

ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE

ANNUAL REPORT – January 15, 2022

2021 ABIAC Officers and Members – appointed by Commissioner of the Department of Health & Human Services

PROVIDERS

Scott Mayo, Co-Chair, Deer Isle
Matthew Hickey, Secretary, Yarmouth
Sharlene Adams, Manchester
Austin Errico, Ph.D., Freeport
Jen Jello, West Ossipee N.H.

ADVOCATE

Sarah Gaffney, Vassalboro
Catherine Slye, Augusta
Courtney Michalec, Brunswick
Trish Thorsen, Greene
Lee Glynn, Co-Chair, Skowhegan

FAMILIES

Lewis Lamont, Mapleton
Suzanne Morneault, Eagle Lake
Ed Russell, Winterport
Gary Wolcott, Chesterville
Annemarie Albiston, Carrabassett Valley

SURVIVOR

Nitzana Aufiero, Newport
Ted Brackett, Westbrook
Anthony Barresi, Presque Isle

STATE LIASONS

Derek Fales, OADS Liaison
Jessica Gartland, Vocational Rehabilitation
Aaron Burke, Maine CDC Injury Prevention
Emily Poland, Maine DOE
Theresa Barrows, OCFS

PURPOSE & OVERVIEW

Every 9 seconds, someone in the United States sustains a brain injury.

An acquired brain injury (ABI) is a brain injury that occurs after birth and is not hereditary, congenital, degenerative, or induced by birth trauma. ABI is the umbrella term for all brain injuries, including traumatic and non-traumatic injuries (e.g., strokes, brain tumors, anoxic injuries). ABIs can affect every aspect of an individual's being: physical, emotional, and cognitive impacts are common. More than 3.6 million children and adults sustain an ABI each year, but the total incidence is unknown (BIAA). It is estimated that 10,000 Mainers experience a brain injury every year.

ABIAC RESPONSIBILITIES AND HISTORY

- Formed in 2002 to support a federal grant
- Established in Statute in 2007 to provide oversight and advice to DHHS & Legislature
- Meets at least four times/year and holds at least two public hearings annually. Over the past 15 years, the ABIAC has held more than 50 public hearings throughout the state.
- Over the past 15 years, the ABIAC has served as the mandated Advisory Board for four Federal Traumatic Brain Injury (TBI) Partnership grants to improve the Maine's system of care for persons living

with brain injuries and their families. As part of those grants, the Council has sponsored more than a dozen statewide forums on critical issues and partnered with multiple provider organizations to provide training for hundreds of professionals and paraprofessionals.

- In 2021 the Council met ten times and held two public hearings.

CURRENT SERVICE SYSTEMS

Operated by provider organizations under contract with Maine DHHS or Maine DOL.

Medicaid Funding:

Specialized Nursing Care (Section 67)

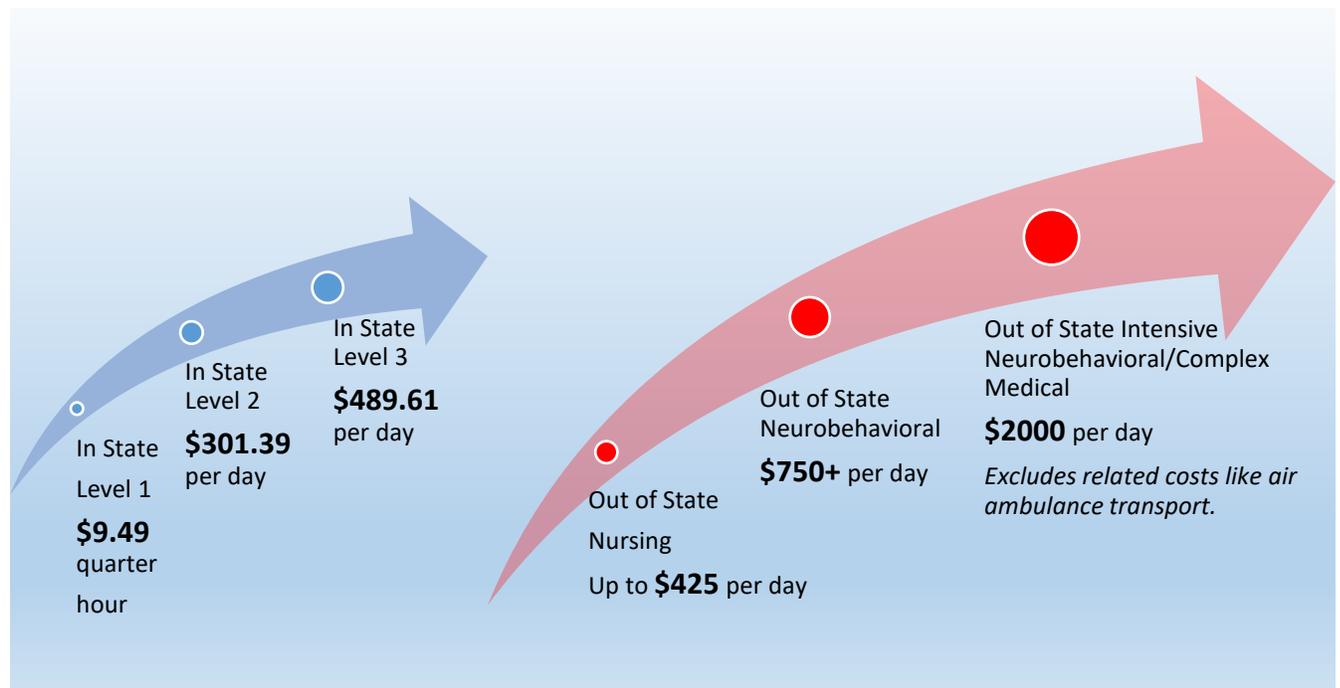
2 Specialized Skilled Nursing/Rehabilitation Facilities with **44** licensed specialized beds for persons with ABI

