# **Alaska State Plan for Brain Injury**

July 2025 – June 2030 State Fiscal Years 26 through 30

Brain Injury Council of Alaska

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#### Introduction

## **Purpose**

The State Plan is a document for everyone in Alaska. There is no single agency responsible for completing the plan. It is designed to be used by all agencies in the state, showing them where they should prioritize their efforts. Therefore, agencies can use this document to inform their strategic planning, advocate for funding, and contribute to goal completion. The State Plan is developed based on current data and input from experts, including individuals with brain injury, family members, and providers across Alaska.

### **Brain injury definitions**

The state plan outlines the most pressing needs across Alaska for all types of acquired brain injury. The Brain Injury Association of America (BIAA, n.d.-a) definition of this type of brain injury is:

- Acquired Brain Injury (ABI): a brain injury that has occurred after birth that is not congenital, hereditary, degenerative, or caused by birth trauma. ABI is an overarching term that includes both traumatic and non-traumatic brain injury.
  - Traumatic Brain Injury (TBI): an alteration in brain function caused by an external force (e.g., a bump to the head, penetrating head injury).
     Incidents like falls, assaults, motor vehicle accidents, and sports injuries could cause these.
  - Non-traumatic brain injury: damage to the brain from internal factors that occur after birth (e.g., due to a lack of oxygen or pressure from a tumor).
     Factors that may cause these include stroke, near-drowning, aneurysm, and infectious disease.
- Traumatic and Acquired Brain Injury (TABI): a term commonly used in Alaska that incorporates all types of acquired brain injuries.

#### **Brain injury outcomes**

Brain injuries can happen to anyone, and the implications can be lifelong, especially without diagnosis and treatment. For some individuals, symptoms may appear immediately, while for others, they can take days to present (Centers for Disease Control and Prevention [CDC], 2024a). The brain controls everything, including our thoughts, movements, and functions of internal organs, such as the heart (BIAA, n.d.-b). Therefore, after a brain injury has occurred, the symptoms can be varied and significant. Potential symptoms include problems with memory, balance, thinking, vision, headaches, sleep disturbances, changes in heart rate, and difficulties with both behavioral and emotional regulation.

When looking at TBIs specifically, the majority occurring are mild TBIs or concussions (CDC, 2024b). Most people recover from these within a few weeks; however, this is not always the case, as some individuals may experience ongoing symptoms for months or years. Moderate to severe TBIs can result in lifelong health problems (CDC, 2024c). In fact, as of January 2025, the Centers for Medicare and Medicaid Services acknowledged the ongoing and potentially lifelong consequences of TBI by officially recognizing it as a chronic condition (BIAA, 2024; Federal Register, n.d.).

#### Brain injury in Alaska

Alaska is the nation's largest and most rural state, with an estimated 740,133 individuals dispersed across this vast landmass (Census Bureau, n.d.). It is a unique state, with approximately 240 remote villages, many of which are only accessible by boat or airplane (Census Bureau, 2019). Consequently, the experiences of those seeking treatment after brain injury can be varied and challenging.

#### TBI-related mortality

National Vital Statistics System data from 2016 to 2018 showed that Alaska had the highest TBI-related death rate in the nation, with 34.8 per 100,000 population experiencing this annually (Daugherty et al., 2021). This rate was 101.2% higher than the national average. For intentional TBI-related deaths, the leading causes in Alaska were homicide (12%) and suicide (40%). For unintentional TBI-related deaths, it was

falls (14%) and motor vehicle crashes, including motorized vehicles such as all-terrain vehicles (ATV) (20%). Overall, the highest rates were seen in individuals aged 85 and above, males, American Indian/Alaska Native (AI/AN) populations, and residents of the Northern region (Newell, 2023).

When looking specifically at TBI-related deaths due to suicide, the highest rates were in those aged 25 to 35 (Newell, 2023). However, it should be noted that this data does not show whether individuals had a previous brain injury, which studies have found can be a contributing factor. For example, research has shown that brain injury is linked to an increased risk of suicidal ideation in the general population for all ages (Madsen et al., 2018; Richard et al., 2015).

