ALASKA STATE LEGISLATURE

Interim:
716 West 4th 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.

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

HOUSE BILL NO. 328

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-SIXTH LEGISLATURE - SECOND SESSION

BY REPRESENTATIVES JOHNSON, Dahlstrom, Peggy Wilson, Herron, Cissna, Buch

Introduced: 2/5/10
Referred: Health and Social Services, Finance

A BILL

FOR AN ACT ENTITLED

"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."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* **Section 1.** AS 18.15.360(a) is amended to read:

(a) The department is authorized to collect, analyze, and maintain databases of information related to

(1) risk factors identified for conditions of public health importance;

(2) morbidity and mortality rates for conditions of public health importance;

(3) community indicators relevant to conditions of public health importance; [AND]

(4) **longitudinal data on traumatic or acquired brain injury from the registry established under AS 47.80.500(c)(1); and**

(5) any other data needed to accomplish or further the mission or goals of public health or provide essential public health services and functions.

*** Sec. 2.** AS 47.07.030(b) is amended to read:

(b) In addition to the mandatory services specified in (a) of this section and the services provided under (d) of this section, the department may offer only the following optional services: **case management services for traumatic or acquired brain injury;** case management and nutrition services for pregnant women; personal care services in a recipient's home; emergency hospital services; long-term care noninstitutional services; medical supplies and equipment; advanced nurse practitioner services; clinic services; rehabilitative services for children eligible for services under AS 47.07.063, substance abusers, and emotionally disturbed or chronically mentally ill adults; targeted case management services; inpatient psychiatric facility services for individuals age 65 or older and individuals under age 21; psychologists' services; clinical social workers' services; midwife services; prescribed drugs; physical therapy; occupational therapy; chiropractic services; low-dose mammography screening, as defined in AS 21.42.375(e); hospice care; treatment of speech, hearing, and language disorders; adult dental services; prosthetic devices and eyeglasses; optometrists' services; intermediate care facility services, including intermediate care facility services for the mentally retarded; skilled nursing facility services for individuals under age 21; and reasonable transportation to and from the point of medical care.

*** Sec. 3.** AS 47.07.030 is amended by adding a new subsection to read:

(e) In this section,

(1) "case management services for traumatic or acquired brain injury" means

(A) care and service coordination to assist individuals and families affected by traumatic or acquired brain injury to minimize the disabling effects of the injury;

(B) collaboration with providers and other organizations to expand and strengthen the local capacity for delivery of needed services, including housing, for the care and support of a recipient who is diagnosed with traumatic or acquired brain injury;

(C) participation in planning and accessing services within the community for the care and support of a recipient who is diagnosed with traumatic or acquired brain injury;

(D) the provision of information, referral, and case consultation services to a recipient who is diagnosed with traumatic or acquired brain injury;

(2) "traumatic or acquired brain injury" has the meaning given in AS 47.80.590.

* **Sec. 4.** AS 47.07 is amended by adding a new section to read:

Sec. 47.07.046. Traumatic or acquired brain injury services. (a) The department shall provide traumatic or acquired brain injury services under a waiver in accordance with 42 U.S.C. 1396 - 1396p (Title XIX, Social Security Act), this chapter, and regulations adopted under this chapter, if the department has received approval from the federal government and the department has appropriations allocated for the purpose. In addition to the annual assessment required in (b) of this section, the department shall establish in regulation additional standards for eligibility and payment for the services.

(b) Before the department may terminate payment for services provided under (a) of this section, the recipient must have had an annual assessment to determine whether the recipient continues to meet the standards established by regulation under (a) of this section.

(c) In this section, "traumatic or acquired brain injury" has the meaning given in AS 47.80.590.

* **Sec. 5.** AS 47.80 is amended by adding new sections to read:

Article 5A. Traumatic or Acquired Brain Injury.

Sec. 47.80.500. Statewide traumatic or acquired brain injury program. (a) A statewide traumatic or acquired brain injury program is established in the department for the purpose of evaluating the effectiveness and availability of information and services for the prevention and treatment of traumatic or acquired brain injury in the state. The department shall consult and collaborate with state agencies, private nonprofit entities, and other organizations in the state that provide

brain injury services in implementing all aspects of the program.

