Alaska State Plan for Brain Injury

July 2020 – June 2025

State Fiscal Years 21 through 25

Alaska Traumatic and Acquired Brain Injury Advisory Council

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Introduction

This document is intended for public review and comment regarding the priorities, goals and objectives for the FY21-25 Alaska State Plan for Brain Injury. This document is not the final FY21-25 Alaska State Plan for Brain Injury. The public comment period is open from June 8 through June 29. Please complete a short AK State Plan for Brain Injury survey after reviewing this document. Visit the Brain Injury State Partnership website for more information (bit.ly/CHDBrainInjury).

Purpose

The need for an updated State Plan for Brain Injury is overdue. The previous state plan was a 10-year plan written in 2008. The purpose of the state plan is to clearly define measurable and achievable goals for the State in order to address system challenges and to increase capacity in Alaska to provide a continuum of care for individuals with brain injury and their families across the lifespan. It is expected that these services will be culturally responsive, person-centered, comprehensive, and coordinated.

Brain Injury Defined

This state plan document is intended broadly for individuals with brain injury, that is to say it is inclusive of traumatic and non-traumatic brain injury. Brain injury terms are defined as follows:

> *Acquired Brain Injury* – Acquired brain injury is an overarching term that includes both traumatic and non-traumatic brain injury. According to the Brain Injury Association of America, an "acquired brain injury is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that occurred after birth."[1] Examples include, near drowning, falls, stroke, sports injury, asphyxiation, or tumor.
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> *Traumatic Brain Injury* – According to the Brain Injury Association of America, a "traumatic brain injury is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force."[1] The CDC defines a traumatic brain injury (TBI) as "a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury."[2] Examples include, falls, assaults, motor vehicle accidents, snow machine/ATV accidents, or sports injuries.
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> *Non-traumatic Brain Injury* – According to the Brain Injury Association of America, a "non-traumatic brain injury causes damage to the brain by internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc."[1] Examples include, stroke, near-drowning, aneurysm, infectious disease that affects the brain.

[1] https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury

[2] https://www.cdc.gov/traumaticbraininjury/index.html

Traumatic and Acquired Brain Injury (TABI) – In Alaska a common term used is TABI which incorporates the above definitions. Therefore, TABI refers to all acquired brain injuries.

Brain Injury in Alaska

Brain injury symptoms can be evident immediately for some individuals, however, for others they can appear days, weeks, or even months after the initial injury occurs (Centers for Disease Control and Prevention, 2019). This creates difficulties in both diagnosing brain injury and in gathering statistics on those affected. In Alaska, there are two main data sources that capture incidence of brain injury, the Alaska Trauma Registry (ATR) and Health Facilities Data Reporting (HFDR) (See Appendix A for descriptions and limitations of these data sources). In the most current review of ATR data, traumatic brain injuries (TBI) made up 19.2% of all reported injuries resulting in a hospital stay over 24 hours (Strayer et al., 2019). Additionally, between 2012 and 2016 the statewide hospitalization rate for brain injury was 8.5 per 10,000 for non-native residents and 18.1 per 10,000 for Alaska Native /American Indian residents. According to 2017 and 2018 data from HFDR, which includes inpatient and outpatient discharge data for Alaska healthcare facilities, the incidence of TBI was 84.6 per 10,000 and 85.3 per 10,000, respectively (Smith, 2020). Note the large discrepancy in incidence between the two data sources is related to the difference in data collected, HFDR includes ER visits and outpatient data thus includes a broader spectrum from mild to severe injury than ATR which collects data on incidence requiring a hospitalization of greater than 24 hours.

TBI incidence is often higher birth to age four, among adolescents ages 15 to 24, and among the elderly (Smith, 2020). In 2018, incidence rates were highest among ages 90+ at 256.9 per 10,000 followed by ages 85 to 89 at 178.2, and ages 80 to 84 at 156.9. The boroughs with the highest incidence of TBI among their residence in 2018 were Northwest Artic (226.4 per 10,000), Nome (157.4 per 10,000), Juneau (113.3 per 10,000), and Ketchikan Gateway (105.6 per 10,000) (Smith, 2020). According to both ATR and HFDR, the number one cause for brain injury in Alaska is falls, followed by motor vehicle incidents, and assaults (Strayer et al., 2019; Smith 2020).