## TBI morbidity

When looking at morbidity rates, referring to those who experienced a TBI and survived, the State of Alaska Epidemiology bulletin reported that unintentional falls were the leading cause in Alaska (Newell, 2023). Thirty-nine percent of TBI-related emergency department (ED) visits from 2016 to 2021 were due to falls, as were 44% of TBI-related hospitalizations from 2017 to 2021. However, it should be noted that the State of Alaska Epidemiology report discovered that the cause of injury varies depending on the population group, namely:

- Age: For people aged 15 to 34, the leading cause of TBI-related ED visits and
  hospitalizations was motor vehicle crashes, which include motorized vehicles
  such as ATVs. In contrast, falls were the leading cause of TBI-related ED visits
  for people aged 35 and above and for TBI-related hospitalizations for those aged
  45 and over.
- Sex: Males were 1.6 to 3.7 times more likely than females to receive a TBI due to assault.
- Location: Assault was the most common cause of TBI-related ED visits in the Southwest region. For all other regions, it was unintentional falls. For inpatient hospitalization, unintentional falls were the most common cause in all regions except the Southwest and Northern regions, where it was due to motor vehicle crashes, including motorized vehicles. Moreover, 39% of TBI-related

hospitalizations in the Northern region were due to snowmachines and all-terrain vehicles.

 Race: Al/AN people had higher rates of TBI-related ED visits and hospitalizations.

#### **Brain Injury Council of Alaska**

The Brain Injury Council of Alaska (BICA) has been in existence since 2001 (University of Alaska Anchorage [UAA], n.d.). Its mission is to understand, educate, and advocate for the needs of all Alaskans regarding acquired brain injury. The council was renamed from TABI Advisory Council in 2023 to the BICA. This council is responsible for creating the Alaska State Plan for Brain Injury. They developed the previous five-year State Plan, covering June 2020 to July 2025, as well as the current State Plan. The council is a requirement of the TBI State Partnership Program federal grant. Currently, the Alaska Mental Health Trust Authority supports the Council Coordinator position. The council has a total of 21 voting and non-voting members, of which 57% are individuals with brain injury or family members. There are 18 voting members on the council, with 56% being individuals who have experienced a brain injury.

## Methodology

#### Creation of the plan

Between November 2024 and January 2025, BICA received monthly presentations from various organizations that had recently conducted research focused on brain injury services and experiences across Alaska. These presentations were from the Concussion Legacy Foundation, the Southcentral Foundation, and the UAA Center for Human Development. This information was used to inform the State Plan goals and objectives. The data used by BICA are listed in the Appendix.

Following the presentations, BICA formed workgroups based on the key areas of need identified. These priority areas were focused on: 1) Prevention, 2) Awareness, 3) Resources, 4) Data, 5) Infrastructure, and 6) Advocacy. Workgroups met monthly from January 2025 to April 2025 to develop the State Plans draft goals and objectives. The process for each priority area consisted of 1) reviewing the previous state plan to

ascertain if any goals needed to remain or be revised, 2) determining all potential goals within the priority area, 3) considering each goal's potential impact along with its barriers and facilitators, 4), prioritizing goals, 5) developing a vision and overarching goals, and 6) establishing specific objectives to achieve the goals. The final step was to open the State Plan for public comment, consisting of live drop-in sessions and an anonymous survey.

#### Priorities, goals, and objectives

The following section outlines the main recommendations to address the most pressing areas for improvement in Alaska. These recommendations have been informed by data, research findings, and needs assessments undertaken throughout the state. There is no one agency responsible for completing the recommended goals. Instead, the State Plan is designed to be used by all agencies across Alaska to help them understand where they should prioritize their efforts. The sections are broken into the six identified priority areas. These are 1) prevention, 2) awareness, 3) resources, 4) data, 5) infrastructure, and 6) advocacy. Each area contains a *vision* of what could be achieved through the recommendations. These recommendations are presented as *goals* and *objectives*.

## **Priority Area: Prevention**

#### Vision

Statewide prevention partners will collaborate 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 early intervention for brain injury survivors of all ages, thereby improving the quality of life for Alaskans.

## **Goals and Objectives**

<u>Goal 1</u>: Maintain BICA representation on existing injury prevention and other relevant coalitions, with a particular focus on populations at high risk of brain injury or underserved by existing resources.