(b) The program established under this section must include

(1) review and consideration of data collected under (c)(1) of this section;

(2) supervision and coordination of services provided to persons with traumatic or acquired brain injury;

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

(4) assessment of the availability of acute and long-term treatment, care, and support options in and outside the state for persons with traumatic or acquired brain injury;

(5) evaluation of the need for and scope of community services for persons with traumatic or acquired brain injury throughout the state;

(6) investigation of the models of service coordination that can be replicated at a local level in the state;

(7) coordination and expansion of publicly and privately funded residential and nonresidential acute and long-term services to persons with traumatic or acquired brain injury, including education, referral, and home and community-based services;

(8) facilitation of admissions to and discharges from acute and long-term care facilities for the treatment of traumatic or acquired brain injury;

(9) identification and description of available treatment and care facilities of all types for persons with traumatic or acquired brain injury based on length of stay, patient capacity, available services, and barriers encountered to community placement after discharge;

(10) a plan that describes recommendations for the development of a statewide service delivery continuum of comprehensive rehabilitative, supportive living, and community programs.

(c) The department shall

(1) establish and implement a traumatic or acquired brain injury

registry of information from service providers that includes

(A) health status, including age, cause, and severity of injury and region of brain affected;

(B) acute recovery period;

(C) location of the

(i) event that caused the injury;

(ii) hospital treating the injury; and

(iii) residence of the person with traumatic or acquired brain injury;

(D) access to and use of rehabilitation services, including behavioral, vocational, and long-term care services;

(E) access to and use of neuropsychological assessment;

(F) status of long-term recovery at five-year intervals;

(G) financial and social effects on family;

(H) cost associated with services;

(2) establish standards and recommendations for improvement of prevention, assessment, treatment, and care of persons with traumatic or acquired brain injury in the state;

(3) contract with service providers and qualified entities to carry out the purposes of this section;

(4) provide a standardized reporting form for use in gathering data for the registry.

(d) In (c) of this section, "service provider" means a public or private entity that provides health education, group shelter, or criminal justice services to individuals in the state.

Sec. 47.80.590. Definition. In AS 47.80.500 - 47.80.590, "traumatic or acquired brain injury" means an insult from physical force or internal damage to the brain or its coverings, not of a degenerative or congenital nature, that produces an altered mental state and that results in a decrease in cognitive, behavioral, emotional, or physical functioning.

Title 18. Health, Safety, and Housing.

Chapter

Revisor's notes. — The provisions of this title were redrafted in 1986 to remove personal pronouns pursuant to § 4, ch. 58, SLA 1982, and in 1986, 1991, 1994, and 2002 to make other minor word changes under AS 01.05.031.

Administrative Code. — For health and social services, see 7 AAC.

Title 47. Welfare, Social Services and Institutions.

Chapter

Revisor's notes. — The provisions of this title were redrafted in 1984 to remove personal pronouns pursuant to § 4, ch. 58, SLA 1982, and in 1984, 1990, 1995, and 2008 to make other minor word changes.

Administrative Code. — For health and social services, see 7 AAC.

For hearings, see 7 AAC 49.

Chapter 05. Administration of Welfare, Social Services and Institutions.

Article

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
SCORECARD: A "scorecard" provides a snapshot of the status of TBI issues in the State of Alaska			
Traumatic Brain Injury Non-fatal Incidence Rates			
TBI rate per 100,000	●	98.6	1
Causes			
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
Gender			
TBI percentage among males		65.4 %	1
TBI percentage among females	⟺	33.2 %	1
Ethnicity			
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
Those at highest risk for hospitalization due to TBI (rate per 100,000)			
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
Traumatic Brain Injury Numbers			
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
TBI and Substance Use			
Alcohol-related TBI 100,000		33%	1
TBI and Suicide			
Percentage of suicide victims with history of TBI		32%	4
Dashboard: Education			
Special Education			
Number of children in Special Education statewide with TBI diagnosis (2007)	⟺	66	5
Dashboard: Justice			
Corrections			
Percent of incarcerated Alaskans (adults) who are Trust beneficiaries, including those with cognitive disabilities		42%	6
Dashboard: Employment			
Vocational Rehabilitation			
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			
ImPACT Program			
Number of baselines (ImPACT)		57	8
Number of student/athletes seen in program (ImPACT)		25	8
Emergency Department			
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			
TBI Advisory Board			
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
TBI Resource Navigation			
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
4 Suicide Follow-back Study
5 http://www.eed.state.ak.us/stats/
6 Trust/DOC Study 07
7 Division of Vocational Rehabilitation (FY07)
8 Providence Neuroservices
9 Alaska Brain Injury Network

