

Acquired Brain Injury in Maine

State Action Plan

2023 - 2028

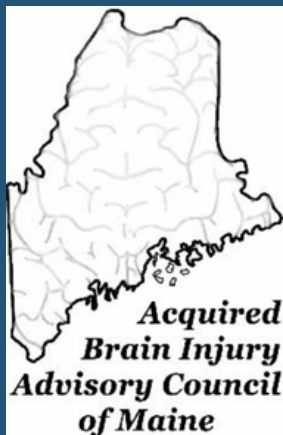


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Mission, Vision, and Values

Mission

The mission of the Acquired Brain Injury Advisory Council (ABIAC) of Maine is to provide oversight and advice to improve the state's system of care for people living with acquired brain injury (ABI) and their families to the Department of Health and Human Services (DHHS) and the Legislature.

Vision

Our vision is for all people with ABI and their families to have access to a comprehensive continuum of care and support, regardless of where they live in the state, and all people to have an awareness of brain injury services in Maine.

Core Values

Leadership: We stand up for what we believe in

Integrity: We tell the truth and keep our promises

Respect: We treat others the way we want to be treated

Diligence: We work hard every day

Strategy: We think before we act

Growth: We aspire to do more and be more

Collaborative: We work together as a team

Person-centered: We keep the focus on individuals affected by brain injury

Outcome-oriented: We are focused on results

Plan At A Glance

Strategic Priorities



Improve access to ABI services, natural supports, transportation, and housing, and a reduction in waitlists for adults and children



Increase awareness



Improve screening



Improve statewide data collection and reporting

The primary focus of Maine's Acquired Brain Injury (ABI) State Action Plan is to help guide the building, expansion and enhancement of state infrastructure to improve services and support for all persons living with brain injury. This includes: restoring community based services to pre-pandemic levels; providing all services within the State of Maine to allow individuals that have been placed out of state to return to their home communities; and improving the transportation system to allow access to services on a consistent and reliable basis. The plan also aims to improve access to ABI services, including neuropsychologists, psychiatrists, neurologists, and allied health providers who have clinical experience with persons with brain injury.

The Plan outlines four strategic priorities, each including a set of actionable goals and performance measures.

Introduction

The Acquired Brain Injury Advisory Council (ABIAC) is pleased to present the 2023 State Action Plan, setting the vision and roadmap for addressing current and future needs of acquired brain injury services in Maine. The overall goal of Maine's Acquired Brain Injury (ABI) State Action Plan is to help guide the building, expansion and enhancement of state infrastructure to improve services and support for all persons living with brain injury. The Plan was developed to address each area of need and identify ways to improve the system of care for Maine residents with ABI.

Established in 2007, the ABIAC provides oversight and advice to DHHS and the Legislature. The Council, which represents and advocates on behalf of the brain injury community in Maine, is composed of survivors, family members and caregivers, service providers, state representatives, and advocates. The Office of Aging and Disability Services (OADS) included funding for this state action plan as one of the key strategies in their Administration of Community Living (ACL) federal Traumatic Brain Injury State Partnership Program (SPP). This effort was led by the ABIAC in partnership with the BIAA and an independent consulting group. Council members from each affinity group and other local stakeholders played an important role in the development of the Plan. The process began by conducting a formal needs assessment in 2021 to identify the needs and common gaps in Maine's ABI services. The assessment identified gaps in the availability and accessibility of services, training for providers, and funding.

Once the needs were identified, the Council began the process of developing a state action plan for the state of Maine. Through the collaborative efforts of local stakeholders, the Council assessed the current level of services, identified current projects, and developed actionable steps for addressing the gaps. Performance measures for each strategic priority are also incorporated into the Plan to track progress over time. The plan is presented with the goal of guiding state leaders in developing and supporting a path to implementation.

Methodology

2021 Needs Assessment



12 Interviews

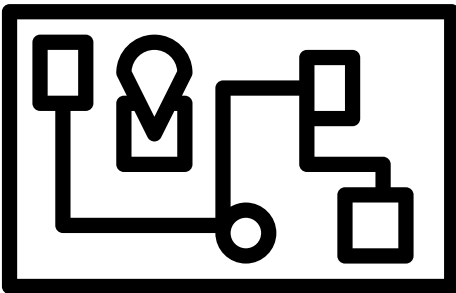


2 Surveys



2 Focus Groups

2022-2023 Strategic Planning Process



**1 Ecocycle Planning
Session with Steering
Committee**



**7 Council
Workshops**



**5 Affinity
Groups**

2021 Needs Assessment

The [2021 Needs Assessment](#) explored Maine's brain injury services, including training and resource needs of providers, needs of survivors and caregivers, and the intersection of brain injury and behavioral health. The assessment involved stakeholders from across the state, including individuals with ABI, their family members and caregivers, service providers, advocates, and other state leaders. After collecting and analysis the information gathered through interviews, surveys, and focus groups, the following unmet needs were identified:

