain Injury Advisory Board incorporated; non-profit status.

2006

Changed name to Alaska Brain Injury Network, Inc.



Millie Ryan, ABIN Board Member, Executive Director Governor's Council on Disabilities and Special Education.

Advisory Board

The Alaska Traumatic Brain Injury Advisory Board (ATBIAB) was formed in 2000 to fulfill the requirements of the grant and conduct business as an advisory board; holding quarterly board meetings and inviting public comment. ATBIAB earned non-profit status in 2003 and changed its name to the Alaska Brain Injury Network, Inc. in 2006. *See appendix for more information*.

Alaska Mental Health Trust Authority

An integral player in the Alaska service delivery system is the Alaska Mental Health Trust Authority. The Trust ensures that a comprehensive integrated mental health program is developed for use by its beneficiaries, including people with mental illness, people with developmental disabilities, people with chronic alcoholism, people with Alzheimer's disease and related disorders, and people with traumatic brain injury resulting in permanent brain injury.

Current TBI initiatives funded by the Trust include the TBI Advisory Board, development of post-acute residential rehabilitation, information and referral, care coordination, ImPACT concussion management program for high school athletes, and TBI curriculum development and consultation.

Statutory Boards

Four governor-appointed boards plan services for The Trust's Beneficiaries and advise the Trust on issues and funding. Each executive director (of the following boards) is a voting director on the TBI Advisory Board. This was organized so that all boards are aware of the needs of Alaskans with TBI and can work collaboratively in developing TBI programs within existing services and recommendations for new programs.

- · Alaska Commission on Aging
- · Alaska Mental Health Board
- Governor's Advisory Board on Alcohol and Drug Abuse
- Governor's Council on Disabilities and Special Education

Olmstead Task Force

The Alaska Legislature created four planning and advocacy boards that provide policy direction and guide budget decisions related to community-based care. The Alaska Mental Health Trust Authority and state general funds fund the boards. Composed of consumers, public and private providers, and interested members of the public, each planning and advocacy board is responsible for a statewide plan. Although Alaska does not have a specific Olmstead planning group, the state is carrying out Olmstead planning through the boards.

Current TBI Services

Alaskans do have access to some TBI services through state-funded and private providers; however, services are limited. Chapter 3 will share what services are available and recommendations on how to improve the TBI services in Alaska so citizens can recover and live productive lives close to home.

DEVELOPING THE PLAN

VISION

The Alaska TBI service delivery system improves outcomes of individuals with traumatic brain injury by facilitating services that provide the highest quality care.



Lael V. - ABIN Board Member and TBI Survivor visits Dillingham, Alaska.

Our fifteen year old son is a traumatic brain injury (TBI) survivor. It took nearly five years from his injury to diagnose his TBI and get the appropriate care. We are fortunate in that he is progressing well now, seven years after his injury...

TBI impacts not just the person who is injured but families, businesses, schools, local health care and entire communities. For these reasons, it is important to provide a comprehensive Traumatic Brain Injury Program. The ideal program would include a coordinated global approach in which the initial acute care provided in the hospital would be connected with a comprehensive outpatient facility that together offers a variety of care.

As things are now, patients and families are having to piecemeal information and even various therapies often on their own in unfamiliar settings.... Recovering from a brain injury is sometimes a long process; facilitating communication is essential. Building a comprehensive TBI program could be the anchor for such interactions between health care, patients, families and communities. – M, ABIN Public Comment

The Alaska Brain Injury Network, Inc. and participating partners have defined services and resources that need to be in place to support individuals with TBI and their families in the least restrictive environment and that promote self-sufficiency, independence and productivity. These service recommendations are based on previous needs and resources assessments conducted by ABIN and Behavioral Health, which was the designated lead agency for TBI from 2000-2008. Through these assessments, input has been provided from an array of consumers, professionals and human service providers.

ABIN has also involved state agency program staff administering similar programs for other disabilities and populations in this planning process to assess potential interagency collaboration and resources that would result in services being provided for TBI. Also, ABIN has reviewed other state agency action plans to identify common goals. This plan recognizes the strengths in the system and has attempted to suggest that wherever possible, existing resources are enhanced through training, education and, where appropriate, increased funding to better serve individuals with TBI and their families.

ABIN and its partners recognize that a strong system of services that are delivered in a timely and efficient manner will be dependent on interagency collaboration, common goals and defined outcomes. Common data across systems to assess program and individual progress will identify progress toward the overall goal of this plan, which is to improve systems and expand services to Alaskans who are living with a traumatic brain injury and their families.

DEFINING CORE SERVICES

GUIDING PRINCIPLES

ABIN developed a set of guiding principles to frame the plan recommendations. These are shared values that are believed to be critical for a delivery system of services and supports for individuals with traumatic brain injury and their families. The beliefs are that services and supports should be:

Person-Centered

Individualized and self-determined

Easy to access

No "wrong door" for services

Timely

Right services at the right time

Effective

Evidence and outcome based

Appropriate

Based on individual strengths, needs, age and least restrictive environment

Efficient

Maximizes resources; avoids duplication

Seamless

Transitions through continuum of care and across systems

Equitable

Access to services and quality of care are provided regardless of gender, ethnicity, age, geographic location and ability to pay

Safe

Provides a safe and healthy environment, yet supports dignity of risk

ABIN has defined basic services that need to be available to all individuals with traumatic brain injury and their families throughout the state. These basic services are referred to as core services and include: Information and Referral (l&R), service coordination, acute and post-acute rehabilitation, education and related services, and vocational rehabilitation and employment. Some individuals may also need long-term care or community services that may be intermittent, short-term or long-term. Depending on the number of individuals who need these long-term services and supports, it may not be feasible to have these resources in every community in the state. However, individuals who need these services need to be able to access them in Alaska, as opposed to out-of-state, or have assistance in locating similar resources in their own community.

Delivering direct services requires an infrastructure in place to coordinate program policies, assuring program quality and effectiveness. This formal system infrastructure includes public awareness, prevention and advocacy; outreach and identification; a trained workforce and employers; and statewide planning and policy coordination.

ABIN has defined these core services under two major headings: I. Services and Support and II. Systems Infrastructure

I. SERVICES AND SUPPORT

Refers to the array of assistance, resources and strategies that may be needed to assist individuals to recover and/or learn to live with a brain injury. Allowing individuals to live in their homes and communities as independently as possible, and to return to school and work. These services may be delivered in a facility or by a program or organization, or they may be provided in the home setting. These may be provided on a short-term, long-term, or intermittent basis. Supports may also come from family, friends and community, often referred to as natural supports. TBI services and support include:

Information and Referral

Provides community information and educational materials on available resources and services.

Service Coordination

Facilitates assessment and planning; and coordinates, links, monitors and evaluates resources and services needed to carry out the plan.

Acute and Post-Acute Rehabilitation

Reduces severity of injury; improves and restores functioning.

Children and Youth: Educational and Related Services

Identification, assessment and appropriate educational and behavioral strategies necessary for learning.

DEFINING CORE SERVICES



"I am lucky to have the support of family, friends and community."

- Nicole H. from Kenai, Alaska

Vocational Rehabilitation and Employment

To increase productivity, promote self-sufficiency and self-worth through employment and voluntary work.

Long-Term Care and On-Going Support

Services that may be needed to support individuals to live or work in the community; peer support, financial management, counseling, therapies, crisis interventions, behavioral health, family education, respite, in-home supports, personal care, transportation, supported housing, day programs, residential and long-term care.

II. SYSTEMS INFRASTRUCTURE

Refers to the foundation and organization that needs to be in place for the delivery of treatment, services and supports. These elements include data necessary for systems and individual services planning; informational materials; trained and experienced workforce; quality assurance and overall systems planning, monitoring and coordination. For purposes of this plan, these elements are identified as needed in Alaska:

Public Awareness, Prevention and Advocacy

Promotes prevention and early intervention strategies, information relating to causes and symptoms of traumatic brain injury, and risk and protective factors.

Outreach and Identification

Provides screening, diagnosis and assessment for identification and referral.

Training and Workforce Development

Provides on-going training and in-service to support professionals and direct care staff providing assistance, services and supports to individuals with traumatic brain injury.

Statewide Planning and Policy Coordination

Provides comprehensive planning, systems evaluation, policy coordination and recommendations for systems improvement to ensure services and supports are provided effectively, efficiently and appropriately.

CORE SERVICES: I. SERVICES AND SUPPORT - INFORMATION AND REFERRAL

"My nine-year-old son suffered a TBI after being hit by a car. The out-of-state medical center gave us a big binder full of information that was very easily understood and was very specific in helping us understand what TBI was. Now that we're in Alaska we need assistance with financial advocacy and continuing mental health services including family counseling.

-Family member

With the creation of the Resource Navigator position, I&R services were increased to 275 people with brain injury during the period of March 1, 2007 through Oct. 1, 2008 who were not served previously.

CORE SERVICES: I. SERVICES AND SUPPORT

INFORMATION AND REFERRAL

After a traumatic brain injury, families and individuals with TBI need help with finding information on TBI and available resources to meet an array of needs. Providers also may need information on other available resources and services in order to provide the information to individuals they may serve or who may be discharged from their program. Information & Referral (I&R) services are designed to bring people and services together through trained staff who have the ability and expertise to listen to families or individuals and assess their needs. Without I&R services, individuals seeking information may call dozens of phone numbers or contact a myriad of agencies in the hope of connecting to a resource that can help them.

I&R services are provided by trained staff to bring people and services together. I&R organizations create and maintain databases on programs and services, and disseminate the information in a variety ways, including a dedicated phone number, website and printed materials. Some I&R agencies operate these services in conjunction with crisis management services.

Currently, there are at least three potential sources in Alaska for individuals with TBI and their families to learn about existing resources: The Alaska Brain Injury Network, Inc., the Alaska Aging and Disability Resource Center and the 2-1-1 system. While the TBI Resource Navigator assists individuals and families seeking brain injury resources; the latter two agencies assist individuals with all disabilities, including TBI. These agencies could expand TBI information and referral capabilities by being able to offer TBI resource information.

ABIN TBI Resource Navigator

The ABIN TBI Resource Navigator assists anyone with a brain injury or those helping them (providers, family members, etc.) to find resources and information. Currently, the ABIN has a two-year funding grant from the Alaska Mental Health Trust Authority for a staff person to provide TBI information and referral resources. Included in the FY 2009 General Fund Capital Budget is a \$50,000 project for Development of Brain Injury Online Resources. The focus of this project is to help rural communities access brain injury information, as well as to link brain injury survivors across the state. The ABIN has developed a Resource Directory identifying Alaskan providers who serve people with brain injuries.

The TBI Resource Navigator:

- Responds to request for assistance, information, resources, and referral.
- Distributes the Brain Injury Resource Directory.
- Distributes educational and informational resources to the public.
- Is working to establish a TBI hotline and brain injury support groups.

CORE SERVICES: I. SERVICES AND SUPPORT - INFORMATION AND REFERRAL

"I have a friend who suffered a severe brain injury. Hereceived good care at the hospital right after he had his accident and now he's back to work, driving, and lives on his own. But he has issues on the emotional and behavioral side of things and it's been very difficult to find services for that stage of recovery. Also the legal issues involved with the accident are ongoing, which can be over whelming even for a person who has not been impacted by a brain injury. Help comes in small pieces, but there are still a lot of issues to deal with."

--Friend of TBI Survivor



Information and referral specialist.

Alaska Aging and Disability Resource Center (ADRC)

The Alaska ADRC serves primarily individuals who are elderly and people with disabilities; however, assistance is provided for anyone who seeks information or referral services on any long-term care issue. Beginning in 2004, Alaska received ADRC funding through a collaboration of the Administration on Aging (AOA) and Centers for Medicare/ Medicaid Services (CMS). Alaska Housing Finance Corporation was the grantee and delegated project management of the grant to the State Independent Living Council (SILC). Under the management of the SILC, 5 ADRC sites were established in Centers for Independent Living (CILs) statewide. ADRC sites provide information and referral services along with assistance with completing applications for services, and provide follow up for referrals and assistance.

The SILC does not plan to provide this service in the future. Regardless of who provides this service, information and training on TBI could be provided to help individuals with TBI seeking long-term care and community services.

2-1-1 System

The 2-1-1 phone number and supporting website connect individuals with vital resources in their community 24 hours a day, 365 days a year. It is a statewide project being lead by United Way of Anchorage that partners with a number of state and local governmental agencies. Individuals who call via the phone line will speak to a trained Information and Referral Specialist. Individuals seeking services through the website are asked to click on categories that include: basic needs; income security; health care; individual and family life; mental health care and counseling; education; consumer services; criminal justice and legal services; environmental quality; organizational/community services; and target population. Individuals may also submit a word search.

Currently, there are very few resources or services listed using "brain injury" as a word search on the website of the Alaska 2-1-1 system. Those listed primarily refer to prevention or substance abuse programs.

CORE SERVICES: I. SERVICES AND SUPPORT - INFORMATION AND REFERRAL

Key Agencies

Aging Disability Resource Center Behavioral Health Agencies Children's Services Developmental Disability Agencies Health Clinics Hospitals Medicaid Senior Services United Way Vocational Rehabilitation

Funding Opportunities

Alaska Mental Health Trust Authority General Fund Private Donations and Contributions Federal Grants:

- HRSA TBI State Grant Funding
- Administration on Aging/Centers for Medicare & Medicaid Grants

INFORMATION AND REFERRAL

GOAL 1:

To improve access to TBI information, services and resources.