Alaska is Combating Traumatic Brain Injury

Jill Hodges
Executive Director
Alaska Brain Injury Network

Jeff Jessee
Chief Executive Officer
Alaska Mental Health Trust Authority

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 AK-1990-2000

Phase 1: 1990-1995

Advocacy

- Brain injury survivors mobilize
- Early 1990's
  - Testimony to GDCSE, Legislature, AMHTA
- 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
- 1st 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 and data collection
- Consumer Satisfaction Surveys
- AK Trauma Registry Data

Phase 5: 2005-2007

State of Alaska: TBI Dir. turnover

Data- AKAIMS(32% in BH screen TBI)

Workforce: 1st 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 partnerships 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, planning, 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 for Residential and Day Program
  - Workforce

2010 Session: SB 219 and HB 328

SB 219 and HB 328

- Traumatic/Acquired Brain Injury Program
  - 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 <u>brain injury systems development</u>

- 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
  - Composition of ABIN
  - Recommendation Philosophy
  - Perspective: State role (data collection) and ABIN chair.

- Alaska providers: readiness to partner- TBI post-acute programs
  - Dr. Lester, St. Elias (LTACH)
  - Margaret Carloni, Trauma Nurse, ANMC

- Shannon- Juneau resident, experienced TBI
  - TBI treatment works
  - Family support

Many of Alaska's challenging questions have 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 CDC
  - Created State grant program (HRSA)
- 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 reentry, clubhouse, and long-term living..
- TBI specific workforce will build as TBI programs are operationalized.
  - Professional/para-professional specialists have on the job training, does not 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?

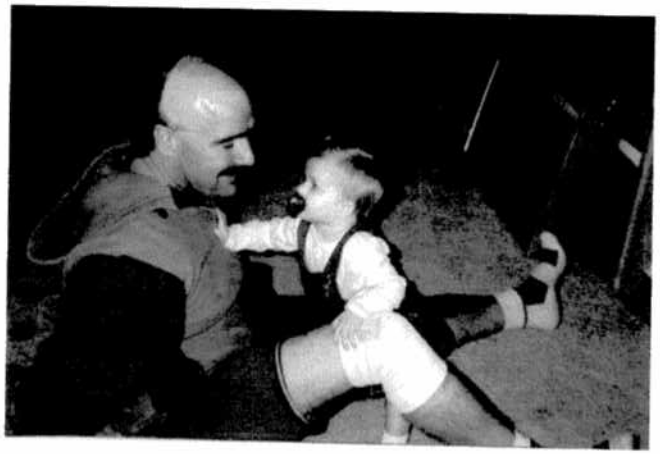
- Resolutions- awareness
  - Last five years
- Prevention
  - AK primary seatbelt law and child safety/ booster seat)
- T/ABI Program into Statute
  - SB 219 and HB Companion
- Interagency Taskforce
- Prevention-concussion management
- Military-screening

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...

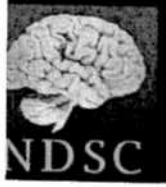
For recognizing the 10,000+ Alaskans with TBI and working to bring more services close to home



The Traumatic Brain Injury Model Systems of Care

A project funded by the US Department of Education

National Institute on Disability and Rehabilitation Research



Conclusions

The TBI Model Systems Program:

- Demonstrates a system of care for TBI
- Performs several types of research
  - Several center-specific clinical trials and other types of studies
  - Innovative module (collaborative) studies
  - A comprehensive longitudinal database already containing over 8,000 cases with up to 20 years of follow-up.

NDSC

COOK INLET
TRIBAL
COUNCIL, INC.

3600 SAN JERONIMO DRIVE, ANCHORAGE, ALASKA 99508

FAX: (907) 793-3422

PHONE: (907) 793-3600

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

alaska brain injury network

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

Jill Hodges
Executive Director

brain injury network

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?