Common Gaps

- **Long waiting lists due to workforce shortages, lack of funding, and limited training for providers.** Long wait times often lead to survivors going out of state to receive care.
- **Barriers to affording and/or accessing services.** Barriers to access include a lack of awareness of services available, not having services available nearby, and not understanding the process to get services. In particular, survivors indicated that the time immediately after the brain injury is the point when services are most difficult to access. Lack of reliable transportation is also a barrier to receiving services, especially in rural areas. Survivors also indicated a need for assistance in navigating the community-based system of care for chronic, lifelong phase of recovery.
- **Support for housing.** Survivors indicated that the cost of housing and having the skills to live safely on their own prevented them from getting and/or maintaining a place to live. Providers identified long-term residential services as an unmet need.
- **Lack of a standardized screening tool and statewide incidence and prevalence data.** The lack of data and a screening tool makes it difficult to not only identify brain injuries in the state, but also to connect people to services and funding support. Screening and early identification are important factors in a person's recovery.

As a result of these gaps, many Maine residents with ABI are met with barriers to accessing the services they need. To close these gaps and better serve survivors, the Council developed a comprehensive list of strategic priorities, actionable goals, and performance measures.

Strategic Priorities, Goals, and Performance Measures

The following strategic priorities and actionable goals are designed to address the identified needs of Maine residents with ABI. To develop these goals, members of the Advisory Council and its subcommittee spent innumerable hours reviewing the results of the Needs Assessment, assessing current initiatives, and assessing the current state of Maine's system of care.

The following **four strategic priorities** were identified:

1. Improve access to ABI services, natural supports, transportation, and housing, and a reduction in waitlists for adults and children;
2. Increase awareness;
3. Improve screening; and
4. Improve statewide data collection and reporting.

Goals and performance measures were developed for each strategic priority. Actionable goals are prioritized into short term and long term goals.

Strategic Priority 1

Improve Accessibility to ABI Services, Transportation, Housing, and a Reduction in Waitlists



Overview

There is a lack of access to affordable housing, transportation, and other BI services in Maine. This exists for two reasons: lack of funding and lack of capacity. Improving accessibility – including reliable transportation and telehealth options in rural areas, and acknowledging a BI is devastating in a lot of ways (including financial) – is critical to ensure a comprehensive continuum of care throughout the state for all. There is also a need to reduce waiting lists for services so persons with brain injury receive timely care. Waitlists for primary and specialty care are currently 12 months long. Due to the COVID-19 pandemic, Maine is experiencing a workforce shortage, specifically of specialists and in-home care providers. Maine is an aging state, reducing the number of available providers and increasing waiting times as a result. Reducing waitlists is critical because the essence of BI often requires long term or life long services, causing waitlists to move slowly due to the duration of those needs. It is also important for people with BI to receive timely treatment at the most critical time of the rehabilitation process.

Short Term Goals

1. Begin to explore additional state, federal, public, private, or philanthropic funding opportunities in addition to the ACL TBI State Partnership Program.
2. Provide community-based supports – such as neuro-resource facilitation or targeted case management – for those on a waitlist to support basic needs while a funded offer spot is secured or until people start services.
3. Increased focus on telehealth for appropriate services - especially in rural areas.
4. Monitor the implementation of a new model for self direction for ABI services.
5. Identify the need for comprehensive pediatric brain injury services (needs assessment? Services inventory?)
6. Provide sustainable funding for brain injury core support services such as peer support, support groups, helpline, or neuro-resource facilitation.
7. Provide support for persons ineligible for state services or MaineCare.



Long Term Goals

1. Build the state's capacity to identify and support the needs of brain injured children and their families.
2. Address the crisis in ABI services workforce shortage and expand the number of ABI service providers, including in rural areas.
3. Improve transportation for MaineCare and non-MaineCare, including in rural areas.
4. Focus on neurobehavioral treatment facility and funding in Maine and roadmap for care.
5. Increase affordable housing for people with BI in Maine through expanded Section 8 vouchers by working with Affordable Housing Coalition with the option of having coordinated supports when needed.
6. Increase access to a person-centered planning process and targeted case management, and reduce wait time for the brain injury waiver (fully utilize 250 slots) by increasing provider capacity and funding to study the root causes.



