

**HB**

**328**



# ALASKA STATE LEGISLATURE

Interim:  
716 West 4<sup>th</sup> Avenue, Suite 640  
Anchorage, Alaska 99501  
Phone (907) 269-0200  
Fax (907) 269-0204  
Rep. Craig.Johnson@legis.state.ak.us



Session:  
State Capitol, Room 126  
Juneau, Alaska  
99801-1182  
Phone (907) 465-4993  
Fax (907) 465-3872

REPRESENTATIVE CRAIG JOHNSON  
HOUSE DISTRICT 28

## Sponsor Statement for HB 328

House Bill 328 establishes a traumatic or acquired brain injury program and registry in the Department of Health and Social Services. Alaska has no program specifically to deal with brain injury and yet Alaska has one of the highest rates in the nation. Annually, there are 800 Alaskans hospitalized with a traumatic brain injury each year resulting from falls, car crashes, domestic violence, All Terrain Vehicle crashes, and snowmachine crashes, among others. There are an approximately equal number of Alaskans suffering from acquired brain injuries resulting from stroke, aneurism, or tumors.

Alaska urban and rural residents, including military are being discharged to their homes with little understanding of brain injury or access to in-state rehabilitation, severely impacting their families. Limited education about the injury, learning to cope with a person who has changed, overwhelming stress from insurance, bureaucracy, and financial burdens and change in family roles may render families dysfunctional.

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

Funding a Traumatic or Acquired Brain Injury (T/ABI) Program gives authority to the department to collect data on the injured, positioning the state to access Medicaid funds for T/ABI. Medicaid services for T/ABI will be matched 50% by federal funds. The bill allows for streamlining department services and activities that are unique to T/ABI. This would better assist families and individuals with T/ABI in knowing how to access services and supports.

Early treatment may reduce future medical and social costs. Without appropriate services, some individuals with T/ABI may pose a threat to themselves or others. Without assistance, individuals with TBI often end up homeless, in jail or in nursing homes. Service coordination, rehabilitation, and appropriate supports can help to minimize these risks.

February 8, 2010

26-LS1355\E

# LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES  
LEGISLATIVE AFFAIRS AGENCY  
STATE OF ALASKA

(907) 465-3867 or 465-2450  
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State Capitol  
Juneau, Alaska 99801-1182  
Deliveries to: 129 6th St., Rm. 329

## MEMORANDUM

February 9, 2010

**SUBJECT:** Sectional Summary (HB 328 (Work Order No. 26-LS1355\E))

**TO:** Representative Craig Johnson  
Attn: Jeanné Ostnes

**FROM:** Jean M. Mischel  
Legislative Counsel 

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

**Section 1.** Adds longitudinal data on traumatic or acquired brain injury from the registry established under sec. 5 of the bill to the list of databases that the Department of Health and Social Services is authorized to collect, analyze, and maintain.

**Section 2.** Adds case management services for traumatic or acquired brain injury to the optional services provided to recipients of state medical assistance (Medicaid).

**Section 3.** Defines "case management services for traumatic or acquired brain injury" and "traumatic or acquired brain injury" for purposes of the optional services added by sec. 2 of the bill.

**Section 4.** Requires the Department of Health and Social Services to provide medical assistance services under a waiver if approved by the federal government and if the legislature appropriates necessary funding for the services.

**Section 5.** Establishes a statewide traumatic or acquired brain injury program in the Department of Health and Social Services to evaluate the effectiveness and availability of information and services for the prevention and treatment of traumatic or acquired brain injury in the state. Requires consultation and collaboration with public and private entities to fulfill a list of programmatic requirements including development of a statewide service delivery plan and registry of information and evaluation of current laws and standards pertaining to traumatic or acquired brain injury.

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10-058.plm



COOK INLET  
T R I B A L  
COUNCIL, INC.

March 5, 2010

The Honorable Craig Johnson  
Alaska State House of Representatives  
State Capitol  
Juneau, AK 99801-1182

Dear Representative Johnson:

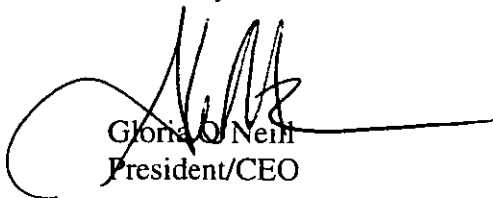
Thank you for your sponsorship of House Bill 328, which would establish a registry and program for Traumatic or Acquired Brain Injury (TABI) and provides for the inclusion of case management services to the Alaska list of optional Medicaid services. The reporting and data collection of Alaskans with these injuries is long overdue and would be of great benefit.

Cook Inlet Tribal Council (CITC) is about People, Partnership, and Potential. We serve 13,000 participants annually, administering 85 grants and contracts funded by federal, state, and private agencies. Our programs address many of the social, economic, and educational challenges faced by Native people in Anchorage and in the Cook Inlet Region. One of our main departments is Recovery Services. CITC provides outpatient services and also operates the Ernie Turner Center for residential care pertaining to alcohol and drug treatment.

CITC can attest to the high level of TABI cases in Alaska. Statistics from 2009 indicate that about 37% of our participants seeking intervention services (including brief treatment and outpatient recovery) report head trauma or have a history of TABI. From a sampling of 552 individuals seeking admission last year to the Ernie Turner Center (for detox or residential treatment), 46% of them had experienced some type of brain injury in their past.

If I can provide any further assistance with passage of this measure through the legislative process, please let me know. I would be willing to testify on the impact of TABI and the need for this bill to be enacted. On behalf of Cook Inlet Tribal Council and the many participants we serve, you have our full support for HB 328.

Sincerely,

  
Gloria O'Neill  
President/CEO

3600 SAN JERONIMO DRIVE, ANCHORAGE, ALASKA 99508

FAX: (907) 793-3422

PHONE: (907) 793-3600



3745 Community Park Loop, Ste. 140  
Anchorage, Alaska 99508  
office: (907) 274-2824 fax: (907) 274-2826  
www.alaskabraininjury.net

The Honorable Craig Johnson  
House of Representatives  
Alaska State Capitol, Rm 126  
Juneau, Alaska 99801

Dear Representative Johnson,

Thank you for introducing HB 328, the act which relates to medical assistance coverage for traumatic or acquired brain injury services and which will establish a traumatic or acquired brain injury program and registry within the Department of Health and Social Services.

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 eighteen member board represents all regions of Alaska and at least 50 percent are TBI survivors or family members.

The primary 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. ABIN also serves as a statewide resource navigation agency specializing in information and referral for brain injury services and supports available in Alaska. ABIN has heard from 600 Alaskans requesting brain injury services since 2007. In addition, ABIN has heard public testimony from hundreds of Alaskans from Anchorage, Juneau, Fairbanks, Kenai, Barrow, Nome, Kodiak, Dillingham, Bethel, Copper River Basin, Tok, Ketchikan, Sitka, and more.

In the past several years, ABIN has worked collaboratively with the State of Alaska, Alaska Mental Health Trust Authority, the Alaska Native Tribal Health Consortium, Alaska Federal Health Care Partnership, major hospital providers, community providers, and many more agencies to coordinate the development of brain injury services in Alaska. We have coordinated meetings with these agencies to identify:

1. the services we have available in the State,
2. the services we do not have available,
3. which providers have the capacity to develop different segments in the continuum of care,
4. barriers; and
5. solutions for the development of this care.

The agencies participating and the findings are depicted in a document titled "Demonstrating the Need for Community-Based Rehabilitation."

Barriers to treating brain injury include:

- Brain injury as a medical condition versus a long-term condition: Patient often enters an injury-based medical model to treat what may become a manageable, chronic condition.
- Post-acute/Treatment/Rehabilitation funding for those who are Medicaid eligible: Currently, Medicaid funding is available for acute care, but does not cover brain injury specialty residential and day programs, often resulting in a higher level of care (more expensive) than what is needed.
- Workforce capacity- Alaska is too small of a state, with a strong yet limited workforce, to support separate brain injury systems of care in each service sector: military, tribal, and civilian.

- Screening/assessment in all state programs and primary care clinics- appropriate identification begins with screening and then assessment. Behavioral Health is the only state program that includes brain injury screening questions.

**HB328 provides many direct and indirect opportunities to resolve these barriers:**

- Creates longitudinal data on persons with brain injury to identify demographics, cause of injury, severity, diagnosis, treatments, medical and social costs which will help determine future policy and budget recommendations.
- Increases access to case management for those who are Medicaid eligible.
- Evaluates the need for and scope of acute, post-acute, long-term, and community treatment, care, and supports.
- Positions the state to identify the best 'menu' of brain injury services to include under a Medicaid Waiver.
- Positions the state to access federal funding for TBI services and for targeted case management.
- Encourages a seamless transition from acute settings to transitional and community settings.
- Establishes standards and recommendations for improvement of prevention, assessment, treatment, and care.

**Indirect Opportunities**

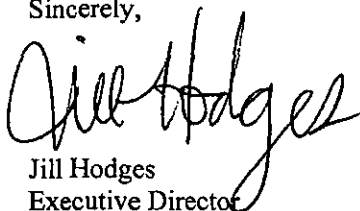
- Many Alaskans with undiagnosed or unrecognized brain injury currently access State of Alaska services and supports. The T/ABI program encourages screening and identification, as well as development of and access to appropriate treatment.
- A T/ABI program may create cost savings in acute care costs and existing state programs budgets, including behavioral health, juvenile justice, corrections, homeless initiatives, and long-term care in institutional facilities.
- Research shows, Medicaid funding specifically for brain injury services supports the growth of community-based rehabilitation programs (residential and day programs).
- Provides framework for the Department of Defense (DoD), Alaska Veterans Affairs Health System, Alaska Tribal Health System, State of Alaska, and private/non-profit entities to coordinate planning and implementation of rehabilitation and community re-entry programs.
- Development of these programs increases access for all Alaskans with a variety of pay sources, including insurance, private pay, and federal health care.
- Research shows early treatment and access to appropriate brain injury services may reduce future medical and social costs.

The Alaska Brain Injury Network has worked diligently to create a 'framework' for successful development of a seamless system of care for Alaskans with brain injury, including the development of a comprehensive plan and the coordination of the many key providers that will build the system. The State of Alaska T/ABI program will be the 'foundation' that will allow the 'entire state system' to develop and grow. The State T/ABI Program, the 'foundation', is the first step to resolving the barriers, so providers can act, and Alaskans will have an opportunity for a more successful and positive life.

The Alaska Brain Injury Network appreciates your ongoing support of this important legislation.

Our organization is made up of many professionals, providers, and specialists. If you have any questions I would be happy to answer them or connect you to someone with that knowledge.

Sincerely,



Jill Hodges  
Executive Director

**Attachment: ABIN Letter of Support for SB 219/HB 328**

**Why brain injury begins as an emergency medical condition and often becomes a social catastrophe?**

Several decades ago brain injury was viewed solely as a medical condition, more specifically a life or death injury. Because of the advances in emergency medical services and intensive/acute care, more people are surviving very severe brain injuries. These advances have created an entire new system of care, a brain injury continuum of care. This system of care is essential because of the long-term cognitive effects caused by the injury. After 30 years of state and federal government recognition, research, and longitudinal studies, it is now understood that 'brain injury begins as an emergency medical condition, and often becomes a social catastrophe.' Because of the potential for many different social challenges, it is essential that those who survive brain injuries receive timely, appropriate services and ongoing supports.

**How did other states develop brain injury programs?**

In addition to the local networking, ABIN is well connected to many state brain injury programs (public and private) outside of Alaska. Through conferences and ongoing dialogue, ABIN has learned the role legislation (in other states) has played in developing a seamless, comprehensive service system for after hospital care for brain injury. In 1980 the first appropriation for brain injury funding for case management was accomplished in Missouri. Legislation for a T/ABI program soon followed. 2005 data shows at least 44 states had a formal T/ABI program in their state government or funded brain injury specific programs.

The following is an example of the order in which legislation and funding has progressed in other states.

- Step 1: Establish a T/ABI program in statute
- Step 2: Approve general funds for case management, position state to access federal funds to expand this service to more people (targeted case management).
- Step 3: Approve a Medicaid brain injury waiver (50% Federal match)
- Step 4: Prevention and concussion management legislation.
- Step 5: Screening and case management for military

HB 328/SB 219 gives Alaska the opportunity to not only 'catch up' developmentally with other States, but it also positions Alaska to become a national leader in providing brain injury case management and treatment to rural and remote citizens across service sectors (military, tribal, civilian).

**How do other states fund and sustain a T/ABI Program?**

States use a variety and combination of funding streams for planning, policy, prevention and research activities, and to serve individuals with brain injuries and their families who have no other access to needed care or supports. Medicaid, Home and Community-Based Services and Medicaid Waivers, and Federal Block Grant programs are used to serve individuals with disabilities and special health care needs including people with brain injury. At the State level, common non-Federal funding sources for TBI service delivery include trust funds, general



revenue and special revenue. Often when two or more sources exist, funds from one are used to leverage funds from the other.

There are 24 States that have a Brain Injury Medicaid Waiver (2006). There are 20 states that have General Revenue or Special Revenue specific to brain injury (NASHIA 2005).

Medicaid waivers targeted to individuals with brain injuries operate in half of the states and are small when compared to waivers targeting other groups. These waivers provide significant cost savings, on average \$30,000 annually per person, when compared to institutional facility-based services (Rutgers 2008).

These waivers have been successful both programmatically and financially. In addition to cost savings, these waivers have provided other significant benefits. The existence of these waivers supports the growth of community non-profit brain injury agencies. There is clear evidence of the desirability of home and community-based services among those directly affected by brain injury: there has been growth of these waivers that has resulted in a doubling of the number of persons served over five years; in addition, there is a visible role played by advocates in encouraging states to develop these waivers. These waivers, over time, have contributed to states' efforts to create and grow an in-state service capacity to provide services to individuals with brain injuries.<sup>1</sup>

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<sup>1</sup>Hendrickson, L. & Blume, R. (2008). Issue brief: A survey of Medicaid brain injury programs. *Rutgers Center for State Health Policy*



*Mat-Su Health Services, Inc.*

February 25, 2010

The Honorable Craig Johnson  
120 4<sup>th</sup> St, State Capitol, Room 126  
Juneau, AK 99801

Dear Representative Johnson:

I am writing in support of House Bill 328, an act concerning traumatic or acquired brain injuries. As a health care professional who administers an agency that provides both primary health care and behavioral health care I and my Agency are well acquainted with the devastating consequences of even a mild brain injury can have on individuals and their families. The bill you have sponsored, if passed, will enable the State to take important, concrete steps that are necessary in creating evidence based, coordinated and effective services to this group of citizens in need. The creation of an operational definition, the development and tracking of important incident data, the promotion of waiver services and the building of case management capacity are all important first steps.

Sincerely,

Kevin Munson  
CEO

# The TRUST

The Alaska Mental Health Trust Authority

February 10, 2010

The Honorable Craig Johnson  
Alaska State Representative  
Alaska State Capitol, Room 126  
Juneau, Alaska 99801

Re: **Letter of Support for HB 328**

Dear Representative Johnson,

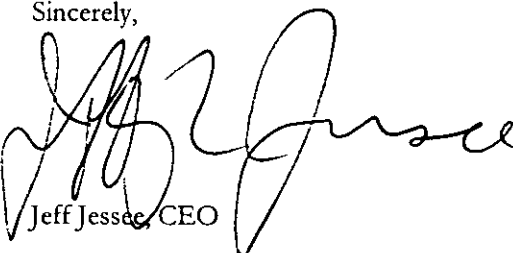
The Alaska Mental Health Trust Authority (The Trust) is pleased to support HB 328, an act establishing a traumatic or acquired brain injury program and registry within the Department of Health and Social Services (DHSS); and relating to medical assistance coverage for traumatic or acquired brain injury services. This bill is a significant step forward and will bolster the existing statewide efforts of a diverse and active committee which has been focused on brain injury services for several years.

The Trust is a state corporation that administers the Alaska Mental Health Trust, a perpetual trust managed on behalf of Trust beneficiaries who include individuals with mental illness, developmental disabilities, chronic alcoholism and those with dementia or other related disorders; many also have a co-occurring traumatic brain injury. Our goal is to partner with the Department of Health and Social Services as well as other state departments and branches of government, as a catalyst for change towards the improvement in Alaska's mental health continuum of care. The Trust has and will continue to partner with DHSS and the aforementioned statewide committee to ensure a system of care for Alaskans with brain injuries is developed.

It is an unfortunate reality that Alaska has one of the highest rates of TBI in the country. Upwards of 800 Alaskans are seriously injured or die from a TBI annually. It is estimated that at least 10,000 Alaskans are currently living with TBI in our communities, some with support services, most undoubtedly without. This bill will assure the development and implementation of services for Alaskans with brain injuries; specifically, it provides direction to the Department of Health and Social Services to assess prevalence, service gaps, and the development services in a targeted, effective, and fiscally responsible manner. Thereby, increasing and improving access to much needed services and supports for these Alaskans. Furthermore, this bill places the State of Alaska in position to access federal dollars for payment of these services through grants and Medicaid.

The Trust appreciates your leadership on this very important issue. Please let us know if there is anything we can do to further support your efforts and the successful passage of this bill.

Sincerely,



Jeff Jessée, CEO

February 11, 2010

To Whom It May Concern:

I worked for years as a Care Coordinator for people experiencing Alzheimer's and/or mental illness. As a professional in this field I helped many people find services and information. I didn't realize I'd be the one needing assistance so soon. For an unknown reason, I've lost my eyesight over the last couple of years. I'm in my 30's. While struggling to learn to live with a visual impairment, I lost my job. One of the dangers of living with a visual impairment that I had not anticipated was the numerous concussions I have experienced.



The most serious of these was when my weed-whacker fell on my head causing a mild brain injury. It took me at least five to six months to feel "normal" again after that. I believe many people experiencing visual impairments are suffering brain injuries at a rather high rate.

Just as it is important for those with Alzheimer's to have access to services and information through a Care Coordinator, it is also important for those experiencing brain injury to have assistance. Accessing services is very difficult when your brain isn't functioning at its' best. Each person who has experienced a brain injury should be linked to a care coordinator so that they have help accessing services. It's hard enough for me to find the help with a visual impairment, it is even harder when I've suffered yet another concussion and can't remember who to call or don't know what services will help.

It's imperative that people with brain injuries have a good advocate. It can be very hard to access services even when they are available. Often times a person with a brain injury has difficulty remembering things, making phone calls, knowing how to ask the right questions to get an appointment, etc. Having strong advocates such as Alaska Brain Injury Network and a Care Coordinator is necessary for a good recovery.

I encourage you to please support Senate Bill 219 presented by Senator McGuire and House Bill 328 presented by Representative Johnson. Having a brain injury program as they describe would benefit many Alaskans currently struggling on their own. There is also \$350,000 currently in the budget for brain injury. Please support the bill and leave the funding that is in the budget there. Thank you for your support. This is something that mattered to me as a provider and now it matters to me on a personal level.

Sincerely,

Fay Nakamura

2746 W 42nd Place Apt #1

Anchorage, AK 99517

Note: I had assistance writing this letter.

Dave Eubank  
9527 Victor Rd.  
Anchorage, AK 99515

Good afternoon:

My name is Dave Eubank and I approve this message. A few long years ago I sustained an acquired brain injury, not to be confused with traumatic; it was pretty traumatic to me but acquired? I didn't ask for any of this but it seems as though it was required because I see life through a different set of eyes and have been blessed with a different set of values. I, as well as a host of many others, have had to work twice as hard to get back half of what I lost but I appreciate life more than twice as much so in a sense, ... doesn't that make me twice the person I once was?

Just for starters I have an awful lot of admiration for the people who are in the health care industry for the support, care, and understanding they provide to others who are less fortunate than you. The T.B.I. Resource Navigator allows access to monitor a wealth of information for this silent minority. The DHSS provides additional funding for thankful services to a thankful people. I am not thankless; I am thankful, I am thankful I do not require such needful things but I know. I know exactly what it's like to be on the inside looking out and I know exactly what it's like to have the ability to absorb the incoming information but not having the capability to process it and I know exactly how frustrating that can be and for some people there is no way out and I know that too.



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You see, once upon a time, in a land far, far, away, I collapsed as the result of a life threatening, death defying, brain aneurysm; grade 5. You name it and I did not have it but in comparison to what I had lost, I have gained a whole lot more and what it was that I really lost, really was not even worth having and I am thankful for the things I have gained rather than being resentful over the things I have lost but it literally turned my life upside down yet here I am ... 10 years post, standing right side up and sitting right side down, still there are an awful lot of questions and *not* many answers; however:

**Would a T.B.I. Care Coordinator have been helpful in my own recovery?** Absolutely! We all have to crawl before we can walk and we seem to forget all about that but not me because in the bitter end of this past century I tried to walk before I could crawl and I fell flat on my face. But when I went down, I got up and when I got up, I woke up, and when I woke up, I got a grip and I can see much more clear this second time around but instead of taking my life, it gave me a life *however*; I may have gotten it a whole lot quicker with a T.B.I. Care Coordinator.

**Would the funding for T.B.I. Care Coordination and Case Management have been helpful in my situation?** Absolutely! I as well as a host of many others often felt like beating my head up against a brick wall but soon discovered that there was nobody home but suddenly on one bright, sunny, and cheerful summer day, a light bulb went off, BING!!! And as I wondered my way through this maze of uncertainty, I realized that I could not change people. I could not change anything about them. The only thing I could change was *myself* and when I changed myself? Poof!!! It was magic because I would change the perception of how others perceived me. A T.B.I. survivor is scarred for life and even though it may not be the kiss of death, there is a distinction and it is *not* a real good one but, ... *By choosing the path of least resistance and combining the elements of good with that of the bad, you rise above the distinguished height of an unjust society and you still embrace it* (Martin Luther King).....and yet it works.

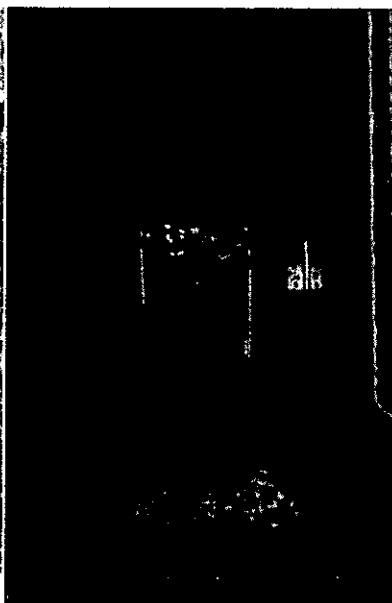
**Do I have any regrets on how I've approached and sidestepped the obstacles that have obstructed my most difficult challenges?** Absolutely not! Very few of us get out of here alive without being rudely slammed down by some sort of adversity but there's an old saying that adversity has a peculiar way of introducing you to yourself. Welcome to my world; we all make choices in life but I really don't know anyone who chose to walk a path which has no end and for some people there is no end but for others who wish to boldly go where many have gone before, with careful consideration of care coordination and case management there is. You probably think it's pretty easy for me to discuss this stuff; it's not easy, ... it's not easy at all. That's it, my work is done here.