Brain Injury Home and Community Waiver – Section 18 MaineCare Benefits

202 Section 18 recipients, **48** Section 18 funded offers, **155** on Section 18 waitlist

37 Maine residents placed out-of-state due to lack of services. *The current rates for skilled neurorehabilitation in an “Out of State nursing facility” are up to \$425 dollars per day. The current rate for community based neurobehavioral treatment can start at around \$750 per day and the rate for intensive neurobehavioral treatment also in combination with complex medical needs can be up to \$ 2,000 per day. (The 2021 rate for Level 3 neurobehavioral services in Maine was \$489 per day).*

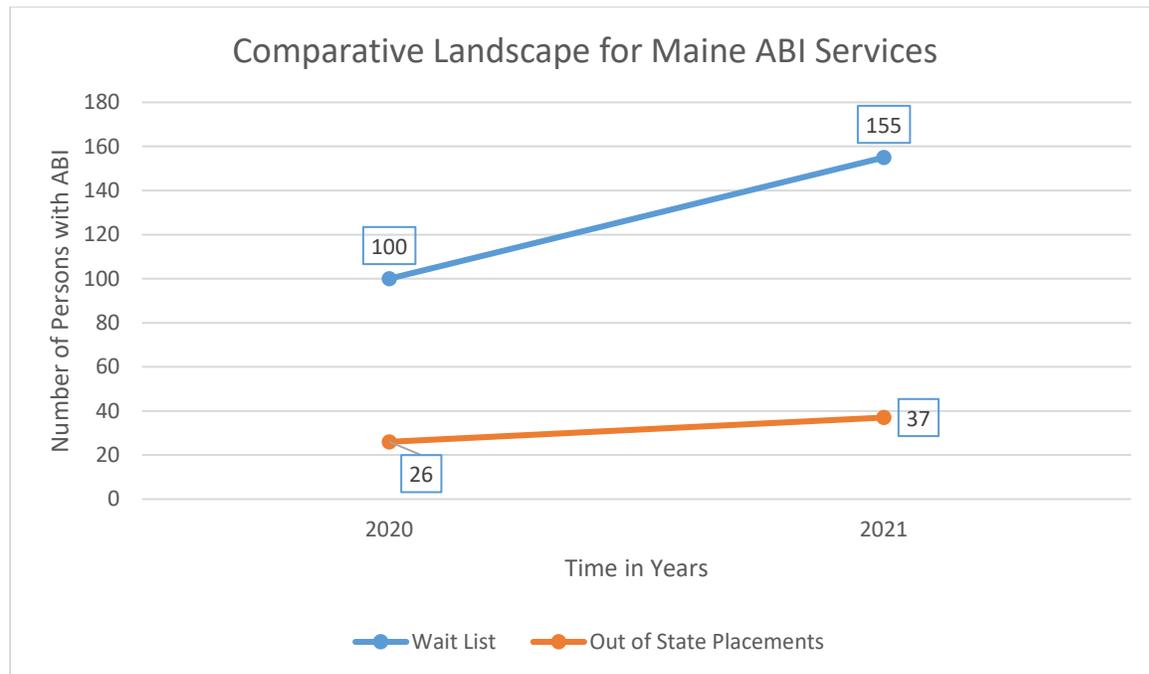
Comparative Costs: In State versus Out of State



To help stabilize the workforce and improve an HCBS system that has been strained by the COVID-19 pandemic, effective retroactively to January 1, 2021, the Department will temporarily increase rates for certain Home Support Services (T2016) under Section 18 (Home and Community-Based Services for Adults with Brain Injury).