## Objective 1.1

Continuously identify appropriate coalitions that BICA members could join to raise awareness of brain injury. For example, consider councils focused on injury prevention, crisis response, and justice-related initiatives.

#### Objective 1.2

Establish regular lines of communication between existing coalitions and the BICA to facilitate collaboration, such as sharing presenters to raise awareness.

**Goal 2**: Continue to develop and distribute information on brain injury prevention.

## Objective 2.1

Use data to identify priority prevention topics, determine appropriate communication methods, and target specific populations, including any barriers to reaching them.

#### Objective 2.2

Utilize theory and previous health campaigns to develop and distribute evidence-based information to improve brain injury prevention.

## **Priority Area: Awareness**

#### Vision

Through collaborative and coordinated training and outreach, raise awareness of the high prevalence of brain injury, related chronic health needs, available resources, and best practice diagnostic and treatment practices to support better long-term health and social outcomes for brain injury survivors. Knowledge of the common symptoms of brain injury will enable people to recognize these symptoms when they occur, allowing them to seek help in a timely manner.

## Goals and Objectives

<u>Goal 1</u>: Increase awareness of this invisible disability, including symptoms and impacts of brain injury on individuals and families, to produce societal change by increasing empathy toward survivors.

## Objective 1.1

Increase brain injury awareness within Alaskan communities by identifying target populations, determining appropriate methods of communication, and prioritizing areas that require heightened awareness, such as education on the causes of brain injury or recognizing the signs and symptoms of a brain injury.

#### Objective 1.2

Create regular learning opportunities for healthcare professionals, behavioral health professionals, teachers and educators, and service providers.

 Key elements of this objective include identifying target audiences, such as medical providers or those who serve at-risk populations, and having appropriate agencies provide training in these areas.

## **Priority Area: Resources**

#### Vision

Individuals who have experienced a brain injury, their families, caregivers, and medical and support professionals have information about and access to available educational resources that assist in their recovery and ongoing quality of life.

## Goals and Objectives

<u>Goal 1</u>: Develop and produce brain injury informational/educational resources based on data and identified needs.

#### Objective 1.1

Informational/educational materials will be created to increase understanding of the impacts of brain injury and available treatments. These resources will be made available to ensure that individuals, their families, and providers can access information to help them understand this condition, what to expect, and what supports are available.

## **Priority Area: Data**

#### Vision

Brain injury-related data is published in regular reports across Alaska. This data is used to identify the areas of greatest need and can inform resource allocation, infrastructure development, and funding decisions.

## Goals and Objectives

<u>Goal 1</u>: Agencies and providers most likely to encounter individuals with ongoing impacts of brain injury collect screening data.

#### Objective 1.1

Identify appropriate agencies and providers, such as Primary Care Providers, who are most likely to encounter individuals with ongoing impacts of brain injury. Refer to Infrastructure Goal 2, Objective 2.1 and Objective 2.2 for details on building provider screening capability.

#### Objective 1.2

Identify a suitable state agency to maintain brain injury screening data.

#### Objective 1.3

Have appropriate providers collect and report brain injury screening data to the suitable state agency identified.

## **Goal 2**: Identify and fill gaps in data.

#### Objective 2.1

Explore potential data sources that are currently not being gathered. Examples of this uncollected data include screening specific populations, such as individuals who are homeless, or prevalence rates of brain injury through the Behavioral Risk Factor Surveillance System Survey.

## Objective 2.2

Agencies apply for funding to collect brain injury data identified in Objective 2.1 above.

<u>Goal 3</u>: Agencies across Alaska publish regular reports on their brain injury-related data.

## Objective 3.1

Identify specific agencies and collaborate with them to publish an annual report on the number of people with brain injury served by healthcare providers, aggregated emergency room data, leading causes of brain injury in Alaska, and Alaskan incidence rates.

## Objective 3.2

Advocate to have one agency produce a five-year state of brain injury in Alaska report, combining information from multiple data sources. This would involve identifying an agency and applying for funding to support their efforts.

## **Priority Area: Infrastructure**

#### Vision

Develop infrastructure in Alaska that meets the healthcare, rehabilitation, and community reintegration needs of Alaskans recovering from brain injury, their families, and their care supports. Ensure that the BICA is sustainable, offering an organized, consistent, and collaborative space for stakeholders to make progress on issues related to brain injury.