Thank you

To Whom It May Concern:



With my son - before the brain injury



After my brain injury

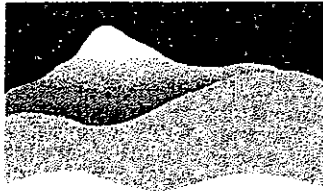
Apx 3years ago I was a Flight Attendant with Alaska Airlines. Now I dont swim, drive or do ANYTHING because overnight my life was CHANGED. Basically I had an ARYCHNOID CYCST which the Doctors watched, at Providence Hospital, since I was a teenager (although I was born with it) and suffered horrendous headaches. Noone ever told me that it could change my life so. In any case, I have two kids with Autism, 11 and 12 and a 15yr old with ADD so my life has been in shambles for quite sometime in any case. As for Providence, the commercials they put on TV are GREAT however noone ever tells you the BAD SIDE of things. I underwent surgery to no avail. There was NO PROBLEM until I came down with STAFF INFECTIONS that the doctors couldnt stop it. Needless to say, There was NOTHING in Alaska for me then and I was medivacked to Seattle after suffering Staff Infections but where the doctors only do ONE TYPE of surgery , basically up here it is OK if you have a broken arm or something but Brain Injury is nothing you want to MESS WITH. Needless to say I was put in OT, PT and SPEECH services and the only thing to come out of it all was that I had BRAIN INJURY! I couldnt, or still cannot, walk a straight line, I lost my job, what good is a F/A who cannot walk a straight line, I wear Prisms in my glasses now as well as DARK GLASSES, the sun hurts my eyes, I am in a Wheelchair and I was destined to live a life of NO DRIVING! Not even to the Grocery Store. Because I was married it was ASSUMED that my husband could work all day, do all the housework and watch the kids. I had three kids and he had Three kids and the BRADY BUNCH IT WASNT! In any case, my marriage has ended in divorce because of many different reasons however Brain Injury was NOT the least of the worries I had come to deal with! Only recently there is a hospital up here that deals with Brain Injury, at the Bases. It is HARD to find a doctor who knows ANYTHING about Brain Injury, much less a PCA (Personal Care Attendant) who knows anything about Brain Injury. I have had two PCA's quit on me and

am on my third, mainly because they are UNTRAINED in the needs of TBI. They were good as PCA's however NOT at Brain Injury and finding a doctor is a FIASCO because no doctors know about Brain Injury either. In any case, I was set to retire and "lost" my job and cannot get another one without alot of work and someone who knows about TBI. Brain Injury is EXPENSIVE to say the least and I am on Medicaid and Medicare due to all the tests I have to have done and all the medication I am on. For years I advocated for my kids with Autism however that was NOTHING COMPARED to what I go through now. I have managed to get around my house and take my own showers. Needless to say, even as a CONSUMER now there are certain things I will NOT, I am too proud, to let people do for me. Help me go to the bathroom is one of them but it is HARD and I rely on my BARS in the bathroom plus a toilet that is up a little higher. I am destined to be in a Wheelchair and flying, I am the Chair of the Governors Council now and need someone to go with me WHEREVER I GO! My life has CHANGED to say the least and I dont have the ability to be SELF SUFFICIENT in any case, I used to go to Prince Willian Sound Halibut fishing and owned a TimeShare in Puerto Vallarta where I caught a WORLD RENOWNED SailFish. THANK GOD FOR THOSE DAYS AND THOSE MEMORIES of which I have to look at pictures or have to be TOLD to remember, remember I have TBI so those dont come NATURALLY to me! Those times are all but over for me and even though I still love Fishing, I HATE THE WATER so fishing and I dont go together so well. In any case, I used to advocate for my kids and AUTISM, which I still do, but now I am a CONSUMER FOR BRAIN INJURY which has opened my eyes big time. I still go to Key Campaign and am on the BOD (Board of Directors) of the Key Coalition which deals with Legislatures on an ongoing basis and am a founding mother for LINKS in the Mat-Su. We are a Community PTI and work very closely with MATSU SCHOOL DISTRICT, and am past Chair of the EIC (Early Intervention Committee) of the Gov. Council, however that will not take away my problems and makes being involved very difficult for me. THANK GOD also for the Flight Attendants of Alaska Airlines because without them my kids wouldnt have had a Christmas! I can only say my life has taken a TURN and Brain Injury only takes a SECOND but can ruin your ENTIRE LIFE! This is something I will live with EVERY DAY and not something that will ever GO AWAY! In closing. I can say that life DOESNT END HERE! I have taken the "bull by the horns" so to speak and have become quite the advocate of Brain Injury on top of it all. I joke about Disabilities and it was my own mother who said she thinks I AM GETTING BETTER! When I asked WHY she said BECAUSE I CAN JOKE ABOUT IT NOW where before I could NOT.

Please oh please take this to heart. It can happen in an instant and take your entire life away from you. PLEASE CONSIDER what you can do to help not only people with BRAIN INJURY but to also get the word out that this EFFECTS THE REST OF YOUR LIFE! It is EXPENSIVE MONETARILY and HARD ON FAMILIES and ON THE CONSUMER AS WELL. Thank you for your time.

Donna Swihart, MAT-SU, ABIN ADVOCATE AND CONSUMER  
5450 N. Rhonda Drive  
Palmer, AK 99645

# Anchorage Community



**Mental Health  
Services, Inc.**

4020 Folker Street • Anchorage, Alaska 99508 • 907-563-1000 • (Fax) 907-563-2045 • e-mail: [acmhs@acmhs.com](mailto:acmhs@acmhs.com) • website: [www.acmhs.com](http://www.acmhs.com)

17 February 2010

The Honorable Craig Johnson  
Alaska State Capitol, Room 126  
Juneau, Alaska 99801

Dear Representative Johnson:

First, thank you for your interest in traumatic or acquired brain injury. Second, thank you for supporting the development of specific services addressing traumatic or acquired brain injury.

Anchorage Community Mental Health Services serves a number of clients impacted by brain injury. Some have been impacted by stroke while others have injuries resulting from accidents. The long lasting impact of brain injury results in some of our clients having great difficulty in adapting to normal life. Issues include things like being able to maintain housing, being able to work and self care. Additional focus on developing community based brain injury rehabilitative services will be invaluable to this population and their families.

So, thank you for introducing House Bill 328. Let us know if we can be assistance in promoting passage.

Sincerely,

John Fugett, MA, LPC  
Director, Adult Services

Jerry A. Jenkins, M.Ed., MAC  
Executive Directors

Continued Care  
2735 Tudor Rd.  
562-7900

Senior Services  
Day Break  
9210 Jupiter Dr.  
346-2234

Downtown Annex  
610 E. Fifth Ave.  
274-0352

Family Services  
4045 Lake Otis Pkwy.  
561-0954

Adult Services  
4020 Folker Street  
563-1000

Emergency Services  
24 hrs  
563-3200



Christine A. DeCourtney  
6920 Gemini Dr.  
Anchorage AK, 99504  
February 15, 2010

The Honorable Lesil McGuire  
Alaska State Capitol, Rm 125  
Juneau, Alaska 99801

Dear Senator Lesil McGuire:

I am writing to request your support of Senate Bill 219: An Act establishing a traumatic or acquired brain injury program and registry within the Department of Health and Social Services; and relating to medical assistance coverage for traumatic or acquired brain injury services. I wish to speak from two views:

- 1) I have worked in the healthcare field ever since I graduated from university
- 2) I have suffered two Traumatic Brain Injuries (TBI) and major surgery for a brain tumor in the last five years

I have worked in healthcare for many years, including ten years at the Bristol Bay Area Health Corporation in Dillingham and the past seven years at the Alaska Native Tribal Health Consortium. As such, I strongly believe that not only are there many people living in remote communities who have suffered a brain injury with no treatment available, I also believe that there are many people who have physical, mental and emotional problems as a result of an undiagnosed brain injury. The Trauma Registry only counts those that are hospitalized. It is critical that the people of Alaska have better access to brain injury prevention, treatment and rehabilitation services.

I suffered head and severe facial injuries from a bicycle fall in 2004. Though I spent many hours in the Emergency Room having many tests and 50 facial stitches, I received no information about head injuries. Eight months later, I was at a stop sign in downtown Anchorage and was hit in the driver's side by a van that came around the corner. This time I did not experience visible injuries. However, I suffered neck injuries and another TBI. It is not healthy to have another TBI so soon after the first one. It is also "easier" to have an injury that people can "see."

In spite of the fact that I am gainfully employed and insured, I have spent a great deal of out-of-pocket funds to try to "get better." While my insurer was quite willing to pay for physician visits and medications, which did not help me a great deal, they were not willing to pay for other therapies that have helped me. When I had out-of-state major neurosurgery two years ago, once again therapy modalities that helped me return to work and function at the level I am expected to by my employer, were denied.

My injuries and experiences are minor compared to some of the people in Alaska who now face a lifetime of problems so different from those that they had pre-TBI. The people of Alaska need to have prevention, treatment and rehabilitation services that can help increase awareness of preventing TBI's; treatment provided regardless of location or insurance availability and rehabilitation services that incorporate all programs and services that give the patient the best quality of life possible.

I never expected to be in a position of fighting to explain my difficulties as a result of a TBI or trying to find care that helped me get better. After all, being now defined as "average" should be ok. Right?

On behalf of myself and all the patients, families and providers who work to prevent TBI's, provide treatment and care for patients, I urge you to support SB 219.

Respectfully,



Christine A. DeCourtney



**From:** Murphy, Sean [Sean.Murphy@ascenergy.com]  
**Sent:** Thursday, February 04, 2010 9:19 AM  
**To:** Jeanne Ostnes  
**Cc:** jill@alaskabraininjury.net  
**Subject:** FW: SB 219  
**Attachments:** TBI Accident.pdf

Sean & Dee Murphy  
5745 Greece Dr.  
Anchorage, AK 99516  
Feb 3<sup>rd</sup>, 2010

Dear Representative Craig Johnson:

First, I would like to thank you for introducing the bill titled: An Act establishing a traumatic or acquired brain injury program and registry within the Department of Health and Social Services; and relating to medical assistance coverage for traumatic or acquired brain injury services.

My name is Sean Murphy and I am recovering from a traumatic brain injury from a skiing accident two years ago at Whistler/Blackcomb B.C. I hit a tree at nearly 30 MPH head first, thankfully I was wearing a helmet or the recovery process could have been much worse. I was air lifted down the mountain to the clinic at W/B where they kept me on life support until the second air medivac was available to transport me to Vancouver General Hospital. Three days later I awoke from my coma and my wife realized she would have to raise another child (husband) since I could not talk, walk or even feed myself.

The bill gives the Department of Health and Social Services many specifics to help address issues related to TBI which are all necessary here in Alaska. However, the main reason for writing you today is not for me or the treatment and support from my injury; but the needed support for family members dealing with TBI patients. TBI patients often have emotional issues that impact the entire family. It was extremely difficult to obtain any information, a single agency to assist in identifying resources, support groups, etc. would have been most beneficial for families in this situation.

As I found out weeks or understood months later, was the amount of stress that my wife had to endure. From first, being out of the country, then in Seattle and then again in Anchorage my wife had to continually start the processes over again to get me needed treatment. Again, having case management services to assist would have been extremely helpful in finding a neurologist, physical therapist, and the resources needed to aide in the recovery process. While researching these types of injuries, my wife and I noticed that the majority of states have facilities to assist people in obtaining the information and contacts needed. We could not find this in the state of Alaska. With the many outdoor activities and amount of highway accidents in Alaska we were surprised to find that this was the case.

Attached is a letter my wife wrote from my injury and the stress she endured and difficulties she encountered along the way.

Sincerely,

Sean Murphy

My husband Sean and I spent a week in Whistler/Blackcomb, BC. Sean was skiing expert terrain all week. On the last day of the trip, he and his buddies stopped for a bowl of soup before heading home. After lunch, he got into his skis and picked a casual groomed ski trail to head down the mountain. He was the first one back in his skis as they started down the mountain. When his friends started down the trail, they saw him veer across the trail over an embankment into the tree line. To this day, having lunch is the last thing that he remembers. They both called down to see if he was ok, when he doesn't respond, one friend came down to check on him and found that he was not conscious. The second friend began stopping others for assistance. A doctor and nurse happened to ski near the accident and began CPR and a ski instructor stopped and contacted ski patrol. Ski patrol arrived within minutes and provided an open airway and artificial respiration while packaging Sean for transport to a helicopter arriving. We believe that due to preparation for the Olympics, the response time of the ski patrol and helicopter was extremely quick, within minutes, Sean was transported to the clinic at the base of the mountain, examined and prepped for another helicopter ride to Vancouver General Hospital.

Our friends and I packed and drove from Whistler to Vancouver only to discover that he had still not awoken and they might have to drill into his brain to release some of the pressure due to swelling caused from severe bruising and 8 sub dermal hematomas. The good news was that after a full body CAT scan to determine the extent of his injuries, other than the head injury, he had a broken finger. After three unconscious days in the ER Sean finally came out of a coma. The doctors asked if he knew what happened, he shook his head no, he asked if he knew who was next to him. All he could do was say wife, but that was more than enough considering we were told that his long term memory would probably be affected by the injury.

On the evening of the third day, Sean was transferred to the Neurological Intensive Care Unit. He was unable to speak coherently, sit up, walk, and other basic motor functions. The doctors informed me that the recovery process would more than likely take months and that we would need to stay in Vancouver until the pressure on his brain decreased considerably and he was able to walk with assistance. The Neurologist stated that if he hadn't been wearing a helmet he would not be here today. In fact, his helmet was used during several meetings to encourage the use of helmets with the staff at VGH.

Sean began the process of recovery, and I began the process of notifying employers and family of our situation. Luckily for me, two of the friends that were on vacation with us offered to stay in Vancouver for support. I was surprised to find out that Canada does not accept health insurance, so having to figure out how to pay for this care, and my stay in Vancouver and trying to keep our daughter from knowing how serious the injury was since she was alone in Anchorage was almost more than I could tolerate. To this day, I cannot thank our friends enough who stayed with us in Vancouver.

The days following consisted of me massaging his legs and arms, little stretches to keep him from stiffening up and numerous trips to the nurse's station trying to reach the Doctor for an update. I was told that he did not see patients during visiting hours because time was allotted for surgeries. The only care provide for the first two days in NICU were hourly vitals check by the nursing staff and my attempts to do stretches with him lying in bed. After 3 days in the NICU, and dozens of requests to see the doctor, he finally stopped in to provide an update. He stated that the bruising was improving, but had not decreased enough for air travel and that air travel could cause further damage to his brain. I asked about road travel so that we could get back to the US, he indicated that since he was barely able to feed himself, had not walked yet, and could not speak more than a word or two when responding to questions, that we needed to realize that long term hospital care and physical therapy was required. I asked when physical therapy would begin, and he indicated that the physical therapist would be by to see us that day.

I increased our efforts to get him to do more on his own. I asked that he feed himself; even though he wore more of the food then he ate. I got him to stand next to the bed with me and our friend on either side to see if he was able. He was not able to take a step or stand on his own, but it strengthened my resolve to get him walking again. Later that date, the PT examined Sean and gave us stretches that we could do to help him improve and that we could attempt to get him to stand periodically throughout the day. We followed the regiment for two days, than were given approval to see if he could walk. We began walking him to the restroom, which was only about 8-10 steps from the bed. The following day the Physical Therapist was surprised to see how much he had improved. Much less food on his clothes, able to speak short sentences and could walk with assistance to the restroom. She then gave us permission to walk the halls as long as our friend and I were with him at all times. We began this trek immediately after she left and continued every hour if he was awake. Day 8, he can walk two times around the NICU floor and we attempt the stairs without the PT's knowledge. He was able to take two steps. We continued to walk as often as possible so that he could build up his strength and improve his balance. The following day, I asked that he be examined again to see if the bleeding and swelling had gone down. It had, I then ask the PT if we can attempt the 5 steps so that we could travel to Washington by car. Sean climbed 5 stairs with Danny and me on either side. The PT consulted with the doctor and they gave us authorization to travel to Washington after resting at the hotel for 1-2 days to ensure that he is able to travel. I asked that they provide a CD of his cat scan and all medical records; they indicated that they would fax the reports to the doctor in Seattle and would provide the CD prior to checkout. So with a stop by accounting, I paid the bill by check and credit card. (I had contacted our credit card company earlier in the week and told them of the situation. They agreed to increase our limit enough to cover the hotel and hospital bill). Sean rested in the hotel and our friends from Seattle came to pick us up. I felt we were one step closer to getting home.

In Seattle, I made numerous calls to Neurologists, but none would take a new patient without a referral. After several calls to Vancouver General and little success in

getting help, our friend Jane said she had an appointment and we could go with her, so we did. We explained to her doctor why we were crashing Jane's appointment, and to our surprise, she examined Jane in 10 minutes and the remainder of the appointment was Sean's. She was astounded that this accident was less than two weeks prior and immediately contacted a Neurologist that she knew and had an appointment for Sean the following day. Again, we were told that it would be several weeks before we could travel and were surprised that we were given approval to leave Vancouver as there were still several areas still swollen and bleeding on the brain. Three times a week, Sean and I went to see the Neurologist. They worked motor skills and did brain teasers and each visit seemed to be better than the last. At the end of the third week, we were given the green light to travel home to Anchorage.

I thought the process would be much easier in Anchorage, only to find out we had to start the process all over again. Neurologists and Physical Therapists require a referral. We went to our family physician and were referred. My Dad agreed to come to Alaska to help care for Sean since he could not be left alone and I needed to get back to work since we had used all of our vacation time and all that could be done now FMLA, which is family medical leave without pay. Without both our incomes, this was not an option.

Sean could not be left alone, could not cook, could not take stairs on his own, etc. So I was so thankful that my Dad was with me to care for him because I needed to get back to work at least part time. As I finish this letter, I have a tough time keeping my composure, I reflect on the stress that I had to endure due to Sean's accident and the fact there wasn't someone I could talk to that understood what we were going through. The angry outburst from Sean which are typical of head injuries, the fact that he was basically having to develop mentally and physically, newborn through adult hood all over again.

After two years, there are still outburst, but they are less frequent, and his short term memory has been affected where he must keep more detailed notes. But on a positive note, the recovery was much quicker than anyone thought it would be and physically he is in the best shape of his life. He is running under 6 minute miles now and he continues to improve emotionally, mentally and physically.

**Jeanne Ostnes**

---

**From:** Andi Nations [nationsa.silc@gmail.com]  
**Sent:** Monday, January 25, 2010 12:34 PM  
**To:** Rep. Craig Johnson  
**Subject:** Traumatic Brain Injury Service Coordination

Thank you for sponsoring a House Bill relating to an act establishing a traumatic (or acquired) brain injury program. This legislation will make great strides towards providing needed services for Alaskans who have been impacted by brain injuries. We look forward to working with you on this important issue.

--  
Andi Nations  
Statewide Independent Living Council of Alaska  
1057 W. Fireweed Lane # 206  
Anchorage, AK 99503  
[nationsa.silc@gmail.com](mailto:nationsa.silc@gmail.com)

907-263-2092 (V/TTY)  
907-244-1496 (cell)  
907-263-2012 (Fax)

[www.alaskasilc.org](http://www.alaskasilc.org)



**FOR IMMEDIATE RELEASE: Personal Stories and HB 328 and SB 219**

**March 2010 is Brain Injury Awareness Month!**

*Anchorage, Alaska –*

March 2010 will mark the commencement of Brain Injury Awareness Month! The Alaska Brain Injury Network, Inc. (ABIN) encourages you to develop stories to raise awareness of "the silent epidemic."

Brain injury can affect any one of us...in an instant. Not only are the personal stories gripping, but the impact on the family can often end up inspiring or devastating. Families that endure life after brain injury need acknowledgement. Many of the strongest family units are torn apart after a traumatic injury. Why do Alaska families and communities end up devastated, torn apart, and defeated? Is this a personal issue or a system's issue? Often times it is both, but who is to blame families when the state does not have a single program specifically to deal with brain injury treatment, rehabilitation, and support? There are very few in-state resources to help individuals learn to live again and to support families through this often lifelong process. Alaskans deserve better.

ABIN is connected to hundreds of Alaskans and their families that have been affected by brain injury: Alaska natives, military, urban residents, children, adults, CEO's, nurses, teachers, and more. If you are looking for a heart-wrenching and news worthy story, we can connect you to these individuals and families across the State.

In addition to personal stories, there are two companion bills in the legislature that will build state capacity to develop brain injury specialty programs. House Bill 328, sponsored by Representative Craig Johnson, and Senate Bill 219, sponsored by Senator Lesil McGuire, establishes a traumatic or acquired brain injury (T/ABI) program and registry within the Department of Health and Social Services.

HB 328 and SB 219 provides the leadership and incentive to create a service delivery system where children, adults, and service members who sustain a brain injury and their families, will have the opportunities that all Alaskans desire; to learn, love and be loved, and find meaningful work or activities.

**Statistics:** The Alaska's Department of Health and Social Services show that traumatic brain injury is a leading cause of death and disability among children and young adults in the State of Alaska; an estimated 12,000 people in the State of Alaska have suffered a traumatic brain injury; approximately 800 people in the State of Alaska report traumatic brain injuries each year; the number of Alaskans with a traumatic brain injury is increasing significantly as military service members injured overseas return home to Alaska; 20 percent of traumatic brain injuries result in death; many people who suffer traumatic brain injuries live with permanent disabilities; most cases of traumatic brain injury are preventable; and the lack of public awareness is so vast that traumatic brain injury is known in the disability community as the nation's "silent epidemic"

For general information or media information, contact Jill Hodges at (907) 274-2824 or [jill@alaskabraininjury.net](mailto:jill@alaskabraininjury.net).