These changes are made pursuant to P.L. 2019, ch. 616, Part A, Sec. A-7, *An Act Making Supplemental Appropriations and Allocations for the Expenditures of State Government, General Fund and Other Funds and Changing Certain Provisions of the Law Necessary to the Proper Operations of State Government for the Fiscal Years Ending June 30, 2020 and June 30, 2021*, and have been approved by the federal Centers for Medicare & Medicaid Services (CMS) in Maine’s amended 1915(c) HCBS waivers with the Emergency Preparedness and Response Appendix Ks.

- 3** Providers of care coordination services with **201** individuals served in 2021
- 35** Community residential programs with **153** beds
- 2** In-home support programs
- 16** Section 18 recipients are receiving attendant care services, a new service offered in 2021.



BI Outpatient Services

8 Outpatient neurorehabilitation clinics served **464** individuals in 2021 with MaineCare funding, more individuals were served with a different payer.

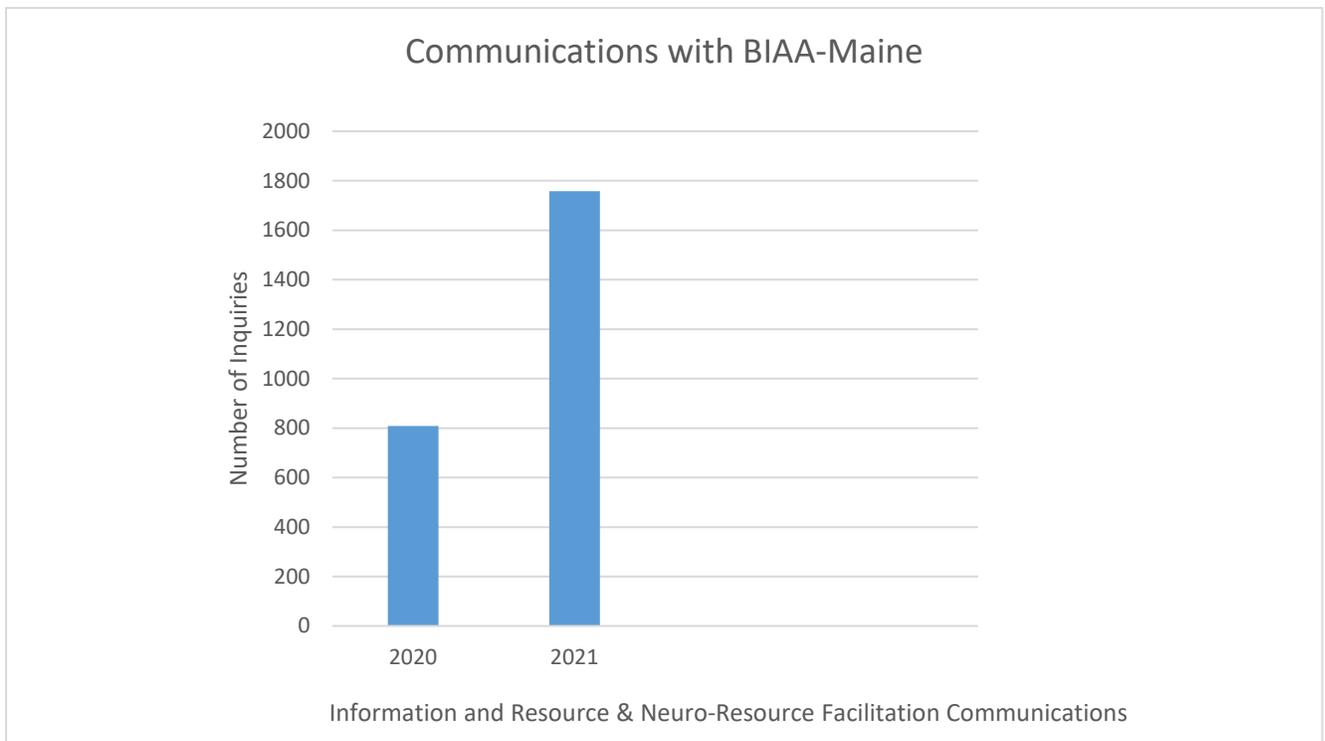
1 Work-ordered day club house, serving 28. However, the club house was initially closed in 2021 due to the Governor’s indoor gathering limits, and remained temporarily closed due to workforce shortages.