## Goals and Objectives

<u>Goal 1</u>: Brain injury survivors, their families, and care supports will have access to a trained and adequately staffed workforce providing brain injury services in the state.

## Objective 1.1

Define what comprises an adequately staffed brain injury workforce in Alaska.

Key elements of this objective include identifying healthcare and related positions
essential to brain injury screening, treatment, healing, and rehabilitation, as well as
establishing metrics to determine the appropriate level of this workforce.

#### Objective 1.2

Provide consistent training to the workforce, focused on current best practices and innovative approaches to screening, diagnosis, treatment, healing, rehabilitation, and management of long-term symptoms associated with brain injury.

 Key elements of this objective include identifying organizations and agencies that can offer training, increasing partnerships with organizations to provide training, and including cultural considerations and the screening needs of different age groups.

## Objective 1.3

Expand the network of trained school-based professionals supporting the return to school process for youth following a brain injury.

<u>Goal 2</u>: Alaska will have sufficient clinics, resources, and services to address screening, treatment, healing, and rehabilitation from brain injury.

## Objective 2.1

Expand brain injury screening to make it accessible and available in more communities.

• Key elements of this objective include identifying high-risk populations and determining the most appropriate providers, such as Primary Care Providers who may see individuals with ongoing symptoms. Also, building relationships with local providers to enhance their screening capability and considering options for telehealth or temporary clinics to augment capacity. For reporting of screening data see Data Goal 1: Agencies and providers most likely to encounter individuals with ongoing impacts of brain injury collect screening data.

#### Objective 2.2

Enhance the use of accurate diagnosis and coding in medical and educational records to support informed referrals, effective treatment, and accurate data collection.

 Key elements of this objective include training healthcare professionals on the diagnosis and coding of brain injury, as well as training education staff on the documentation of brain injury to support Individualized Education Programs (IEPs).

## Objective 2.3

Ensure individual access to local services in the post-acute phase of recovery and, as a result, realize the potential for improved outcomes.

Key elements of this objective include identifying services needed to produce an
accessible, person-centered continuum of care, ensuring access to resource
facilitation or navigation, peer support, and after-care services, and identifying
innovative ways to address the service disparity for brain injury in rural Alaska.

## Objective 2.4

Explore the development of a model for brain injury rehabilitation in Alaska that includes support for long-term symptoms throughout the lifespan.

 Key elements of this objective include considerations for rural communities, collaboration with local and state programs to build support for the recommended model, recognition of brain injury as a chronic condition, and clinic/agency capability to support patients with long-term symptoms.

<u>Goal 3</u>: Identify and recommend an option for sustainable funding for brain injury services through the establishment of a structured long-term support option.

## Objective 3.1

Identify gaps between the services that brain injury survivors need and the available payment models and resources for these services.

 Key elements of this objective include: a gap analysis, research, and data analysis to better understand existing payment barriers.

#### Objective 3.2

Explore healthcare models and payment approaches that could be beneficial to survivors of brain injury. Identify at least one model to pursue for implementation.

Key elements of this objective include exploring approaches such as Targeted
Case Management, a TABI Waiver, and an integrated healthcare model, as well as
finding sustainable funding for programs that serve brain injury survivors, their
families, and care supports.

## **Goal 4: Sustain BICA's structure and functions.**

## Objective 4.1

Maintain BICA membership levels in accordance with operational procedures and ensure substantive participation from different agencies and individuals.

 Key elements of this objective include the participation of individuals with lived experience and ensuring a wide variety of representation in terms of geographical areas, organizational representation, and other relevant considerations.

## Objective 4.2

Identify and secure an ongoing funding source to maintain a dedicated Council Coordinator to ensure the long-term sustainability of all Council functions.

## **Priority Area: Advocacy**

#### Vision

Advocate for legislative, policy, funding, support, and related priorities on behalf of Alaska brain injury survivors, their families, caregivers, and healthcare providers, with a focus on existing resource and service gaps.

## **Goals and Objectives**

## **Goal 1**: Advocate for brain injury legislation and policy.

#### Objective 1.1

Advocate for local and/or state helmet use legislation for any motorized transportation or recreation vehicles for individuals under age 19.