##

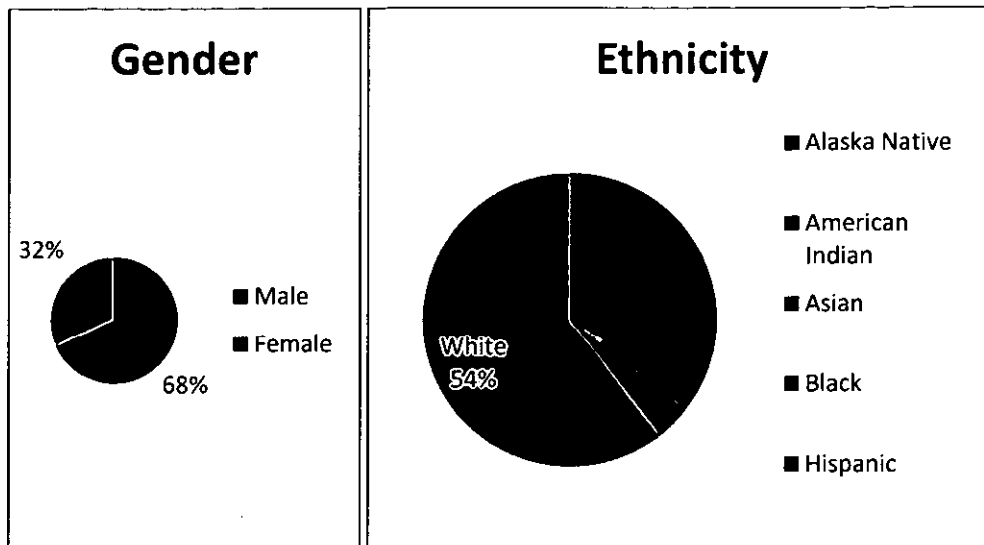


Figure 1: Males sustain TBI at twice the rate of females

Figure 2: TBI's are sustained primarily by White and Alaska Native populations

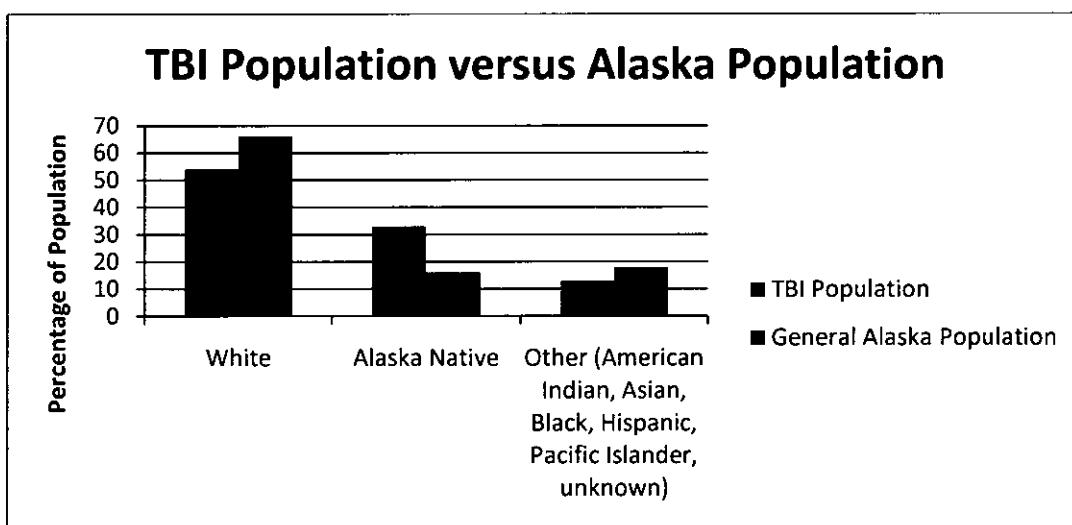


Figure 3: Alaskan Natives and rural residents sustain TBI at disproportionate rates compared to census data

TBI in Alaska, 1995-2005 Hospitalization greater than 24 hours

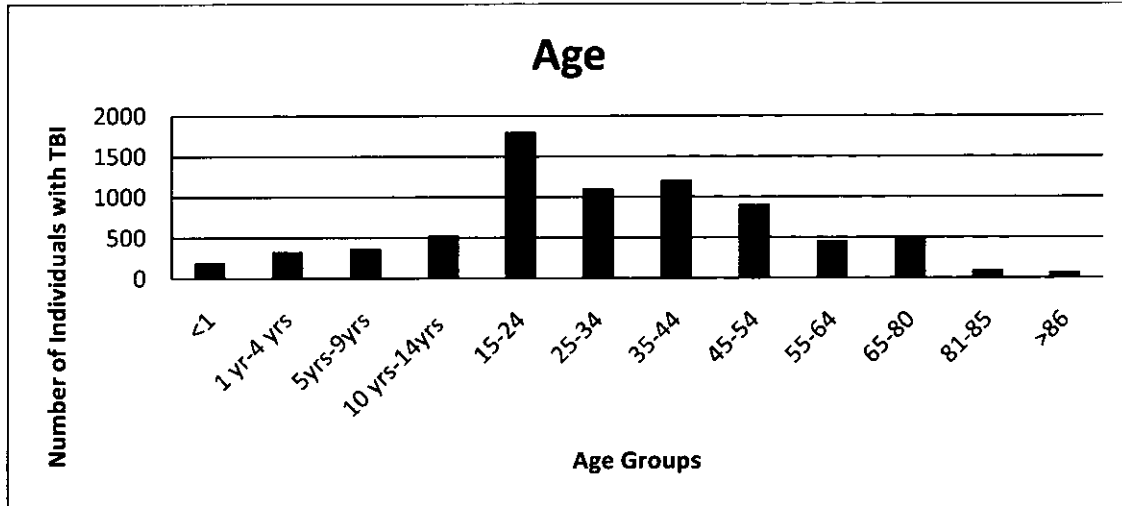


Figure 4: Highest incidence rates are among 15-24 year old males. The highest prevalence rates are among Elders who fall.

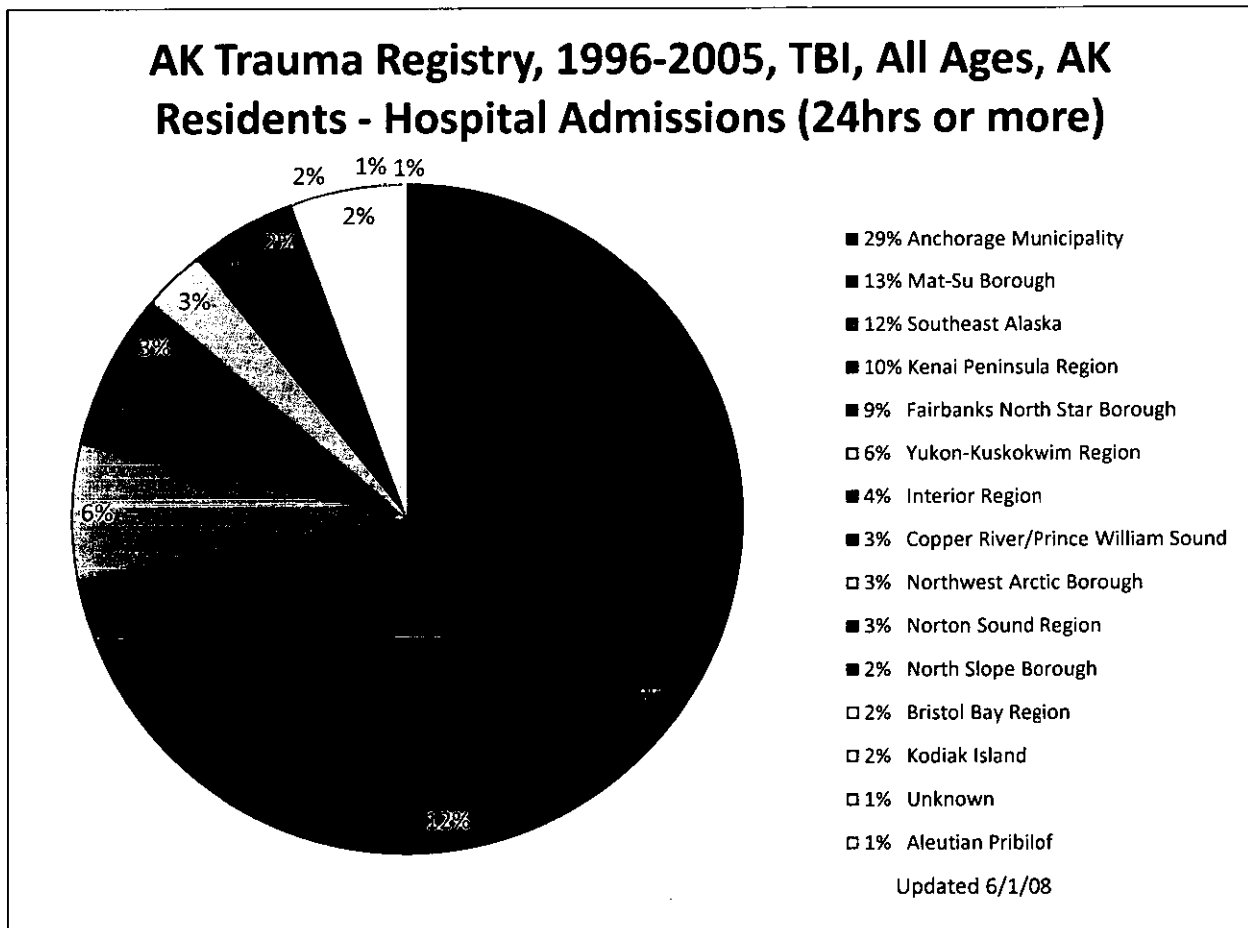


Figure 5: Highest incidence rates are among Anchorage, Mat-Su, and Southeast regions. The highest prevalence rates are in the Yukon-Kuskokwim Region.

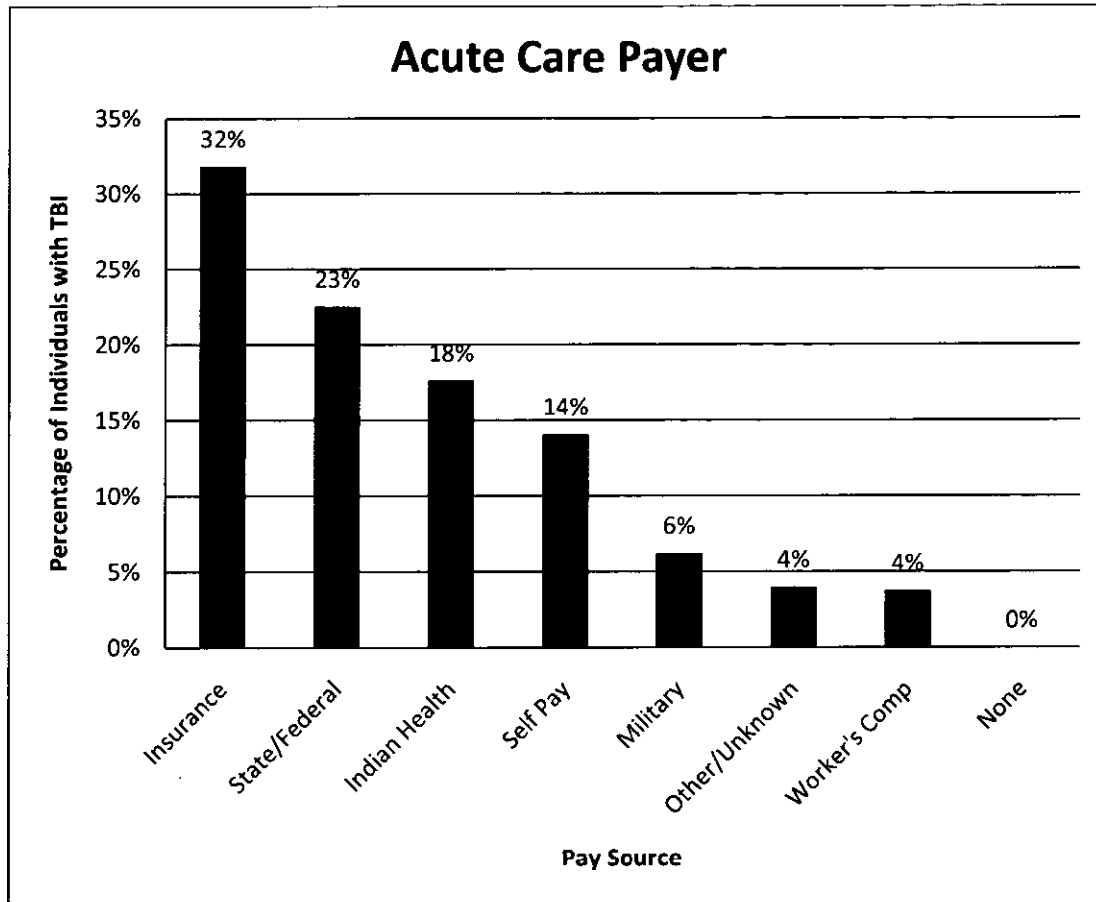


Figure 6: Acute care costs are paid by major payers. Inpatient and post-acute rehabilitation is limited. There is not a post-acute rehabilitation facility in-state.

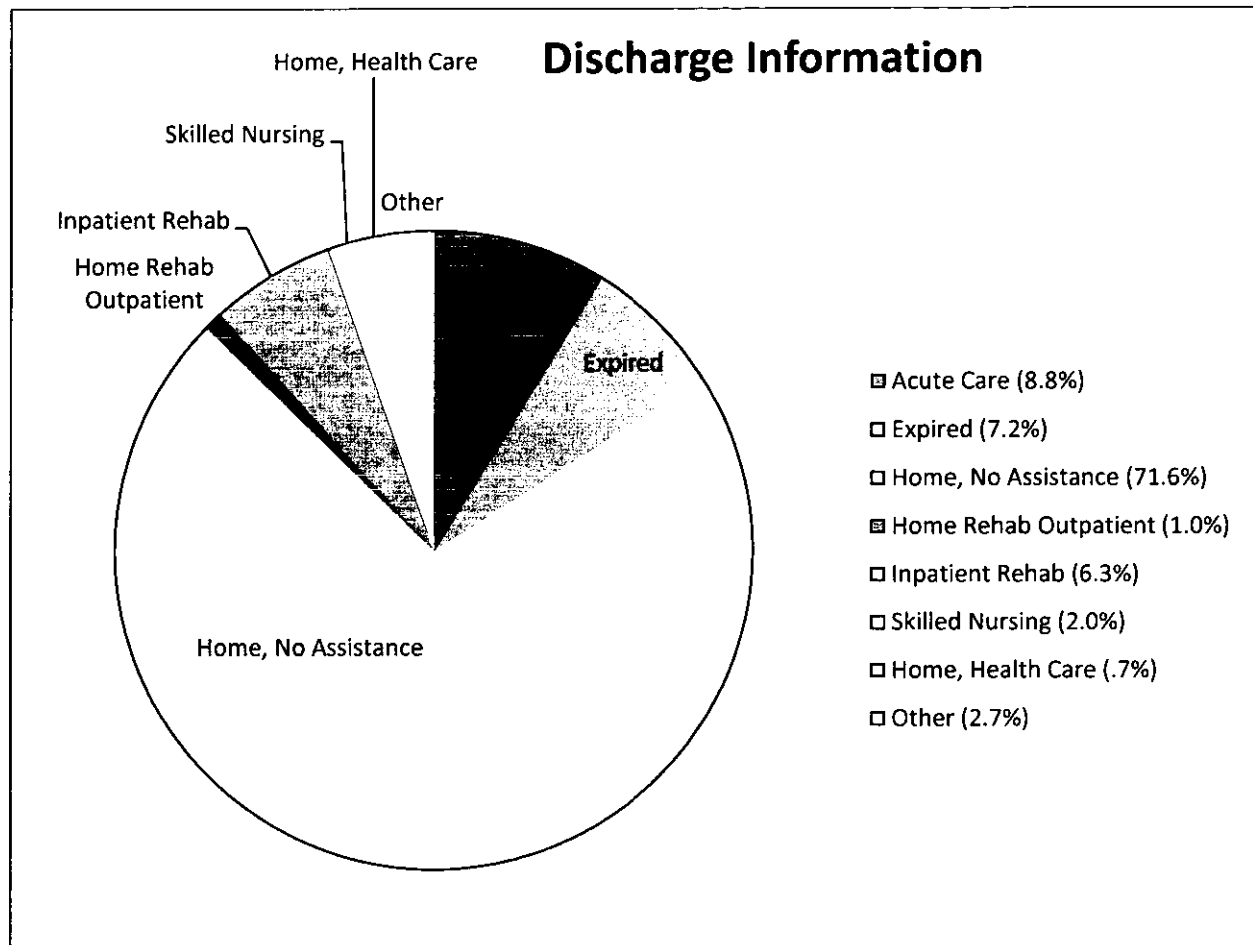


Figure 7: 72% of TBI survivors are sent home with no assistance. 1% of TBI survivors have access to rehab once they return home.

| Alaska Brain Injury Network                                                                                    |              |                |             |
|----------------------------------------------------------------------------------------------------------------|--------------|----------------|-------------|
| Alaska Scorecard and TBI Dashboard – (DRAFT)                                                                   |              |                |             |
| DRAFT #1 – May 22, 2008                                                                                        |              |                |             |
| ○ Getting worse                                                                                                |              | ↔ Not changing | ● Improving |
|                                                                                                                | 5-year Trend | Current Data   | Source      |
| <b>SCORECARD: A “scorecard” provides a snapshot of the status of TBI issues in the State of Alaska</b>         |              |                |             |
| <b>Traumatic Brain Injury Non-fatal Incidence Rates</b>                                                        |              |                |             |
| TBI rate per 100,000                                                                                           | ●            | 98.6           | 1           |
| <b>Causes</b>                                                                                                  |              |                |             |
| Falls                                                                                                          | ○            | 28.7           | 1           |
| Motor Vehicle Transportation Occupant                                                                          | ●            | 24.7           | 1           |
| Assault                                                                                                        | ●            | 12.2           | 1           |
| ATV                                                                                                            | ○            | 6.5            | 1           |
| Bicycle                                                                                                        | ●            | 4.5            | 1           |
| Snowmachine                                                                                                    | ●            | 4.4            | 1           |
| Pedestrian                                                                                                     | ●            | 3.6            | 1           |
| Sports                                                                                                         | ●            | 1.8            | 1           |
| Water Transport                                                                                                | ↔            | 1.3            | 1           |
| Suicide Attempt                                                                                                | ●            | .8             | 1           |
| <b>Gender</b>                                                                                                  |              |                |             |
| TBI percentage among males                                                                                     |              | 65.4 %         | 1           |
| TBI percentage among females                                                                                   | ↔            | 33.2 %         | 1           |
| <b>Ethnicity</b>                                                                                               |              |                |             |
| Percentage of TBI population that is Alaska Native                                                             |              | 34%            | 1.a         |
| Percentage of TBI population that is White                                                                     |              | 53%            | 1.a         |
| Percentage of TBI population that is Other; unknown, Pacific Islander, Hispanic, Black, American Indian, Asian |              | 22%            | 1.a         |
| <b>Those at highest risk for hospitalization due to TBI (rate per 100,000)</b>                                 |              |                |             |
| Males age 80+                                                                                                  |              | 301.3          | 1           |
| Females age 80+                                                                                                |              | 217.2          | 1           |
| Males age 70-79                                                                                                |              | 215.7          | 1           |
| Males age 15-19                                                                                                |              | 200.9          | 1           |
| <b>Traumatic Brain Injury Numbers</b>                                                                          |              |                |             |
| TBI hospitalizations/year                                                                                      |              | 640            | 1.b         |
| TBI deaths/year                                                                                                |              | 150            | 1.b         |
| Est. TBI-related Emergency Department Visits                                                                   |              | 2953           | 2           |

- 1 Alaska Trauma Registry 2001-2005 – Non-fatal TBI hospitalizations
- 1.a Alaska Trauma Registry 1996-2005 – Non-fatal TBI hospitalizations
- 1.b Alaska Trauma Registry 2006 – Non-fatal TBI hospitalizations
- 2 HRSA TBI Implementation Grant

Alaska Trauma Registry records those who are hospitalized for more than 24 hours. This does not include the number of people who visit the emergency department and are sent home in the same day. This does not include the number of returning service members with traumatic brain injury.

**DASHBOARD: A "dashboard" provides a way to see how well an activity is working to affect the TBI population**

○ Getting worse

↔ Not changing

● Improving

**Dashboard: Behavioral Health**

| TBI and Mental Health                             | Spot look trend | Current Data | Source |
|---------------------------------------------------|-----------------|--------------|--------|
| Percentage BH clients screening positive for TBI  | ↔               | 32%          | 3      |
| <b>TBI and Substance Use</b>                      |                 |              |        |
| Alcohol-related TBI 100,000                       |                 | 33%          | 1      |
| <b>TBI and Suicide</b>                            |                 |              |        |
| Percentage of suicide victims with history of TBI |                 | 32%          | 4      |

**Dashboard: Education**

| Special Education                                                           | Spot look trend | Current Data | Source |
|-----------------------------------------------------------------------------|-----------------|--------------|--------|
| Number of children in Special Education statewide with TBI diagnosis (2007) | ↔               | 66           | 5      |

**Dashboard: Justice**

| Corrections                                                                                                        | Spot look trend | Current Data | Source |
|--------------------------------------------------------------------------------------------------------------------|-----------------|--------------|--------|
| Percent of incarcerated Alaskans (adults) who are Trust beneficiaries, including those with cognitive disabilities |                 | 42%          | 6      |

**Dashboard: Employment**

| Vocational Rehabilitation                           | Spot look trend | Current Data | Source |
|-----------------------------------------------------|-----------------|--------------|--------|
| Number of TBI cases                                 |                 | 167          | 7      |
| Number of TBI cases closed employed                 |                 | 17           | 7      |
| Number of TBI cases closed with plan for employment |                 | 11           | 7      |
| Average wage at closure                             |                 | \$12.54      | 7      |

**Dashboard: Providence**

| <b>ImPACT Program</b>                                                                        |  |     |   |
|----------------------------------------------------------------------------------------------|--|-----|---|
| Number of baselines (ImPACT)                                                                 |  | 57  | 8 |
| Number of student/athletes seen in program (ImPACT)                                          |  | 25  | 8 |
| <b>Emergency Department</b>                                                                  |  |     |   |
| Patients given the diagnosis of "head injury" or "concussion in Emergency Department in 2006 |  | 547 | 8 |
| % of TBI-related ED visits that led to hospitalizations                                      |  | 1%  | 8 |
| % of ED visits that are Pediatric                                                            |  | 15% | 8 |

**Dashboard: Alaska Brain Injury Network**

| <b>TBI Advisory Board</b>                              |   |        |   |
|--------------------------------------------------------|---|--------|---|
| Est. Board Member Volunteer hours/year                 | ⊕ | 1054   | 9 |
| Board Member Participation in Quarterly Board Meetings |   | 83%    | 9 |
| Ex-officio participation in quarterly board meetings   |   | 65-80% | 9 |
| % of survivors/family members on TBI board             |   | 55%    | 9 |
| % Board Members who give a financial contribution      |   | 100%   | 9 |
| <b>TBI Resource Navigation</b>                         |   |        |   |
| Average new consumer contacts per month                | ⊕ | 30     | 9 |
| Average unique visitors/month to ABIN website          | ⊕ | 750    | 9 |
| Number of people on Alaska Brain Matters Listserve     | ⊕ | 100+   | 9 |

- |                                                                                     |                                                |
|-------------------------------------------------------------------------------------|------------------------------------------------|
| 3 AKAIMS                                                                            | 7 Division of Vocational Rehabilitation (FY07) |
| 4 Suicide Follow-back Study                                                         | 8 Providence Neuroservices                     |
| 5 <a href="http://www.eed.state.ak.us/stats/">http://www.eed.state.ak.us/stats/</a> | 9 Alaska Brain Injury Network                  |
| 6 Trust/DOC Study 07                                                                |                                                |



# Traumatic Brain Injury:

## A Guide for Criminal Justice Professionals

Many prison and jail inmates are living with traumatic brain injury (TBI)-related problems that complicate their management and treatment while incarcerated. Because most inmates will be released, these problems also pose challenges when they return to the community. The Centers for Disease Control and Prevention (CDC) recognizes TBI in prisons and jails as an important public health problem.