Vocational Rehabilitation Funding

2 Vocational Rehabilitation providers served **202** individuals in 2021.

DHHS Contract Funding with the Brain Injury Association of America - Maine Chapter Providing Core State Brain Injury Supports (CSBIS) for vulnerable populations.

- Neuro-Resource Facilitation to ensure access to brain injury services in Maine for high-risk individuals and support for families
- Information & Resource services to assist at-risk individuals and their families to navigate the brain injury system of care, including access to joint state and national HELPLINE.
- **1758** Neuro-Resource Facilitation and Information & Resource communications in 2021
- Outreach to newly injured/diagnosed persons with ABI
- Education and training, including the annual state brain injury conference, a Maine brain injury resource fair, a Maine-based resource directory, and family caregiver training
- Support and education for hospitals and agencies working with at-risk ABI populations
- Support for **17** Support Groups for survivors and families that engaged more than **2000** participants in 2021



CURRENT ACL FEDERAL PARTNERSHIP GRANT

In 2021, the Office of Aging & Disability Services (OADS) wrapped up a 2-year Federal TBI Partnership Grant through the Administration for Community Living (ACL) focused on addressing the intersection of the opioid crisis and brain injury. Accomplishments included webinars; a forum connecting the mental health, substance use disorder, and brain injury communities; and a statewide brain injury needs assessment. Additionally, in 2021, OADS received a new 5-year TBI Partnership Grant through the ACL. The focus of this new grant is to strengthen systems and services of support for Maine’s underserved brain injury populations.

ABIAC PRIORITIES FOR 2021 and OUTCOMES

- Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to ensure humane, cost-effective, evidenced-based treatment in Maine. Explore collaboration with New Hampshire and Vermont on development of mobile neurobehavioral team for assessment, treatment, and consultation for individuals served by community agencies. *Outcome- The ABIAC has created a subcommittee on policy and legislative initiatives. Committee members will provide recommendations for the full ABIAC to consider, review, and present to DHHS.*
- Advocate for a state law clearly describing the Rights of Service Recipients with ABI. *Outcome- LD 559 became law in 2021: An Act to Improve the Rights and Basic Protections of Persons with Acquired Brain Injury. The ABIAC had advocated for this action for more than a decade, and the ABIAC participated on the task force to develop recommendations on rules and procedures regarding the rights and basic protections of persons with acquired brain injury.*
- Advocate for ongoing coordination and funding for services to address the confluence of persons with substance use disorder and a brain injury. Support efforts to increase awareness, professional education, and treatment coordination. Advocate for MaineCare rule changes and funding for Substance Abuse Counseling as a billable service in the Neurorehabilitation Clinics in Section 102. *Outcome – The ABIAC supported the efforts of the recently completed Federal TBI Partnership Grant, which focused on the intersection of brain injury and substance use disorder. Next steps include finding a pathway to opening the Section 102 rules so Substance Abuse Counseling can once again be a billable service provided in the Section 102 Neurorehabilitation clinics.*
- Improve access and impact of Assistive Technologies/Telehealth for service recipients and providers through advocacy for DHHS rule changes that provide greater flexibility. Such changes can cause more efficient and effective use of funds and personnel to support service recipients. *Outcome - The ABIAC has created a subcommittee on policy and legislative initiatives. This sub-committee will participate in a work group that will provide assistance and advise DHHS regarding assistive technology policy.*
- Support the creation of an ABI trust fund to help Maine children and adults with ABI who lack financial resources/eligibility for timely, effective treatment. *Outcome- The brain injury trust fund subcommittee has demonstrated that there is a need in Maine for a funding source to support survivors through flexible, financial grants to obtain equipment and resources that may be beyond their means. The ABIAC has advocated for the formation of a group of individuals who will form a 501(c)(3) charitable trust to administer and assist the fund and to conduct fund raising on its behalf. The goal is to fund an initial round of modest grants in the spring of 2023.*
- Improve understanding and coordination of services for children with ABI through regular participation of a representative of OCFS on the ABIAC. *Outcome – In 2021, the ABIAC welcomed a representative from OCFS who is regularly participating in ABIAC meetings and activities.*
- Improve the effectiveness of the ABIAC through providing advanced, formal, quarterly status reports describing critical indicators of brain injury services from OADS, MaineCare, Maine CDC, and OCFS. *The ABIAC has created a subcommittee for efficacy and data collection. Committee members will provide recommendations for the full ABIAC to review, consider, and present to appropriate State of Maine departments.*