Objectives

- A. To increase I&R services through ABIN TBI Resource Navigation; expanded services through ADRC and 2-1-1 to include TBI.
- B. To develop and increase availability of informational packets and literature to families at hospitals, emergency departments, health clinics.
- C. To develop protocols for providing resource information and contacts to individuals reported to the trauma registry as hospitalized with a TBI.

Recommendations

Years One-Two

- Continue ABIN Resource Navigation services, including staff, 800 number, website and public educational materials on the availability of I&R services.
- Produce and disseminate educational packets and materials to hospitals, emergency departments, health clinics and so forth.
- Provide TBI resource information to the Aging and Disability Resource Centers, the 2-1-1 system, and other organizations/agencies.

Years Three-Five

- Update and distribute materials.
- Expand informational materials in other languages.
- Provide training/workshops to disability, health and social service agencies providing I&R to include TBI information.
- Provide information on I&R services and resources at other disability, health and social services conferences.

Years Five-Ten

- Develop methods for following up with individuals hospitalized and reported to the trauma registry.
- Update and distribute materials.
- Provide training/workshops to disability, health and social service agencies providing I&R to include TBI information.
- Provide information on I&R services and resources at other disability, health and social services conferences.

CORE SERVICES: I. SERVICES AND SUPPORT - SERVICE COORDINATION



Care coordination.



SERVICE COORDINATION

Following a traumatic brain injury, families and individuals with TBI need help with connecting to community services and supports. Without these resources individuals with TBI may be referred to skilled long-term care following hospitalization or will receive no help at all. Service coordination serves as the hub of the system and helps individuals identify what they need, helps them to get it, coordinate activities and resources, and to ensure that these services and resources are carried out. A service coordinator will work with the individual to identify strengths and weaknesses, and assist the individual to achieve optimal living through planning, coordinating, linking, locating, accessing and monitoring services and supports. Through collaborative efforts, service coordination will often result in eliminating duplicative services as well as maximizing existing services.

States that have also developed an early referral system with their trauma centers, acute hospitals and/or rehabilitation facilities, as part of their service coordination system, find that:

- The family spends less time finding services and more time on the services needed for rehabilitation.
- Service coordinators can often identify community resources instead of just state funded services.
- Service coordinators can save time and effort by making sure individuals are eligible and ready for state services.
- Potential overall Medicaid and general health care dollar savings occur when individuals access medical care in a planned manner.
- Hospital discharge planners know of options for community placement rather than institutional placements, potentially improving the outcome.

Alaska employs and contracts for care coordination services for various programs and populations. These are often associated with the Medicaid Home and Community-Based Services (HCBS) Waiver Programs. Senior and Disabilities Services provides a web-based training for SDS care coordinators that leads to certification.

However, there are no TBI designated service coordinators, i.e. case managers/care coordinators, to specifically assist families and individuals with TBI who do not qualify for these HCBS programs, to link and coordinate needed services. Individuals who are over the age of 60 years old can access case management from Alzheimer's Resource Agencies and other senior grantees. Individuals who have a co-occurring disorder (i.e. mental health condition or substance abuse issue) may access case management through community mental health centers.

CORE SERVICES: I. SERVICES AND SUPPORT - SERVICE COORDINATION

Key Agencies

Behavioral Health Children's Programs Hospitals Senior and Disability Services

Funding Opportunities

Alaska Mental Health Trust Authority General Fund Medicaid

Federal Grants;

- HRSA TBI State grant funding
- Administration on Aging/Centers for Medicare & Medicaid Grants

SERVICE COORDINATION

GOAL 1:

To help individuals with TBI obtain quality services and supports necessary to meet their needs and personal goals.

Objectives

- A. Implement service coordination services to individuals with TBI ineligible for existing care coordination services, in order to improve overall health and quality of life.
- B. Improve service coordination for those who may be eligible through training on TBI related disability, needs and resources.
- C. Develop service coordination linkages from hospital and rehabilitation services to community resources.
- D. Maximize resources among state systems through interagency coordination.

Recommendations

Years One-Two

- Support funding for TBI service coordinators; develop program.
- Develop program guidelines, hire staff, assessment criteria, evaluation outcomes.
- Develop and distribute informational materials on TBI service coordination.
- Train service coordinators/case managers in other programs/agencies regarding TBI and available resources.
- Develop MOUs with agencies to help coordinate case management services across agencies (establish primary, secondary TBI service coordinators; facilitate team planning).
- Develop and/or continue protocols with hospitals for linking individuals to services following TBI.

Years Three-Ten

• Evaluate TBI service coordination program and expand as needed.

CORE SERVICES: I. SERVICES AND SUPPORT - ACUTE AND POST-ACUTE REHABILITATION

"Post-acute care in a hospital environment is not conducive to recovery for TBI patients because the normal course of business in a hospital is over-stimulating. There is no consistent structure or routine, and often times keeping a TBI patient in their room increases their agitation. TBI patients would benefit from a strong rehabilitation track with a low stimulus environment and a social component."

-- Hospital case manager



Post-acute rehabilitation.

ACUTE AND POST-ACUTE REHABILITATION

Rehabilitation is a critical part of the recovery process for individuals with traumatic brain injury. During the acute stage, individuals with moderate to severe injuries may receive treatment and care in a hospital intensive care unit. Once medically stable, the patient may be transferred to a sub-acute unit of the medical center or to a long-term acute care facility, to a rehabilitation inpatient treatment unit contained within the trauma center, or to rehabilitation that may be provided in a 'free-standing' rehabilitation facility.

The goal of rehabilitation is to restore physical functioning (i.e. walking, talking) and activities of daily living (i.e. dressing, bathing). Rehabilitation is generally provided by a team of professionals including therapists (occupational, physical, speech/language), neuropsychologist, physiatrist (doctor of physical medicine), and social worker. Individuals with TBI generally will learn compensatory strategies for memory and other cognitive problems to help them function as independently as possible. Transitional living rehabilitation programs provide opportunities for individuals to be responsible for activities of daily living, volunteer or work in the community, learn transportation systems and other independent living functions in a structured living environment prior to community integration.

Several factors play in to who receives rehabilitative services including the severity of injury, prognosis for recovery and age of the individual. The extent of rehabilitation to be provided is often determined by the payor (i.e. health insurance, Workers' Comp, settlements), which often has parameters and guidelines as to how many days or under what circumstances rehabilitation services will be covered. Other factors may include access to outpatient rehabilitation programs following hospitalization. Families may find that they live too far away to transport their injured member to and from daily rehabilitation programs.

Through focus groups for purposes of developing the Alaska State Planning Grant on Health Insurance Coverage in 2007, the Department of Health and Social Services in collaboration with the Department of Labor and Workforce Development, and the Department of Commerce, Community and Economic Development found that:

About 114,000 Alaskans (17 percent of the population) were counted as uninsured in 2005.

- Young adults, males, and Alaska Natives are more likely to be uninsured.
- People who are self employed, part time workers, seasonal workers, and people who work for small firms are most likely to be uninsured.
- Most of the uninsured are employed; most uninsured who are not employed are children and others not in the workforce; only one in ten of the uninsured are unemployed people in the workforce.

CORE SERVICES: I. SERVICES AND SUPPORT - ACUTE AND POST-ACUTE REHABILITATION

Research has concluded that patients who received inpatient rehabilitation after brain injury had better outcomes than patients who received only acute care.

Currently, there are very few options for Alaskans who need post-acute rehabilitation services who do not have insurance, or whose insurance does not provide adequate coverage for the services needed. At the same time, there are few, if any, post-acute rehabilitation programs in Alaska. Some individuals, including children, may be sent out of state for rehabilitation and residential care.

Medicaid is a federal/state health care program and is the primary public program for financing basic health and long-term care services for low-income Alaskans. Medicaid must pay for acute care, but rehabilitation services are viewed as an optional service.

To address some of these issues the Alaska Mental Health Trust Authority allocated funding to help a provider in Anchorage to develop rehabilitation support that would include a residential component (short-term) for five individuals who reside outside of Anchorage needing post-acute rehabilitation services. Another provider is also exploring feasibility of providing rehabilitation services in addition to the behavioral health services and community health services currently provided. Both of these programs, as well as any other rehabilitation provider, will need rehabilitation clients to be able to pay for services through insurance or other source of income (i.e. TBI waiver).

As Alaska is a geographically large state, ABIN supports innovative models for assisting individuals with rehabilitation or individual therapies needed to restore functioning after injury, including therapies that may be provided in the home, or by a mobile clinic, similar to a mobile health clinic, and through telehealth or telerehabilitation programs.



Telehealth technology.

CORE SERVICES: I. SERVICES AND SUPPORT - ACUTE AND POST-ACUTE REHABILITATION

Key Agencies

Community Providers
Department of Defense
Department of Health and Social Services
Hospitals
Indian Health Services
School Reintegration and Special Education
Programs
Senior and Disability Services

Funding Opportunities

Alaska Mental Health Trust Authority Department of Defense General Fund Indian Health Services Veteran Affairs Worker's Compensation Federal Grants;

- HRSA TBI State Grant Funding
- Administration on Aging/Centers for Medicare & Medicaid Grants



ACUTE AND POST-ACUTE REHABILITATION

GOAL 1:

To restore and improve functioning after TBI

Objectives

- A. Funding options for post-acute rehabilitation and rehabilitation models.
- B. In-state post-acute rehabilitation facility for traumatic brain injury.

Recommendations

Years One-Two

- Develop funding options through general revenue, federal grant, Medicaid and private insurance to pay for post-acute rehabilitation and therapies.
- Identify and develop community providers for rehabilitation services.
- Pilot program models for delivery of rehabilitation services (i.e. in-state rehabilitation facility, telerehab, mobile rehab clinic, in-home therapies).
- Pool resources for rehabilitation service system (i.e. Veteran Affairs, Department of Defense, Indian Health Services, and Worker's Compensation).

Years Three-Five

- Document outcomes of rehabilitation to show benefits for coverage and/or funding.
- Adopt program standards, best practices and outcomes.
- Determine rehabilitation options for unserved or under served populations (i.e. children, Alaskans living in remote areas, elderly).
- Evaluate rehabilitation models and assess needs for expanded services.

Years Five-Ten

• Expand capacity in the established rehabilitation programs.

CORE SERVICES: I. SERVICES AND SUPPORT - CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES

"I am a mother of a child who suffered a brain injury at two-and-a-half months. He is 11 years old now and in middle school. Situations have arisen when he transferred from elementary school to middle school. I feel that teachers are at a loss to figure out how to help my son and need more training, especially in behavioral management."

- Family member of TBI survivor



It's in the school setting that children with TBI often continue to receive therapies after hospitalization.

CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES

Although many children with TBI may receive inpatient rehabilitation, then be referred to post-acute (pediatric) rehabilitation or long-term care facilities, most children with TBI return to home and school following rehabilitation. It is in the school setting that children with TBI often continue to receive the therapies after hospitalization. Ideally, the hospital or post-acute rehabilitation team would provide information regarding the child's TBI and abilities to the child's school that would help educators to develop and provide the child with appropriate educational strategies.

Some children may need educational and related services provided through the Individuals with Disabilities Education Act (IDEA), while others may need reasonable accommodations which may be addressed in a 504 Plan. A 504 plan is a legal document under the provisions of the Rehabilitation Act of 1973 that provides a program of instructional services to assist students with special needs who are in a regular education setting. A 504 plan is not an Individualized Education Program (IEP) as is required for special education students.

IDEA also requires that students with disabilities' IEPs address transitional services from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. Vocational education, special education, and vocational rehabilitation are the three primary providers of school-to-work transition services to youth with disabilities.

Division of Vocational Rehabilitation (DVR) participates in student transition planning as in accordance with the Rehabilitation Act Regulations. Alaska DVR may meet the needs of transitioning students by providing informational meetings on a regular basis to students, parents and teachers. The Department of Education and Early Development and ADVR co-authored "SET FOR LIFE", a transition resource manual available online at: www.eed.state.ak.us/tls/sped/SIG.html. ADVR counselors and educators are to follow the guidance outlined in this manual. ADVR counselors are assigned to schools to help with transitional services.

DVR also helps with financing post-secondary training and college for students with disabilities. The Alaska Pell Grant is used for attending college and is a federal grant that provides free financial aid awarded based on financial need. This grant may be used at any college in Alaska as long as the college participates in the Federal Student Aid Program.

CORE SERVICES: I. SERVICES AND SUPPORT - CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES

J.C. is 17 year old girl who had a car crash just before high school graduation. She was sent out of state for initial rehabilitation and treatment. In addition to a brain injury she is also quadriplegic. She is now on Children with Complex Medical Conditions waiver services. This provides her with 8 hours per day of personal care assistance (PCA) services. Her Grandmother is her caregiver and entire family support system. Grandma has to keep working full time as well as care for her so that they can afford to keep their house, which is handicap accessible. Other than the limited PCA services that J.C. receives, there is no additional help for Grandma to take care of her, when she is not at work. J.C. is working toward graduating high school soon and plans to go to college.



J.C. - Ketchikan High School graduation.

Parent Training

There are resources in Alaska to help families with children with special education needs. The Alaska Parent Training and Information Center at Stone Soup Group is working with parents, educators and other partners across the state to build collaborative relationships and offer training to support Alaskan students needing special education services. The program is using a variety of different formats to provide training to under served and rural families.