### What is Traumatic Brain Injury?

- A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain.<sup>1</sup>
- Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," with a brief change in mental status or consciousness, to "severe," with an extended period of unconsciousness or amnesia after the injury.<sup>1</sup>
- A study of young adults found that those with a TBI were at risk for sustaining another,<sup>2,3</sup> and that a history of multiple TBIs is associated with slower recovery.<sup>4</sup>

### How many people have TBI?

- Each year, on average 1.4 million people in the United States sustain a TBI. Of this number, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department.<sup>5</sup>
- At least 5.3 million Americans are living with TBI-related disabilities.<sup>6</sup>
- The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.<sup>7</sup>

### What are the causes of TBI?

- The leading causes of TBI are falls, motor vehicle-traffic crashes, struck by or against events, and assaults.<sup>5</sup>
- Blasts are the leading cause of TBI among active duty military personnel in war zones.<sup>8</sup>

### What are the long-term consequences of TBI?

- A person with a TBI can experience short- or long-term problems, requiring help in performing activities of daily living.<sup>1,6</sup>
- A TBI can cause a wide range of problems in thinking, sensation, learning, language, behavior, and/or emotions.<sup>9-11</sup>
- Persons with TBI may experience mental health problems such as severe depression,<sup>12</sup> anxiety,<sup>13</sup> difficulty controlling anger<sup>14</sup> and alcohol or substance abuse.<sup>15,16</sup>



- TBI can also cause epilepsy and increase the risk for both Alzheimer's and Parkinson's diseases and other brain disorders associated with increasing age.<sup>9</sup>

## What is known about the extent of TBI and related problems within the criminal justice system?

### General:

- According to jail and prison studies, 25-87% of inmates report having experienced a head injury or TBI<sup>17-19</sup> as compared to 8.5% in a general population reporting a history of TBI.<sup>20</sup>
- Inmates who reported head injuries are more likely to have disciplinary problems during incarceration.<sup>21</sup>
- Inmates with head injuries may have seizures<sup>19</sup> or mental health problems such as anxiety<sup>22</sup> or suicidal thoughts and/or attempts.<sup>22,23</sup>
- Studies of inmates' self-reported health indicated that inmates with one or more head injuries have significantly higher levels of alcohol and/or drug use during the year preceding their current incarceration.<sup>22</sup>
- The U.S. Department of Justice has reported that 52% of female and 41% of male offenders were under the influence of drugs, alcohol, or both at the time of their arrest,<sup>24</sup> and that 64% of male arrestees tested positive for at least one of five illicit drugs (cocaine, opioids, marijuana, methamphetamines, or PCP).<sup>25</sup>
- Although more than half of prison inmates have a lifetime history of drug use disorders,<sup>26</sup> fewer than 15% receive substance abuse treatment services while in prison.<sup>27</sup>

### Women and Families:

- Female inmates who are convicted of a violent crime, are more likely to have sustained a pre-crime TBI and/or some other form of physical abuse.<sup>28</sup>
- Children and teenagers who have been convicted of a crime are more likely to have sustained a pre-crime TBI<sup>29</sup> and/or some other form of physical abuse.<sup>29-31</sup>

- Among male inmates, a history of TBI is strongly associated with perpetration of domestic violence and other kinds of violence during their lifetimes.<sup>32</sup>

### Corrections and Law Enforcement Officers:

- Corrections personnel and law enforcement officers are at risk for head injury or fatal head trauma.<sup>33,34</sup>
- Interactions with suspects prior to arrest and with inmates during their incarceration are considered high risk situations for injury or death due to head trauma.<sup>35</sup>

## How might inmates with TBI and others be affected by TBI-related problems?

Within the correctional setting, TBI can contribute to situations that lead to disciplinary action. Here are some common TBI problems and strategies for management:

- Attention deficits may make it difficult for the inmate with TBI to focus on a required task or respond to directions given by a corrections officer. Either situation may be misinterpreted, thus leading to an impression of deliberate defiance on the part of the inmate.<sup>17,36</sup>
  - Management strategies:
    - Ask the inmate to repeat what you have said to confirm that he or she has heard and understood your directions
    - Encourage the inmate to write down steps for the task
    - Allow extra time for the task to be done
    - Clear or reduce environmental distractions
- Memory deficits can make it difficult to understand or remember rules or directions, which may lead to disciplinary actions by jail or prison staff.<sup>21</sup>
  - Management strategies:
    - Explain rules or directions slowly, step-by-step

- Ask the inmate to repeat the steps and encourage him or her to write down the information
  - Provide examples and ask the inmate to provide his or her own
  - Teach the inmate to ask questions when he or she doesn't understand
- Slowed verbal and physical responses may be interpreted by corrections officers as uncooperative behavior.<sup>36,37</sup>
  - Management strategies:
    - Give directions, or ask questions, slowly; repeat if necessary
    - Allow the inmate additional time to respond
- Irritability or anger may be difficult to control which can lead to an incident with another inmate or corrections officer. Such incidents can lead to further injury for the inmate with TBI and others.<sup>37,38</sup>
  - Management strategies:
    - Avoid arguing with the inmate
    - Try re-phrasing the problem, breaking it down into parts
    - Reinforce positive behaviors
- Uninhibited or impulsive behavior, including unacceptable sexual behavior, may provoke other inmates or result in disciplinary action by jail or prison staff.<sup>36,39</sup>
  - Management strategies:
    - Tell the inmate calmly that the behavior is unacceptable
    - Seek assistance from mental health professionals

## How can the problem of TBI in prisons and jails be addressed?

A recent report from the Commission on Safety and Abuse in America's Prisons recommended increased health screenings, evaluations, and treatment for inmates and development of partnerships with community health providers to assure continuity of care and case management for released inmates.<sup>40</sup>

In addition, TBI experts and some prison officials have suggested the following:

- Routinely screen jail and prison populations to identify a history of TBI.<sup>41,42</sup>
- Screen inmates with TBI for possible alcohol and/or substance abuse and provide treatment for these co-occurring conditions.<sup>25,43,44</sup>
- Conduct additional evaluations to identify specific TBI-related problems and determine how they should be managed.<sup>41</sup> Special attention should be given to impulsive behavior, including violence,<sup>39</sup> sexual activity,<sup>36</sup> and suicide risk if the inmate is depressed.<sup>45</sup>

## How should TBI-related problems be addressed after release from jails and prisons?

Lack of treatment and rehabilitation for inmates with mental health and substance abuse problems while incarcerated increases the probability that they will again abuse alcohol and/or drugs when released.<sup>25,44</sup> Persistent substance abuse can lead to homelessness,<sup>46</sup> return to illegal drug activities,<sup>47</sup> re-arrest,<sup>48</sup> and increased risk of death<sup>49</sup> after release. As a result, criminal justice professionals and TBI experts have suggested the following:

- Community re-entry staff should be trained to identify a history of TBI and have access to appropriate consultation with other professionals with expertise in TBI.<sup>29,41,42</sup>
- Transition services should be capable of accommodating the effects of an inmate's TBI upon their release and return to the community.<sup>29,41,42</sup>
- Released inmates with mental health and/or substance abuse problems should receive case management services and assistance with placement into community treatment programs.<sup>40,43,49</sup>

CDC supports new research to develop better methods for identifying inmates with a history of TBI and related problems and for determining how many are living with such injury.

## Further information is available from these websites:

### **Traumatic Brain Injury (TBI):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/tbi/TBI.htm](http://www.cdc.gov/ncipc/tbi/TBI.htm)

This site provides information for professionals and the general public regarding TBI. Topics include prevention, causes, outcomes, and research. Data reports on TBI in the United States and many free publications and fact sheets can be downloaded. Materials are available in English and Spanish.

### **Health Issues in Correctional Settings:**

CDC, National Center for HIV, STD, and TB Prevention  
[www.cdc.gov/nchstp/od/cccwg/default.htm](http://www.cdc.gov/nchstp/od/cccwg/default.htm)

This site provides information for public health and criminal justice professionals about health topics with an emphasis on infectious diseases in the correctional setting. It also includes materials for the general public with links to related organizations.

### **Intimate Partner Violence (IPV):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/factsheets/ipvfacts.htm](http://www.cdc.gov/ncipc/factsheets/ipvfacts.htm)

This site provides information for professionals and the general public regarding IPV. The site contains an overview and fact sheet about IPV, prevention strategies, links to other IPV organizations, and a list of current CDC publications.

### **Legal Issues of Persons with TBI within Correctional Settings:**

National Disability Rights Network  
[www.ndrn.org/aboutus/consumer.htm](http://www.ndrn.org/aboutus/consumer.htm)

This site provides information about the laws protecting the civil and human rights of people with disabilities including those with TBI. Inmates with disabilities or their families can receive help from the Network about inmates' legal rights, access to mental health services and/or medication, and restoration of benefits upon release.

### **Substance Abuse:**

Substance Abuse & Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)

This site provides information for professionals and the general public regarding treatment resources for persons with, or at risk for, mental health and/or substance abuse problems. It also has materials for specific populations and age groups and hotlines.

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# Summary: State Legislation on Returning Troops and Veterans

October 1, 2008

## Overview

Increasingly, state legislatures and governors are calling for state leadership in providing outreach, information and resources to returning troops, veterans and their families with regard to traumatic brain injury (TBI), post traumatic stress disorder (PTSD) and related issues.

In July 2007, Illinois Governor Rod R. Blagojevich and the Director of the Illinois Department of Veterans' Affairs announced a first-of-its-kind program to screen every returning Illinois National Guard member for TBI and to provide a 24-hour toll-free psychological assistance for veterans suffering from PTSD. Similar efforts are beginning in other states. Below is a summary of legislation that has passed over the past two years pertaining to these and other efforts as reported in *State Watch* produced by the Federal HRSA TBI Program's Technical Assistance Center at NASHIA.

## Study Commissions

**NH** – On June 26, 2008, Governor John Lynch signed H.B. 1335 establishing a commission to study the effects of PTSD and TBI suffered by New Hampshire soldiers and veterans returning from Iraq and Afghanistan.

**NJ** – In August 2007, Governor Jon Corzine signed A.B. 3281 requiring state officials to study community-based care alternatives for the state's disabled veterans to avoid placement in a nursing home or other long-term care facility.

**WV** – Legislators passed H.C.R. 75 requesting the Joint Committee on Government and Finance to make a study of the needs of soldiers and veterans who have been injured in the Iraq/Afghanistan wars for the purpose of making recommendations on how the State of West Virginia can assist in getting them the care they deserve. The Division of Veterans Affairs, West Virginia Congressional Delegation and the National Guard are to help with the study and recommendations.

## Screening and Outreach

**CA** – On September 30, 2008, Governor Arnold Schwarzenegger signed S.B. 1401, requiring the

Department of Veterans Affairs and the Military Department to develop outreach plans to National Guard members or veterans returning to California from combat and assist them in obtaining a screening for PTSD and TBI. The bill takes effect January 1, 2009.

**MI** – On May 28, 2008 Governor Jennifer M. Granholm signed S.B. 731, that requires the Department of Military and Veterans Affairs to administer a PTSD and a TBI questionnaire to an officer or enlisted person serving in the National Guard who has returned from Operation Iraqi Freedom or Operation Enduring Freedom, unless he or she has completed similar questionnaires approved by the US Departments of Veterans Affairs or Defense.

## Referral, Counseling, Services and Coordination

**MN** – On May 29, 2008, Governor Tim Pawlenty signed H.B. 1812 appropriating \$500,000 for casework services for veterans, including in-home counseling. The bill also directed the veterans' agency to design a treatment program for veterans with TBI within the State Veterans Homes.

Other budget items included funding for the Linkvet telephone line service for veterans; a grant to the Minnesota Assistance Council for their work in helping veterans and their families affected by homelessness; for the veterans claims office for outreach and training to improve services and benefits; a pilot program for peer-to-peer counseling among combat veterans; and for an intergovernmental and veterans strategic planning study for the Minnesota Veterans Homes, with special emphasis on exploring alternative models to help veterans to live more independently.

In addition, the Department of Military Affairs received permanent funding for a "State Navigator" to coordinate state agency programs and activities to support and assist soldiers and their families during and after the reintegration process. The "State Navigator" position is viewed as an extension of the nationally recognized "Beyond the Yellow Ribbon" program.

**VA** -- The Virginia General Assembly appropriated \$4.5 million for wounded warrior legislation passed to provide assistance for soldiers with TBI. On March 12, 2008, Governor Tim Kaine signed H.B. 475 and on March 12, 2008, he signed S.B. 297, that requires the Department of Veterans Services, in cooperation with the Department of Mental Health, Mental Retardation and Substance Abuse and the Department of Rehabilitative Services to establish a program to monitor and coordinate mental health and rehabilitative services support for Virginia veterans, members of the Virginia National Guard and Virginia residents in the Armed Forces Reserves not in federal service. The program is to also support family members affected by covered military members' service and deployments.

The purpose of the program is to ensure that adequate and timely assessment, treatment and support for stress-related injuries and TBI resulting from service in combat areas are available to veterans, service members and affected family members. Subject to the availability of public and private funds appropriated for them, these services include case management services, outpatient, family support and other appropriate behavioral health and brain injury services necessary to provide individual services and support to military service members and their families.

**VT** -- Governor Jim Douglas signed H.B. 691, May 20, 2008, creating the Traumatic Brain Injury Fund to serve Vermonters with TBI, including residents who have served in the Armed Forces in Operation Iraqi Freedom and Operation Enduring Freedom.

**TX** -- On June 15, 2007, Governor Rick Perry signed S.B. 1058, relating to reintegration counseling services and related resources for military servicemembers. The legislation enabled veterans in parts of Texas that are served by the Texas Information and Referral Network (2-1-1) to call that service to receive information on services for veterans and military personnel. S.B. 1058 requires a comprehensive array of governmental agencies to identify state, local and private or government resources--medical, social and economic--that are available to military personnel and their immediate families.

**Suicide Prevention and Mental Health Services CA** -- On September 30, 2008, Governor Arnold Schwarzenegger signed A.B. 3083 to extend mental health services provided by the Adult and Older Adult Mental Health System of Care Act to include veterans, and requires counties to provide mental health services to veterans to the extent such services are available to other adults. The bill takes effect January 1, 2009

**MN** -- On May 4, 2007, Governor Tim Pawlenty signed H.B. 2227, an appropriations bill that appropriated \$50,000 to fund a study on the mental health needs of returning servicemen and women to be conducted by the National Guard Adjutant General and the Commissioner of Veterans Affairs, and \$30,000 to create a telephone hotline to refer veterans to available mental health services.

#### **Resolutions**

Several state legislatures have adopted resolutions to express gratitude for the sacrifices made by veterans who have sustained medical or mental health conditions or TBIs as the result of serving in the United States Armed Forces; and have urged Congress to ensure adequate funding for veterans' health care.

These states include Alaska (S.J.R. 11); Louisiana (H.C.R. 23); Vermont (H.J.R. 57); Texas (S.R. 594; H.C.R. 1) in 2007; and Michigan (H.R. 175) also in 2007.

Vermont lawmakers also urged the US Department of Defense to screen all military personnel leaving a combat theater for traumatic brain injury, urged the US Department of Veterans Affairs to create a traumatic brain injury registry; a comprehensive program to provide long-term traumatic brain injury rehabilitation; and a pilot program in Vermont to deliver traumatic brain injury screening, readjustment counseling, mental health services, and benefits outreach to rural veterans through mobile Vet Centers.

For copies of these cited bills or resolutions please contact the National Association of State Head Injury Administrators at:

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*NASHIA assists state government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.*

## Traumatic Brain Injury and Domestic Violence Facts:

### What is Traumatic Brain Injury?

A traumatic brain injury (TBI) is an injury to the head that results from a blow to the head of sufficient force to create blunt trauma, such as being hit in the head with a baseball bat or having one's head slammed against a hard object, the result of trauma secondary to a penetrating object into the brain itself, for example, a bullet entering the brain or the result of rapid movement of the brain within the skull, e.g., repetitive shaking of the body/head.



### What is Domestic Violence?

Domestic violence is a deliberate pattern of abusive tactics used by one partner in an intimate relationship to obtain and maintain power and control over the other. (Alabama Coalition Against Domestic Violence)

### How are Traumatic Brain Injury and Domestic Violence linked?

Research studies on the incidence of traumatic brain injury in domestic violence cases have revealed greater than 90% of all injuries secondary to domestic violence occur to the head, neck or face region (Monohan and O'Leary 1999). In a 1998 study by Jackson and Phillips of 53 women living in a domestic violence shelter on average the women experience five (5) brain injuries in the prior year. Almost 30% reported 10 injuries the prior year. Valera, in 2003, found that of the 99 battered women he studied, 75% sustained at least one partner related brain injury and 50% sustained multiple partner-related injuries.

Unfortunately repeated brain injury is typical of ongoing domestic violence leading to increased thinking, physical and emotional dysfunction over time, with the most disabling problems in the thinking process.

### How do Domestic Violence victims become Brain Injured?

For victims of domestic violence, physical assault and/or use of violence are the assumed major causes of traumatic brain injury. The following are some ways in which victims of domestic violence sustain a brain injury:

- Blow to the head with any object
- Pushed against a wall or any other solid surface
- Punched in the face or head
- Strenuous shaking of the body
- Falling and hitting your head
- Being strangled
- Near drowning
- Being shot in the face or head

### How does a Brain Injury and Domestic Violence increase the victim's risk of continued harm?

Abused individuals typically lack the knowledge of the long-term consequences of a brain injury and therefore do not seek specialized services. In addition service providers are often unaware of the high risk of a traumatic brain injury in victims. As a result professionals fail to link the psychodynamic issues presented by the victims and the challenges emerging from an undiagnosed brain injury. Without linking domestic violence and brain injury, they fail to recognize brain injury so are unable to refer for appropriate brain injury services and related rehabilitation services. Thus the lack of knowledge about brain injury serves to increase the likelihood of failure in intervention and rehabilitation success. In addition, once individuals experience one TBI they have an increased risk of having another TBI. Several things may happen after a TBI: the person's reaction time may be slower, judgement may be off, she may be more impulsive and inattentive to what might increase her likelihood of a second injury. The risk of repeated TBI is even greater for individuals who are victims of domestic violence since the most common target of abuse is the head, neck, and face. Repeated brain injuries increase symptoms. Each time the domestic violence victim comes into the shelter they may be a less functional as a result of a traumatic brain injury.

### What are the symptoms of a Brain Injury?

An individual sustaining a brain injury generally experiences a period of altered mental state or a brief loss of consciousness following the blow to the head. Some of the common initial symptoms are as follows:

- Headaches
- Dizziness
- Slowed processing of information
- Forgetfulness
- Fatigue
- Sensitivity to noise and lights

Most of the symptoms will disappear after a period of time.

### What are the most common problems a victim of Domestic Violence and a Brain Injury might exhibit?

The person may be more difficult to engage in planning, and show poorer follow-through on tasks. She may have greater difficulty adjusting to group living with shared responsibilities. She may be more likely to "not remember" prior discussions or routines. She may exhibit greater behavioral control issues. These things can result in the person having difficulty profiting from a shelter program.

### What are the most common problems after a Brain Injury?

**Physical Changes:** Specific physical changes are more frequently reported after a TBI. These changes include

- *Overall slowing/Clumsiness*-- A person can have motor difficulties, meaning that they have trouble moving their arms, legs, and so forth. This may be a generalized weakness or it can be very specific to one part of the body. In most cases motor difficulties tend to improve fairly quickly.
- *Decreased vision/hearing/smell*-- All can be affected by a TBI
- *Dizziness*-- A person can experience significant dizziness as a result of a head injury caused by trauma to the inner ear.
- *Headaches*-- A fairly common problem among people with traumatic brain injury; and can persist for

many weeks or months.

- **Fatigue**- It is not uncommon for people with traumatic brain injury to have significant fatigue to the extent that they tire very quickly. Things that are easy for us to do physically may require much more effort for them.
- **Increased sensitivity to noise or to bright lights**

The most common and persistent complaints are headache and excessive fatigue.

**Thinking Changes:** Reduced attention and processing speed are two common changes after a TBI.

- **Attention problems**- difficulties with concentration, paying attention to visual details, and dividing one's attention between two differing tasks.
- **Processing speed**- A person may report that all actions have slowed down. moving, talking, thinking and reading. They often feel that they are in slow motion.
- **Communication**- People may complain of problems with word finding and having trouble staying organized when talking with others.
- **Learning and memory**- These are almost universal problems after a brain injury. Information learned before the TBI remains intact, however memory for new information after the TBI is impaired.

**Executive Functioning:** A person often has an impairment in various combinations of the following that create the most difficulty in day-to-day functioning:

- difficulty planning and setting goals
- difficulty being organized
- difficulty being flexible
- difficulty problem solving
- difficulty prioritizing
- decreased awareness of thinking changes in self



The individual may still function under the idea of who they were before the injury without the same functioning ability.

**Emotional/Behavioral/Social changes:** The most common emotional changes following a brain injury are depression and anxiety. These are sometimes exhibited as sadness, loss of interest, feelings of worthlessness and hopelessness. These may be the result of difficulties in reasoning as a result of the TBI. If an individual is no longer able to do things they took for granted after a TBI they can become frustrated and even depressed. In addition, if an individual can't reason their way out of a situation they may become anxious.

After a brain injury an individual may have difficulty with self-monitoring. This may result in a rapid loss of emotional control. As adults the emotions we all feel, but not always express, are under control because of a gating mechanism. We may feel certain emotions but not necessarily exhibit them. When somebody has a significant brain injury, the gating mechanisms keeping those emotions under control are often disrupted. The gates are knocked askew and things come out that the person used to be able to control. Hence their emotions are displayed very readily. This can extend to the point of being irritable.