- Provide guidance to the ACL Partnership grant efforts including the statewide needs assessment to be conducted in 2021. *Outcome – Several members of the ABIAC participated as members of the steering committee for the statewide brain injury needs assessment conducted by OADS in 2021. In addition, several members provided testimony and interviews during the needs assessment, and the ABIAC helped distribute the provider and survivor/caregiver surveys to the Maine brain injury community.*

ABIAC PRIORITIES FOR 2022

- Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to ensure humane, cost-effective, evidenced-based treatment in Maine. Explore collaboration with New Hampshire and Vermont on development of mobile neurobehavioral team for assessment, treatment, and consultation for individuals served by community agencies.
- Advocate for ongoing coordination and funding for services to address the confluence of persons with substance use disorder and a brain injury. Support efforts to increase awareness, professional education, and treatment coordination. Advocate for MaineCare rule changes and funding for Substance Abuse Counseling as a billable service in the Neurorehabilitation Clinics in Section 102.
- Improve the effectiveness of the ABIAC by acquiring from OADS, MaineCare, Maine CDC, and OCFS advanced formal quarterly status reports describing critical indicators of brain injury services.
- Revise by-laws, remote meeting procedures, and new member orientation and development.
- Through the needs and awareness subcommittee of the ABIAC, identify transportation barriers and make recommendations for improvements to DHHS.
- Participate in the Rights of Service Recipients with ABI task force.
- Improve access and impact of Assistive Technologies/Telehealth for service recipients and providers through advocacy for DHHS rule changes and practices that provide greater flexibility.
- Advocate/support legislation related to Stroke Response care in Maine.
- Advocate for plan and program design to increase member awareness of MaineCare benefits.
- Support Brain Injury prevention strategies and campaigns. Make recommendations to DHHS.

REPORT SUMMARY

The COVID-19 pandemic has greatly impacted Maine's brain injury community: increased isolation and anxiety, difficulty accessing services, and the day-to-day obstacles of living through a global pandemic have been extremely challenging. The ABIAC commends the outstanding efforts of Maine's brain injury providers, healthcare workers, advocates, and State service providers in their efforts to support and protect Maine's brain injury survivors and their families during the ongoing pandemic.

Brain Injury is a significant, on-going public health issue that affects all communities in Maine. More than 10,000 Mainers will experience a brain injury in 2022. Falls, motor vehicle crashes, sports-related concussions, violence, combat-related injuries, opioid overdoses, strokes, brain tumors, infections, and other causes can result in ABIs. The Council is also concerned about brain injuries caused by emerging infectious diseases, including COVID-19, and the resultant impact on Maine citizens. ABIs are often accompanied by significant, long-term cognitive, emotional, behavioral, and physical changes that alter the lives of brain injury survivors and their families. In addition, brain injury survivors are at increased risk of experiencing social, mental health, and substance use disorder challenges.

The Federal Centers for Disease Control and Prevention (CDC) reports that traumatic brain injury (TBI) alone is the leading cause of death and disability in children and young adults in the United States. Overall, the number of persons currently living with disability due to acquired brain injury represents

4.5% of the U.S population (including stroke, TBI, and epilepsy combined). Many will make meaningful recoveries, especially if they get the needed rehabilitative care. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. Immediate access to specialized neurorehabilitation treatment (including information and care coordination) is crucial for positive outcomes. Unfortunately, public and private health insurance continues to impose limits for rehabilitative care based solely on financial costs rather than based on functional goals or treatment outcomes.

Sometimes, the system of community care ends prematurely for individuals, condemning them to costly nursing homes or institutions and cutting off options for the person to return home and to a productive life. History shows that these individuals can live successfully outside of institutions when treatment and supports are available. In addition, some individuals appear physically uninjured, but have significant cognitive and behavioral disabilities, and struggle to access services and support.