## Objective 1.2

Advocate for a sustainable state and/or federal funding plan for the Youth Brain Injury Program as an evidence-based model to connect medical and educational services for Alaska youth with brain injury.

## Objective 1.3

Advocate for a mandatory immediate post-concussion return-to-school plan to provide necessary accommodations for all public-school students (prior to 504/IEP plan implementation, if applicable).

**Goal 2**: Advocate to increase the number of staff who understand brain injury and patients who leave healthcare facilities with brain injury information.

## Objective 2.1

Advocate for healthcare facilities to have policies ensuring their employees are trained on brain injury. Appropriate staff may include primary care providers, emergency room doctors, and behavioral health providers.

#### Objective 2.3

Advocate for hospitals to have policies that ensure brain injury educational materials are provided to all patients and families who have sustained a potential brain injury.

**Goal 3:** Advocate to increase the number of brain injury-specific case managers and TABI Resource Facilitators in Alaska.

#### Objective 3.1

Identify an appropriate number of necessary brain injury-specific case managers and brain injury resource facilitators to support individuals with brain injury across Alaska.

## Objective 3.2

Advocate at the state level to fund brain injury-specific case managers and additional TABI resource facilitators.

**Goal 4**: Advocate for methods to ensure individuals can afford to access services throughout all stages of care.

#### Objective 4.1

Advocate for public insurance coverage of all stages of brain injury treatment and care, from screening and emergency services to inpatient care and inpatient and outpatient rehabilitation for children and adults.

 Note: Ensure that activities are aligned with Infrastructure Goal 3: Identify and recommend an option for sustainable funding for brain injury services through the establishment of a structured long-term support option.

## **Highlighted Success Stories from the Previous State Plan**

This section contains examples of success stories that have occurred across Alaska during the July 2020 to June 2025 Alaska State Plan for Brain Injury. These stories are by no means the only efforts that have occurred across the state. However, they highlight some of the work organizations have done to achieve the previous State Plan's goals, including efforts to increase brain injury education, awareness, prevention, data collection, services, and screening.

#### Alaska Division of Public Health and the Youth Brain Injury Program

The Section of Chronic Disease Prevention and Health Promotion at the State of Alaska's Division of Public Health received a Core State Injury Prevention Program grant from the Administration for Community Living to conduct several activities across Alaska. These initiatives included creating a state TBI prevention website and implementing a "Defend Your Brain" public education campaign. The campaign utilized multiple online methods, such as YouTube and television, to disseminate information. This resulted in more than 2,650,000 online displays and 4,700 visits to the Defend Your Brain website. Moreover, they collaborated with the Center on Brain Injury Research and Training (CBIRT) at the University of Oregon to develop the Alaska TBI Resource Locator online tool, designed to serve as a centralized resource for all Alaskans across the state to find brain injury providers.

They also worked with the Alaska Division of Juvenile Justice, the National Association of State Head Injury Administrators, the Southeast Regional Resource Center (SERRC), and CBIRT to give support to youth with potential TBI. This included providing screening, education and connecting youth within Alaska's juvenile justice system to resources. As part of this work, the Alaska Mental Health Trust Authority provided funding to create a Youth Brain Injury Program situated at SERRC. This resource is available to all youth across Alaska, both within and outside of the juvenile justice system. It offers support in creating educational plans, facilitates communication between schools and medical providers, and supplies brain injury training for school staff, students, and family members.

## Alaska Brain Injury Consortium and the Alaska Brain Bus

The Alaska Brain Injury Consortium (ABIC) is a nonprofit organization run by brain injury providers who aim to improve the lives of individuals with brain injuries and their families. ABIC has provided training across Alaska, offering free <a href="Brain Injury">Brain Injury</a>
<a href="Fundamentals Certificate">Fundamentals Certificate</a>
 training to Resource Facilitators and Peer Support staff throughout the state, funded by the UAA Center for Human Development through its TBI State Partnership Program grant. Moreover, ABIC collaborated with the UAA Center for Human Development to provide free joint training sessions to Alaskan domestic violence organizations on identifying and offering accessibility accommodations to survivors with potential brain injuries.