Other changes after a brain injury may include:

- Difficulty with self-initiation
- Impatience
- Inability to get along with others
- Increased risk taking
- Increased impulsivity
- Irritability or agitation

- Intolerance
- Socially inappropriate behavior

### How do I recognize if my client experienced a Brain Injury?

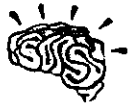
A "Brief Screening for Possible Brain Injury" was developed for use by domestic violence shelter staff as a tool to pre-screen survivors who may have experienced a brain injury during the course of a domestic violence incident. This tool is the first step. Part 1 questions the victim about events where a blow to the head may have occurred. Part 2 concerns common post TBI symptoms. If the screening results are positive you should consider referral to the Alabama Head Injury Foundation at 1-800-433-8002 for further assessments.

### What approach should be used to address challenges of resulting from a TBI?

Depending on the specific symptoms your client is experiencing, there are a number of things you can do to help them compensate for the brain injury. Examples of compensations for challenges individuals with a brain injury may experience are as follows:

#### Physical-

- Allow extra time for your client to get from place to place
- Keep the environment quiet with noises and bright lights to a minimum.
- Keep sessions with the client short.
- Schedule rest periods and breaks from planned activities.



#### Thinking-

- Work on one task at a time.
- Meet in a quiet room to limit distractions
- Have client become active in discussions and plan development, rechecking to ensure comprehension
- Slow down your speed of discussion to allow time for client to process what you are saying
- Allow the client additional time to provide written and/or verbal responses
- Encourage client to prepare an "agenda" for your meetings in advance, when issues/questions occur to her.
- Cue client if she is experiencing difficulty finding the words to express her ideas or thoughts
- Provide written documentation/information to supplement verbal discussions.
- Encourage client to write down instructions/information in a notebook she keeps with her
- Present information in factual manner, avoid abstract concepts
- Provide several solutions to the problem and encourage client to make the best choice
- Help client to prioritize and organize tasks

#### Emotional/Behavioral-

- Minimize anxiety with reassurance, education and structure.
- Provide neutral, but direct feedback if client behaves inappropriately.

### Where can I go for help in serving my client who acquires a brain injury?

If you suspect your client may have acquired a traumatic brain injury your first point of contact should be the

Alabama Head Injury Foundation  
 HelpLine 1-800-433-8002

This statewide team of family resource coordinators serve all ages affected by brain injury.

# CHAPTER 4: TBI IN ALASKA

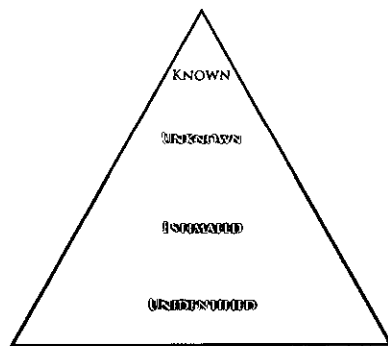
## OVERVIEW

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



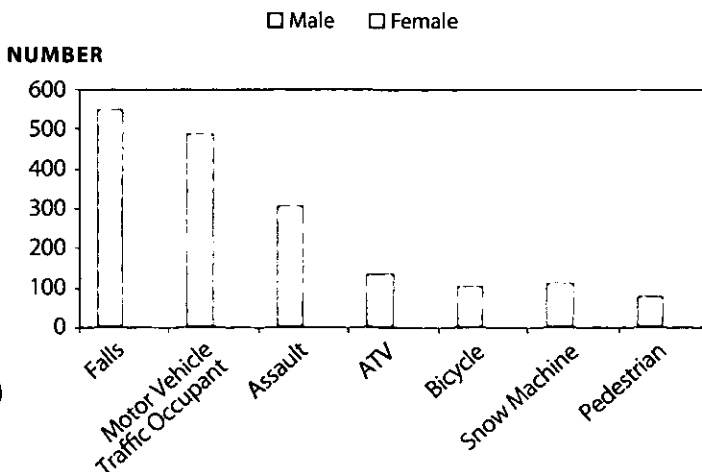
**Known** 800 hospitalized or fatal TBI/year

**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.

## CHAPTER 4: TBI IN ALASKA

### 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 age 70-79.....  | 200.9 |



Males 15-19



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.

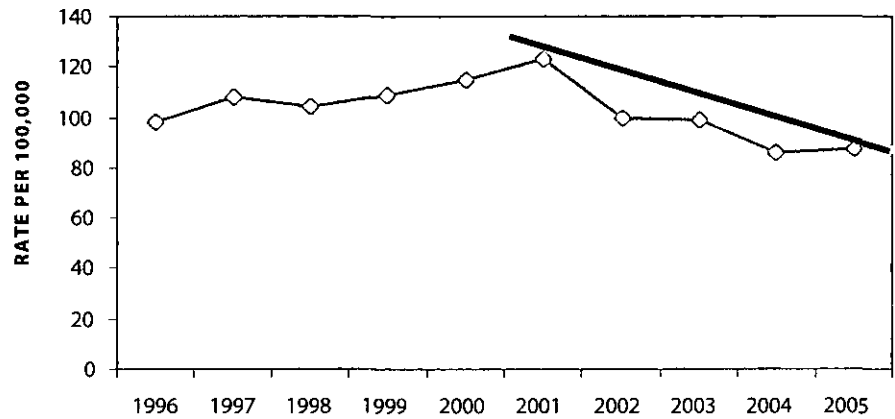
# CHAPTER 4: TBI IN ALASKA

## 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

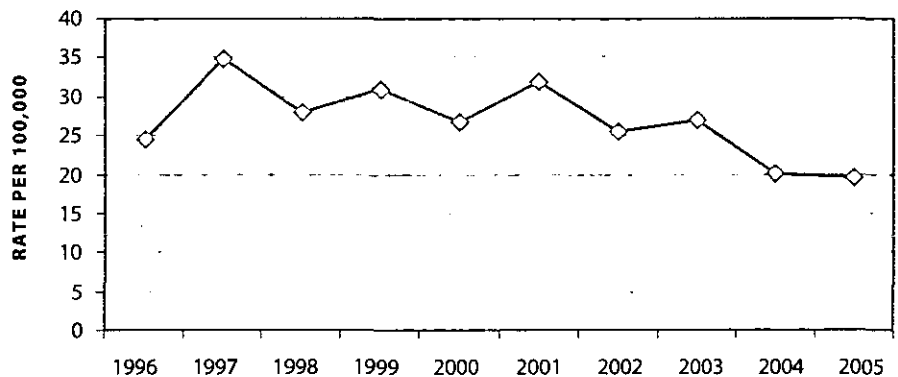


### THE TBI RATE DUE TO MOTOR VEHICLE CRASHES ON THE HIGHWAY HAS DECREASED 38 PERCENT FROM 2001 TO 2005.

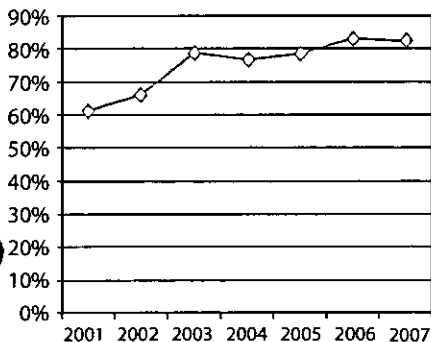
#### Primary Enforcement Seatbelt Law

On May 1, 2003 Alaska passed a law to change their seatbelt law from secondary to primary enforcement, i.e. 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.

HOSPITALIZATION TBI BY YEAR DUE TO MOTOR VEHICLE CRASH



SEATBELT USE OBSERVATION STUDIES ALASKA



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.

# CHAPTER 4: TBI IN ALASKA

## 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.

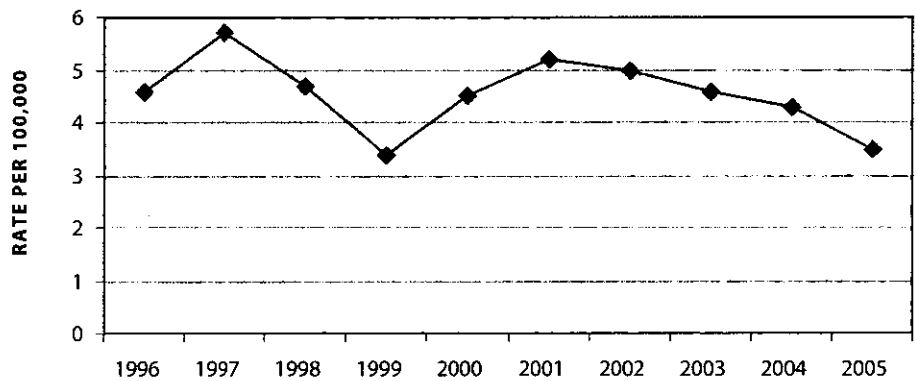
Four of the twelve communities surveyed in 2000 and in 2006 had recently passed ordinances requiring helmet use for children. The average change for bicycle helmet use in the "helmet ordinance" communities was +56 percent, while the communities with no ordinance had an average change of +17 percent.

[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.

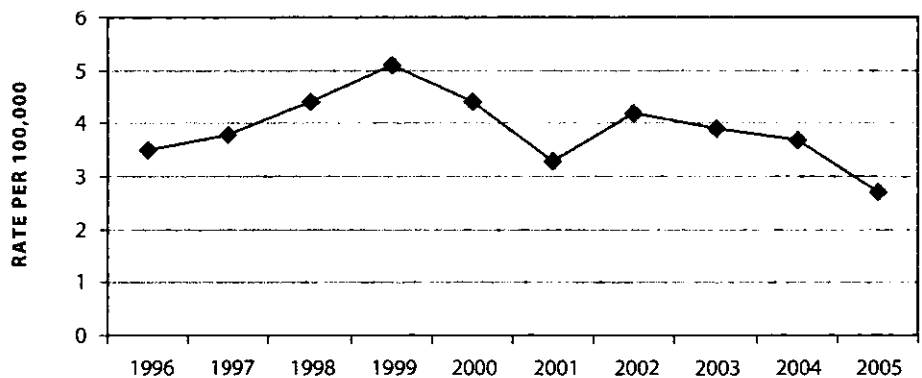
HOSPITALIZATION TBI BY YEAR DUE TO BICYCLE CRASH



### PEDESTRIAN INJURY

There is no clear trend in pedestrian injuries.

HOSPITALIZATION TBI BY YEAR DUE TO PEDESTRIAN INJURY



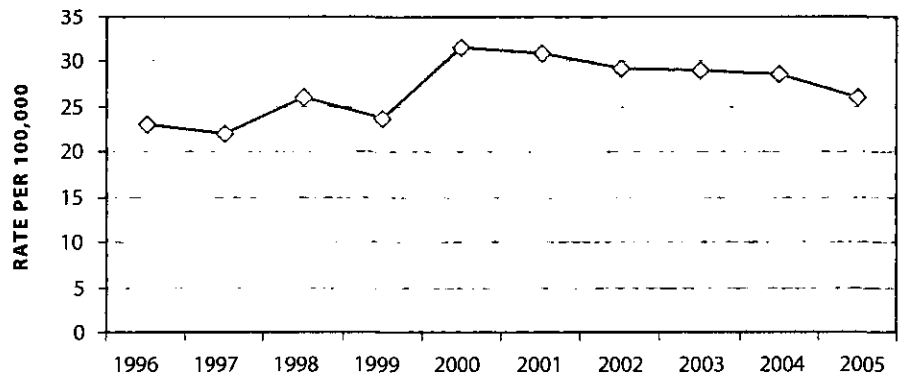
# CHAPTER 4: TBI IN ALASKA

## 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.

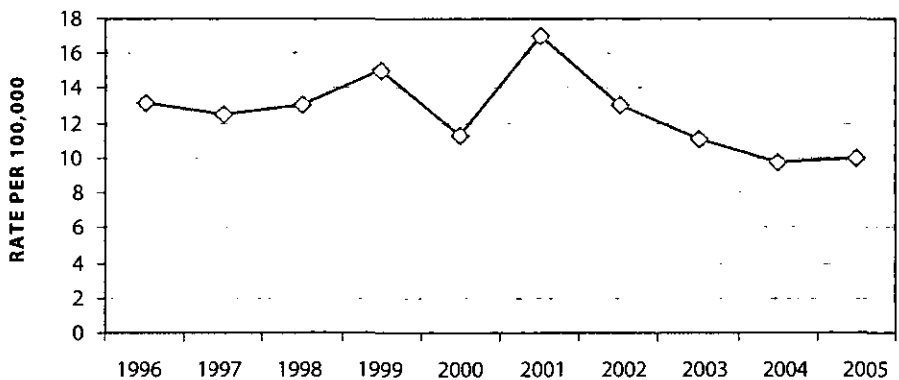
HOSPITALIZATION TBI BY YEAR DUE TO FALLS



### ASSAULTS

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

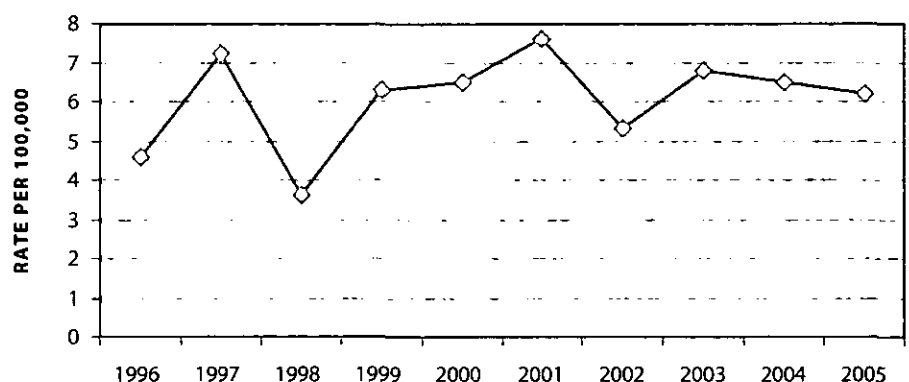
HOSPITALIZATION TBI BY YEAR DUE TO ASSAULT



### 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



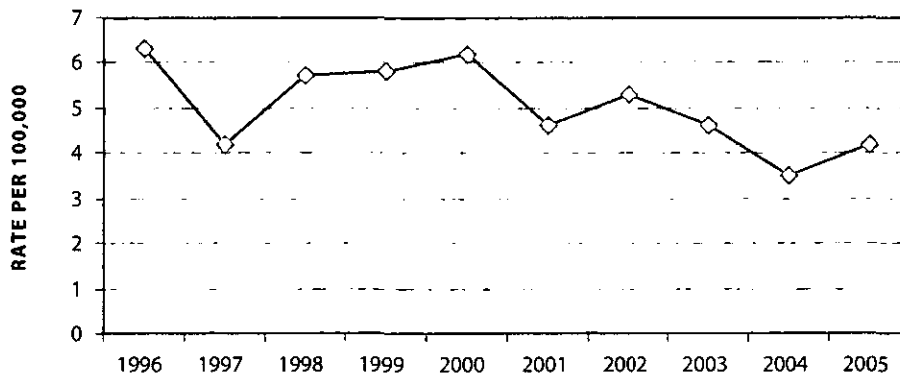
# CHAPTER 4: TBI IN ALASKA

## 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



## Rutgers Centers for State Health Policy, Issue Brief: A Survey of Medicaid Brain Injury Programs, March 2008

| State          | Waiver year ending | Number Served | Expenditures (GF and Federal match) | Annual Per Capita Costs | Average Length of Stay | Per Diem Costs |
|----------------|--------------------|---------------|-------------------------------------|-------------------------|------------------------|----------------|
| New York       | 2006               | 1953          | \$79,029,120                        | \$40,465                | 310                    | \$131          |
| Illinois       | 2006               | 3,601         | \$42,541,226                        | \$11,814                | 264                    | \$45           |
| Connecticut    | 2006               | 344           | \$25,691,011                        | \$74,683                | 305                    | \$245          |
| Wisconsin      | 2006               | 334           | \$20,095,110                        | \$60,165                | 351                    | \$171          |
| New Jersey     | 2006               | 276           | \$18,374,797                        | \$66,575                | 329                    | \$202          |
| South Carolina | 2006               | 497           | \$12,247,128                        | \$24,642                | 338                    | \$73           |
| New Hampshire  | 2006               | 140           | \$11,487,626                        | \$82,054                | 332                    | \$247          |
| Iowa           | 2006               | 825           | \$10,883,459                        | \$13,192                | 296                    | \$45           |
| Colorado       | 2006               | 293           | \$9,027,736                         | \$30,811                | 247                    | \$125          |
| Pennsylvania   | 2005               | 152-324       | \$6,897,762                         | \$45,380                | 285                    | \$159          |
|                | 2005               | 98            | \$6,532,587                         | \$66,659                | 285                    | \$234          |
| Kansas         | 2006               | 269           | \$6,289,071                         | \$23,379                | 242                    | \$97           |
| Florida        | 2006               | 283           | \$5,903,410                         | \$20,860                | 316                    | \$66           |
| Massachusetts  | 2006               | 90            | \$4,883,813                         | \$54,265                | 315                    | \$172          |
| Wyoming        | 2006               | 137           | \$3,940,878                         | \$28,766                | 297                    | \$97           |
| Indiana        | 2006               | 131           | \$3,390,758                         | \$25,884                | 355                    | \$73           |
| Utah           | 2006               | 91            | \$2,079,141                         | \$22,848                | 333                    | \$69           |
| Maryland       | 2006               | 23            | \$1,489,321                         | \$64,753                | 255                    | \$254          |
| Idaho          | 2006               | 19            | \$1,133,542                         | \$59,660                | 354                    | \$169          |
| North Dakota   | 2006               | 29            | \$797,371                           | \$27,496                | 315                    | \$29           |
| Nebraska       | 2006               | 26            | \$733,247                           | \$28,202                | 335                    | \$84           |
| Vermont        | 2006               | 68            |                                     | \$5,500/month           | no data                |                |
| Alaska         | 2008               |               | \$0.00*                             |                         |                        |                |

\$150,000 FY10 MHTAAR for brain injury case management-DHSS SDS Administration

Blue states have been identified as having waiver programs that may meet Alaska's needs (more up to date funding levels needed)

Yellow areas are waiver programs that have a rehabilitation focus and long-term care option

## Brain Injuries in Alaska

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## Traumatic Brain Injury in Alaska



### What is traumatic brain injury (TBI)?

TBI is a jolt, blow to the head, or penetrating head injury that disrupts the function of the brain. (TBI has many names: concussion, head injury, head trauma, bump on the head, bell rung, and hit my head and saw stars).

### What are the top 5 causes of hospitalizations due to brain injury in Alaska? (highest to lowest incidence) <sup>i</sup>

1. Falls
2. Motor Vehicle Crashes
3. Domestic Violence/Assault
4. ATV/Snowmachine crashes
5. Bicycle crashes

### Did you know?

- Brain injury is the leading cause of death and disability among children and youth in the nation and the world. <sup>ii</sup>
- Alaska has no program specifically to deal with brain injury.
- Only 1% of Alaskans have access to brain injury rehabilitation, and that is often outside the state. <sup>iii</sup>
- Alaska's annual brain injury rates are more than new diagnoses for breast and lung cancer combined. <sup>iv</sup>

### How many brain injuries occur statewide each year?

- An estimated 3,000 visit ERs and go home. <sup>v</sup>
- An additional 800 are hospitalized due to severe TBI. <sup>vi</sup>
- An estimated 22-32% of returning war-wounded have TBI. <sup>vii</sup>

### Can the brain recover after a brain injury?

- With mild brain injuries, 80-90% of individuals recover fully.
- With moderate to severe injuries, recovery and relearning is possible with intensive treatment and rehabilitation.
- Long-term recovery is often a life-long process.

### How is brain injury treated?

Once a severe brain injury occurs, rehabilitation greatly increases the probability of recovery.

Brain injury treatment includes a multidisciplinary array of services including cognitive, speech, occupational, and physical therapy; medication management; educational/vocational services; and counseling.

There is nowhere in the state to receive these services in a coordinated manner.

### What other problems often result from untreated TBI?

People with TBI often have cognitive, behavioral, and emotional impairments. These can lead to short-term memory loss, aggressive social interactions, job loss, divorce, substance abuse, bankruptcy, incarceration, and homelessness.

### How does brain injury affect families?

Alaskans are being discharged to their homes with little understanding of or access to rehabilitation. Alaskan families are often torn apart after brain injury because of limited access to in-state services, limited education about the injury, learning to live and cope with a person who has changed, change in family roles, and overwhelming stress from insurance, forms, bureaucracy, and financial burdens.

### Can brain injury be prevented?

Some brain injuries can be prevented. TBI from motor vehicles crashes has decreased due to use of seat belts. Using helmets when riding ATV, snowmachines, and bicycles is having a positive effect.

Brain injuries caused by unforeseen accidents will continue to occur. ***Brain injury can happen to anyone, in an instant.***

## Next steps will need State of Alaska support and leadership

### We ask that Policy Makers...

- Support SB 219 and HB 328 related to a Traumatic/Acquired Brain Injury Program
- Support \$350,000 in FY11 Governor's Operating Budget for Brain Injury Service Coordination
- Provide feedback on the planning efforts and the 10 Year Plan for TBI in Alaska.
- Partner with Alaska Brain Injury Network and the various military, tribal, and private/public providers in determining TBI rehabilitation options including funding levels, eligibility, and how to best support military members.

**TBI Program may consist of the following:** A TBI Program will provide services and create a multiplier effect for additional funding and service providers.

- Pilot brain injury rehabilitation options: Adult NeuroRehabilitation, Adult NeuroBehavioral, Supportive Living, Adolescent Integration, and Host Home.
- Change Medicaid program and waivers to include residential TBI rehabilitation.
- Support and expand case management to support and educate families concerning available services and funding options.
- Establish brain injury screening across existing programs, i.e. emergency rooms, primary care, schools, juvenile justice, and corrections.
- Direct other Departments and Divisions to coordinate planning and service delivery.
- Support existing information and referral services.
- Support brain injury prevention and public awareness, including mandating sports concussion training.
- Improve workforce ability to identify TBI and provide appropriate treatment.

### Results of funding a TBI Program

- Medicaid services for TBI will be matched 50% by federal funds by FY12.
- In addition to cost savings, brain injury waivers have provided other significant benefits. The existence of these waivers supports the growth of community non-profit brain injury agencies.
- Department of Defense, Alaska Veteran Affairs Health Systems, Alaska Tribal Health System, and private providers will have the opportunity to coordinate planning and implementation of rehabilitation and community re-entry programs.
- Alaska Veterans, Active Duty, National Guard members, civilian children/youth, adults, and Alaska Native/rural residents will be able to obtain coordinated, and much needed, brain injury education, screening, assessment, and treatment, without leaving the state.
- Alaskans with brain injury will have increased opportunity to return to work and school, maintain family roles, and positively participate in their community.
- Early treatment may reduce future medical and social costs.
- Potential cost savings in acute care, existing state programs; behavioral health, juvenile justice, corrections, homeless activities, and long-term care in institutional facilities.
- Prevention funding and public awareness efforts may help reduce the future escalation of costs for the TBI Program over time.