In addition to collecting data on incidence some states collect data from various efforts to screen for brain injury. Screening tools like the Ohio State University TBI-ID are designed to determine lifetime history of brain injury (Bogner & Corrigan, 2009; Corrigan & Bogner, 2007). Some states consider screening in specific settings for populations who may have a higher likelihood of a lifetime history of TBI, e.g. homeless shelters, behavioral health clinics, or prisons. Screening data in Alaska is limited, however from 2006 to 2017 the Alaska Screening Tool for those seeking behavioral health services, reported through the Alaska Automated Information System (AK AIMs), included two questions related to brain injury. The questions asked if an individual had ever had a “blow to the head” severe enough to make them lose consciousness and if they’ve had a “blow to the head” severe enough to cause concussion (Ak DHSS, 2011). In 2017, over 40% of individuals accessing behavioral health services had experienced a brain injury during their lifetime, as indicated by a “yes” response to one or both of the brain injury screening questions (CHD, 2019).

Traumatic and Acquired Brain Injury (TABI) Advisory Council

The Statewide TABI Advisory Council is a requirement of the federal TBI State Partnership grant with the Administration for Community Living. The TABI Advisory Council was first established in 2001, when Alaska was awarded its first federal TBI grant. The mission of the TABI Advisory Council is to understand,

educate, and advocate for the needs of all Alaskans regarding traumatic and acquired brain injury. The Council currently has 31 members, of which 42% are persons with brain injury or family members. The council has a total of 21 voting members, of which 52% are persons with brain injury.[3]

Methodology & Data Sources

This plan was developed by the statewide TABI Advisory Council. The Council began by defining five priority areas: a) Prevention, b) Awareness, c) Resources, d) Data, and e) Infrastructure. On May 29, 2019 University of Alaska Anchorage Center for Human Development hosted a Brain Injury Data Party to review a variety of current data regarding brain injury in Alaska and identify gaps in services. Data was shared from the TBI Legal Needs Assessment, Brain Injury Needs Assessment survey, as well as data from secondary sources (See Appendix A for a list of data sources and how to access). Over the past year, in addition to meeting monthly the Council worked in smaller groups based on the five identified priority areas. Each group used the following steps to develop a vision, purpose, and goals for the priority area: 1) Identify strengths, opportunities, weaknesses, and threats; 2) Define vision and purpose; 3) Identify and refine goals and activities. The final step was to combine the work from all the groups and refine the goals and activities by considering achievability and eliminating redundancies.

Priorities, Goals, & Activities

The following details the vision, purpose, and goals for each of the five priority areas: a) Prevention, b) Awareness, c) Resources, d) Data, and e) Infrastructure. Each goal is further defined with detailed year one activities and activities for the following year. The activities for following years will be updated and revised annually.

Priority Area: Prevention

Vision:

We will have established a strong collaboration with statewide prevention and early intervention partners to coordinate culturally responsive and inclusive education campaigns, awareness of brain injury, and prevention strategies for the most common causes of brain injury. These coordinated efforts will result in a decrease in brain injury incidence and an increase in timely early intervention for brain injury survivors to improve the quality of life for Alaskans.

Purpose:

Awareness of brain injury and its causes will be commonplace so that individuals, families, and stakeholders will be better equipped to prevent brain injury. A sustained coordinated statewide effort among brain injury stakeholders will ensure a widespread message that is consistent with evidence surrounding brain injury prevention and early intervention. Knowledge of the common symptoms of brain injury will allow people to recognize symptoms when it occurs so they can get help in a timely manner.

Goal 1: Establish TABI Advisory Council representation on existing injury prevention and other relevant coalitions

Year 1 Activities:

[3] For more information on the TABI Advisory Council and Data visit the Brain Injury State Partnership Program website (bit.ly/CHDBrainInjury).