ABIC also hosts the <u>Alaska Brain Bus</u>, which works to drive change for Alaskans with brain injury. The Alaska Brain Bus travels around communities on the road system providing education and performing brain injury screening. This work has been funded by the Alaska Mental Health Trust Authority and the Alaska Department of Health, Division of Public Health, Injury Prevention Programs, through a Chronic Disease Prevention and Health Promotion Sponsorship.

#### **Concussion Legacy Foundation and Alaska's Helpline**

In 2021, the <u>Concussion Legacy Foundation (CLF)</u> began collaborating with BICA to improve the availability and accessibility of TBI resources with support and funding from the Alaska Mental Health Trust Authority. CLF's core focus areas included public awareness and education initiatives, continuing medical education for clinicians, and direct resource facilitation services for patients and caregivers.

In close collaboration with BICA and key stakeholders across Alaska, CLF developed and distributed the first *Concussion Guidebook for Alaskan Patients and Caregivers* to support concussion recovery through comprehensive education and guidance. More than 10,000 physical postcards with QR links to the guidebook were distributed across the state through BICA members, healthcare providers, and local organizations, along with 500 full-color printed copies delivered to partner organizations for distribution at centralized, high-traffic locations. Additional education and awareness efforts have

reached over 30,000 individuals with access to the guidebook and links to organizations and services for Alaskans living with brain trauma. Recognizing the ongoing need for medical provider education, CLF has also offered free, accredited continuing education courses covering clinical best practices for mild TBI, including recent injuries, persistent symptoms, long-term outcomes, domestic violence, and mental health. Courses were shaped in part by findings from needs assessments conducted by UAA and CLF. Out of more than 625 local and regional attendees who provide care for Alaskan patients, 62% reported intent to implement immediate practice changes based on what they learned.

At the heart of these efforts is <a href="CLF HelpLine Alaska">CLF HelpLine Alaska</a>. This is a free, confidential service offering personalized resource facilitation. Since its launch, the CLF HelpLine has supported 59 Alaskan families, most seeking help for recent concussions or lingering symptoms, across both urban and rural communities. With upcoming initiatives such as launching a statewide virtual peer support group and delivering new education materials, CLF remains committed to supporting Alaskans impacted by brain trauma and looks forward to continuing this vital work through community collaborations.

## Publication of the Traumatic Brain Injury in Alaska Epidemiology Bulletin

In 2023, the State of Alaska, Section of Epidemiology, released the <u>Traumatic Brain</u>
<u>Injury in Alaska Epidemiology Bulletin</u>. This report compiled state data to provide an indepth picture of the ways that brain injury impacts Alaskans. The wide breadth of data sources included the Alaska Trauma Registry, Health Facilities Data Reporting
Program, Health Analytics and Vital Records, Medicaid Expenditures, and the UAA
Center for Human Development's 2019 Alaska Brain Injury Needs Assessment. Topics addressed in this report include data related to brain injury morbidity, mortality, hospitalizations, costs, and prevention recommendations. This report is crucial in supporting organizations that provide education on the current state of brain injury in Alaska.

#### Glossary

**Acquired Brain Injury** is an overarching term that includes both traumatic and non-traumatic brain injury. It refers to injuries to the brain that have occurred but were not caused by trauma during birth and are not degenerative, congenital, or hereditary.

Administration for Community Living (ACL) is a federal agency focused on promoting inclusion and independence for individuals with disabilities and older people. At the time of this report, the ACL is part of the United States Department of Health and Human Services.

Alaska Brain Injury Consortium (ABIC) is a nonprofit organization that operates the Alaska Brain Bus and provides education and resources across the state.

**Alaska Division of Juvenile Justice** runs the state's juvenile correctional facilities and is part of the State of Alaska Department of Family and Community Services.

Alaska Mental Health Trust Authority (AMHTA) serves Trust beneficiaries, who are individuals experiencing mental illness, intellectual and developmental disabilities, chronic alcohol or drug addiction, Alzheimer's disease and related dementia, and TBIs.

Alaska Trauma Registry collects information from all acute care hospitals on the incidence of trauma. The data is focused on patients who experienced an injury within the last 30 days who were hospitalized, transferred, observed, or dead in the emergency department.