Strategic Priority 1

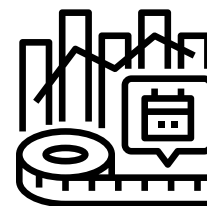
Improve Accessibility to ABI Services, Transportation, Housing, and a Reduction in Waitlists



Performance Measures

Accessibility:

- 10% increase in people with BI diagnosis receiving core support and services (Help line, neuro-resource facilitation, peer support), with a focus on representation for underserved populations that includes but is not limited to children and youth, indigenous persons, individuals in rural areas, unhoused individuals, and victims of domestic violence
- 5% increase in BI service providers in rural areas
- At least 1,500 people receive brain injury training over the next three years



Waitlists:

- Conduct waitlist study by October 2023 which identifies the number of MaineCare services individuals on the waitlist receive and report to the ABIAC
- 86% of the individuals on the waitlist for Home and Community-Based Services will receive information on applying for state plan brain injury services



Strategic Priority 2

Increase Awareness



Overview

There is a need for the ABIAC of Maine to take a greater role in increasing awareness of ABI so there is broad community recognition of ABI within Maine society. Limited awareness impacts prevention of brain injury and reinforces stigma at the community level. Awareness is the base of the pyramid. It supports the other strategic priorities, especially accessibility.

Short Term Goals

1. Increase awareness among policy making stakeholders.
2. Raise awareness around connection between overdose and ABI.
3. Raise awareness for schools around children with ABI, an underserved and unidentified group.
4. Stronger connections with the substance use prevention, treatment and awareness community to ensure co-occurring SUD/BI treatment continues.
5. Educating on symptoms and care needs of ABI to reduce stigma and promote self advocacy.
6. Promote awareness kicking off every brain injury awareness month and continuing throughout the year.
7. Sustainable grant funding to ensure continuing opportunities for awareness.



Long Term Goals

1. Address the crisis in workforce shortage and expand the number of service providers, especially in rural areas.
2. Sustainable state funding and other sources to ensure continuing opportunities for awareness.
3. Annual strategic media campaigns kicking off every brain injury awareness month.
4. Strengthen interagency or cross-agency coordination, education and partnerships to integrate brain injury awareness, identification and best practice.

Performance Measures

- Include information on brain injury on the Maine CDC Prevention Store by the end of 2023
- 30% increase in the number of BIAA-ME Facebook followers
- Increase the number of BIAA-ME newsletter recipients by 30%
- Identify priority target audiences for public media campaigns by March 2024
- 25% increase in individuals who receive education on symptoms and care needs of ABI



Strategic Priority 3

Improve Screening



Overview

There is a need to increase timely screening for brain injury in order to improve continuity of care so people with BI don't wait months or years to get treatment and services. Diagnosing a brain injury soon after it happens is crucial in providing support and care to the survivor and their family members and caregivers. Maine needs standardized and efficient screening tools and a data collection process for use in emergency rooms, at hospital discharge, in schools, and in the domestic violence and behavioral health systems.

Short Term Goals

1. Develop and implement training on screening tool through the grant.
2. Promote utilization of screening tools to the community and high risk populations such as individuals within SUD/behavioral health system for history of ABI.
3. Aggregate data from screening tools to identify gaps and trends and support funding requests.
4. Grant Funding for screening and other identification and tracking system.
5. Develop and implement training on screening tool that is accessible publicly.
6. Assess and identify an existing standardized screening tool for adults and children - make this information publicly available.



Long Term Goals

1. Funding for screening and other identification and tracking system statewide.

Performance Measures

- Training developed for the use of the National Association of State Head Injury Administrators (NASHIA) Online Brain Injury Screening and Support System (OBISS) and three organizations trained to use the tool.
- Creation of three pilot sites.
- At least 20 individuals screened in year one of implementation.



Strategic Priority 4

Improve Statewide Data Collection and Reporting



Overview

There is a need to improve statewide data collection and reporting in Maine so we can improve services using reliable data. Improved data collection assists with the identification of brain injuries and helps connect people to services and adequately fund support services. The data should track easily comparable baselines and outcomes and should be updated regularly and shared on a publicly available website. Data on brain injury should also be available for people receiving services through the Department of Education Special Education Services, the Department of Corrections, and the Office of Behavioral Health.

Short Term Goals

1. Produce annual report on TBI incidence and estimate of prevalence.
2. Share data with policy makers and state departments.
3. Raise awareness about the new concussion dataset available at the State (DOE).
4. Conduct regular needs assessments to identify unmet needs and gaps in services.



Long Term Goals

1. Recommend agencies within DHHS create one accessible system for tracking people with BI for outreach and support throughout their life.
2. Ensure the ABIAC has the resources needed to conduct annual needs assessments of unmet needs and gaps in services.

Performance Measures

- Publish annual data for the completed screens of NASHIA's OBISS.
- Publish quarterly reports on the Brain Injury Home and Community-Based Services (HCBS) utilization and waitlists.
- Provide reports annually to key policy makers and stakeholders on the gaps and unmet needs in BI services.