1. Identify existing coalitions focused on injury prevention including suicide, falls, and/or overdose prevention
2. Identify TABI Advisory Council members to represent the Council on relevant coalitions
3. TABI Advisory Council representative(s) coordinate with 1-2 existing coalitions to join meetings and prevention efforts
4. Establish regular lines of communication between existing coalitions to TABI Advisory Council work

Year 2-5 Activities:

1. Identify and join 1-2 additional coalitions for collaboration
2. Continue to coordinate outreach to identified partners

Goal 2: Develop and distribute information on brain injury prevention

Year 1-2 Activities:

1. Identify barriers to communicating to rural communities such as lack of access to internet and cultural differences
2. Identify existing prevention communications and how to develop partnerships with those implementing these communications
3. Identify the mediums (e.g., social media, television, radio, print) that can be used to communicate
4. Identify Alaska specific TABI causes and focus on those targeted prevention areas (e.g., utilizing data from the Trauma Registry or Health Facilities Data Reporting)
5. Develop a plan for coordinated efforts towards brain injury prevention

Year 2-5 Activities:

1. Advocate for funding or pursue funding opportunities
2. Implement plan and revise as needed
3. Evaluate impact of communication strategies

Priority Area: Awareness

Vision:

Collaborative and coordinated training and advertisements produce raised awareness across Alaskan communities, including within healthcare, employment, and schools resulting in de-stigmatization for survivors, better understanding of TABI signs, and improvements in diagnostic and treatment practices.

Purpose:

Increased awareness of this invisible disability, including symptoms, services and impacts of TABI on individuals and families can produce societal change by increasing empathy toward survivors, and by revealing the need to develop and connect available services to produce an accessible, person-centered continuum of care.

Goal 1: Increase brain injury awareness within Alaskan communities

Year 1 Activities include:

1. Identify target populations in collaboration with community stakeholders
2. Discover barriers to communicating with different populations (e.g., hold focus groups)
3. Perform environment scan of existing awareness campaigns and determine how to develop partnerships

4. Identify potential methods of dissemination, e.g., web, social media, television, radio
5. Determine priority information to be communicated (e.g., by utilizing findings from the Brain Injury Needs Assessment)
6. Create awareness plan

Years 2 – 5 Activities include:

1. Advocate for funding or pursue funding opportunities
2. Implement plan and revise as needed
3. Evaluate impact of communication strategies

Goal 2: Develop and expand learning opportunities for healthcare, behavioral health, and service providers

Year 1 Activities include:

1. Identify target audiences in collaboration with community stakeholders and with particular consideration for providers working with underserved, vulnerable, and/or at-risk populations
2. Determine feasible number of training events
3. Consider appropriate venues or communication methods
4. Determine and prioritize training topics (e.g., by utilizing findings from the Brain Injury Needs Assessment)
5. Consider potential educators
6. Identify existing learning opportunities and potential partnerships
7. Establish, with the Alaska Brain Injury Network, an annual brain injury conference that is routine and predictable as a way to increase learning and build partnerships across the state
8. Continue Head Injury ECHO, consider longer-term sustainability, and incorporate brain injury into other ECHOs where appropriate

Years 2 – 5 Activities include:

1. Advocate for funding or pursue funding opportunities
2. Collaborate on Annual TABI conference
3. Share outcomes from Head Injury ECHO and advocate for funding
4. Evaluate impact of learning opportunities

Priority Area: Resources

Vision:

Individuals who have experienced a brain injury have information about, and access to, available direct resources and telehealth resources that will assist in their recovery and ongoing quality of life. Services are expanded and additional resources developed based upon identified gaps.

Purpose:

TABI survivors can receive timely and accurate information to aid in their healing and wellness. Awareness and access to TABI assessments, treatments, and community resources can allow a person-centered approach to meet each individual's physical and recovery needs inside their community. This system can adequately support survivors requiring both short- and long-term service and support.

Goal 1: Develop and produce brain injury resources based on data and identified needs

Year 1 Activities include:

1. Perform environmental scan of current resources delivered
2. Develop a Brain Injury Resource Guide for families and professionals to identify existing services and resources in both urban and rural health systems, including telehealth resources
3. Determine how Brain Injury Resource Guide information would be continuously gathered and maintained
4. Develop a structure for the Brain Injury Resource Guide including budget, staffing, procedures (e.g., where staff are housed, funding)

Year 2 – 5 Activities include:

1. Continue to gather data on unmet needs (e.g., from the Brain Injury Needs Assessment) to identify gaps and guide new resource development
2. Advocate for funding or pursue funding opportunities
3. Evaluate success of developed resources