**Behavioral Risk Factor Surveillance System (BRFSS)** is a national telephone survey that collects data from all 50 states regarding residents' chronic health conditions and health behaviors.

**Brain Injury Association of America (BIAA)** is a national organization dedicated to enhancing prevention, awareness, treatment, knowledge, research, and advocacy efforts for brain injury.

**Brain Injury Council of Alaska (BICA)**, previously known as the TABI Advisory Council, is a volunteer council responsible for developing the Alaska State Plan for

Brain Injury. BICA's mission is "to understand, educate, and advocate for the needs of all Alaskans regarding traumatic and acquired brain injury."

Center on Brain Injury Research and Training (CBIRT) is situated within the Department of Psychology at the University of Oregon. CBIRT performs research and offers training focused on improving the lives of individuals of all ages with TBI.

Center for Human Development (CHD) conducts research and provides educational services. CHD also runs the BICA through a Memorandum of Agreement with the State of Alaska Division of Senior and Disabilities Services, which is the lead agency for TBI in Alaska. CHD is situated within the University of Alaska Anchorage. Its mission is focused on enhancing the quality of life for individuals experiencing disabilities and their families. CHD is Alaska's University Center for Excellence in Developmental Disabilities (UCEDD).

**Concussion Legacy Foundation (CLF)** is a non-profit organization supporting people impacted by concussions and chronic traumatic encephalopathy (CTE). In Alaska, CLF provides education, conducts research, provides informational resources, and runs a helpline.

Core State Injury Prevention Program (Core SIPP) grant is funded by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC).

**Health Analytics and Vital Records (HAVRS)** is situated within the Alaska Department of Health. It is responsible for managing vital records and health data, including death data.

**Health Facilities Data Reporting (HFDR) Program** collects inpatient and outpatient discharge data from healthcare facilities across Alaska, including private, municipal, state, federal, Alaska Native, and psychiatric hospitals. However, it does not include military hospitals.

**National Association of State Head Injury Administrators** supports public brain injury programs by providing information and education to state employees and other organizations serving those with brain injury.

National Vital Statistics System houses data on births and deaths in the United States.

**Non-traumatic brain injury** is damage to the brain from internal factors (e.g., due to a lack of oxygen or pressure from a tumor). Factors that may cause these include stroke, near-drowning, aneurysm, and infectious disease.

**Section of Chronic Disease Prevention and Health Promotion (CDPHP)** is housed within the State of Alaska's Division of Public Health. CDPHP is focused on preventable health problems, including reducing rates of injury, chronic disease, and substance misuse.

**Southcentral Foundation** offers a wide range of health and wellness services for Alaska Native and American Indian people living in Anchorage and the Matanuska-Susitna Borough, and nearby villages.

**Southeast Regional Resource Center (SERRC)** is Alaska's Educational Service Agency. It is a nonprofit providing support to educators and learners across the state.

**TABI Mini-Grant** is a state-funded program. Alaskans with brain injury can receive up to \$2,500 each year, with a limit of \$5,000 over five years, to help fund needed supplies or services.

**TABI Resource Facilitators** provide information and resources to individuals with acquired brain injury across Alaska. They can also assist individuals in applying for the TABI Mini-Grant.

**Traumatic and Acquired Brain Injury (TABI)** is a term commonly used in Alaska that emphasizes that it incorporates all types of acquired brain injuries.

**Traumatic Brain Injury (TBI)** is an alteration in brain function caused by an external force (e.g., a bump to the head, penetrating head injury). Incidents like falls, assaults, motor vehicle accidents, and sports injuries could cause these.

**Waiver** programs, often referred to as Medicaid Waiver programs, provide services to individuals with chronic health conditions and disabilities, enabling them to receive care in the community. Each state has its own waivers. Currently, Alaska does not have a brain injury-focused waiver.

**Youth Brain Injury Program** is housed within SERRC. It provides support to students in Alaska aged 0 to 21 who have a suspected or diagnosed brain injury. This program also offers brain injury screening with the Juvenile Justice System.