The Alaska Family Directory is a parent oriented web based information system (www.asdk12.org/AFD) maintained by the Anchorage School District with funds from the Alaska Department of Education and Early Development. The Alaska Family Directory, a monthly newsletter, provides information on laws and policies affecting special education, ideas and hints for supporting individuals with disabilities, where to go for resources and assistance, and what's happening around the state. This newsletter applies to all individuals with disabilities from early childhood development to adult life and seniors.

LINKS is another program primarily funded by a grant from the US Department of Education to serve as a Community Parent Resource Center (CPRC) to provide information, support, and assistance to the parents of children with disabilities, their professional partners, and their communities. The program receives funding support from the State of Alaska Department of Education, the Mat-Su Health Foundation, the Mental Health Trust Authority and private donors (www.linksprc.org). LINKS is funded to serve communities located within the Mat-Su Borough School District, including outreach to remote areas, to provide support and training, parent-to-parent connections to mentors, information and referral, and access to library materials. These services are provided through one-on-one assistance and individualized workshops for small or large groups.

Medical and Health Needs

A few children with severe TBI may be placed in residential rehabilitation programs out of state. Other children with severe TBI may receive services from the Alaska Short-Term Assistance & Referral Programs (STAR), which assists people with developmental disabilities and their families in addressing short-term needs before a crisis occurs and to defer the need for more expensive residential services or long-term care. Many people who are on the Developmental Disabilities (DD) Waiting List access STAR services. Allowable costs under the STAR Program include, but are not limited to, environmental modifications, adaptive equipment, and services that assist the family such as behavioral training, personal care or medical appointments. Assistance with basic living needs necessary to avert a crisis that is not covered by another public or private program such as emergency transportation and clothing may be approved on a limited basis.

CORE SERVICES: I. SERVICES AND SUPPORT - CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES



Most children, including those with moderate and severe TBI, will return to their homes and to school following their brain injury. William B. returned home after 46 days in the hospital.

The STAR program or any other non-profit may help the individual apply for a mini-Grant through the Trust, which are one-time awards made to individuals not to exceed \$2,500 per recipient for health and safety needs not covered by grants or other programs, in order to help beneficiaries attain and maintain healthy and productive lifestyles. The kinds of supplies or services the Alaska Mental Health Trust Authority considers appropriate for Mini-Grants include, but are not limited to, therapeutic devices, access to medical, dental and vision care, or special health-care needs. Adult dental care is the most frequently requested service by those who receive Mini-grants.

Most children, including those with moderate and severe TBI, will return to their homes and to school following their brain injury.

Children under the age of 21 and who are Medicaid eligible are eligible for services under the Early Periodic Screening, Diagnostic and Treatment (EPSDT) program. EPSDT services are to improve the health status of children through preventative services and follow-through care. The focus of the EPSDT program is to ensure preventative care and treatment designed to:

- Help families effectively use health care resources.
- Assess children's health needs through initial and periodic exams and evaluations.
- Ensure that health problems found are diagnosed and treated early, before they become more complex and their treatment more costly.

Senior and Disability Services administers the Home and Community Based Services Waiver for Children with Complex Medical Conditions who have a severe chronic physical condition and who would receive long-term care in a facility for more than 30 days per year, who have a severe chronic physical condition which results in a prolonged dependency on medical care or technology to maintain health and well-being and who:

- 1. Experience periods of acute exacerbation or life-threatening conditions.
- 2. Need extraordinary supervision and observation.
- 3. Need frequent or life-saving administration of specialized treatments or dependency on mechanical support devices.

The waiver is to serve medically fragile children from birth through age 21.

CORE SERVICES: I. SERVICES AND SUPPORT - CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES

Key Agencies

Alaska Health Care Services
Alaska Mental Health Trust Authority
Alaska Vocational Rehabilitation
Public Schools
Department of Education and Early
Development
Governor's Council on Disabilities and Special
Education
Seniors and Disability Services
Special Education Service Agency (SESA)

Funding Opportunities

Stone Soup Group

Alaska Mental Health Trust Authority Federal Grants General Fund Indian Health Services Veterans Affairs Vocational Rehabilitation

CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES

GOAL 1:

Children with severe brain injury live in their own homes.

Objectives

- A. To expand supports to enable families to care for their children in their own homes.
- B. Develop and implement training for families caring for their children with severe TBI.

Recommendations

Years One-Three

- Identify TBI youth associated with Bring The Kids Home.
- Support in-state TBI services and family supports through Bring The Kids Home.
- Training for STAR (Short-Term Assistance & Referral) Program care coordinators to better understand TBI issues.
- Provide information to families on educational and transition services and supports available for TBI youth.
- Partner with Statewide Positive Behavior Support Initiative to address TBIspecific behavior.

GOAL 2

To improve educational outcomes after TBI.

Objectives

- A. Increase information to families regarding TBI and educational programs (i.e. IDEA, 504) by working through existing parent training program.
- B. Increase the number of educators and related school personnel in understanding TBI.
- C. Increase the identification of children with TBI in special education.
- D. Develop and provide training for education paraprofessional.
- E. Expand post-secondary education coursework to include TBI information and appropriate educational strategies.

Recommendations

Years One -Two

 Expand capacity for helping families of children with TBI under the Alaska Parent Training Initiative at Stone Soup Group and other parent training programs.

CORE SERVICES: I. SERVICES AND SUPPORT - CHILDREN AND YOUTH: EDUCATION AND RELATED SERVICES



TBI Training to educators.

- Provide training to educators and paraprofessionals on brain injuries, identify resources to help educators work with students who have TBI on academics and behavior.
- Utilize Special Education Service Agency (SESA) and Stone Soup Group as resources and as trainers to school districts.

Years Three-Five

- Develop a consultant pool to work with educators as needed to address behavioral and cognitive issues.
- Implement screening measure for the kindergarten screening.
- Increase the identification of children with TBI in special education.

Years Five-Ten

• Require pre-service training for educators to include TBI.

GOAL 3:

To improve transition from school to work.

Objectives

- A. To improve transition services through the vocational rehabilitation process.
- B. To increase the referrals of children with TBI to vocational rehabilitation or vocational training classes.
- C. To increase the number of children with TBI attending college or trade school.

Recommendations

Years One -Five

- Collaborate with Vocational Rehabilitation and Tribal Vocational Rehabilitation to increase employment opportunities for students with TBI who are transitioning from school into adult life.
- Train school counselors and educators on transitional needs of TBI youth.
- Train university disability support services personnel on the accommodations needed for TBI youth in a college setting.

Years Five-Ten

 Continue and expand capacity through web-based and other innovative technology.

CORE SERVICES: I. SERVICES AND SUPPORT - VOCATIONAL REHABILITATION AND EMPLOYMENT

"I have been in Alaska since 1980 and have had several traumatic brain injuries. It is hard for me to be able to hold a job with the deficiencies I experience. I find transportation a real challenge. Supported employment would be very helpful for people in my situation."

-- TBI Survivor

Richard W. - Kenai, Alaska

VOCATIONAL REHABILITATION AND EMPLOYMENT

During the State FY 2007, Vocational Rehabilitation served 167 clients with traumatic brain injury as the source of their disability. Of those, 51 cases were closed. Seventeen closed were employed and an additional eleven were closed with a plan for employment. The average wage at closure was \$12.54.

Employment initiatives of DVR with a focus on Mental Health Trust beneficiaries include the Customized Employment Grant (CEG), supported employment services, and micro-enterprise grants from The Trust. The goal of the CEG is to build the capacity in Job Centers in Juneau, Kenai, Anchorage, Wasilla and Fairbanks to better serve people with severe disabilities so that they have a more responsive and individualized employment relationship based on their strengths, needs and interests, while meeting the needs of the employer. The micro-enterprise grants require DVR to match the funds and focus on self-employment ventures. Supported employment is a service delivery system within the vocational rehabilitation program to provide employment opportunities to individuals who require intensive services to gain employment and extended services to maintain employment.



Individualized employment.

CORE SERVICES: I. SERVICES AND SUPPORT - VOCATIONAL REHABILITATION AND EMPLOYMENT

Key Agencies

Alaska Health Care Services

Alaska Mental Health Trust Authority
Department of Education and Early
Development
Governor's Council on Disabilities and Special
Education
Public schools
Seniors and Disability Services
Special Education Service Agency (SESA)
Stone Soup Group

Funding Opportunities

Vocational Rehabilitation

Alaska Mental Health Trust Authority Federal Grants General Fund Indian Health Services Veterans Affairs Vocational Rehabilitation

VOCATIONAL REHABILITATION AND EMPLOYMENT

GOAL 1:

Individuals with TBI will achieve and maintain employment.

Objectives

- A. To increase referrals to DVR.
- B. To increase opportunities for supported employment and job coaching, specific to TBI.
- C. To provide supports as necessary to maintain employment.
- D. To increase employers' knowledge of TBI related disabilities and compensatory strategies.

Recommendations

Years One -Ten

- Long-term supported employment programs (job coaching).
- Expand Mental Health Customized Employment Grant to include TBI.
- Provide training to VR counselors and community VR providers on TBI.
- Develop pre-vocational options to prepare people for vocational rehabilitation services.
- Recruit and provide training to employers on TBI related disabilities.
- Provide information at job fairs and other employer events.

CORE SERVICES: I. SERVICES AND SUPPORT - LONG-TERM CARE AND ON-GOING SUPPORT

"I have a dear friend whose husband hit a moose on the highway and got a brain injury. He had to live out-of-state, and it was so hard on the family. I believe it would help the healing process if people can heal in the environment and with the people they are used to. If you are taken completely away from everything you know, how are you going to rebuild your memory quickly and effectively?"

--Friend of TBI Survivor

LONG-TERM CARE AND ON-GOING SUPPORT

Individuals with TBI may need an array of assistance or supports after their injury to carry out activities of daily living. The intensity or level of care needed may range from hands on care to less intensive supports that help the individual with memory deficits by reminding individuals to conduct certain activities. Families and individuals with TBI often need these types of services following hospitalization and they should be provided information on resources and services available. Overtime, the range of services individuals may need may vary, as needs change or issues arise. The key to delivering a system of services and supports is to have a flexible, yet responsive system that responds to the needs of individuals in a timely fashion to enable individuals to live as independently as possible.

Without a system of services or supports, individuals with TBI are at risk of being homeless, referred to nursing home/institutional care, or in correctional facilities. Families are the primary caregivers of individuals who have sustained a TBI. An individual who may not have a family member to care for him/her or when the family is no longer able to care for him/her or can not provide for the person for any reason leaves the person with a TBI at risk for being placed inappropriately in a facility or being homeless. At the same time with some supports, such as respite, counseling, day program and family training, families are able to care for an individual with a TBI.

Community and family supports enable individuals with TBI to live, work and attend school in the community.

These services include:

- Counseling
- Behavioral health
- Crisis interventions
- In-home support, personal care
- Respite
- Residential
- Peer support

- Therapies
- Personal care
- Family education
- Long-term support
- Transportation
- Housing (i.e. supported living)
- Financial management

Some individuals with severe disabilities may have medical conditions that may require residential care, while others with severe behaviors may need a structured living program. Individuals who may not be able to hold a job or stay home by him/herself without supervision may need a day program or club house to attend during the day. For some individuals this service will enable a person to remain in his or her own home, and will allow their family member or care taker to return to work.

CORE SERVICES: I. SERVICES AND SUPPORT - LONG-TERM CARE AND ON-GOING SUPPORT

"On January 21st when I was a senior in high school, I was in a motor vehicle accident. On August 8th I arrived back in Ketchikan, my hometown. I had to be totally cared for. My grandmother, who adopted me almost at birth, was my only caregiver. Yet she had to go to work 40 hours a week so she could keep insurance for us, as well as house and feed us. The CCMC waiver is a wonderful provision: however it doesn't fit the bill for all cases. A waiver needs to work with me and be flexible to change as my needs change. This will benefit the State as much as it does me. The better I get, the less money it will cost the state, the healthier it keeps mv Nana. A waiver needs to be made that will address the needs of traumatic brain injured people. With the proper medical and physical care we can be put back into the community as viable citizens and taxpayers."

--TBI Survivor

Behavioral Health provides behavioral health services to individuals with TBI who have co-occurring conditions. Senior and Disability Services administers four Home and Community Based Services Medicaid (HCBS) Waivers of which may offer services similar to what is needed by some individuals with TBI.

Alaska Home and Community Based (HCB) Waiver Programs include:

- Older Alaskans (OA)
- Mentally Retarded/ Developmentally Disabled (MRDD)
- Children with Complex Medical Conditions (CCMC)
- Adults with Physical Disabilities (APD)

These waivers offer a package of services that include care coordination, residential and day habilitation, supported employment, respite, transportation, chore services, meal services, private duty, intensive active treatment, specialized medical equipment and supplies, and environmental modifications.

In its 2008 report, the AARP cites Alaska as having one of the most balanced long-term care systems for older adults and for people with physical disabilities. According to the report, Alaska spends more on HCBS than for nursing home care. The long-term care system, however, tends to be fragmented.

The Medicaid program also offers personal care assistance (PCA) that provides support for about 4,000 Alaskan seniors and individuals with disabilities. PCA services provide support related to an individual's activities of daily living (i.e. bathing, dressing, and eating) as well as Instrumental Activities of Daily Living (i.e. shopping, laundry, light housework). PCA is provided statewide in Alaska through private agencies. The program also offers a consumer-directed model.