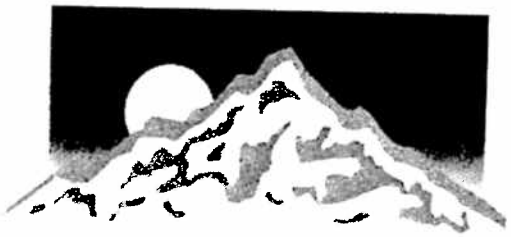
States use a variety and combination of funding streams for planning, policy, prevention and research activities, and to serve individuals with brain injuries and their families who have no other access to needed care or supports. Medicaid, Home and Community-Based Services and Medicaid Waivers, and 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.[1]

[1]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 4th 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

1363 West Spruce Ave, Wasilla, AK 99654 Ph: 907-376-2411 • Fax: 907-352-3363
Member Agency United Way

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 Jesse, CEO

3745 Community Park Loop, Suite 200 Anchorage, Alaska 99508 Tel: 907-269-7960 Fax: 907-269-7966 www.mhtrust.org

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.

****

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.

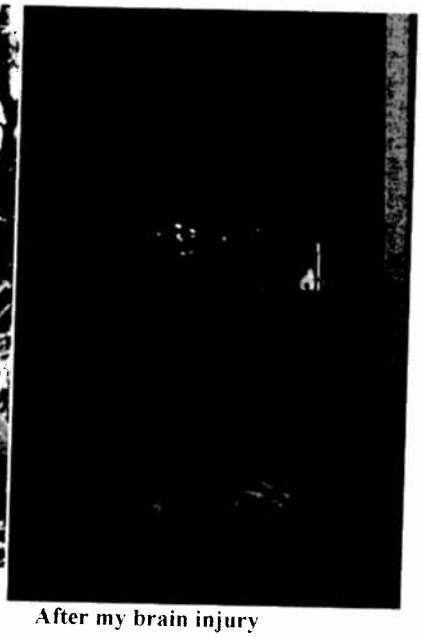
Would the funding for T.B.I. Care Coordination and Case Management have been helpful in my situation? Absolutely! I as well as a host of many others often felt like beating my head up against a brick wall but soon discovered that there was nobody home but suddenly on one bright, sunny, and cheerful summer 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

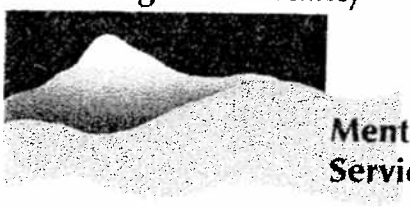
Apx 3years ago I was a Flight Attendant with Alaska Airlines. Now I dont swim, drive or do ANYTHING because overnight my life was CHANGED. Basically I had an ARYCHNOID CYCST which the Doctors watched, at Providence Hospital, since I was a teenager (although I was born with it) and suffered horrendous 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 cought 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 • website: 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

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

St. Elias
Specialty Hospital
a Providence Partner

January 29, 2010

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

Dear Representative Johnson,

Thank you for introducing the House Bill, 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.

At St. Elias Special Hospital, we treat and assist many patients who are affected by brain injury. Our patients' stories are personal to them and to us. But the outcomes of their injuries effect us all. Frequently, many patients who have suffered from a brain injury will come to St. Elias on a ventilator and will be unable to speak, eat or walk. We have been fortunate to be able to watch many patients walk out of the hospital. Others have suffered significant injuries and are not that lucky. We are very concerned about the resources available to our patients after they leave St. Elias.

We, at St. Elias support the House Bill because it would provide a mechanism to better track the traumatic brain injury patients in Alaska. It would also identify services lacking for patients post hospital discharge. Sadly, some of our patients and their families are being required to leave the state for long term rehabilitative care because services are not always available in Alaska. This puts tremendous financial hardship on the families and patients both emotionally and financially and is also costly to the state. This House Bill would serve all Alaskans better by combining TBI reporting for all entities including those that are for profit and non-profit, including military and native services.

St. Elias Specialty Hospital is expanding its programs to better serve patients with traumatic and acquired brain injuries; however, this house bill could help us provide a better discharge plan for our patients with brain injury, thereby allowing the patients to continue their recovery and lead productive lives.

This house bill would help TBI patients get early treatment and keep the patients healthier and safer. These patients could become productive, contributing members of the Alaskan community.

Representative Johnson, thank you so much for your support, consideration and concern for this bill. It is vital for our state, hospitals and most importantly our patients.

Sincerely,

Sharon Kurz

Sharon Kurz, PhD
Chief Executive Officer
St. Elias Specialty Hospital

4800 Cordova Street Anchorage, AK 99503 • Phone: 907.561.3333 • Fax: 907.561.3332 • www.st-eliashospital.com

From: Murphy, Sean [Sean.Murphy@asrcenergy.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 3rd, 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 terain 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 awaken 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

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

www.alaskasilc.org