#### References

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## **Appendix**

## **Description of main data sources**

## State of Alaska Epidemiology Bulletin: Traumatic Brain Injury in Alaska

The epidemiology bulletin compiled data sources from across Alaska and synthesized them into a single report (Newell, 2023). Data sources included morbidity rates from the Health Facilities Data Reporting Program from 2016 to 2021 and from the Alaska Trauma Registry between 2017 and 2021, mortality rates from 2016 to 2021 as reported by Alaska Vital Statistics through the Health Analytics and Vital Records system, Medicaid Expenditures from 2017 to 2021, and results from the 2019 Brain Injury Needs Assessment. Data showed that suicide and unintentional falls were the leading causes of TBI mortality and morbidity in the state. This bulletin also used the data to identify and discuss some of the key priority prevention areas, namely suicide prevention, firearm storage, intimate partner violence, and motor vehicle safety.

Bulletin available at: <a href="https://epi.alaska.gov/bulletins/docs/rr2023\_02.pdf">https://epi.alaska.gov/bulletins/docs/rr2023\_02.pdf</a>

#### Alaska specific CDC report findings

The CDC produced a report titled "Differences in State Traumatic Brain Injury-Related Deaths, by Principal Mechanism of Injury, Intent, and Percentage of Population Living in Rural Areas: United States, 2016–2018." Using the National Vital Statistics System, the CDC reported that for intentional TBI-related deaths, the two leading causes were suicide (40%) and homicide (12%). For unintentional TBI-related deaths, the leading causes were motor vehicle crashes (20%) and falls (14%). Alaska had the highest rate of TBI-related deaths nationally, with 34.8 per 100,000 population per year. This rate was 101.2% higher than the overall U.S. average.

CDC report available here: <a href="https://www.cdc.gov/mmwr/volumes/70/wr/mm7041a3.htm">https://www.cdc.gov/mmwr/volumes/70/wr/mm7041a3.htm</a>

#### 2024 Alaska Brain Injury Needs Assessment Survey

The UAA Center for Human Development opened the Alaska Brain Injury Needs Assessment Survey from August 1, 2024, to September 30, 2024. The survey took approximately 15 minutes to complete and was available online, in hardcopy, or over

the telephone. It consisted of three survey tracks for 1) individuals with brain injury, 2) family members, caregivers, and guardians, and 3) medical and service providers. Three hundred and eight participants completed, or partially completed, the survey, with 71 (23%) completing the first track, 55 (18%) the second track, and 182 (59%) completing the third track. The first two survey tracks inquired about the survivor's history of brain injury, services received, unavailable services, satisfaction with the availability of programs, and experiences with employment, healthcare, housing, and transportation. Additional questions only asked in the first survey track inquired about engagement in social relationships. Extra questions in the second survey track asked about the availability of support for family members, caregivers, and guardians. The third survey track for providers inquired about job details, barriers to supporting individuals with brain injury, referral sources, training topics most needed, and knowledge of brain injury screening, prevention, Return to Play protocols, and brain injury organizations that can offer support across Alaska.

Summary results available at: <a href="https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/brain-injury-partnership-program/index.cshtml">https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/brain-injury-partnership-program/index.cshtml</a>

## Concussion Legacy Foundation 2022 Alaska Provider Survey

The Concussion Legacy Foundation (CLF) conducted the Alaska Medical Providers Concussion and Chronic Traumatic Encephalopathy (CTE) Knowledge Survey commissioned by the Alaska Mental Health Trust Authority. The survey aimed to ascertain the standard of care in Alaska by using case studies to review provider knowledge. Areas assessed included screening, diagnosis, and treatment of concussion, post-concussion syndrome, and CTE. The findings from the 127 providers who completed the survey were used to develop and hold free continuing education classes across Alaska, which were created and held by the CLF.

Provider Survey results available at: www.concussionfoundation.org/alaska

## Southcentral Foundation Customer-Owner interviews and focus group

This small-scale qualitative study aimed to discover SCF Customer-Owner thoughts regarding brain injury care. Several interviews and one focus group were held in which participants were asked for their feedback on 1) how they think brain injury services at SCF look and feel, 2) what the scope of the brain injury system should be, and 3) what should be done to improve the delivery of brain injury-related services at SCF. Although this information focused specifically on SCF, the findings provided insights into the experiences of patients receiving brain injury care in Alaska; therefore, they were utilized in state planning efforts.

This was an internal study at SCF; therefore, the study results are not available online.