With regard to long-term residential care, there are six Alaska Pioneer Homes which are licensed Assisted Living Homes for older Alaskans. There are three service levels for residents in the Pioneer Homes. Each resident receives care based on a comprehensive assessment that identifies them for placement within one particular service level:

The Rural Long-Term Care Development program

Assists in the development of a variety of services in rural areas so that elders can remain as close to home as possible when they need extended care. The program provides training and technical assistance for the community. The Trust also assists communities to develop home and community based services, such as care coordination, chore and respite services, personal care assistance programs, adult day centers, and other HCBS waiver services. While these services are targeted to older adults, these programs provide models that could be adapted or modified for TBI survivors needing similar services.

CORE SERVICE I: SERVICES AND SUPPORT - LONG-TERM CARE AND ON-GOING SUPPORT



Nursing facility transition.



The Nursing Facility Transition Program

Can be used to help an elderly person or person with a disability transition from a nursing facility back into the community.

One-time funds may be available for:

- 1. Home or environmental modifications.
- 2. Travel/room/board to bring caregivers in from a rural community to receive training.
- 3. Trial trips to home or an assisted living home.
- 4. Payment for an appropriate worker for skill level needed.
- 5. Security deposits.
- 6. One-time initial cleaning of home.
- 7. Basic furnishings necessary to set up a livable home.
- 8. Transportation to the new home.
- 9. Other needed items or services may be approved by Program Coordinators.

An eligible person is one who qualifies both medically and financially for the Medicaid Home and Community Based Services Waiver (HCBS) program. The grant is used only for one-time costs associated with the transition; thereafter, the Medicaid program will pay for all services when the HCBS waiver is approved.

While all of these options noted above are needed by individuals with TBI, individuals with TBI may not be eligible for these programs.

CORE SERVICE I: SERVICES AND SUPPORT - LONG-TERM CARE AND ON-GOING SUPPORT

Key Agencies

Behavioral Health
Day Program providers
Department of Health and Social Services
Hospitals and/or Rehabilitation Programs
Providers of Waiver services
Senior and Disability Services
Supported Housing programs

Funding Opportunities

Alaska Mental Health Trust Authority
Department of Defense
Department of Health and Social Services
General Fund
Indian Health Services
Veteran Affairs
Worker's Compensation
Federal grants;

- HRSA TBI State Grant Funding;
- Administration on Aging/Centers for Medicare & Medicaid Grants)

LONG-TERM CARE AND ON-GOING SUPPORT

GOAL 1:

To help individuals with TBI to live as independently as possible in their own communities.

Objectives

A. To offer support services to individuals with TBI to live and participate in their home/community.

Recommendations

Years One-Two

- Expand existing HCBS waivers to include TBI with cognitive and behavioral problems.
- Expand existing HCBS waivers to include TBI services, including therapies, behavioral therapies, counseling.
- Develop TBI HCBS Waiver to cover those who are not eligible for existing waivers.
- Develop funding for housing and residential options.
- Obtain dedicated funding or general funds to pay for the array of services needed for individuals who are not Medicaid eligible.
- Include TBI in Senior and Disability Services efforts to develop personcentered hospital discharge planning model to help transition to community services.

Years Three-Five

- Develop housing alternatives (i.e. supportive living, structured residential, long-term living homes for people with cognitive disabilities).
- Obtain state or MHTA funds as seed money to start Club House/day programs for TBI.
- Promote technology in activities of daily living (i.e. assistive technology, PDA, etc).

Years Five-Ten

- Develop technology to support TBI survivors in their homes (i.e. online clubhouse model, support groups).
- Develop a crisis intervention model for children and adults.
- Support emergency management plans to address individuals with cognitive disabilities.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

"I received my injury in 1989 and it took 15 years before I actually thought about my brain injury, and it changed my life. When I started attending the traumatic brain injury support group I learned how to put it into words."

--TBI Survivor



"Ride Another Day" safety campaign. Ski and snowboard professionals promote helmet use.

CORE SERVICES: II. SYSTEMS INFRASTRUCTURE

PUBLIC AWARENESS, PREVENTION AND ADVOCACY

Injuries are a significant public health and social services problem because of the prevalence of injuries, the impact on the young, and the high cost in terms of care, treatment, long-term care and resources. Consequently, Public Health has identified injury prevention as one of its focused areas as reported in Healthy Alaskans 2010, prepared by the Alaska Department of Health and Social Services.

Falls, motor vehicle crashes, occupational injuries, including war-related injuries, are all contributing causes of TBI. The Alaska State Plan for Senior Services (FY 2008-2011) notes that falls are a serious public health problem in Alaska. In Alaska, falls are the number one source of non-fatal hospitalized injuries in every age group but two (the 15-24 and 25-34 age groups). Nationally, falls are emerging as a serious problem among individuals who are elderly. The Alaska Office of Traffic Safety also is concerned that driver inattention is a major contributor to highway crashes. And, another concern is the high incidence of underage drinking. According to the Alaska Highway Safety Office 2006 Annual Report, a third of alcohol impaired drivers and 47 percent of speeding drivers were under the age of 26.

One prevention strategy is to conduct public education and awareness campaigns to inform the public of risk factors and behaviors that may result in fatality or a traumatic brain injury. Educating the public on brain injury cause and resulting problems may also help individuals to seek care if they have had a concussion or "mild" brain injury and are experiencing problems. Public awareness is designed to encourage the public to alter their behaviors to minimize risk of injury. Another way to change behavior is through laws that mandate individuals to adopt certain behaviors, such as buckling seat belts and obeying speed limits, to minimize risks.

Accurate and available data to report information regarding the impact of injuries in Alaska is needed to develop appropriate prevention strategies and public awareness activities.

Surveillance

The Alaska Trauma Registry (ATR) administered within the Alaska Department of Health and Social Services (ADHSS) gathers detailed information on all injuries resulting in full hospital admission, transfer to another facility for continuing acute care, or emergency department death, including circumstances, treatments and outcomes. Other data sets contributing to TBI information include vital records, hospital discharge data, the Fatality Analysis Reporting System (FARS), the Alaska Violent Death Reporting System (AVDRS), and the Census of Fatal Occupational

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

Injury (COIF). The monitoring of safe behaviors has been accomplished through Alaska Seatbelt Observational Surveys, the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Surveillance System (YRBSS) and the Alaska Injury Prevention Center helmet use observational surveys.

Through these data sources the incidence of TBI fatalities and serious injuries in Alaska can be tracked and trends monitored over time. TBI rates for specific populations, regions, and injury categories are determined and compared with national rates. Also, an estimate of the prevalence of TBI in Alaska has been projected using the national data. TBI in Alaska is described via fact sheets by the Alaska Brain Injury Network and distributed widely, providing the necessary supporting evidence for TBI prevention and advocacy. Detailed study of TBI events and outcomes provides a foundation for the design and implementation of injury prevention programs, and for measuring successes.

Public Awareness

The success of any initiative to prevent TBI and improve services to TBI survivors and their families relies directly and indirectly on public awareness of TBI and cultivating a constituency for change. Only as Alaskans appreciate the severity and pervasiveness of the problem will the social and political will to act build momentum.

TBI awareness includes knowledge of the following:

- · What is TBI?
- What causes TBI?
- Who is at highest risk for TBI?
- How can TBI be prevented or mitigated?
- What are the long-term consequences of TBI?
- What are the challenges facing TBI survivors and their families?
- Where can one go for TBI services and supports?

TBI advocacy brings together those individuals who are personally impacted by TBI, the providers of medical care and health and social services, policy makers, and the concerned public for the purpose of improving the health and welfare of all citizens by promoting TBI prevention and facilitating access to services that provide the highest quality care and productive life.

Primary Prevention

Prevention is often cited as the only cure for brain injuries. In 1985, the book "Injury in America: A Continuing Public Health Problem", was published by the Council on Trauma Research, National Research Council and the Institute of Medicine, that called attention to the magnitude of the problems associated with injuries and called for public health to join traffic safety, occupational safety and other safety advocates to reduce injuries in America.



Public awareness brain injury workshop in Barrow, Alaska.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY



Child Passenger Safety Program.

This document cited three approaches to injury prevention:

- Persuade people to alter their behavior (public education).
- Require behavior change (laws and administrative rules).
- Provide automatic protection, such as air bags.

Alaska Injury Prevention Partners and Programs

Major injury prevention organizations in Alaska include the ADHSS Section of Injury Prevention and EMS, the Alaska Native Tribal Health Consortium Injury Prevention Program, the Alaska Injury Prevention Center, Safe Kids Alaska, the Alaska Highway Safety Office, and the National Institute for Occupational Safety and Health Alaska Field Office. Each bring unique expertise and funding to the table to focus on various populations within the state and collaboration among them occurs as needed.

Behavioral Health Prevention and Early Intervention developed a State of Alaska Plan to Reduce and Prevent Underage Drinking. Alcohol is often a contributing factor to the cause of injury.

The injury prevention efforts conducted by these organizations and others are too voluminous to list, but a sampling of programs promoting TBI prevention are:

- Child Passenger Safety Program
- Click It or Ticket campaign
- Alaska Focus on Safety (a rural school-based injury prevention curriculum)
- Teen Driving Safety
- Reflector Program
- Fall Prevention Programs
- Youth ATV and Snowmobile Safety Programs
- · Moose Safety

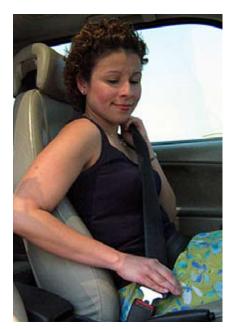
Secondary Prevention

While primary prevention is designed to prevent injuries from taking place, secondary prevention activities are focused on early detection, interventions and management of the injury to increase the chance of survival and minimize the extent of the injury. The sooner the medical treatment is available at the scene of the injury, the greater is the chance of survival. Referred to as the "golden hour", the 60-minute period following an injury is the critical time for preventing death or serious permanent injury. Treatment begins at the scene of the injury, and with appropriate treatment during that first hour, the risks of death and morbidity are greatly reduced.

The survival of individuals with TBI relies upon the strength of a trauma system, which ideally provides immediate response and medical care at the scene, rapid transport and stabilization, and treatment at a qualified trauma center. A trauma center provides an organized and timely response to traumatic injury and has

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

A single mom in her thirties in Fairbanks suffered a serious concussion. She went to the ER, but they were really busy and she got tired of waiting and asked if it would be ok if she just went home and put ice on it. They said that would be fine. It took months for her to be able to work almost normally again. She has been having biofeedback and is on meds. The combination of the two seems to be helping.



Primary enforcement seatbelt law increases seat belt usage and has lowered TBI rates.

demonstrated commitment to providing the best trauma care possible through its participation in the review and certification process set up by the State of Alaska and the American Trauma Society. Alaska currently has one Level II trauma center in Anchorage and four Level IV trauma centers.

The absence of CT scans in many rural communities increases the cost of ruling out TBI because patients must be Medivaced (transported) to Anchorage or Seattle for evaluation.

Physicians can improve patient outcomes after diagnosis of mild to moderate brain injury by implementing early treatment and appropriate referral. There is no standard for patient /family education and referral following mild TBI, which is critical for helping these patients achieve optimal recovery and reduce or avoid sequelae or further injury. Physicians can also play a key role in helping to reduce the occurrence of TBI by educating patients and the community about risks and injury prevention.

Athletes who have a concussion may present with a wide variety of symptoms. ImPACT is a concussion management program which was designed to evaluate the concussed athlete's post-injury condition and track recovery for safe return to play, thereby preventing the potential of a secondary injury. It is a user-friendly computer based testing program designed after approximately 10 years of University-based, grant-supported research. Currently, Anchorage is piloting the program with the Providence Health System providing consultative services. It is hoped that other school and local sporting programs will adopt this program.

Laws

Alaska has several traffic safety laws designed to reduce fatalities and injuries. Alaska has had a primary enforcement seat belt law since May 1, 2006. The 2008 seatbelt usage observation study put usage rate in Alaska at 84.9 percent. Alaska does not require helmet use on motorcycles, except for passengers and riders under age 18. There are no state laws requiring helmets for riders of snowmobiles, all terrain vehicles, or bicycles. Some Alaskan communities have adopted local helmet use ordinances for bicycle and off-road vehicle use. Alaska is one of a handful of states that does not have a booster seat law for children age 4 to 8. The Alaska Highway Safety Office also is concerned that driver inattention is a major contributor to highway crashes. Some states or local communities ban the use of handheld cellular devices and other devices that distract drivers.

The Driving While Intoxicated (DWI) law lowered the Blood Alcohol Content (BAC) level to .08 as signed into Alaska law on September 1, 2001.

In 1993 Alaska passed enabling legislation for trauma care system development and accompanying regulations were adopted in 1996. The Trauma System

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

Richard and Mary Warrington live and volunteer in the community of Kenai, Alaska. Richard is a TBI survivor and Mary was a family member of TBI survivors in her own family before meeting Richard. Every year for the last 12 years they have organized a TBI awareness walk in their community, soliciting donations, and turning the profits into education and helmets. They have become contacts for TBI information and support in the Kenai-Soldotna area. Volunteers like these quickly become overwhelmed by the requests for help and information. Many more Alaskan communities could benefit from TBI advocacy.



Richard and Mary - Kenai, Alaska

Review Committee under the ADHSS researches issues for improved trauma care, patient transport, and surgeon response times. In 2003 the committee released the Guidelines for the Management of Head Injuries in Remote and Rural Alaska. This group also facilitates trauma center review and verification. ADHSS has requested an American College of Surgeons review of the statewide trauma system.