**What planning has been completed to better meet the needs of Alaskans with brain injury?**

**1996**-State of Alaska, DHSS, Public Health identifies traumatic brain injury has a public health crisis. Public Health applies for, but is unsuccessful in receiving, the Health Resource Services Agency TBI Planning Grant.

**1999**- State of Alaska, DHSS, Mental Health Developmental Disabilities (now Behavioral Health) applies for and is awarded the HRSA TBI Planning Grant (3 year grant).

**2000**-Alaska Traumatic Brain Injury Advisory Board is formed.

**2001**-Formal TBI Needs Assessment completed

**2002**-State TBI Action plan developed

**2003**-2<sup>nd</sup> TBI Needs Assessment completed (283 pages of information)

**2004-2009** Senator McGuire sponsors resolution for Brain Injury Awareness Month.

**2004**- DBH receives HRSA TBI grant (additional 3 years)

**2005**- Behavioral Health mandates brain injury screening and data collection for all grantees.

**2006**-TBI Consumer Satisfaction Survey completed.

**2007**- AMHTA funds TBI information and referral

**2007**- ABIN organizes TBI Partnership to include all military partners in Alaska.

**2008**- \$100,000 for brain injury funding included in FY09 Governor's Budget, but moved to and approved in the MHTAAR budget

**2008**- Senior and Disabilities Services becomes lead agency for brain injury for State of Alaska

**2008**- The "10 Year Plan for TBI in Alaska" was developed by ABIN in conjunction with the Department of Health and Social Services, the Alaska Mental Health Trust Authority, and numerous public and tribal partners.

**As a result of the "10 Year Plan for TBI in Alaska," 2009 activities have focused on brain injury rehabilitation**

Senator McGuire and Senator Paskvan sponsor Senate Bill 118, Medicaid: Traumatic Brain Injury Services

2<sup>nd</sup> TBI Consumer Satisfaction Survey completed.

AMHTA (the Trust) funds TBI Care Coordination demonstration project.

Senior and Disabilities Services works with ABIN and consultant to develop TBI Care Coordination programs including policies and procedures manual.

Senator McGuire, Representative Johnson and ABIN host "Roundtable Discussion on Brain Injury Rehabilitation" with a focus on military research and programs.

ABIN hosts the Directors of the Defense and Veterans Brain Injury Center and the National Intrepid Center for Excellence for Psychological Health and Traumatic Brain Injury.

ABIN meets with Alaska Federal Health Care Partnership.

Senior and Disabilities Services applies for Federal HRSA TBI Implementation grant program.

10 Year Plan for TBI recognized by the North American Brain Injury Society as a model for other states to follow.

Received input from highest officials in Alaska and in the field of brain injury: Col. Michael Jaffee, Dr. James Kelly, Col. Paul Friedrichs, Mr. Alex Spector, Don Kasheveroff, Commissioner Bill Hogan, AMHTA Trustees and CEO.

ABIN researches other state brain injury programs, sustainable funding options, including Medicaid and grant programs.

ABIN drafts options for Governor Parnell's review and recommendations.

**Projected savings when brain injury rehabilitation is available in-state**

**\*Emergency Room and Acute Care Savings, length of stay and # visits<sup>viii</sup>**

Because there is not a post-acute rehabilitation program in-state, Alaskans are using acute care beds longer than needed.

Also, Alaskans with brain injury are returning to emergency rooms and acute care more often than the general public because there are no community programs to support them.

The following information relates to TBI patients held in an acute care hospital due to non-availability of a rehabilitation facility.

|               | Average   | Highest   | Lowest   |
|---------------|-----------|-----------|----------|
| Costs         | \$143,000 | \$276,000 | \$34,000 |
| Hospital Stay | 43 days   | 123 days  | 11 days  |

**\*State Budget Savings**

When programs specific to brain injury are not available other state programs are burdened.

Untreated or undiagnosed TBI may lead to individuals becoming functionally disabled in the society, and may fall into other state programs as their lives decline.

The following programs may see cost savings if a TBI Program were funded

| State of Alaska                  | As relates to TBI   | Funding <sup>ix</sup> |
|----------------------------------|---------------------|-----------------------|
| Corrections <sup>x</sup>         | 25-87% TBI history  | GF \$212.2 million    |
| Juvenile Justice <sup>xi</sup>   | Significant portion | GF \$52.5 million     |
| Behavioral Health <sup>xii</sup> | 32% TBI history     | GF \$66.3 million     |
| Homeless                         | 53% <sup>xiii</sup> | \$8 million total     |

**\*Long-Term Care Savings<sup>xiv</sup>**

Brain injury waivers provide significant cost savings, on average \$30,000 annually per person, when compared to institutional facility-based services.

**Costs associated with providing continuum of brain injury rehabilitation programs<sup>xv</sup>**

| Continuum of Rehabilitation Program (Residential) | Range: Per Diem Costs | Annual Costs for eight participants (high range) |
|---------------------------------------------------|-----------------------|--------------------------------------------------|
| Adult NeuroRehabilitation                         | \$450-\$780           | \$2.3 million                                    |
| Adult NeuroBehavioral                             | \$450-\$780           | \$2.3 million                                    |
| Supported Living                                  | \$300-\$595           | \$1.8 million                                    |
| Adolescent Integration                            | \$600                 | \$1.8 million                                    |
| Host Home (no therapies included)                 | \$163-\$198           | \$600,000                                        |
| Total                                             |                       | \$8.8 million                                    |

**National Medicaid Brain Injury Program Facts<sup>xvi</sup>**

|                           |                                                |
|---------------------------|------------------------------------------------|
| # of States participating | 24 states have a brain injury Medicaid program |
| Funding range             | \$80.0 million-\$800,000                       |
| Numbers Served            | 3,600-26                                       |
| Annual per capita costs   | \$82,000-\$12,000                              |
| Per diem costs            | \$247-\$45                                     |

**Current State of Alaska Funding Levels<sup>xvii</sup>**

| Programs                             | Prevalence | GF Funds       |
|--------------------------------------|------------|----------------|
| Seriously Mentally Ill               | 21,754     | \$11.6 million |
| Behavioral Health (Grants)           | 17,000     | \$13.7 million |
| Behavioral Health (Medicaid)         |            | \$52.8 million |
| Severely Emotionally Disturbed Youth | 12,725     | \$11.6 million |
| Developmental Disabilities (Grants)  | 12,185     | \$13.7 million |
| Traumatic Brain Injury               | 12,000     | \$0.00         |

## Alaskans share their story

### William Barrington, teenager, Anchorage



- Memorial Day weekend – State Motocross Races – Kincaid Park, wearing all protective equipment including a helmet
- Set of triples – hit 2nd, headfirst into 3<sup>rd</sup>
- Unresponsive – rushed to Providence
- 3 hour surgery – bleeding and clotting in the brain – no external injuries
- Diagnosis – TBI – due to weakened blood vessels bursting in the brain
- **Cause of weakened blood vessels? Multiple sports injuries**

#### First 47 days in the hospital

- Day 1-12 Medicated Coma
- Day 13 Sign language/whiteboard



- Day 14 Learning to swallow
- Day 19 First real food and water
- Day 23 First sounds/ Day 24 words at a whisper
- Day 32 Walked with walker
- Day 46 First movement in arm system
- Day 47 Discharged from hospital

### Life after hospital- Family search for resources takes one full year!

#### Will's schedule one year after injury

- Monday – 4 classes-West High , pickup by Dad-to Sylvan,3:30 I take to Counseling, 5-Acupuncture
- Tuesday – 4 classes at West High, pickup by uncle Nate-to Sylvan, 2pm mom takes to physical and speech therapy
- Wednesday - 4 classes-West High, pickup by Dad to Sylvan, 3:30 mom takes to wheelchair basketball
- Thursday - 4 classes-West High, pickup by Uncle Nate to Sylvan, 2pm mom takes to occupational therapy
- Friday – 4 classes-West – in office until 2, rides bus home, 3:30 mom takes to Acupuncture, 6 to wheelchair soccer
- Sunday – Youth group at church

#### What is next?

- Family is looking for new therapy ideas for Will's hand
- Will is in his senior year of high school. Preparing for college – studying for SAT/ACT; utilizing Accuplacer and King Career Center
- Will is deciding where to go for College – Possibly UAA or a college with wheelchair basketball?
- Will is learning to drive – preparing to get his driver's license

## The Barrington Family

Why did their journey after brain injury have advantages as compared to the majority of Alaskans?

| Advantage                                                                                                                    | Why is this important?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Will was unconscious; no doubt he had an injury to the brain.                                                                | <p>Within hours of the injury, there is an accurate diagnosis, focus on prevention of further injury, focus on minimizing the severity of the injury.</p> <p>Many brain injuries go undiagnosed leading to further injury, lack of understanding of changes, and inappropriate or no treatment.</p>                                                                                                                                                                                                                                                                |
| Family had comprehensive insurance, no question in receiving acute intensive care.                                           | <p>Less than 6% of Alaskans hospitalized with TBI have access to inpatient rehabilitation. If there is a physical disability, it is easier to qualify for inpatient rehabilitation as compared to only a cognitive disability.</p> <p>Few Alaskan families are able to access the neurorehabilitation unit because of financial limitations (restricted or lack of insurance).</p>                                                                                                                                                                                 |
| Access to <u>inpatient rehabilitation</u> was challenged but allowed, due to Will's age.                                     | <p>He was accepted into adult neuro-rehab program even though he was 14 years old.</p> <p>There are no inpatient neurorehabilitation programs for children/youth in Alaska.</p> <p>Families that do go out of state often have to be separated and bear greater financial burden maintaining two households. Only 1% of Alaskan families have access to outpatient rehabilitation.</p>                                                                                                                                                                             |
| Will had mom to advocate and coordinate treatment, educational resources, emotional supports, and community support services | <p>Many Alaskans do not have a person to make this happen for them. Nature of their injury prevents them from doing it on their own.</p> <p>Mom starting from scratch. Took over a year to find resources that were appropriate and available in-state for Will.</p> <p>Brain injury rehabilitation program would have had all the resources coordinated and delivered soon after the injury which is when these services are most important.</p>                                                                                                                  |
| Will had access to some outpatient rehabilitation.                                                                           | <p>There is not a residential/outpatient program specifically for brain injury in Alaska (children, adults, or service members)</p> <p>Had to be creative to get outpatient services at the level needed to support his recovery. Limited to 75 visits/year. Insurance was exhausted only 4 months into his rehabilitation. Had to find alternative treatments until the beginning of the calendar year when he could resume much needed therapies</p> <p>Will had the best insurance there is, and he was still limited in getting what he needed to recover.</p> |
| Will's injury was not a frontal lobe injury. It was a deep bleed in the temporal lobe (side of the brain).                   | <p>Didn't have the personality change, mood swings, that many people with brain injury have.</p> <p>Brain injury treatment teaches individuals and families how to recognize and cope with the cognitive, emotional, and behavioral changes after brain injury.</p>                                                                                                                                                                                                                                                                                                |
| Will had/has lots of community support and faith-based family.                                                               | <p>Depression is often an outcome after brain injury. Both individual and family need the support to keep moving forward with life after brain injury.</p> <p>There are many families that take care of their loved one with a TBI. With rehabilitation, treatment, and natural supports, individuals can get better.</p> <p>Families need access to these programs to support their efforts; brain injury is a lifelong process.</p>                                                                                                                              |

**Alaska organizations ready to see State of Alaska take a leadership role in brain injury rehabilitation**

Department and Health and Social Services-  
Senior and Disability Services and Behavioral  
Health  
Department of Labor- Vocational Rehabilitation  
Alaska Mental Health Trust Authority  
Alaska Federal Health Care Partnership  
Elmendorf, 3<sup>rd</sup> Medical Unit  
Alaska VA Health Systems  
Alaska National Guard  
Service/Family Resource Center -Warrior  
Transition Battalion  
Alaska Vet Centers  
Representatives for the Marines  
Alaska Native Tribal Health Consortium  
Alaska Native Medical Center  
Southcentral Foundation  
Providence Alaska Medical Center  
St. Elias Specialty Hospital  
Mat-Su Health Services  
Natural Health Center  
Anchorage Community Mental Health Services  
Alaska Brain Injury Network  
Governor's Council on Disabilities and Special  
Education  
Alaska Commission on Aging  
Alaska Mental Health Board/Advisory Board on  
Alcoholism and Drug Abuse  
Statewide Independent Living Council  
Disability Law Center  
Rural/Tribal Hospitals and Clinics

**ABIN has heard from over 1000 Alaskans directly affected by brain injury**

Alaska Communities ABIN has visited, who are asking for brain injury services and education include:

Anchorage, Atmautluak, Barrow, Bethel, Dillingham, Fairbanks, Galena, Juneau, Kenai Peninsula communities, Ketchikan, Kodiak, Kotzebue, Nome, Palmer, Prince of Wales, Sitka, Tok, and Wasilla.

*For more information, contact Jill Hodges, Executive Director, Alaska Brain Injury Network (ABIN), [www.alaskabraininjury.net](http://www.alaskabraininjury.net) or call (888)-574-2824.*

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- <sup>i</sup> AK DHSS Division of Public Health, Section of Injury Prevention and EMS, Alaska Trauma Registry (email correspondence with T. Ali, 2009)  
<sup>ii</sup> World Health Organization (WHO), [www.projectbrain.org](http://www.projectbrain.org)  
<sup>iii</sup> Alaska Trauma Registry, TBI hospitalizations 1995-2005  
<sup>iv</sup> Cancer Incidence and Mortality in Alaska 1996-2004  
<http://www.hss.state.ak.us/dph/chronic/cancer/assets/cancerRegistry1996-2004.pdf>  
<sup>v</sup> National Association of State Head Injury Administrators State Fact Sheet  
<sup>vi</sup> Alaska Trauma Registry, 2006  
<sup>vii</sup> RAND Study  
<sup>viii</sup> January, 2001 - June, 2004 Alaska Trauma Registry Data on 13 Patients  
<sup>ix</sup> Alaska FY10 Budget  
<sup>x</sup> CDC, TBI in Prisons and Jails: An Unrecognized Problem  
<sup>xi</sup> Virginia Study for Joint Legislative Audit Committee  
<sup>xii</sup> AKAIMS, Alaska Behavioral Health 2006  
<sup>xiii</sup> Stephen W. Hwang, MD MPH, et al. *The effect of traumatic brain injury on the health of homeless people*. CMAJ; October 7, 2008; 179 (8).  
<sup>xiv</sup> Rutgers Center for State Health Policy, Issue Brief  
<sup>xv</sup> MentorABI, Tori Harding email correspondence 11/8/09  
<sup>xvi</sup> Rutgers Center for State Health Policy, Issue Brief: Medicaid Brain Injury Programs, March 2008  
<sup>xvii</sup> Alaska FY10 Budget



## At A Glance...

### 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.

### 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 Behavioral Health (DBH), successfully applied for HRSA TBI Planning & Implementation Grants. DBH held the grant for 9 years. In 2009, Senior and Disabilities Services transitioned to the lead agency role.

The original HRSA grant required that Alaska fulfill the following:

- Identify a State Lead Agency: The State of Alaska, Department of Health and Social Services, Division of Behavioral Health (then DMHDD)
- 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
- Craft an implementation plan (completed March 2003)

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.

### Current Program Activities

ABIN has two primary functions: TBI Advisory Board and TBI Resource Navigation 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 (Information and Referral)

- 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

- Visited 15 Alaska communities since 2003, hosted public comment 27 times, and heard public comment from an estimated 300 Alaskans.
- Developed the Comprehensive "10 Year Plan for TBI in Alaska".
- Increased brain injury awareness in the state.
- Advocacy efforts resulting in Alaska Mental Health Trust Authority Authorized Receipts and Authority Grant Funding approved:
  - TBI Advisory Board (FY01-FY11)
  - TBI Resource Navigation (FY07-FY11)
  - TBI Training (FY09-FY11)
  - TBI Care Coordination (FY10-FY11)
- Organized the TBI Partnership with Military including 3<sup>rd</sup> Medical Unit, Elmendorf; Veteran Affairs; Vet Centers; National Guard; and Marines.
- Instrumental in the Comprehensive Integrated Mental Health Plan, Alaska Scorecard highlights traumatic brain injury prevalence.

## **Accomplishments**

### **TBI Resource Navigation**

- Developed Statewide TBI Resource Directory.
- Provided information and referral to 500 Alaskans.
- Developed a 'hospital packet' of TBI information; distributed to 34 Alaska hospitals.
- Developed online discussion group for brain injury; 130 Alaskans participate.
- Organized more than 30 trainings, workshops, forums about brain injury.
- Provided technical assistance to six (6) head injury support groups. New support group organized in Mat-Su.

### **Resource Navigation Success Stories**

A woman of approximately 48 years old called ABIN. 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.

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 social security disability income and her situation is improving.

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.

## **ABIN Funding**

Alaska Mental Health Trust Authority  
State of Alaska, Department of Health and Social Services,  
Division of Senior and Disabilities Services via  
Federal HRSA TBI Implementation Grant  
Alaska Native Tribal Health Consortium  
State of Alaska, Department of Commerce, Community,  
and Economic Development  
U.S. Department of Health and Human Services/HRSA-  
Special Congressional Initiative  
Individual Donors

### **To learn more about ABIN:**

**visit our website: [www.alaskabraininjury.net](http://www.alaskabraininjury.net)**

**email: [contact@alaskabraininjury.net](mailto:contact@alaskabraininjury.net)**



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Toll-Free: (888) 574-2824  
Fax: (907) 274-2826

## Regional Traumatic Brain Injury Information



### TBI in Southcentral Alaska

#### How many Southcentral Alaskans are hospitalized due to a brain injury?

Reports show over **2300 residents** have been hospitalized over a 7 year period (An average of 338 residents/year).

#### What are the top 3 causes of brain injury in Southcentral Alaska?

- Motor Vehicle Accidents
- Falls
- Assault

#### Did you know?

Over a 7 year period, over 200 people in Southcentral Alaska were hospitalized with a TBI due to assault.

### TBI in Southeast Alaska

#### How many Southeast residents are hospitalized due to a brain injury?

Reports show nearly **430 residents** have been hospitalized over a 7 year period (An average of 61 residents/year).

#### What are the top 3 causes of brain injury in Southeast Alaska?

- Falls
- Motor Vehicle Accidents
- Assault

#### Did you know?

In Southeast Alaska over a 7 year period, there were almost twice as many TBI hospitalizations from falling (162) as for TBI due to motor vehicle accidents (92).

### TBI in Southwest Alaska

#### How many Southwest Alaskans are hospitalized due to a brain injury?

Reports show over **450 residents** have been hospitalized over a 7 year period. (An average of 64 residents/year).

#### What are the top 3 causes of brain injury in Southwest Alaska?

- ATV/Snowmachine
- Falls
- Assault

#### Did you know?

The Southwest region of Alaska has the highest prevalence rates of traumatic brain injury (TBI), *per capita*, in the state.

### TBI in Interior Alaska

#### How many Interior Alaskans are hospitalized due to a brain injury?

Reports show over 450 Interior Alaskans have been hospitalized over a 7 year period (An average of 66 residents/year).

#### What are the top 3 causes of brain injury in Interior Alaska?

- Motor Vehicle Accidents
- Falls
- Assault

#### Did you know?

Over a 7 year period, the Interior region of Alaska had the second highest incidence rate of hospitalizations due to TBI.

### TBI in Far North Alaska

#### How many Far North region Alaskans are hospitalized due to a brain injury?

Reports show nearly 250 Far North Alaskans have been hospitalized over a 7 year period. (An average of 35 residents/year).

#### What are the top 3 causes of brain injury in the Far North region of Alaska?

- ATV/Snowmachine
- Falls
- Assault

#### Did you know?

Over a 7 year period, the Far North region of Alaska had more TBIs caused by ATV/Snowmachine accidents (100) than falls and assault combined (98).

BARRIERS  
and  
RECOMMENDATIONS

Addressing the Challenge of Brain Injury in America

**2008**

*A report provided by the*  
**Brain Injury Consensus Conference**

# Executive Summary

## Introduction

**Brain injury has created serious challenges for both the Department of Defense and the Department of Veterans Affairs; these challenges exist because brain injury has been, and continues to be, a critical healthcare problem in America.**

Survivors, family members, and professionals all meet with a number of barriers that impede best practices in brain injury treatment and create debilitating hardships.

This report addresses those barriers, and calls for unified efforts between civilian and military systems, agencies, and organizations. Today, more than 5.3 million American civilians face challenges resulting from a brain injury. Additionally, 19.5 % of US servicemembers who have returned from Afghanistan and Iraq report experiencing a traumatic brain injury during deployment.<sup>1</sup>

As recently as 2006, an Institute of Medicine report stated:

"...many people with TBI experience persistent, lifelong disabilities. For these individuals, and their caregivers, finding needed services is, far too often, an overwhelming logistical, financial, and psychological challenge. Individuals with TBI-related disabilities, their family members, and caregivers report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation, and respite for caregivers. Yet efforts to address these issues are stymied by inadequate data systems, insufficient resources, and lack of coordination. TBI services are rarely coordinated across programs except in some service sites. Furthermore, in most states, there is no single entry point into TBI systems of care."

Brain injury is also a leading cause of death and disability among Americans. Data indicates that approximately 1.6 million Americans sustain a brain injury each year, and 125,000 are permanently disabled.<sup>2,3</sup> Economically, the total impact of direct and indirect medical and other costs in 1995 dollars is reported to exceed \$56 billion.<sup>4</sup> Despite the prominence of affects of brain injury in the United States, it remains one of the least understood and recognized healthcare issues in our nation.

Addressing the Challenge of Brain Injury in America

## History

On November 2, 2007, more than one hundred of the nation's most respected authorities on brain injury convened in Washington D.C. to highlight accomplishments in brain injury treatment and to provide recommendations where barriers to care exist. Called the Brain Injury Consensus Conference, the two-day workgroup produced the groundwork for **Barriers and Recommendations: Addressing the Challenge of Brain Injury in America**.

Participants included members from:

- Department of Defense (DOD),
- Department of Veterans Affairs (VA)
- Defense and Veterans Brain Injury Center (DVBIC)
- Brain Injury Association of America (BIAA)
- North American Brain Injury Society (NABIS)
- National Association of State Head Injury Administrators (NASHIA)
- American Neuropsychiatric Association (ANPA)
- Over 30 other civilian public and private organizations

*This report represents the results of an authoritative, cross-systems assessment on the state of brain injury in America. It addresses the treatment of all survivors across the continuum of care, from the point of injury through lifelong needs. It also includes the input of a number of other brain injury professionals who were unable to attend the conference.*

**This report is a free, publicly available document** intended for multiple applications. It can be used as an advocacy tool, an informational resource, and a call to action. It was created to draw attention to the challenges that face Americans with brain injury, for the ultimate purpose of creating better identification of brain injury, access to care and overall bettering of their lives.