Goal 2: Expand Brain Injury Screening Clinics[4]

Year 1 Activities include:

1. Identify 2 new communities for rural screening clinics
2. Identify high-risk populations, e.g., Department of Corrections, and build relationships
3. Clarify process for verification of diagnosis
4. Improve clinic data collection for documenting clinic outcomes
5. Build partnerships with local providers and offer educational opportunities
6. Consider and investigate options for telehealth screening and follow up

Years 2 – 5 Activities include:

1. Advocate for funding or pursue funding opportunities
2. Continue outreach to communities across Alaska
3. Implement plan and revise as needed

Goal 3: Establish statewide brain injury screening

Year 1 Activities include:

1. Identify provider types and systems for incorporating screening, particularly considering providers working with underserved, vulnerable, and/or at-risk populations
2. Establish protocols for screening based on provider type
3. Establish methods for collecting data on screening efforts
4. Consider methods for telehealth screening
5. Develop plan for brain injury screening with phases for implementation

[4] The brain injury screening clinics have been offered by the Alaska Brain Injury Network as part of the federal grant through UAA CHD. The clinics include a pre-screening with the OSU-ID and then in person assessments with specific providers, e.g. physical therapist, speech therapist, occupational therapist, mental health counselor, optometrist. For many the end result is a verification of diagnosis that can be used to access programs like the TABI mini grant.

Years 2 – 5 Activities include:

1. Train providers on brain injury screening
2. Collect data on screening training and implementation
3. Implement plan and revise as needed

Priority Area: Data

Vision:

Reliable data from across Alaska that is available for an annual report on brain injury and can be used to inform a TBI registry, continued funding, resource allocation, infrastructure development, systems change and state planning efforts.

Purpose:

Meaningful data can be used to advocate for programs and services that benefit individuals with disabilities. Data can help determine how systems are functioning and how to make improvements. Data, like the TBI Registry, can be used to help connect people to services. Individuals and family members may also have a voice by participating in data collection like community needs assessments.

Goal 1: Establish an operational TBI registry to connect people to services as per statute 47.80.500

Year 1 Activities include:

1. Determine registry purpose and use (e.g. connecting people to services, supporting research/needs assessments)
2. Determine data sources
3. Review existing state registries for budget, staffing, etc.
4. Create structure for registry including budget, staffing, procedures (e.g., who has access, where is it housed, how is it funded, how to ensure HIPAA compliance, how to connect people to services)
5. Create registry plan

Years 2 - 5 Activities include:

1. Advocate for funding or pursue funding opportunities
2. Implement plan and revise as needed
3. Consider addition of non-traumatic brain injuries to the registry (e.g., brain injury as a result of stroke, COVID-19, aneurysms)

Goal 2: Establish an Alaska brain injury data clearinghouse

Year 1 Activities include:

1. Define brain injury data needs
2. Review available data sources through state and local agencies (e.g. Vocational Rehabilitation, TABI Mini Grants, TABI Case Management)
3. Determine location, budget, and staffing

Year 2-5 Activities include:

1. Developing timeline for annual report on brain injury

2. Develop annual report on brain injury
3. Add brain injury questions to Behavior Risk Factor Surveillance System (BRFSS) and Youth Risk Behavior Survey (YRBS)
4. Approach public health about adding brain injury specific questions to any future follow with COVID-19 survivors

Priority Area: Infrastructure

Vision:

Create a plan to develop infrastructure in Alaska to support the healthcare and community rehabilitation needs of Alaskan's recovering from brain injury and reduce the number of people being discharged home with no follow up. In addition, the TABI Advisory Council will exist in a more permanent structure as a way to stabilize state infrastructure and support advocacy.

Purpose:

Individuals will have access to local resources in the post-acute phase of recovery and as a result have the potential for improved outcomes. The TABI Advisory Council will develop by-laws and a means for advocating for the state plan and improved services.