Advocacy and Training

Advocacy takes many forms. A person or self-advocate may argue or advocate on behalf of a person or him/herself to obtain services. The person advocating, to be successful, should know the system and rights of the individual. On another level, individuals or a collective group of individuals may advocate to influence public policy to benefit a group of individuals or citizens as a whole. Effective TBI advocacy begins at the grass roots level in small communities. The Alaska Mental Health Trust Authority has adopted ABIN as a partner board and provides TBI education and advocacy through their coordinated communication campaign. They also share legislative information and tracking with ABIN.

The Brain Injury Association of America was founded in 1980 by a group of individuals who wanted to improve the quality of life for their family members who had sustained brain injuries. This group is a model for grass roots advocacy in TBI and since its inception, many more brain injury organizations have formed and are involved with information sharing. Presently, Alaska does not have a state association. However, the Alaska Brain Injury Network by virtue of its vision and mission aspires to be the focal point for coordination of TBI information and advocacy for Alaska.

The Alaska Department of Health and Social Services is involved with TBI awareness and advocacy through Public Health, Behavioral Health, and Senior and Developmental Disabilities.

The Alaska Disability Law Center (DLC) is an independent non-profit organization that provides legal advocacy services for people with disabilities anywhere in Alaska. DLC is designated under federal law as the State of Alaska's "Protection and Advocacy" (P & A) agency. The DLC receives federal funds from the US HRSA Federal TBI Grant Program and uses some of these funds to train TBI survivors and family members to effectively access and advocate for services.

The Alaska Mental Health Trust Authority funds Partners in Policymaking, which is a national model of advocacy and leadership training. Alaska's Partners in Policymaking Program has been designed for Trust beneficiaries and their families. This project identifies individuals from around the state who have not held a leadership position and helps them develop advocacy and leadership skills to improve their lives.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

SEATBELT USE OBSERVATION STUDIES ALASKA





Anchorage residents.

Primary Enforcement Seatbelt Law

On May 1, 2003 Alaska passed a law to change their seat belt law from secondary enforcement to a primary enforcement state, ie. a vehicle can be stopped solely for seat belt non-use by an occupant. A study of Alaska has seen a steady increase in seatbelt use in the last decade. In 2007 the percent use as seen in the annual observations study was 82.4 percent. The national rate is 82 percent. The NHTSA goal is 95 percent use.

States with primary seat belt laws on average had seat belt use rates about 10 percentage points higher than States without primary laws in 2005. Wearing a seat belt is the best defense for an occupant in a motor vehicle crash and the single most effective measure to prevent serious traumatic brain injury. 56 percent of Alaskans with TBI resulting from a motor vehicle crash on the highway were not wearing seat belts. If every state with a secondary seat belt law upgraded to primary enforcement, about 1,000 lives and \$4 billion in crash costs could be saved each year.

The TBI rate due to motor vehicle crashes on the highway has decreased 38 percent from 2001 to 2005.

Bicycle Helmets

Bicycle helmets are 85-88 percent effective in mitigating head and brain injuries. Every dollar spent on a bike helmet saves \$40 in direct medical costs and other costs to society. (NHTSA)

A baseline observation survey of bicycle rider's helmet use was conducted during the summer of 2000 by the Alaska Injury Prevention Center in nine communities and then repeated in 2006 in 12 communities. The mean average of bicycle helmet usage rate for all the communities surveyed was 39 percent, compared to 31 percent in 2000.

Four of the twelve communities surveyed in 2000 and in 2006 had recently passed ordinances requiring helmet use for children. The average change for bicycle helmet use in the "helmet ordinance" communities was +56 percent, while the communities with no ordinance had an average change of +17 percent.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY

Key Agencies

Alaska Brain Injury Network
Alaska Commission on Aging
Alaska Injury Prevention and EMS
(ADHSS, DPH)
Alaska Injury Prevention Center
Alaska Native Tribal Health Consortium
Alaska School Activities Association
Behavioral Health
Highway Safety Office (DOTPF)
Prevention Program

Funding Opportunities

Safe Kids Alaska

Alaska School Activities Association Alaska Mental Health Trust Authority General Fund National Highway and Traffic Safety Providence Alaska Medical Center Federal Grants:

- CDC, HRSA TBI State Grant Funding
- Prevention Block Grants
- MCH Block Grant

PUBLIC AWARENESS, PREVENTION AND ADVOCACY

GOALI:

Alaskans have knowledge of traumatic brain injury in Alaska.

Objectives

- A. To inform Alaskans about TBI, causes, effective prevention, extent and resulting problems through public education campaigns and materials.
- B. Strengthen the TBI information sharing network across the state.

Recommendations

Years One-Ten

- Use injury surveillance data sets to describe TBI in Alaska.
- Provide TBI information through resources library, website, and conferences.
- Raise awareness of TBI through participation in the AMHTA Coordinated Communications Campaign.
- Participate in March Brain Injury Awareness Month activities through resolutions, proclamations, press kits and so forth.
- Recruit a self-advocate to put a face on TBI and serve as spokesperson.

GOAL 2:

Reduce the incidence of TBI-related disabilities.

Objectives

- A. To prevent TBI in child occupants of motor vehicle crashes through correct booster seat use.
- B. To prevent TBI in young Alaskans in off-road vehicle and bicycle crashes through helmet use.
- C. To reduce risky behaviors among teens.
- D. To prevent TBI in elders due to falls through awareness and training of long-term care, community service providers and other caretakers.
- E. To prevent repetitive injuries by educating individuals with TBI, family members and others about the risk of second and third injuries.
- F. To promote collaboration among prevention agencies and organizations to include TBI in the prevention message (in addition to fatalities).
- G. To reduce TBI among elders due to falls.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY









Alaska Model Helmet Program www.hss.stat.ak.us

Recommendations

Years One-Two

- Enact booster seat legislation.
- Funding for prevention education programs and collaboration among programs.
- TBI self-advocates to assist with injury prevention education programs.
- Collaboration among injury prevention agencies to coordinate TBI prevention and support best practices.
- Funding for "Second Impact Syndrome" training of health professionals and school coaches.
- ASAA adopt IMPACT program for school sports.
- Support local helmet use ordinances.
- Fund and implement the Alaska Model Helmet program.
- Develop and implement teen focused TBI awareness events.
- Develop, fund and implement an elderly fall prevention program.

Years Three-Five

- Introduction and passage of local helmet ordinances.
- Funding for falls prevention program targeted to preventing fall-related injuries among the elderly.
- Monitor safe behaviors through BRFSS, YBRFSS and observation studies.
- Funding for helmet use observations studies.

Year Five-Ten

• Enact all rider helmet legislation.

GOAL 3

To minimize the extent of injury through secondary preventative efforts.

Objectives

- To educate hospitals about the importance of distributing TBI educational materials about further injury or prevention information.
- To educate schools on concussion management programs and techniques.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - PUBLIC AWARENESS, PREVENTION AND ADVOCACY



Jessi C. receiving TBI Advocacy Award.

Recommendations

Years One-Two

- Adopt IMPACT program for school sports (Alaska School Activities Association (ASAA)).
- Support hospital trauma programs and trauma center verification reviews.
- Provide TBI information, including information on concussions, to EMS, ED, hospital, health centers and physicians' patients.
- Provide information to families on TBI, symptoms and resources.

GOAL 4:

To build a TBI advocacy constituency.

Objectives

- A. To develop TBI advocates through information and training on systems advocacy.
- B. To help individuals be successful self-advocates and families and others to advocate for appropriate and adequate services.

Recommendations

Years One-Ten

- Develop and provide on-going training for advocates.
- Hold meetings/conferences for showcasing State Plan recommendations and implementation.
- Involve TBI participation in Alaska Partners in Policy Making.
- Form coalitions on TBI issues.
- Release action alerts to TBI advocates including the Alaska Brain Matters support group when advocacy opportunities arise.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - OUTREACH AND IDENTIFICATION

"My background is in behavioral science and for 30-plus years I have worked with jails and prisons. It never ceases to amaze me how many people are incarcerated that have TBI and they are treated wrongly."

-- Behavioral health provider

People with mental illness and cognitive impairments are over-represented in the correctional system compared to their prevalence in society.

It costs the State of Alaska millions of dollars each year in added prison costs and loss of Federal entitlements to have people recycle through the corrections system.

OUTREACH AND IDENTIFICATION

Not all individuals who experience a TBI are hospitalized or treated in an Emergency Department (ED), or they may be treated for other injuries that occurred at the same time – but not treated for a TBI. It is not unusual for individuals to experience problems associated with a TBI for months after the injury. They may seek treatment for headaches or fatigue or other problems from a health professional that may not be aware of their injury. They may have problems functioning in home, school or work, but not be aware that the problems may be associated with an injury -- nor will their employer, family or educator be aware of the cause of their problems. They may go undiagnosed, or misdiagnosed.

One way to help individuals experiencing problems due to a TBI is through a screening process. Individuals administering screening tools usually use a simple questionnaire to identify those at risk and to flag those who need further assessment. Questions posed generally ask if the person has been hit on the head, been seen in an emergency department, lost consciousness, experienced headaches or problems with memory, balance, fatigue, or other problems. These questions may be asked of the individual and/or his family or significant others.

Professionals who are experienced in TBI will often administer a screening questionnaire to a specific population, such as to all children in public schools, or victims of domestic violence or older adults served in long-term care or community programs, to determine if a TBI could be a contributing factor to problems an individual may be experiencing. The individual may be referred to a neuropsychologist or other professional for further evaluation, assessment and diagnosis.

State programs and community agencies often use a screening tool as a first step in determining eligibility, indicating that perhaps a follow up assessment and evaluation are warranted to determine diagnosis. Screening can also assist in coordinating appropriate resources and services for people that need them. Physicians can also improve patient outcomes when MTBI (mild TBI) is suspected or diagnosed by implementing early treatment and appropriate referral.

Behavioral Health provides community mental health and substance abuse services for individuals who may be eligible. Individuals seeking services through mental health or substance abuse agencies are routinely "screened" for TBI, which is a self-assessment or recall of their TBI and problems.

Another way to help individuals to self-identify or to create awareness of TBI and related symptoms is through outreach with existing networks to disseminate information. Working with existing organizations that already have relationships with under served groups may help to identify people who may be undiagnosed,

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - OUTREACH AND IDENTIFICATION

Behavioral health providers routinely screen for TBI and find one third of the clients are identified as having history of TBI.

and to increase referrals to resources and services. These organizations may have access to people through their own network and resources that may be helpful. Information on TBI symptoms may also be distributed at conferences, health clinics, physician offices and other places common to the general public.

TBI Screening in Behavioral Health

SOA Behavioral Health has been nationally recognized for their work in identifying TBI survivors in community mental health and substance abuse programs.

Behavioral Health provides behavioral health services to individuals with TBI who have co-occurring conditions. The Behavioral Health Grants component contains grant funding to local non-profit agencies to support the comprehensive, statewide mental health and substance abuse prevention and treatment system required by law. In addition the agency is responsible for the maintenance of state-owned community mental health facilities. These publicly funded programs primarily serve Alaskans without insurance or the ability to pay for services. This component also supports personal skills development and general support services for people with traumatic brain injury.

Behavioral Health expects that grantee providers will continue to be cross-trained in both mental health and substance abuse treatment and service delivery, commensurate with dual diagnosis capability. Federal funding has also been awarded to the agency to provided TBI training with regard to assessing and treating individuals with TBI and dual diagnosis.

The Alaska Behavioral Health has been screening its clients for TBI for five years and finds that at least a third screen positively for TBI. This screen was developed prior to the wars in Iraq and Afghanistan, and may warrant revisiting to incorporate questions regarding service in the military, exposure to blasts or explosions, rollover injuries and so forth. As screening involves posing questions that usually requires the individual to self report, the questions posed and the experience of the screener are critical in order to determine if the information gathered warrants further evaluation, assessment and referral to services. The individual reporting may not have the awareness or might have other cognitive difficulties that may prevent the person from reporting accurately. "Yes" or "no" questions, for example, may not present the screener with useful information in terms of behavioral problems the person may be experiencing. Ongoing training of screeners may be beneficial to ensure that those who are screening are proficient in being able to follow up with questions in order to ascertain pertinent information.

The Alaska Behavioral Health is committed to implementing and administering a behavioral health management information system that provides Alaska health

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - OUTREACH AND IDENTIFICATION

care providers with modern, streamlined business and clinical tools. The AKAIMS project is being designed to provide data with regard to services provided. However, currently, the Behavioral Health program is unable to separate out data pertaining to those who have a TBI diagnosis to identify services provided; if services are successful in helping individuals who have cognitive and/or behavioral problems to recover from substance abuse issues; if these individuals are successful over the long term, or re-enter the system periodically; other services and supports that may be needed in order to be successful, and if individuals with TBI and substance abuse and/or behavioral problems are able to resume community living, employment and life similar to that before the injury.

Cognitive problems as the result of a TBI impair an individual's learning style; treatment and group interventions used for individuals without cognitive issues may not work for those who have trouble with memory, thinking, fatigue, socially appropriate behavior or understanding environmental cues.

Research Shows Need for TBI Screening

Alcohol is a major contributor and frequent factor in the cause of injury. Research has shown that individuals with TBI frequently return to the use of alcohol and substance abuse two years post injury (Corrigan, Rust et al., 1995; Kreutzer, Witol et al., 1996; Kreutzer, Witol et al., 1996; Corrigan, Smith-Knapp et al., 1998).