The civilian sector, the military, and the VA have made considerable strides in dealing with brain injury, and their focus and energies are to be applauded. However, brain injury in America remains a larger problem than any one entity can manage alone; it is only through a renewed spirit of collaboration that the following barriers can be managed effectively.

For more information on this report, visit: [www.nabis.org](http://www.nabis.org)

# Barriers & Recommendations

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## BARRIER ONE

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**Screening protocols for brain injury are not consistent across military, civilian, and public systems, and each system poses the risk for various gaps in the identification and assessment of brain injury. Currently, no initiatives have been put forward to remedy this disparity in injury screening.**

### *Recommendation*

The screening of brain injury to date is based on a detailed account of the injury event and the resultant alteration in consciousness. To accurately assess brain injury, this screening should offer a standardized, thorough, historical account of the injury event. This is particularly important because the individual involved may have altered perception, and lack insight into the injury sustained. A neurocognitive assessment such as the Standardized Assessment of Concussion is helpful in determining the extent of injury at the point of injury, but limited thereafter.

We recommend the further development of screening tools to be used to screen for TBI in diverse populations. Individuals who screen positive should then undergo further diagnostic testing including: neuroimaging studies, neuropsychological evaluation and neurophysiologic studies.

Furthermore, for populations who are occupationally at increased risk, having a regular baseline cognitive test(s) is of benefit for comparison if risk of injury is present or sustained. Finally, we recommend an evaluation for assistive technologies and compensatory aids and strategies.

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## BARRIER TWO

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**The current classification of brain injury as Mild, Moderate, and Severe are inadequate to describe various and complex sequelae resulting from a brain injury.**

### *Recommendation*

There is much confusion as to the extent of the actual injury severity. Various cognitive impairments can improve or diminish over a period of time. Although gradual improvements can follow the injury event, impairments can manifest even after other symptoms of brain injury have resolved. Confusion is introduced by the fact that years later, debilitating life-long residual effects may exist, yet the results of that injury may be mistakenly diagnosed based on initial trauma.

Addressing the Challenge of Brain Injury in America

Repetitive concussions are dangerous and result in cumulative brain injury. The classification of traumatic brain injury should sufficiently demonstrate residual functionality at various periods of time beyond the initial injury, and incorporate the understanding of brain injury as a disease process.<sup>5</sup>

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## BARRIER THREE

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**Persons accessing mental health services, special education services or imprisoned may have undiagnosed brain injury and the identification/screening for such would help identify effective treatment or placement alternatives. "Unidentified TBI is a major unrecognized cause of social failure: in educational, vocational and economic arenas. Complex barriers often prevent people with mild TBI from: (a) self-identifying as having a brain injury that is seen as the cause of the disabling symptoms they experience, (b) gaining access to help and (c) addressing long-term, TBI-related problems that affect their quality of life." (Gordon & Brown, 2008).**

### *Recommendation*

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

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## BARRIER FOUR

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**While a variety of best practices and evidence-based guidelines exist for the treatment of brain injury, there remain no comprehensive national guidelines for best practices in brain injury treatment.**

### *Recommendation*

Currently, the guidelines for best practices in brain injury treatment vary widely. It is recommended that a national guideline for best practices in brain injury treatment be created in order to ensure consistent, quality treatment across all systems.<sup>6</sup> We acknowledge the excellent work toward this goal achieved by the Brain Trauma Foundation (BTF), in which an independent analysis of their guidelines on TBI outcomes and cost savings by the Centers for Disease Control and Prevention (CDC) found that that "if the BTF guidelines were used more routinely, there would be a 50% decrease in deaths, improved quality of life, and a savings of \$288 million a year in medical and rehabilitation costs."<sup>7</sup> We also call for the identification, development and refinement of additional best practices in brain injury disease management.

# Barriers & Recommendations

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## BARRIER FIVE

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**Persons with brain injury often have difficulty accessing the necessary type of services needed due to finances, geography or a failure to provide best practices.**

### *Recommendation*

We recommend the development of system-wide access to treatment and support protocols to ensure the right treatment at the right time. This includes entitlement to post-acute active rehabilitation incorporating best practices including cognitive rehabilitation, independent living skills training, vocational rehabilitation and leisure therapy. This also includes access to graduated levels of support in the community, in-home, or 24-hr. supported living, allowing for efficient episodes of treatment across the lifespan in order to ensure retention of skills and enhanced quality of life. Until comprehensive guidelines in brain injury disease management are available, we recommend adherence to the Brain Injury Medical Treatment Guidelines of Colorado.<sup>8</sup>

Treatment and supports are needed to address the complexity of individuals with brain injury including substance issues, Post Traumatic Stress Disorder, psychiatric and significant behavioral issues.

Development of geographically disperse rehabilitation and support options are necessary to address the needs of persons in rural settings. Collaboration with civilian and public partners may be needed for servicemen and women to access timely, appropriate levels of care closer to home.

Benefits packages provided by TRICARE, the VA and Medicaid must be reviewed in order to ensure optimum uniform coverage including providing same payment for same services, access to levels of care including post-acute and cognitive rehabilitation and extension of active duty benefits to reimburse necessary after-hospital treatment.

With respect to cognitive rehabilitation, the effectiveness of cognitive rehabilitation has unfortunately proven difficult to study due to several factors, including the heterogeneity of subjects, interventions and outcomes studied, as well as the difficulty involved in attempting to control for spontaneous recovery.

Clinical consensus, along with widespread professional opinion, must be taken into account, in addition to the research evidence attesting to the efficacy of cognitive rehabilitation.<sup>9</sup>

Civilian and military coverage plans must be sufficient to rehabilitate patients and return them to productivity. Moreover, cognitive therapy is an essential component of the rehabilitation process for persons with brain injury and should also be a covered therapy.

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## BARRIER SIX

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**Advances in brain injury care are implemented too slowly between systems. Currently, any current cross-system coordination efforts do not include strategies for effectively supporting person with brain injury over the lifespan. Additionally, case managers/care coordinators are commonly unfamiliar with protocols and practices outside their respective system, causing unnecessary complexity for the survivor who moves between systems. No formal body exists which coordinates an effective communication between systems.**

### *Recommendation*

As the military continues to make advances in the area of brain injury treatment, a vehicle for sharing of information must occur between systems. The advances learned from the resultant military experience from the effects of blast, particularly primary blast, from helmet sensors to balance tables, from screening with standardized assessment tools at point of injury to post deployment health assessment (PDHA), must be shared with other systems in order to allow for more effective brain injury trauma care for all Americans.

Veteran's Administration and Department of Defense hospital data are not included in the states' trauma system data. We recommend coordination and communication between Department of Defense, Veteran's Administration, and civilian agencies, allowing the civilian system to accurately anticipate the impact of wounded veterans as they return to their communities. Seamless coordination should not only occur between military systems, but between military, public, and private systems as well.

Military and civilian case managers must have opportunities to learn each other's systems of care, funding mechanisms, treatment programs, community resources, and communicate with one another. We encourage the DoD, the VA, and the public/private sector to jointly engage in educational and training seminars that allows each entity to benefit from the other's successes and to learn from their challenges.

*Continued on next page*

# Barriers & Recommendations

We also recommend the formation of a Federal Brain Injury Council, established in statute for the purpose of communication and system coordination. Members may include representatives from Federal agencies, advocacy organizations, professional associations/societies, and others.

The Council may be an effective mechanism to foster successful collaborations such as those currently in place between the Centers for Disease Control and the Social Security Administration as well as formal Memoranda of Understanding as are in place between DoD and VHA for the Office of Seamless Transition and for spinal cord injury care and neuro-optometric rehabilitation. The proposed Federal Brain Injury Council will use a variety of mechanisms to facilitate and foster ongoing communication, collaboration, and system coordination among its members. Since the Commission on Accreditation of Rehabilitation Facilities (CARF) is actively engaged with many of the members of the proposed Council, the standards that address the use of feedback from stakeholders for program development, strategic planning, resource planning and performance improvement can be used as innovative practice tools for members to foster these relationships.

In the interim, it is suggested that civilian sector advisors be added to the Senior Oversight Committee for DoD/VA Wounded, Ill and Injured. Further, it is recommended that VHA conduct a formal gap analysis, publicize its needs, as appropriate, and outreach to private sector to obtain assistance in meeting those needs.

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## BARRIER SEVEN

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

### *Recommendation*

In 2007, the Federal AIDS budget was \$22.8 billion dollars. Parkinson's disease received \$250 million dollars. The HRSA Traumatic Brain Injury Program was allotted \$8.5 million dollars in 2007, and in 2008 President Bush proposed eliminating the funding. We recommend that brain injury treatment receive funding on parity with other disease processes

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## BARRIER EIGHT

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**Following brain injury, family members and case managers (care coordinators) are not effectively incorporated into treatment, particularly in the acute phase of care. The family often becomes the primary support unit. Families are typically ill-equipped to respond to the complexity of issues a person with brain injury may experience.**

Addressing the Challenge of Brain Injury in America

### *Recommendation*

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

Case Managers are helpful in tracking and supporting those requiring follow up care. We recommend that all brain injury care providers provide educational and case management services from the moment of injury. When home placement is advised, family members should be trained in maintaining quality care at home.

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## BARRIER NINE

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**There are few or no support systems that consistently monitor care and patient satisfaction throughout the continuum of care.**

### *Recommendation*

Programs should be a collaborative effort; as much as possible, the program should be directed by the person with the brain injury, but there must also be an adequate support system that monitors, advocates, and intervenes on that person's behalf as necessary.

Moreover, mental health supports are also needed, with personnel trained in and knowledgeable about the effects of brain injuries. This level of support should include a continuum of care from a brief counseling session, to an ongoing, in-depth counseling program, to an intensive crisis intervention by a mobile crisis response team. Police departments, the criminal justice system, and emergency health care providers must be trained to prevent the inappropriate placement of an individual with brain injury in psychiatric hospitals or jail.

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## BARRIER TEN

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**Across the lifespan, brain injury programs do not address all aspects of treatment. Instead, only specific symptoms receive care.**

### *Recommendation*

Brain injury programs must address every area of the person's life, including physical, financial, emotional, intellectual, vocational, recreational, and spiritual. The effect of holistic treatment is synergistic, with small efforts in many areas combining to have a large impact on overall success. We recommend adherence to the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, as supported by the World Health Organization.<sup>10</sup> These rules govern areas that span Medical Care, Rehabilitation, Support Services, Accessibility, Education, Employment, Income Maintenance and Social Security, Family Life and Personal Integrity, Culture, Recreation and Sport, and Religion.<sup>11</sup>

# Barriers & Recommendations

## BARRIER ELEVEN

**Respite care services are difficult for most family members and caregivers to access, leading to caregiver burnout, compassion fatigue, and overall lack of quality of care.**

### *Recommendation*

Respite care should be a regular and accessible service for family members and caregivers.

For mentors and life coaches, a delicate balance is required to provide necessary daily structure to ensure health and safety, while simultaneously fostering independence.

## BARRIER TWELVE

**Over the lifespan, offers of independent living and life-skills training are arbitrary, and sometimes unsupported.**

### *Recommendation*

Independent living and life skills training must be offered on a regular basis. As the person with a brain injury works to re-enter the community and rebuild his or her life, he or she will need to be trained in independent living and life skills.<sup>12</sup>

## BARRIER THIRTEEN

**Treatment plans for brain injury do not include strategies for dealing with aging-related issues, nor do they anticipate that brain injury is disease-causative and disease-accelerative.**

### *Recommendation*

Aging issues must be addressed by case managers/care coordinators in the treatment plan. As the person's condition changes, he or she may need additional care including physical, occupational, speech, or recreational therapies, cognitive remediation, psychiatric interventions, or pre-vocational services. We recommend new treatment plans that allow for brain injury disease management.

## BARRIER FOURTEEN

**Long-term, supervised housing and other residential programs for persons with brain injury are regularly denied services under most funding systems.**

### *Recommendation*

Access to affordable housing with associated services, physical access, and support must be financially attainable. Individuals may need long-term, supervised residential programs with related support care sensitive to their specific needs. Others may require a day-treatment program, where they can participate in supervised, meaningful activities. In conjunction with such programs, we recommend the provision of life care planning services such as financial resource management, legal arrangements for durable power of attorney and healthcare, wills, family and/or personal estate planning, health insurance purchase and availability, life insurance purchase and availability, and family member life insurance as a financial planning tool.

Moreover, we recommend a coordinated approach to state and federal assistance programs that are available for housing, food stamps, maternal assistance programs, child nutrition programs, Meals on Wheels, independent living programs, caregiver resources programs, public transportation assistance options, Social Security, aid to dependent families assistance, public utility relief programs, Medicare and Medicaid eligibility and pharmaceutical assistance programs.

## BARRIER FIFTEEN

**Transportation issues plague survivors of brain injury the duration of their lives.**

### *Recommendation*

While some individuals will be completely independent in their transportation needs, others will require assistance with accessing public transportation. Still others will be unable to access or deal with public transportation. Life care planners, case managers, and long-term care providers are encouraged to advocate within the community for supportive transportation services.

## BARRIER SIXTEEN

**Across all systems, case management services are not consistent. In military and VA settings, case management and care coordination services may be complicated, confusing survivors and family members; in the private sector they are either difficult to access or unavailable.**

*Continued on next page*

# Barriers & Recommendations

## *(Barrier 16 Cont'd) Recommendation*

We encourage all case managers, care coordinators, and case management organizations who are experienced, trained and certified in disease management of brain injury to participate in collaborative initiatives to form guidelines that ensure care that offers a particular focus on the many personal needs of survivors of brain injury.

Where services are absent, we call on state healthcare officials to conduct an assessment of needs report detailing the challenges that face their respective population of survivors. We encourage the National Association of State Head Injury Administrators to facilitate dialogue and actions that promote the use of case management services where needed, and programs which help individuals access the service.

## ===== BARRIER SEVENTEEN =====

**Despite the complexity of brain injury, there is no national certification or training for brain injury case management. Few organizations outside direct care providers encourage personnel to receive certification as a brain injury specialist (CBIS).**

### *Recommendation*

We encourage the Case Management Society of America, the Commission for Case Management Certification, and the American Academy of Certified Brain Injury Specialists to collaborate and create an effective credential that educates and empowers case managers involved in the treatment of brain injury.

Furthermore, we recommend that institutions such as mental health centers, community colleges, veterans centers, the criminal justice system, and social service systems all designate individuals who can serve in the capacity of a certified brain injury specialist.

## ===== BARRIER EIGHTEEN =====

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

### *Recommendation*

In the case of individuals with TBI under the age of 21, case managers should provide input to school districts

to develop Individualized Education Plans (IEP) specific to brain injury issues and educational goals.<sup>13</sup>

The 1975 Federal Public Law 94-142 (Disabilities Education Act- IDEA) maintains that states and school districts must develop and implement annual Individual Educational Plans (IEP) on all individuals with disabilities. Community case managers are an asset to the patient's school district in this process.

## ===== BARRIER NINETEEN =====

**Survivors of brain injury do not typically receive special accommodations for their cognitive deficits in state and federal courts.**

### *Recommendation*

Self-advocacy and self-representation in court are basic needs that can be thwarted by cognitive deficits. Most courts currently accommodate language and physical disabilities with the necessary supports. We recommend additional cognitive deficit accommodation by the court system, particularly in matters involving the social agency interactions and medical decision-making transactions.

## ===== BARRIER TWENTY =====

**Throughout all systems, there is a well-documented personnel shortage of healthcare professionals that provide valuable services to survivors of brain injury.<sup>14</sup>**

### *Recommendation*

We recommend that university health science programs incorporate brain injury treatment into their curricula and actively recruit healthcare professionals for the purpose of specialization in brain injury. We also suggest that community-based organizations, professional societies, and schools of higher education provide continuing education opportunities on the topic of brain injury.

# Barriers & Recommendations

## CONCLUSION

The Department of Defense, the Department of Veterans Affairs, and numerous organizations in the public and private sector have made tremendous strides in the treatment and care of brain injury, and they have demonstrated outstanding abilities to meet their responsibilities.

By addressing the barriers to brain injury care, we hope to encourage these different systems to renew their efforts to form collaborations, and to address gaps in service where they exist.

With respect to TBI survivors from Operation Iraqi Freedom and Operation Enduring Freedom, members of the media have been an extremely positive influence in raising public awareness and understanding of TBI and in garnering altruistic feelings for survivors, especially service members, and their and families.

The efforts of military, veteran and civilian advocacy organizations are currently synergized into a political will for TBI care that is unmatched in U.S. history. It is incumbent upon the leaders in civilian, military and veterans' systems to work cooperatively to build on strengths and minimize weaknesses to improve the quality of research, treatment and life-long living for all individuals with brain injury.

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## Acquired Brain Injury

Functional and cognitive deficits resulting from injuries to the main and associated structures that:

- 1) Are results from injury post partum
- 2) Are not a result of a congenital disorder
- 3) Are not a result of a deteriorating disorder related to age (i.e. dementia, picks, etc) a

And fall within in the broad categories:

- a. Hypoxic or Anoxic events
- b. Chemical induced except alcohol related
- c. Medical accidents (i.e. stroke, aneurysm)
- d. Viral, bacterial or parasitic attack
- e. Radiation poisoning
- f. Medication effects (prescribed)
- g. Idiopathic causes

The deficits must be long-standing, significantly below baseline, impact productivity in the three areas, school, work, relationship, and affect the life trajectory of the individual

## Supporting information for HB 328

### State of Alaska, Department of Health and Social Services Alaska Waiver and Service Options for Alaskans with Congenital and Degenerative Brain Injury

According to state law (AS. 47.80.900 (7)), the **term developmental disability (DD) means** a severe, chronic disability that: Is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely;

- results in substantial functional limitations in **three or more** of the following areas of major life activity:
  - self care
  - receptive and expressive language;
  - learning;
  - mobility;
  - self direction; capacity for independent living;
  - economic self-sufficiency;
- and reflects the person's need for a combination and sequence of special, interdisciplinary, or generic assistance, supports or other services that are of lifelong or extended duration and are individually planned and coordinated.

Examples of types of developmental disabilities are mental retardation, cerebral palsy, autism, and seizure disorder. **Mental illness and Fetal Alcohol Syndrome may also be developmental disabilities. However, the disability must result in substantial functional limitations and meet the other criteria in the definition in order to qualify as a DD.**

### **FASD: FETAL ALCHOL SPECTRUM DISORDERS**

**88 possible slots: 10 currently on waiver, 8 in the works, 70 open slots**

Definition: **Congenital** brain injury- the youth's mother consumed alcohol during pregnancy.

Eligibility: Youth must be:

- Under age 21 years
- Eligible for Medicaid
- Have an evaluation by a psychiatrist within 60 days of admission to the program, that identifies a need for the level and intensity of services provided in a Residential Psychiatric Treatment Center (RPTC)
- Have a diagnosis of Fetal Alcohol Spectrum Disorder. (If a youth is suspected of having an FASD, but has not yet received a diagnosis, the youth may receive an FASD diagnosis as part of the screening process)
- Want to receive services in community based services in Alaska instead of in an RPTC.

#### **Waiver services include:**

1. Mentoring Services
2. Daily and hourly respite
3. Residential habilitation
4. Day habilitation
5. Supported employment
6. Training and Consultative services

The Plan of care will be tailored to the specific needs of each individual program participant

## ADRD: ALZHEIMER'S DISEASE AND RELATED DISORDERS

### Definition of Alzheimer's disease: Degenerative

Because Alzheimer's disease and Related Disorders (ADRD) is so difficult to diagnose, the U.S. Department of Health and Social Services Advisory Panel on Alzheimer's disease recommends that ADRD be defined by functional impairment and dependency rather than diagnosis or the causes of the disease. The current working definition of ADRD used by Alaska Commission on Aging grantees, reviewed and refined at a grantee meeting in October 1996, reflects this recommendation.

### For the purpose of this report an ADRD includes:

Alzheimer's, Dementia (any type), Parkinson's, Lewy Body, Creutzfeld-Jacob, Huntington, Pick's, Wernicke-Karsakof, Cerebral degeneration.

AS of 2/24/2010 from Joann Gibbens,

Senior and Disabilities Services

Total number of OA, APD or PCA individuals with Alzheimer's or dementia in their most recent diagnosis

|                                              | with ADRD | TOTAL | non ADRD |
|----------------------------------------------|-----------|-------|----------|
| Older Adults (OA) only                       | 416       | 775   | 359      |
| Adults with Physical Disabilities (APD) only | 61        | 413   | 352      |
| Personal Care Attendant (PCA) only           | 172       | 2271  | 2099     |
| PCA with (OA or APD)                         | 263       | 1697  | 1434     |
| Unduplicated count (PCA, OA or APD)          | 912       | 5156  | 4244     |

|                | under 60 | 60-64 | 65-69 | 70-79 | 80-89 | 90-99 | 100+ | TOTAL |
|----------------|----------|-------|-------|-------|-------|-------|------|-------|
| APD, OA or PCA | 69       | 40    | 52    | 237   | 373   | 136   | 5    | 912   |

### Older Alaskans Waiver (OA)

Eligibility: Over 65 years of age and nursing home level of care.

#### OA Waiver Services:

1. Adult day services
2. Care Coordination
3. Respite
4. Chore
5. Environmental modifications
6. Meals
7. Residential Supported living
8. Specialized medical equipment and supplies
9. Specialized private nursing duties
10. Transportation

### Alaskans With Physical Disabilities (APD)

Eligibility: Ages 21 -64, disabled meeting nursing level of care

#### APD Waiver Services:

1. Adult Day Services
2. Care Coordination
3. Day Habilitation
4. Residential Habilitation
5. Respite
6. Supported Employment
7. Chore
8. Environmental modifications
9. Intensive Active Treatment
10. Meals
11. Residential Supported Living
12. Specialize Medical Equipment
13. Specialized Private Nursing Duty
14. Transportation

# Alaska is Combating Traumatic Brain Injury

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Pat Hefley  
*Deputy Commissioner*  
Department of Health  
and Social Services

## Past legislative hearings

2007- What is traumatic brain injury?  
What does treatment look like?

Guest presenters: Dr. Tina Trudel (national expert) and partner boards

2008- Impact of TBI on the state.