Goals 1: Establish permanent TABI Advisory Council

Year 1 Activities include:

1. Determine statutory vs. voluntary board structure and make recommendation
2. Determine placement within state structure and make recommendation
3. Secure funding to support a position for TABI Advisory Council work
4. Establish sub-committees based on each priority area and including a sub-committee focused on cultural and tribal relations
5. Create Council by-laws

Year 2-5 Activities:

1. Sustain TABI Advisory Council

Goals 2: Explore development of a model for brain injury rehab in Alaska

Year 1 Activities include:

1. Explore models for brain rehab in Alaska
2. Explore models that are mindful of challenges faced by rural and remote communities
3. Make recommendations on a feasible model for the state
4. Build collaboration and by-in from community and state programs to develop support

Years 2-5 Activities include:

1. Conduct cost benefit analysis on in-state vs out-of-state placement for rehab services
2. Review payors - Medicaid, private insurance, workers compensation

Goal 3: Establish a TABI waiver and/or other structured long-term support option

Year 1 Activities include:

1. Review waivers from other states

2. Explore options within the Alaska system including 1115 or 1915c waivers, or Community First Choice state plan option
3. Coordinate with behavioral health and Senior and Disabilities Services
4. Make recommendations on feasible option for long-term support

Years 2-5 Activities include:

1. Review of costs and cost benefit analysis

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Appendix A – Description of Data Sources

AK Trauma Registry (ATR)

The Alaska Trauma Registry (ATR) collects information from all 24 acute care hospitals (22 civilian and 2 department of Defense) on incidence of trauma. Data are included if the patient contact was within 30 days of the injury and one of the following: admitted, held for observation, transferre3d to another acute care facility, declared dead in ER, left against medical advice (i.e., would have been admitted).

For more information on ATR: http://ibis.dhss.alaska.gov/topic/databases/ATR.html

Brain Injury Needs Assessment

The Brain Injury Needs Assessment Survey, conducted in 2019, gathered information from three different sets of participants across Alaska who each completed different survey tracks. Firstly, there were adults with brain injury, then family members, caregivers or guardians of individuals with brain injury, and finally Medical or Service Providers. Responses specifically about brain injury survivors and their experiences were gathered from both the 'individual with a brain injury' survey track, which collected data about the individual themselves, and the 'family member/caregiver/guardian' track, which obtained information about the participants relative/client. For the brain injury survivors represented in this survey, information was gathered around employment, housing, healthcare, and satisfaction of services. For the 'Medical/Service Provider' track, information was obtained on brain injury awareness, prevention, and familiarity with relevant organizations. The survey was available online, by mail, and over the telephone. A total of 311 individuals completed, or partially completed, the survey. This consisted of 74 adults with a brain injury, 72 family members, caregivers or guardians of individuals with a brain injury, and 165 Medical or Service Providers.

Summary of results available at: https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/brain-injury-partnership-program/_documents/Brain%20Injury%20Needs%20Assessment%20Survey.pdf

Health Facilities Data Reporting (HFDR)

HFDR collects inpatient and outpatient discharge data from Alaska health care facilities, including private, municipal, state, or federal hospitals; hospitals operated by Alaska Native organizations; psychiatric hospitals; residential psychiatric treatment centers; and ambulatory surgical facilities. This data set does not include military hospitals.

For more information on HFDR: http://ibis.dhss.alaska.gov/topic/databases/HFDR.html

Listening Sessions

A listening session is a discussion that is open to the community to explore local issues and learn about thoughts, perceptions, and desires about a given topic. Listening sessions focused on brain injury were hosted in-person around the state in conjunction with the brain injury screening clinics. Listening sessions were hosted in communities with some of the highest incidence of TBI, including Kotzebue, Nome, Juneau, and Ketchikan. Unfortunately, due to COVID-19 the spring 2020 screening clinics and listening sessions were canceled.

TBI Legal Needs Assessment

The University of Alaska Anchorage (UAA) Center for Human Development (CHD) was contracted by the Disability Law Center (DLC) of Alaska to conduct a statewide needs assessment on the legal needs of adults with traumatic and acquired brain injuries (TABI). The purpose of this study was two-fold, one, to gather information on the legal needs of adults with TABI, and two, to better understand the experience of adults with TABI in accessing services and benefits. The needs assessment consisted of three activities: key informant interviews, an online survey of adults with TABI, and focus group interviews with adults with TABI.

Final report available at: https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/Research/_documents/TABI%20Legal%20Needs%20Assessment_Final%20Report.pdf