Substance abuse is also prevalent among correctional facility inmates, including those with a TBI. A CDC report states that studies of inmates' self-reported health indicate that those with one or more brain injuries have significantly higher levels of alcohol and/or drug use during the year preceding their current incarceration. Without appropriate treatment and rehabilitation for persons with TBI who have mental health and substance abuse problems the probability that they will again abuse alcohol and/or drugs when released increases. The CDC report recommends training for community- re-entry staff in order for them to be able to identify inmates with a history of TBI and have access to appropriate consultation with other professionals with expertise in the field of TBI and behavioral health issues. The report also emphasized the need for case management services to assist with placement into community treatment programs.

Another study provided evidence that screening for depression should be a standard component of TBI assessment protocols. In this study, researchers found that between 30 percent and 38 percent of patients with TBI were classified as depressed with the NFI Depression Scale and the BDI, respectively (Seel & Kreutzer, 2003). Other mental health problems associated with TBI include anxiety, personality changes, aggression, acting out and social inappropriateness.

Traumatic brain injury in prisons and jails: an unrecognized problem. www.cdc.gov

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - OUTREACH AND IDENTIFICATION



In a more recent study, the Rand Corporation found that:

Approximately 18.5 percent of U.S. service members who have returned from Afghanistan and Iraq currently have post-traumatic stress disorder or depression; and 19.5 percent report experiencing a traumatic brain injury during deployment.

A study reported in the New England Journal of Medicine reported on a survey conducted of 2714 soldiers from two U.S. Army combat infantry brigades — one Active Component and one Reserve Component (Army National Guard) —deployment in Iraq. The study found that mild TBI is strongly associated with PTSD and physical health problems three to four months after the soldiers return home and concluded that mild traumatic brain injury (i.e., concussion) occurring among soldiers deployed in Iraq is strongly associated with PTSD and physical health problems 3 to 4 months after the soldiers return home. PTSD and depression are important mediators of the relationship between mild traumatic brain injury and physical health problems (Hoge, C.W., McGurk, D., Thomas, J.L., Cox, A., Engel, C.C. and . Castro, C.A. 2008).

A few states are beginning to screen returning National Guard troops and others who may not have been screened by the Department of Defense or Veterans Administration or who may not have indicated any problems in those screens, for Post-Traumatic Stress Disorder (PTSD), TBI and substance abuse. Through these screens, the states are providing information on TBI and related problems, available resources and assistance. Some states report that these returning service members are also seeking services from local mental health and other providers.

Case management was cited as being beneficial for adults with TBI and substance abuse problems in terms of life and family satisfaction as well as to have potential cost savings (Heinemann, Corrigan& Moore, 2004).

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - OUTREACH AND IDENTIFICATION

Key Agencies

Behavioral Health Department of Education and Early Developmnet

Domestic Violence Homeless Clinics

Juvenile Justice

National Guard

Public Health Clinics

Public Schools

Veterans Organizations

Women Shelters

Funding Opportunities

Behavioral Health Federal Grants Public Health Public Schools Senior and Disability Services The Trust

OUTREACH AND IDENTIFICATION

GOAL 1:

To provide outreach to undiagnosed/misdiagnosed TBIs.

Objectives

- A. To provide TBI information and outreach through informational materials on symptoms of TBI to such agencies/organizations as domestic violence providers, community health centers, juvenile justice staff/providers, veterans organizations.
- B. To provide information to culturally diverse groups.

Recommendations

Years One-Two

- Develop outreach materials and disseminate.
- Develop materials that are culturally appropriate.

GOAL 2:

To identify individuals with undiagnosed TBI.

Objectives

- A. Identify individuals with TBI who may be experiencing problems through screening and outreach programs targeted to such groups as children and youth in public schools; older adults in long-term care and communitybased programs; correctional facilities; and those who return from Iraq and Afghanistan.
- B. Expand capacity for screening for TBI through partnerships with other organizations and agencies to expand their assessment tools to include TBI questions and information.
- C. Provide training to providers and educators on recognizing symptoms of TBL

Recommendations

Years One-Two

- Expand Behavioral Health screening to include war-related injuries; and train screeners accordingly.
- Expand/refine data capacity for reporting TBI and behavioral health cooccurring disorders in order to evaluate services provided and to identify further needs.

Years Three-Five

- Work with local school districts, Department of Education and Early Development to expand screening to include TBI.
- Incorporate TBI into mental health and substance abuse screenings for inmates in correctional facilities.
- Develop program for training long-term care and community-based programs serving older adults to identify and screen older adults for TBI.
- Develop and provide training to educators on identifying TBI symptoms.

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CORE SERVICE II: SYSTEMS INFRASTRUCTURE - TRAINING AND WORKFORCE DEVELOPMENT

"I am so grateful for the trainings the Alaska Brain Injury Network has organized for people in Bristol Bay. They have really reached out to our community holding board meetings and trainings to raise awareness. Because of the training we have been able to make some referrals for neuropsychological testing."

--Mental health case manager

TRAINING AND WORKFORCE DEVELOPMENT Training

Since 2003, The Alaska Mental Health Trust Authority (The Trust), in partnership with the Department of Health and Social Services and the University of Alaska System, has worked towards remedying workforce challenges, including recruitment, retention, and lack of training opportunities. The Alaska Mental Health Trust Authority (Trust) supports the Trust Training Cooperative which coordinates and provides training, education and career development opportunities for the current and future workforce engaged with Alaska Mental Health Trust Beneficiaries including people with TBI. The Trust also supports various University of Alaska initiatives such as the distance delivered BSW and MSW programs; the Ph.D. clinical internship, and the Alaska Rural Behavioral Health Training Academy. In addition the Trust funds projects through other entities such as the annual vacancy study, marketing and the Alaska Alliance for Direct Care Service providers.

The Alaska Mental Health Trust Authority administered a workforce training survey in May 2007 and found that a top priority for providers is training to manage challenging and disruptive behaviors, strategies for addressing cognitive disabilities, and use of community resources.

The Vocational Rehabilitation counselors have also identified training on best practices for vocational training and job placement for individuals with TBI. Similarly, educators and related staff have expressed the need for training and support for addressing the IEP (Individual Education Plan) needs of students.

The Alaska Senior and Disability Services has developed a web-based training for care coordinators, which could be expanded or a similar training could be replicated in order for care coordinators to understand how to work with people with TBI.

In May 2008, the Trust Authority approved \$100,000 Brain Injury Training for Providers to be administered by Department of Health and Social Services, Behavioral Health. Plans are to incorporate this new effort into existing Center for Human Development, UAA initiatives, such as the Trust Training Cooperative.

The focus of this money is to work with Center for Human Development to:

- Provide training to 5 content experts (i.e neuropsychologists, behavioral health counselor, vocational specialist, community health aide) in course development, distant-delivery options, and earning content management system by December 31, 2008.
- Develop Introduction to Traumatic Brain Injury in conjunction with Direct Service Specialist Occupational Endorsement Certificate (DSSOE).
- Pilot Course with 10-15 TBI mentors from around the state, and the 10-15 mentors will gain skills and knowledge in supporting 2 5 others learning how to support individuals with TBI.
- Work with an instate TBI specialist to offer case consultation by June 30, 2008.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - TRAINING AND WORKFORCE DEVELOPMENT



Anna L. Gustavus, Alaska

Plans for FY 2010 and FY 2011 are to continue MHTAAR request with a GF/MH match, (\$50.000) MHTAAR and \$50.000 GF/MH), to benefit individuals with brain injury through continuation of FY 2009 activities focused on direct service providers, as well as expand to educators, vocational specialists, and employers.

Core Competencies

The Trust Credentialing and Quality Standards Subcommittee (CQSS) has been created to develop and coordinate competencies and credentialing for the direct care workforce in the state.

The CQSS is a subcommittee of the Training and Education Committee, one of the three committees of the Workforce Development Focus Area funded by the Trust. The Subcommittee issued a report in June 2008, noting that competencies have been designed or applied within the State Health and Social Services Department, higher education, provider organizations, the Alaska Native Tribal Health Consortium, and as a part of the Alaska Commission for Behavioral Health Certification. There is currently no singular competency set that is being applied across settings that serve Trust beneficiaries. One of the goals of the Credentialing and Quality Standards Committee (CQSS) is to create a forum for Alaskan providers and educators to communicate with each other and to develop a set of core, direct care competencies necessary to serve all of the Trust beneficiary groups.

However, the report did note that the range of knowledge and skills required to intervene with diverse populations cannot be fully represented in a core set of competencies. Also noted is the lack of involvement of persons in recovery and family members in the development of competencies in health and human services. While TBI is mentioned as a Trust beneficiary, the report did not address specific issues relating to training and competencies necessary to understand TBI-related behavior, cognitive and co-occurring conditions. The report calls for developing a model for a set of core competencies, training and evaluation, curriculum and training modules, credentialing system and specialty competencies.

Consultants

Behavioral Health has funding for FY09 to identify TBI specialists in the state, as described above, in the areas such as behavioral health, vocational rehabilitation, education and psychology who can provide consultative services to professionals/providers who need assistance with assessment, developing appropriate plans and strategies for managing behaviors, compensatory strategies for cognitive problems and co-occurring disabilities.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - TRAINING AND WORKFORCE DEVELOPMENT

Key Agencies

Alaska Rural Behavioral Health Training
Academy
Behavioral Health
Centers for Independent Living
Department of Education and
Early Development
Department of Labor and Workforce
Development
Public Schools
Senior and Disability Services
The Trust
Trust Training Cooperative
University of Alaska
Vocational Rehabilitation

Funding Opportunities

Alaska Mental Health Trust Authority Behavioral Health General Funds Mental Health/General Funds Federal Grants;

- HRSA, NIH, NIMH, VETs, Military Affairs

TRAINING AND WORKFORCE DEVELOPMENT

GOALI:

To increase workforce knowledge in TBI.

Objectives

- A. To increase the number of trained direct care providers in understanding and addressing TBI behaviors, cognitive issues, compensatory strategies and available resources.
- B. To increase the number of trained vocational rehabilitation counselors and community providers on successful employment strategies and work models for individuals with TBI.
- C. To develop and provide in-service to educators on identifying TBI and developing appropriate educational plans, teaching and behavioral strategies.
- D. To include knowledge of TBI in required core competency requirements.
- E. To develop a pool of consultants to assist professionals, educators and direct care providers in developing individual service/education plans, managing behaviors and strategies for accommodating cognitive problems.

Recommendations

Years One-Five

- Develop distance delivered TBI curriculum.
- Conduct training through existing educational certificate and endorsement programs.
- Conduct training through agency sponsored workshops/conferences for direct care providers, educators and other professionals/paraprofessionals.
- Expand core competencies for the workforce to address TBI.
- Expand telehealth for training providers and families, particularly in rural areas.

Years Five-Ten

- · Continue training opportunities.
- Integrate TBI into college and vocational curriculums.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - STATEWIDE PLANNING AND POLICY COORDINATION

"I've been a care coordinator for 23 years and have clients with TBI. The lack of services exclusively for people with TBI in Alaska is very frustrating. I am concerned that the TBI population has gone under served for much too long at the expense of TBI survivors. I hope ABIN can make some suggestions about different types of programs that are being used throughout the Lower 48 and maybe bring some of those to Alaska to help these unfortunate people."

-- Care coordinator

ABIN TIMELINE

1999

State of Alaska (SOA), Department of Health and Social Services (DHSS) awarded Federal TBI Act Grant

2000

SOA, DHSS, Division of Mental Health and Development Disabilities formed Traumatic Brain Injury Advisory Board

2003

Alaska Traumatic Brain Injury Advisory Board incorporated; non-profit status.

2006

Changed name to Alaska Brain Injury Network, Inc.

STATEWIDE PLANNING AND POLICY COORDINATION

The US Health Resources and Services Administration (HRSA) Federal TBI Program requires states to have an advisory board to receive federal grant funding. This is in recognition that services for individuals with TBI are limited and fragmented, and that boards provide an opportunity for individuals with TBI and their families to work with state agencies, local and community agencies and other professionals to develop services and supports that best meet their needs.

Advisory Board

The Alaska Traumatic Brain Injury Advisory Board (ATBIAB) was formed in 2000 to fulfill the requirements of the grant and conduct business as an advisory board; holding quarterly board meetings and inviting public comment. ATBIAB became a 501c3 non-profit in 2003 and changed its name to the Alaska Brain Injury Network, Inc. in 2006.

The ABIN educates, plans, coordinates, and advocates for a comprehensive service delivery system for the survivors of traumatic brain injury and their families. It provides statewide information and referral for persons with brain injury, their families, providers, friends, and many others interested in brain injury services within Alaska's communities. ABIN also develops materials for public education and outreach.

The ABIN received funding to develop this State TBI Plan and has reached out to collaborating partners to envision a seamless system of care. The Board has defined a desired system, as reflected in this report, and engaged partners in developing strategies for implementation. Once the plan has been adopted, the ABIN will continue to push for implementation of these goals through working groups, interagency meetings and advocacy. Obviously, these goals are comprehensive and will require help from all parties for successful implementation and outcomes.

Data for Planning

To effectively plan and evaluate systems and their services, both program and client data are needed. In Alaska the trauma registry data provides information regarding the hospitalizations of TBI that provides some information with regard to incidence, cause, and demographics. This is helpful for determining appropriate prevention and intervention strategies.

Alaska's state programs that provide treatment, care, services and other benefits collect some client information. This information may not be TBI specific in that TBI may not be a diagnostic category. Vocational Rehabilitation, however, does collect information on the number of people with TBI that are served and are placed successfully in a job.