Military issues related to TBI

Guest presenters: Capt. Richard Barker, Elmendorf; Dr. Russell Cherry, Providence; Stephanie Tanner, military wife of TBI survivor

2009- Importance of Medicaid Waiver to develop coordinated, comprehensive brain injury services in-state

Guest Presenters: Dr. Christie Artuso, Providence Neuroscience Director

## Today's presentation- State System Development, ready to operationalize

- Jill Hodges, Past 20 years of AK efforts
- Jeff Jessee , Trust Role
- Pat Hefley , DHSS Role
- Public testimony:
  - Martha Moore, ABIN Chair
  - Providers, partnerships essential
  - Consumer, treatment works, family support
- Jill Hodges-Questions and Solutions
  - State and Legislature

# TBI Systems Development in Alaska 1990-2000

## Phase 1: 1990-1995

### Advocacy

- Brain injury survivors mobilize
- Early 1990's
  - Testimony to GDCSE
  - Registration of MHTTA
- Brain Injury Association of Alaska organizes

## Phase 2: 1995-2000

### Advocacy Continues

### State of Alaska

- State of Alaska-Public Health recognizes TBI
- Public Health awarded CDC grant
  - TBI Registry
- MHDD awarded Federal Grant-systems

# TBI Systems Development in AK 2000-2007

## **Phase 3: 2000-2003**

### Advocacy

### State of Alaska

### Federal TBI HRSA Grant

- Needs Assessment
- 1<sup>st</sup> State Action Plan
- TBI Program Coordinator (FTE)
- Advisory Board

### AMHTA-beneficiary group

### Alaska Brain Injury Network

- TBI Advisory Board (ABIN) organizes and becomes 501 c3

## **Phase 4: 2003-2005**

### Advocacy/TBI Advisory Board

### State of Alaska

- Behavioral Health (lead agency)

### Data/Surveillance

- DBH mandates screening data collection
- Consumer Satisfaction Survey
- AK Trauma Registry

## **Phase 5: 2005-2007**

### State of Alaska: TBI Dir. turnover

### Data- AKAIMS(32% in BH screen TBI)

### Workforce: 1<sup>st</sup> AK Brain Injury Conf

# Momentum builds- 2007-2009

## Phase 6: 2007-2009

### ABIN

- "Service" recommendation

Info and Referral

Case Management

### AMHTA-Funds ABIN recomm.

### State of Alaska

- Lead agency transfers to SDS
- TBI Case Management Program developed

### Workforce:

Intro to TBI Course

Advance Brain Injury

Workshop

Vocational Rehabilitation

Counselors

### Legislation

- SB 118 introduced-medical assistance for TBI

### Medicaid Funding: Waivers

- Preliminary research on Medicaid Waivers
- Targeted Case Management

### Treatment

- After Hospital/Post-Acute

- Site Visits

- AK Providers Coalition

- Military/Tribal partnership sought

## Key Points

- System Planning—  
created framework  
and foundation for  
action
- Next step:  
operationalize
- General Funds or  
GF/MH essential
- Phases 1-4 (1990-2005)
  - advocacy programs
  - increasing awareness
- Phases 5-6 (2005-2009):
  - Direct 'services':
    - info and referral;
    - case management
  - Workforce development
- Phase 7 – 10 (2010-2020)
  - Case Management
  - Treatment: Funding
  - Residential and Day Programs
  - Workforce

## 2010 Session SB 219 and HB 328

### SB 219 and HB 328

- Gives statutory authority to develop/improve program.
- Establishes standards for treatment and services.
- Defines brain injury.
- Develops cost/ longitudinal data
- Planning for Medicaid Waiver/Targeted Case Management

### Opportunities

- Positions the state to access federal funding for TBI services.
- The existence of brain injury waivers supports the growth of community-based rehabilitation programs.
- DoD/VA/Tribal/State coordinate planning and implementation of rehabilitation and community re-entry programs.
- Early treatment may reduce future medical and social costs.
- Potential cost savings in acute care, existing state programs; behavioral health, juvenile justice, corrections, homeless activities, and long-term care in institutional facilities.

# The Trust's Role- Jeff Jessee

- TBI as a beneficiary group (late 1990's)
- Trust role: planning, demonstration
- Maximize collaboration
- Alaska too small of a state to have separate TBI treatment systems of care (VA, DoD, Tribal, State)
- Treatment: General Fund commitment

Past 10 years, Trust has invested \$2.8 million in brain injury systems development

- Trust FY09 Funding specifically for brain injury program: \$628,000

## Core Services Development

- Information and Referral
- Case Management
- Technical Assistance for planning treatment

## Systems Development

- Public Awareness-anti stigma
- Workforce development
- Statewide planning- TBI Advisory Board

# Department of Health and Social Services Role - Pat Hefley

- Development, now operationalizing.
- 44 States use General Revenue and Medicaid Waivers for brain injury treatment/services.
- TBI folks are already in the system - need to move them into specialty programs in order to see results.
- Appropriately staged incremental GF/MH budget requests.

## Upcoming 2010 Activities

- Federal Grant- \$250.0/year 4 years
  - lead agency: Senior and Disabilities Services
- State of Alaska T/ABI program
  - Case Management
  - Research federal funding opportunities: Medicaid Waiver/Targeted Case Management
- Data/Prevention: regional study, Alaska Native and Non-Native

## Public testimony

Martha Moore: ABIN Chair

Recommendation Philosophy  
 Respects State role (data  
 collection) and ABIN chair.

Alaska providers: readiness to  
 partner- TBI post-acute  
 programs

Dr. Lester, St. Elias  
 Margaret Carlom, RN  
 Nurse, ANMC

- Shannon- Juneau resident,  
 experienced TBI

TBI treatment work

Family support

Many of Alaska's challenging questions  
been asked and answered by other States

- Alaska can learn from 30 years of state system experience; and
- treatment research by the Federal Government, State experiences, military advances

# Questions and Solutions

Is brain injury  
impacting  
State  
government?

1980 findings...

- Uninsured or underinsured
- Unemployment
- Trauma/EMS
- Long-term care and support needs
- Family Support

1990 findings...

- Educational System
- Vocational Rehabilitation

2000 findings...

- Criminal Justice
- Behavioral Health

# Question and Solutions

How will State  
Gov't know  
how to develop  
TBI systems?

## TBI Act of 1996

- Federal Statute
  - Defined TBI in Federal statute
  - authorized funding to HHS
  - Established TBI program in VA
  - Created State grant program
- State experience has broadened program definition to ABI- same service needs.
- National Association of State Head Injury Administrators (1990)
- TBI Technical Assistance Center-specifically for state administrators (since 1996)

## Question and Solutions

Is recovery  
possible after a  
TBI?

Does treatment  
work?

- Feds fund TBI model systems since 1987, over 20 years of longitudinal data- yes with specialized support, recovery/independence is possible
- Research at acute/medical level led to need for community reentry programs
- Military funding is supporting research of community reentry programs and Mild TBI assessment and treatment

## Question and Solutions

How will States  
pay for brain  
injury  
treatment?

- 1990's, Centers for Medicare/Medicaid Services (CMS) developed TBI HCBS Waiver prototype
- IDEA 1990 added TBI as disability to report
- State General Funds
- TBI Trust Funds

## Question and Answer

How will states  
develop treatment  
and prepare a  
specialty  
workforce?

- Many providers have 30 years of experience.
  - Utilize existing models: medical, community, clubhouse, and long-term living.
- TBI specific workforce will build as TBI programs are operationalized.
  - Professional/para-professional specialists on the job training, must take special educational training.

## Question and Answer

How will rural residents have access to these treatment and services?

- Military and a few states utilize telemedicine for treatment.
- Opportunity for Alaska to become the national leader in providing care to rural areas?

## Question and Answer

What type of legislation is/has been successful?

- Resolutions- awareness  
Last five years
- Prevention  
(AK primary seatbelt law  
safety/ booster sea.)
- T/ABI Program into Statute  
SB 219 and HB Compas
- Interagency Taskforce
- Prevention-concussion management
- Military-screening

## Alaska has an opportunity

- Alaska can operationalize at a faster rate.
- Alaska can become the leader in rural TBI treatment and supports

# Alaskans Thank the Legislature

For recognizing

the needs of

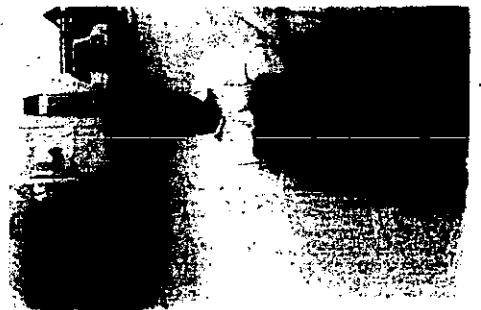
Alaskans with

physical disabilities

and the need to

improve the

quality of



# Mr. Trautman's Brain Injury Model Systems of Care

10/10/10  
10/10/10



Control

The ... el system.

Derives a system

Performs several types

• Services inter-station

• ...

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# FISCAL NOTE

**STATE OF ALASKA**  
**2010 LEGISLATIVE SESSION**

Fiscal Note Number: \_\_\_\_\_  
Bill Version: HB328  
( ) Publish Date: \_\_\_\_\_

Identifier (file name): HB328-DHSS-SDMS-03-15-10 Dept. Affected: Health & Social Services  
Title: Traumatic Brain Injury: Program/ Medicaid RDU: Senior and Disability Services  
Component: Senior and Disability Medicaid Services  
Sponsor: Johnson  
Requester: House HSS Component Number: 2662

**Expenditures/Revenue** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

|                              | Appropriation<br>Required | Information |                |                |                |                |                |         |
|------------------------------|---------------------------|-------------|----------------|----------------|----------------|----------------|----------------|---------|
|                              |                           | FY 2011     | FY 2011        | FY 2012        | FY 2013        | FY 2014        | FY 2015        | FY 2016 |
| <b>OPERATING EXPENDITURE</b> |                           |             |                |                |                |                |                |         |
| Personal Services            |                           |             |                |                |                |                |                |         |
| Travel                       |                           |             |                |                |                |                |                |         |
| Contractual                  |                           |             |                |                |                |                |                |         |
| Supplies                     |                           |             |                |                |                |                |                |         |
| Equipment                    |                           |             |                |                |                |                |                |         |
| Land & Structures            |                           |             |                |                |                |                |                |         |
| Grants & Claims              | 1,272.0                   |             | 1,221.0        | 1,230.0        | 1,239.0        | 1,248.0        | 1,257.0        |         |
| Miscellaneous                |                           |             |                |                |                |                |                |         |
| <b>TOTAL OPERATING</b>       | <b>1,272.0</b>            | <b>0.0</b>  | <b>1,221.0</b> | <b>1,230.0</b> | <b>1,239.0</b> | <b>1,248.0</b> | <b>1,257.0</b> |         |

|                            |  |  |  |  |  |  |  |
|----------------------------|--|--|--|--|--|--|--|
| <b>CAPITAL EXPENDITURE</b> |  |  |  |  |  |  |  |
|----------------------------|--|--|--|--|--|--|--|

|                           |  |  |  |  |  |  |  |
|---------------------------|--|--|--|--|--|--|--|
| <b>CHANGE IN REVENUES</b> |  |  |  |  |  |  |  |
|---------------------------|--|--|--|--|--|--|--|

**FUND SOURCE** (Thousands of Dollars)

|                           |                |            |                |                |                |                |                |
|---------------------------|----------------|------------|----------------|----------------|----------------|----------------|----------------|
| 1002 Federal Receipts     | 777.4          |            | 610.5          | 615.0          | 619.5          | 624.0          | 628.5          |
| 1003 GF Match             | 494.6          |            | 610.5          | 615.0          | 619.5          | 624.0          | 628.5          |
| 1004 GF                   |                |            |                |                |                |                |                |
| 1005 GF/Program Receipt   |                |            |                |                |                |                |                |
| 1037 GF/Mental Health     |                |            |                |                |                |                |                |
| Other Interagency Receipt |                |            |                |                |                |                |                |
| <b>TOTAL</b>              | <b>1,272.0</b> | <b>0.0</b> | <b>1,221.0</b> | <b>1,230.0</b> | <b>1,239.0</b> | <b>1,248.0</b> | <b>1,257.0</b> |

Estimate of any current year (FY2010) change: \_\_\_\_\_

**POSITIONS**

|           |  |  |  |  |  |  |  |
|-----------|--|--|--|--|--|--|--|
| Full-time |  |  |  |  |  |  |  |
| Part-time |  |  |  |  |  |  |  |
| Temporary |  |  |  |  |  |  |  |

**ANALYSIS:** (Attach a separate page if nece:

HB 328 requires the Department of Health & Social Services (DHSS) to establish a traumatic or acquired brain injury (TABI) program and to provide Medicaid coverage for TBI services.

Section 2 amends the Medicaid statutes to include case management services for individuals with TABI to the list of optional Medicaid services. The provision adding TABI case management services to Alaska's optional Medicaid services has the potential to increase Medicaid utilization. This would necessitate an amendment to the state Medicaid Plan.

(continued on page 2)

Prepared by: William J. Streur, Deputy Commissioner  
Division: Health Care Services

Phone 269-7827  
Date/Time 3/15/10 4:25 PM

Approved by: Alison Elgee, Assistant Commissioner  
DHSS Finance & Management Services

Date 3/15/2010

**ANALYSIS CONTINUATION**

Assumptions:

The Alaska Brain Injury network estimates approximately 1,300 new hospital discharges per year due to TABI. The department estimates approximately 20% of new TABI discharges would be on Medicaid, which is the same prevalence of Medicaid enrollees in the general population. Also the number of new TABI cases is expected to grow with the population at 1% per year.

$1,300 * 0.20 = 260$  new cases in FY11

$260 * 1.01 = 262.6$ , rounded to 263 new cases in FY12, and so on

Case management services, based on an examination of similar services covered by Medicaid, is estimated to cost \$250/month for new TABI cases.

New Case Cost for FY12:  $263 * (12 * 250) = 789,000$

In addition, there were approximately 9,200 hospital discharges due to TABI from 2001-2007 and it is estimated that 30% of these discharged individuals are still living with TABI related effects. It is estimated that 30% of people living with disabilities or effects from past TABI (existing cases) are currently on Medicaid. This estimate is somewhat higher than the general population due to a higher prevalence of disability, unemployment and lower income in this group.

$9,200$  past discharges \*  $0.30$  living with effects from TABI =  $2,760$

$2,760 * 0.30$  on Medicaid =  $828$  existing TABI cases

It is expected that approximately half of those cases would continue services. For existing cases - Medicaid currently has about 100 persons on waiver due to TABI (see below).

$828 - 100$  on waiver =  $728$

This would mean approximately 360 existing cases using case management services in FY11. Although it is anticipated that in the first year there would be a higher demand for services that in following years meaning an additional 50 cases in FY11. Future years the demand would level at about 360 continuing cases each year.

It is estimated that these existing cases would use services, but at a lower level than new cases, so \$100/month for 12 months.

Continuing Case Cost for FY12:  $360 * (12 * 100) = 432,000$

Total FY12 Case Management Costs Estimate:  $432,000 + 789,000 = 1,221,000$

For 2011, Title XIX services are expected be reimbursed at 61.12%, in further years, the federal reimbursement rate is estimated at 50%.

The department will also be required to either develop a new TBI Medicaid waiver or modify an existing waiver to accommodate the needs of TABI survivors. Federal regulations require that in order for individuals to be eligible for home- and community-based waivers, they must meet the state's criteria as needing an institutional level of care. Currently, those individuals with TABI who meet this level of care are already being served under the current waiver program. As of February 1, 2010 that number is 102 individuals. An increase in the cost of waiver service is not expected with this bill.

# FISCAL NOTE

**STATE OF ALASKA**  
**2010 LEGISLATIVE SESSION**

Fiscal Note Number: \_\_\_\_\_  
 Bill Version: HB328  
 () Publish Date: \_\_\_\_\_

Identifier (file name): HB328-DHSS-SDSA-03-16-10 Dept. Affected: Health & Social Services  
 Title Traumatic Brain Injury: Program/ Medicaid RDU Senior and Disabilities Services  
 Component Administration  
 Sponsor Johnson  
 Requester House HSS Component Number 2663

**Expenditures/Revenues** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

|                               | Appropriation<br>Required | Information |            |            |            |            |            |            |
|-------------------------------|---------------------------|-------------|------------|------------|------------|------------|------------|------------|
|                               |                           | FY 2011     | FY 2011    | FY 2012    | FY 2013    | FY 2014    | FY 2015    | FY 2016    |
| <b>OPERATING EXPENDITURES</b> |                           |             |            |            |            |            |            |            |
| Personal Services             |                           |             |            |            |            |            |            |            |
| Travel                        |                           |             |            |            |            |            |            |            |
| Contractual                   |                           |             |            |            |            |            |            |            |
| Supplies                      |                           |             |            |            |            |            |            |            |
| Equipment                     |                           |             |            |            |            |            |            |            |
| Land & Structures             |                           |             |            |            |            |            |            |            |
| Grants & Claims               |                           |             |            |            |            |            |            |            |
| Miscellaneous                 |                           |             |            |            |            |            |            |            |
| <b>TOTAL OPERATING</b>        |                           | <b>0.0</b>  | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> |

|                             |  |  |  |  |  |  |  |  |
|-----------------------------|--|--|--|--|--|--|--|--|
| <b>CAPITAL EXPENDITURES</b> |  |  |  |  |  |  |  |  |
|-----------------------------|--|--|--|--|--|--|--|--|

|                             |  |  |  |  |  |  |  |  |
|-----------------------------|--|--|--|--|--|--|--|--|
| <b>CHANGE IN REVENUES (</b> |  |  |  |  |  |  |  |  |
|-----------------------------|--|--|--|--|--|--|--|--|

**FUND SOURCE** (Thousands of Dollars)

|                            |  |            |            |            |            |            |            |            |
|----------------------------|--|------------|------------|------------|------------|------------|------------|------------|
| 1002 Federal Receipts      |  |            |            |            |            |            |            |            |
| 1003 GF Match              |  |            |            |            |            |            |            |            |
| 1004 GF                    |  |            |            |            |            |            |            |            |
| 1005 GF/Program Receipts   |  |            |            |            |            |            |            |            |
| 1037 GF/Mental Health      |  |            |            |            |            |            |            |            |
| Other Interagency Receipts |  |            |            |            |            |            |            |            |
| <b>TOTAL</b>               |  | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> | <b>0.0</b> |

Estimate of any current year (FY2010) cost: \_\_\_\_\_

**POSITIONS**

|           |  |  |  |  |  |  |  |  |
|-----------|--|--|--|--|--|--|--|--|
| Full-time |  |  |  |  |  |  |  |  |
| Part-time |  |  |  |  |  |  |  |  |
| Temporary |  |  |  |  |  |  |  |  |

**ANALYSIS:** (Attach a separate page if necessary)

This bill will establish a Traumatic or Acquired Brain Injury (TABI) Registry; establish a TABI case management program within the Division of Senior and Disabilities Services; and add case management services for people with TABI to the list of optional Medicaid services available in Alaska.

Two positions will be tasked with implementing the proposed legislation: a TABI Program Manager who will supervise data collection and analysis, coordinate services to people with TABI, evaluate standards and laws related to TABI, assess the availability of and evaluate acute and long-term care community services, investigate model community services, and coordinate funding of TABI care; and a Research Analyst to develop procedures for the collection of TABI information statewide, design and present statistical data, construct and modify research procedures and instruct others in their proper use. Current resources within the Division of Senior and Disabilities Services are sufficient to meet program needs.

Prepared by: Rebecca Hilgendorf, Director Phone 269-2083  
 Division Division of Senior and Disabilities Services Date/Time 3/16/10 2:10 PM  
 Approved by: Alison Elgee, Assistant Commissioner Date 3/16/2010  
DHSS Finance & Management Services

AMENDMENT

OFFERED IN THE HOUSE  
TO: HB 328

BY REPRESENTATIVE JOHNSON

- 1 Page 4, lines 7 - 8:
- 2 Delete "and laws pertaining to the prevention of traumatic or acquired brain injury
- 3 and"
- 4 Insert "pertaining"

Conceptional Amendment No. \_\_\_\_\_

26-LS1355\E.WK2

To House Bill 328

Proposed by: Representative Keller

Offered in the House

Amendment to Page 2, line 25 –page 3 line 6

- 1 Delete all material.
- 2 Insert “services furnished to assist individuals who reside in a community setting or who
- 3 are transitioning to a community setting to gain access to needed medical, social,
- 4 educational, and oher available services,”

New Text Underlined [DELETED TEXT BRACKETED]

# LEGAL SERVICES

DIVISION OF LEGAL AND RESEARCH SERVICES  
LEGISLATIVE AFFAIRS AGENCY  
STATE OF ALASKA

(907) 465-3867 or 465-2450  
FAX (907) 465-2029  
Mail Stop 3101

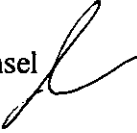
State Capitol  
Juneau, Alaska 99801-1182  
Deliveries to: 129 6th St., Rm. 329

## MEMORANDUM

February 9, 2010

**SUBJECT:** Sectional Summary (HB 328 (Work Order No. 26-LS1355\E))

**TO:** Representative Craig Johnson  
Attn: Jeanne Ostnes

**FROM:** Jean M. Mischel  
Legislative Counsel 

You have requested a sectional summary of the above-described bill.

As a preliminary matter, note that a sectional summary of a bill should not be considered an authoritative interpretation of the bill and the bill itself is the best statement of its contents. If you would like an interpretation of the bill as it may apply to a particular set of circumstances, please advise.

**Section 1.** Adds longitudinal data on traumatic or acquired brain injury from the registry established under sec. 5 of the bill to the list of databases that the Department of Health and Social Services is authorized to collect, analyze, and maintain.

**Section 2.** Adds case management services for traumatic or acquired brain injury to the optional services provided to recipients of state medical assistance (Medicaid).

**Section 3.** Defines "case management services for traumatic or acquired brain injury" and "traumatic or acquired brain injury" for purposes of the optional services added by sec. 2 of the bill.

**Section 4.** Requires the Department of Health and Social Services to provide medical assistance services under a waiver if approved by the federal government and if the legislature appropriates necessary funding for the services.

**Section 5.** Establishes a statewide traumatic or acquired brain injury program in the Department of Health and Social Services to evaluate the effectiveness and availability of information and services for the prevention and treatment of traumatic or acquired brain injury in the state. Requires consultation and collaboration with public and private entities to fulfill a list of programmatic requirements including development of a statewide service delivery plan and registry of information and evaluation of current laws and standards pertaining to traumatic or acquired brain injury.

JMM:plm  
10-058.plm

Amendment request for HB 328 and or SB 219

Page 4 line 7 and 8

06           (3) evaluation of standards [*and laws pertaining to the prevention of*  
07    *traumatic or acquired brain injury*] and to the treatment, care, and support of persons  
08    with traumatic or acquired brain injury;