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - STATEWIDE PLANNING AND POLICY COORDINATION

To help with overall planning, data would be useful to have in terms of numbers served by each agency. Data collection for TBI can be improved. The Alaska Automated Information Management System web-based application and database serves as a management information system (MIS) and clinical documentation tool for Behavioral Health. The Status Review (CSR) tracks the quality of life of consumers of the Alaska behavioral health treatment system. When clients enter the system they are asked a series of questions about their "life domains" such as thoughts of self-harm, feelings of connectedness, productivity, etc. For comparison, they are asked the same questions at different intervals during treatment, and at discharge. While this information is available with regard to clients served by the division, it cannot be teased out specifically for individuals with TBI that have a co-occurring condition (mental health and/or substance abuse).

To help with overall planning, data would be useful to have in terms of numbers served by the agencies (i.e. Behavioral Health, Senior and Disability Services, Medicaid), demographics, extent and costs of services, outcomes, as well as the number who may be turned away from services due to ineligibility (i.e. financial, diagnosis, age).

Self/Family Satisfaction surveys are another way to assess whether services are meeting the needs of individuals, and to assure that services are provided in a timely and coordinated fashion, are appropriate and easy to access.

ALASKANS WITH TBI IN EXISTING STATE SYSTEMS

Agency/Program	Age	Number	Year
Div. of Public Health – Trauma Registry	All ages	800	2007
Div. of Behavioral Health	18+	2080	2006
Div. of Vocational Rehab	16+	167	2007
Div. of Senior and Disability Services (Developmental Disabilities)	All ages (with injury occurring before age 22)	Unknown	
Div. of Senior and Disability Services (Adults and Seniors)	22+	Unknown	
Health Care Services-Medicaid	All ages	Unknown	
Div. of Juvenile Justice	Unknown		
Dept. of Education – Child Find	6-21	66	2007
Dept. of Corrections	18+	Unknown	
Alaska Native Tribal Health Consortium	All ages	Unknown	
Dept. of Military and Veterans Affairs	18+	Unknown	

CORE SERVICE II: SYSTEMS INFRASTRUCTURE - STATEWIDE PLANNING AND POLICY COORDINATION

Key Agencies

Alaska Brain Injury Network
Alaska Mental Health Trust Authority
Center for Human Development
Department of Defense
Department of Health and Social Services
Indian Health Services
4 Statutory Boards
University of Alaska Anchorage
Veterans Administration

Funding Opportunities

Alaska Mental Health Trust Authority General fund HRSA Federal TBI State Grant Program

PLANNING AND POLICY COORDINATION

GOALI:

State services which are coordinated and responsive.

Objectives

- A. To coordinate state policy planning across agencies on crosscutting issues (i.e. prevention, substance abuse, aging, developmental disabilities, Medicaid) as reflected in state agency planning and program documents.
- B. To expand and coordinate data capacity needed for overall systems planning, as well as for individual services planning.
- C. To Increased number of inter-agency referrals.
- D. To ensure participation of families and individuals with TBI in the planning and delivery process.
- E. To recommend a "no wrong door" policy for TBI services through coordination of intake and service procedures.

Recommendations

Years One-Ten

- Continue TBI Advisory Board role as a planning board for the Department of Health and Social Services and the Trust, maintaining funding eligibility under HRSA TBI ACT.
- Continue to provide a venue for consumer input on the TBI service delivery system.
- Expand data capacity across pertinent programs to evaluate the TBI service delivery system; i.e. individuals served, services provided, expenditures and outcomes.
- Continue TBI participation among the 4 statutory advisory boards.
- Develop MOUs to support coordination of program data; individual service planning, including TBI documentation/evaluations, subject to confidentiality release of information.
- Evaluate Post Consumer Satisfaction Surveys every 2 years.

CHAPTER 4: TBI IN ALASKA

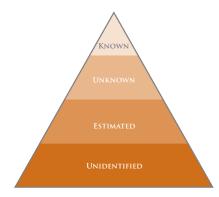
OVERVIEW

Every 15 seconds someone sustains a traumatic brain injury (TBI) in the U.S. Thirty years ago, only half of all people with brain injury survived... now 78 percent survive. This means that many individuals now live with significant disability requiring a full range of services.

Every year the Alaska Department of Health & Social Services reports about 800 traumatic brain injury (TBI) cases resulting in hospitalization or death. The CDC estimates that almost 3,000 Alaskans visit the emergency department each year with a mild TBI. There are an estimated 10,000 plus Alaskans currently living with a disability due to their TBI.

Of recent significance and currently unknown, is the number of Alaskan service members returning with diagnosed and undiagnosed TBI.

TBI PYRAMID



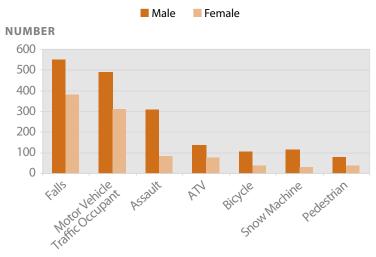
Known 800 hospitalized or fatal TBI/year

Unknown About 3,000 Emergency Visits with mild TBI per year

Estimated 10,000+ Alaskans living with TBI

Unidentified Symptoms not recognized as TBI

ALASKA TRAUMA REGISTRY NON-FATAL TBI HOSPITALIZATIONS OF ALASKA RESIDENTS, 2001-2005



- The three top causes of TBI among those admitted to a hospital from 2001-2005 were falls, motor vehicle traffic crashes and assaults.
- Off-road motor vehicle crashes, snow machine and ATV combined, ranks a close fourth.
- The rate of TBI injury for males is nearly twice that of females. The male rates are significantly higher in all age groups and for all major injury categories.
- Data show that alcohol was involved in one-third of the TBI events.

OVERVIEW

The highest rates of TBI are among Alaska Natives, residents of rural Alaska, youth age 15-19 in motor vehicle crashes, and elder falls. The crude rate of non-fatal hospitalized TBI in Alaska for the five year period (2001-2005) was 98.6 per 100,000.

Non-Fatal TBI Hospitalization Rate per 100,000

All Alaskans	98.6
Males age 80+	301.3
Females 80+	217.2
Males age 15-19	215.7
Males age70-79	200.9







Males and females 80+



Hospitalized for TBI

TBI's among Alaska Natives and rural Alaskans are overrepresented. The Alaska Native population comprises about 16 percent of the population; however, the TBI population is 34 percent Alaska Native. Similarly, highest rates of TBI occur to the residents of the regions of the Northwest, North Slope, Norton Sound, and the rural Interior Region.

Alaska Native Atlas of Injury Morbidity and Mortality

Injury Deaths 1999-2005, and Injury Hospitalizations 1991-2003, reports the following statistics:

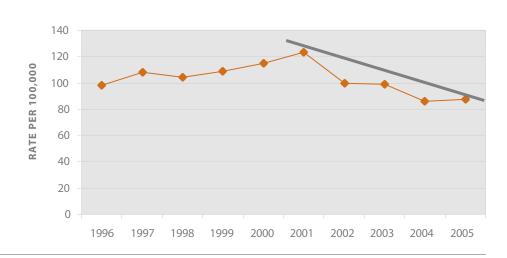
- Injuries (unintentional and intentional combined) were the leading cause of death among Alaska Natives.
- Unintentional injuries alone were the third leading cause of death. The rate was twice that of all Alaskans and three times greater than the rate among the U.S., all races, population.
- Falls were the leading cause of injury hospitalization and suicide attempt the second leading cause among Alaska Natives.
- 70 percent of all injury hospitalizations for Alaska Natives were among young persons (age 0-39).
- 80 percent of all injury hospitalizations for Alaska Natives 70 years of age or older were caused by falls.
- 13.5 percent of injury hospitalizations were for traumatic brain injury (TBI). The most common causes of TBI were falls, motor vehicles, assault, ATVs, and snow-machines.
- Alcohol was a factor in 69 percent of the assault injury hospitalizations.

SUCCESS HIGHLIGHTS

THE RATE OF TBI HAS FLUCTUATED OVER TIME BUT APPEARS TO BE DECLINING SINCE 2001.

The State of Alaska initiated programs to improve TBI awareness and services in the late 1990's.

ALASKA RATE OF HOSPITALIZED TBI BY YEAR

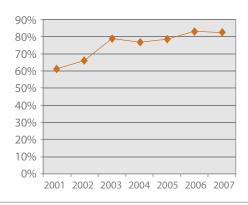


THE TBI RATE DUE TO MOTOR VEHICLE CRASHES ON THE HIGHWAY HAS DECREASED 38 PERCENT FROM 2001 TO 2005.

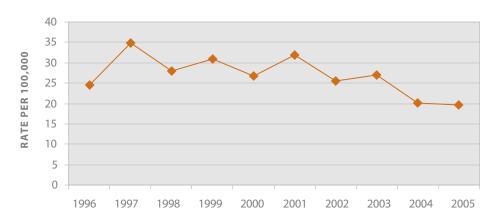
Primary Enforcement Seatbelt Law

On May 1, 2003 Alaska passed a law to change their seatbelt law from secondary to primary enforcement, ie. a vehicle can be stopped solely for seat belt non-use by an occupant. A study of Alaska has seen a steady increase in seatbelt use in the last decade. In 2007, the percent use as seen in the annual observations study was 82.4 percent. The national rate is 82 percent. The NHTSA goal is 95 percent use.

SEATBELT USE OBSERVATION STUDIES ALASKA



HOSPITALIZATION TBI BY YEAR DUE TO MOTOR VEHICLE CRASH



States with primary seatbelt laws on average had seat belt use rates about 10 percentage points higher than States without primary laws in 2005. Wearing a seat belt is the best defense for an occupant in a motor vehicle crash and the single most effective measure to prevent serious traumatic brain injury. 56 percent of Alaskans with TBI resulting from motor vehicle crash on the highway were not wearing seat belts. If every state with a secondary seat belt law upgraded to primary enforcement, about 1,000 lives and \$4 billion in crash costs could be saved each year.

SUCCESS HIGHLIGHTS

BICYCLE HELMET USE INCREASES WITH HELMET ORDINANCES

Bicycle helmets are 85-88 percent effective in mitigating head and brain injuries. Every dollar spent on a bike helmet saves \$40 in direct medical costs and other costs to society. (NHTSA)

A baseline observation survey of bicycle rider's helmet use was conducted during the summer of 2000 by the Alaska Injury Prevention Center in nine communities and then repeated in 2006 in 12 communities. The mean average of bicycle helmet usage rate for all the communities surveyed was 39 percent, compared to 31 percent in 2000.

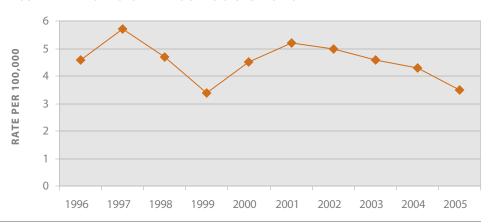
Four of the twelve communities surveyed in 2000 and in 2006 had recently passed ordinances requiring helmet use for children. The average change for bicycle helmet use in the "helmet ordinance" communities was +56 percent, while the communities with no ordinance had an average change of +17 percent.

[Alaska Bicycle Helmet Use Observational Surveys May-August 2006, Ron Perkins, Alaska Injury Prevention Center]

BICYCLE CRASH

Every dollar spent on a bike helmet saves \$40 in direct medical costs and other costs to society.

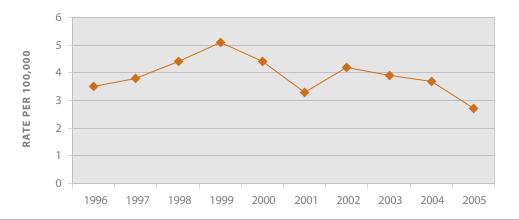
HOSPITALIZATION TBI BY YEAR DUE TO BICYCLE CRASH



PEDESTRIAN INJURY

There is no clear trend in pedestrian injuries.

HOSPITALIZATION TBI BY YEAR DUE TO PEDESTRIAN INJURY

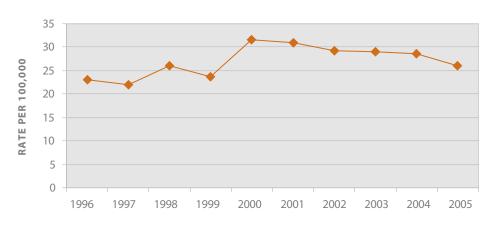


CHALLENGES TO ADDRESS

FALLS

Falls are the leading cause of TBI among the elderly. Programs which emphasize a multidisciplinary approach for prevention have been found most effective. These programs address strength and balance conditioning, treatment of medical conditions, prescription evaluation, and modifying the environment.

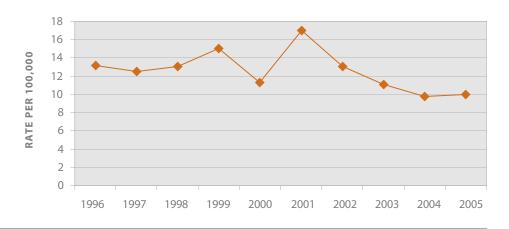
HOSPITALIZATION TBI BY YEAR DUE TO FALLS



ASSAULTS

Data shows that alcohol was involved in one third of TBI events.

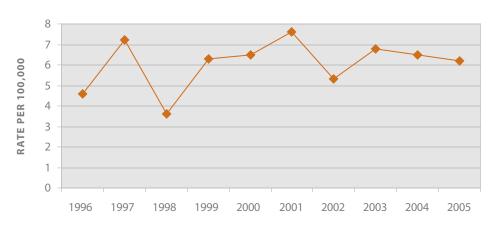
HOSPITALIZATION TBI BY YEAR DUE TO ASSAULT



ATV CRASHES

In rural Alaska helmet use is not always culturally or traditionally accepted and changes in behavior are the most challenging injury prevention model. Many programs have been piloted and implemented using role models, incentives, TBI advocates, local helmet use ordinances, and helmet clinics.

HOSPITALIZATION TBI BY YEAR DUE TO ATV CRASH



CHALLENGES TO ADDRESS

SNOW MACHINE CRASHES

Helmets must be warm and fog-free to meet the needs of Alaskans.

HOSPITALIZATION TBI BY YEAR DUE TO SNOW MACHINE CRASH



ACRONYMS

ABADA

Advisory Board on Alcoholism and Drug Abuse

ABIA

Asset Building Initiative of Alaska (see also IDA)

ABIN

Alaska Brain Injury Network (new name for brain injury board)

ACoA

Alaska Commission on Aging

ACMHS

Anchorage Community Mental Health Services

ADL

Activities of Daily Living. Activities that are performed daily in order to maintain independent living.

ADRD

Alzheimer's Disease and Related Dementia

ADRO

Aging and Disability Resource Centers – a federal grant received by Alaska Housing Finance Corporation and transitioning to the Division of Senior and Disability Services.

AFN

Alaska Federation of Natives

AG

Authority Grant funds – Trust funds administered outside the state budget process with approval by the Board of Trustees

AKAIMS

Alaska Automated Information Management System

ALSC

Alaska Legal Service Corporation

AMHB

Alaska Mental Health Board

AMHTA (MHTA)

Alaska Mental Health Trust (the Trust)

ANMC

Alaska Native Medical Center

ANTHC

Alaska Native Tribal Health Consortium

AOA

Administration on Aging. Alaska is in Region ten under the Older Americans Act

APD

Medicaid Waiver program for Adults with a Physical Disability (age 22+). Typical caps on Medicaid services are waived to provide services in a home/community based setting to avoid institutional level of care placement and costs.

API

Alaska Psychiatric Institute

ATBIAB

Alaska Traumatic Brain Injury Advisory Board (former name of the brain injury planning body prior to FY07 – see ABIN above)

BPI Trust Beneficiary Projects Initiative

Projects sponsored by and for Trust beneficiaries. A current focus area of the Alaska Mental Health Trust.

BTKH

Bring the kids home initiative of the Trust and DHSS

CM

Case Management

CCMC

Medicaid waiver program for Children with Complex Medical Conditions. Typical caps on Medicaid services are waived to provide services in a home/community based setting to avoid institutional level of care placement and costs.

'Chore:'

A service that assists elders and people with disabilities with housekeeping.

CIMHP

Comprehensive Integrated Mental Health Plan. An integrated plan that incorporates the four beneficiary areas of the Alaska Mental Health Trust Authority.

CIHA

Cook Inlet Housing Authority

CITC

Cook Inlet Tribal Council (Southcentral social service provider)

DD

Developmental Disabilities. A broad range of cognitive and physical disability conditions that occur before the age of 22 and results in limitations in 3 or more major life functioning areas.

DD waiver

Medicaid Waiver program for individuals with developmental disabilities. Typical caps on Medicaid services are waived to provide services in a home/community based setting to avoid institutional level of care placement and costs.

DHHS

Dept Health and Human Services (Muni of Anchorage and Federal)

DHSS

Dept Health and Social Services (AK State)

DLC

Disability Law Center

DSDS

Division of Senior and Disability Services (Division of DHSS) (sometimes called "DS squared")

DBH

Division of Behavioral Health (Division of DHSS)

DPA

Division of Public Assistance

DPH

Division of Public Health

DVR

Division of Vocational Rehabilitation under the Department of Labor

E.D.

Executive Director

GCDSE

Governor's Council on Disability and Special Education

FAS/FAS-D

Fetal Alcohol Syndrome and Fetal Alcohol Spectrum disorders

FCBHC

Fairbanks Community Behavioral Health Center

FMAP

Federal Medicaid Allocation Percentage (federal Medicaid match rate)

APPENDIX

ACRONYMS

FNA

Fairbanks Native Association

GF

General Fund from the Alaska State Legislature

GF/MH

State general funds included in the mental health budget bill with recommendations from the Alaska Mental Health Trust Authority and planning partners

HUD

Federal agency, Housing and Urban Development (housing programs for seniors: "202" and chronically mentally ill: "811")

IADI

Instrumental Activities of Daily Living

IDA

Individual Development Accounts

II C

Independent Living Centers (one in each catchments area based on the Rehabilitation act requirements) Also described as CILS See also SILC.

ISER

Institute for Social and Economic Research

JYS

Juneau Youth Services.

KIC

Ketchikan Indian Corporation

LICC

Long Term Care Ombudsman

MH

Mental health

MHTAAR

Mental health trust authority authorized receipts. Trust funds that are Administered by the state and allocated through the state legislative budget process.

NASHIA

National association of state head injury administrators.

NTS

Nutrition, Transportation and Support Services grants under Title III of the federal Older Americans Act funding.

OA

Medicaid 'waiver' program for Older Alaskans. Typical caps on Medicaid services are waived to provide services in a home/community based setting to avoid institutional level of care placement and costs.

OAA

Older Americans Act

PASS

Plan to Achieve Self Sufficiency (a plan under social security for people going to work)

PCA

Personal Care Assistance. A service under the Division of Senior & Disability.

PCAT

Personal Care Assistance assessment tool

RF

Rasmuson Foundation

SCF

Southcentral Foundation (native health corporation)

SCHIP

(S-Chip) program: State Children's Health Insurance Program

SILC

(Pronounced "silk") State Independent Living Council (See also ILCs)

SSA

Social Security Administration

SSI

Social Security Insurance

SSDI

Social Security Disability Insurance

TBGI

Trust Beneficiary Group Initiatives (former name of Trust focus area – now 'Trust Beneficiary Projects Initiative (see BPI)'

TBI

Traumatic Brain Injury (Also see ATBIAB)

TCC

Tanana Chiefs Conference (interior social service provider)

USDA

US Dept of Agriculture (Rural services section – housing and capital funding. Program with subsidized rent in units = "515")

WHCOA

White House Conference on Aging

WICHE

Western Interstate Commission for Higher Education

YKHC

Yukon Kuskokwim Health Corporation

CROSS CUTTING GOALS

CROSS CUTTING GOALS



The ABIN will continue to participate in the planning of the Comprehensive Integrated Mental Health Plan working to align upcoming initiatives with the 10 Year TBI Alaska State Plan.

MOVING FORWARD, COMPREHENSIVE INTEGRATED MENTAL HEALTH PLAN 2006-2011

Health Goal #1

Enhance quality of life through appropriate services for people with mental and cognitive disabilities and substance use disorders

Health Goal #2

Reduce the abusive use of alcohol and other drugs to protect Alaskans' health, safety, and quality of life.

Health Goal #4

Reduce the number of suicides in Alaska.

Health Goal #5

Access: ensure high quality treatment, recovery and support services are provided as close to one's home community as possible.

Safety Goal #2

Prevent and reduce inappropriate or avoidable arrest, prosecution, incarceration and recidivism of persons with mental health problems or developmental disabilities through appropriate treatment and supports.

Dignity Goal #1

Make it possible for Trust beneficiaries to be productively engaged in meaningful activities throughout their communities.

Dignity Goal #2

Enable Trust beneficiaries to live in appropriate, accessible and affordable housing in communities of their choice.

Dignity Goal #3

Assist Trust beneficiaries to receive the guidance and support needed to reach their educational goals.

Economic Security Goal #1

Make it possible for Trust beneficiaries most in need to live with dignity, ensuring they have adequate food, housing, medical care, work opportunities, and consistent access to basic resources.

WHO IS ABIN?

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

ABIN's Board of 18 directors represents all regions of Alaska, and at least 50 percent are TBI survivors or family members.

The ABIN vision encompasses a lifetime of care and services, which are both affordable and close to home.

The ABIN mission is to educate, plan, coordinate, and advocate for a comprehensive service delivery system for the survivors of traumatic brain injury and their families.

Organization

Alaska Brain Injury Network, Inc (ABIN) is a non-profit advocacy, education, and resource navigation agency incorporated in 2003. ABIN is the TBI Advisory Board to the Alaska Mental Health Trust Authority and the Department of Health and Social Services. ABIN educates, plans, coordinates, and advocates for a comprehensive service delivery system for the survivors of traumatic brain injury and their families. It provides statewide information and referral for persons with brain injury, their families, providers, friends, and many others interested in brain injury services within Alaska's communities.

History

Alaska's Division of Public Health received funding from the U.S. Centers for Disease Control and Prevention to initiate traumatic brain injury (TBI) surveillance beginning in 1998. This funding began to systematically quantify what had previously been believed anecdotally to be a significant and growing public health problem.

In 1999, the State of Alaska, Department of Health & Social Services, Division of Mental Health & Developmental Disabilities, now known as Division of Behavioral Health (DBH), under the project leadership of Leonard Abel, Ph.D., Community Mental Health Services Administrator, successfully applied for HRSA TBI Planning & Implementation Grants.

Program Activities

ABIN has two functions: TBI Advisory Board and TBI information and referral agency.

Advisory Board

- Visit both urban and rural communities, and listen to the stories that the public shares about the issues facing Alaskans with brain injuries.
- Collaborate with our partner boards to affect changes in policies to improve programs and services.
- Advocate for safety legislation, in-state brain injury

rehabilitation, and TBI Waiver services.

- Bring TBI professional training to Alaska.
- Conduct 'needs assessment' surveys of survivors, family members, and health workers.
- Maintain up to date information on emerging issues identified through callers, public testimony, and the media.

Resource Navigation

- Respond to requests for assistance, information, resources, and referral.
- Distribute a brain injury resource directory with statewide and local resources and supports available to individuals, families, friends, professionals, caregivers and the general public.
- Work to establish a TBI hotline and brain injury support groups.
- Distribute educational and informational resources to the public.

Accomplishments

TBI Advisory Board

- Development of the Comprehensive 10 Year TBI State Plan.
- Alaska Mental Health Trust Authority Funding . Recommendations approved:
 - TBI Advisory Board (FY01-FY11)
 - TBI Resource Navigation (Information and Referral) (FY07-FY11)
 - TBI Training (FY09-FY11)
 - Care Coordination with Emphasis in Brain Injury (FY10-FY11)
- Partnership with Military including 3rd Medical Unit, Elmendorf; Veteran Affairs; Veteran Centers; National Guard; and Marines.
- Connecting Alaskans to TBI training including Idaho Traumatic Brain Injury Virtual Center (<u>www.idahotbi.org</u>) and Lakeview Specialty Hospital 3rd Thursday at 3 series (<u>lcs@lakeview.ws</u>).
- Comprehensive Integrated Mental Health Plan, Alaska Scorecard includes traumatic brain injury prevalence.

TBI Resource Navigation

Online discussion group success:

In mid December 2007, ABIN started Alaskan Brain Matters – an online discussion group for brain injury. There are now eighty-three people participating in the discussions. These survivors, family members, caregivers, and providers are supporting one another, sharing success stories, swapping resources and recovery ideas.

Case example #1:

A woman approximately 48 years old, initially called ABIN on 4/27/07. She was "couch surfing" and had been living under a bridge and at the Brother Francis Shelter for several years. She had maintained a career as a nurse until multiple brain injuries left her unable to work or drive. Due to several referrals that ABIN's Resource Navigator made, she has now been connected with services that have significantly improved her life. She is now on disability with a payee assisting her; has bought a house with a

friend who is helping look out for her; has PCA services; and has started her own business in her home with the help of Nine-Star.

Case example #2:

On 3/24/08 ABIN received an email through the website from a woman in distress. The first line read "I am so alone – please help. 5 concussions / TBI's in the last 3 years have changed who I am. I have come to realize that my isolation will only increase without serious intervention..." After she joined the online discussion group, Alaskan Brain Matters and received lots of support and good ideas her email read: "It's only been 4 days since I contacted ABIN my life is already improving and becoming less stressful. I am so grateful!" Since then, with the help of the referrals from ABIN's Resource Navigator, she is now on disability and things are looking up.

Case example #3:

On 3/12/08 a woman and her caregiver called. Due to a brain injury from many years ago, she developed a seizure disorder that needs further medical treatment. She was told she would need to travel to Seattle for the necessary treatment. The travel arrangements had been lingering on for a year since she lives in a remote part of Alaska where she could only get to a phone about once a week. ABIN's Resource Navigator assisted by passing detailed messages between the caregiver and the person arranging the treatment and transportation. The situation was finally resolved by mid April 2008.

To learn more about the Alaska Brain Injury Network, Inc. visit www.alaskabraininjury.net

Communities Visited

2003 April 16th & 17th July 16th & 17th October 15th & 16th	Bethel
2004 January 21st & 22nd April 21st & 22nd July 21st & 22nd October 20th & 21st	Fairbanks Kotzebue
2005 January 26th & 27th April 13th & 14th July 20th & 21st October 19th & 20th	Fairbanks Ketchikan
2006 January 25th & 26th April 19th & 20th July 19th & 20th October 19th & 20th	Kenai Dillingham
2007 January 24th & 25th April 25th & 26th June 18th & 19th October 16th & 17th	Kodiak Nome
2008 January 23rd & 24th April 23rd & 24th June/July 30th & 1st October 15th &16th	Tok Barrow
2009 January 21-22 April 22-23 July 15-16 Sept/Oct 30-1	Mat-Su Fairbanks

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