Year after year, testimony in ABIAC public hearings in Maine has demonstrated that individuals continue to experience avoidable challenges related to their brain injuries. Their injuries are often dismissed or misdiagnosed, leading to the provision of ineffective treatment which creates a significant misdirection of valuable resources. Even worse are those who are turned away with no treatment at all.

Public hearing testimony and the recent needs assessment has also emphasized the need for greater geographic access to services, education for professionals, addressing workforce shortages, waitlist for services, expanded care coordination services, increased public awareness for prevention, increased family and peer supports, access to employment opportunities, improved children's services, and addressing the complex needs of individuals with challenging behaviors.

The past year revealed alarming trends related to need and resources. The wait list for home and community-based services (MaineCare Section 18 waiver) increased 55% (from 100 in 2020 to 155 in 2021) and out-of-state placements due to lack of services climbed 42% (from 26 members in 2020 to 37 in 2021). In 2021, two home and community based group homes closed and two temporarily closed. By contrast, resource facilitation communications through the Brain Injury Association of America Maine Chapter more than doubled from the previous year.

The system in Maine must be about improving timely access to the right services and supports, thus creating efficiencies that allow our tax dollars to be used effectively. Effective utilization of resources includes evidence-based treatment approaches and a focus on positive behavioral supports to enhance the outcomes for the individual. By proper use of the tax dollars for treatment of individuals with brain injury, we also lower the burden on other support and service systems such as schools, hospitals, behavioral health services, and the criminal justice system.

THE LEWIS AND CLARA LAMONT ADVOCACY AWARD

In 2010 the ABIAC presented an Advocacy Award to Lewis and Clara Lamont for their amazing work with the Brain Injury Association of America's Maine Chapter as well as their strong advocacy for individuals impacted by brain injury. The award is presented every year in their name to someone who has positively influenced the brain injury community

Past Recipients:

2011-Dr. Berkner, Dr. Atkins, Dr. Heinz- Maine Concussion Management Initiative

2012-Beverly Bryant-Author and Advocate

2013-Marcia Cooper-Acquired Brain Injury Advisory Council and Brain Injury Information Network

2014-Kirsten Capeless-Brain Injury Services Manager DHHS

2015-Sarah Gaffney-Brain Injury Association of America-Maine Chapter

2016-Richard Brown-Family Member and Advocate

2017-Suzanne and Mindy Morneault- All Things Become New-Founder

2018-Gary Wolcott-Former State Service Leader, Family Member and Advocate

2019-Kelley Spencer-Maine A.T. Solutions

2020-Representative Allison Hepler

STATUTORY REQUIREMENTS

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES

Chapter 19: ADVISORY COUNCILS

§19001. Acquired Brain Injury Advisory Council

1. Council established. The Acquired Brain Injury Advisory Council, referred to in this section as "the council," is established to provide independent oversight and advice and to make recommendations to the commissioner. [PL 2011, c. 657, Pt. CC, §4 (AMD).]

2. Duties. The council shall:

A. Identify issues related to brain injury, including prevention and the needs of individuals with disabilities due to brain injuries and the needs of their families; [PL 2007, c. 239, §2 (NEW).]

B. Recommend methods that will enhance health and well-being, promote independence and self-sufficiency, protect and care for those at risk and provide effective and efficient methods of prevention, service and support; [PL 2007, c. 239, §2 (NEW).]

C. Seek information from the broadest range of stakeholders, including persons with brain injuries, their families, rehabilitation experts, providers of services and the public, and hold at least 2 public hearings annually, in different regions of the State, to generate input on unmet needs; [PL 2007, c. 239, §2 (NEW).]

D. Review the status and effectiveness of the array of brain injury programs, services and prevention efforts provided in this State and recommend to the commissioner priorities and criteria for disbursement of available appropriations; and [PL 2007, c. 239, §2 (NEW).]

E. Meet at least 4 times per year and by January 15th of each year submit a report of its activities and recommendations to the commissioner and to the Legislature. [PL 2007, c. 239, §2 (NEW).]

[PL 2007, c. 239, §2 (NEW).]

3. Administrative support. The department shall provide administrative support to the council. [PL 2011, c. 657, Pt. CC, §4 (AMD).]

4. Membership. The commissioner shall appoint 25 persons to serve as members of the council and shall annually appoint one person to serve as chair. Members serve 2-year terms. Members must represent the following persons and interests:

- A. Five members with acquired brain injuries must represent persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]
 - B. Five members must represent families of persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]
 - C. Two members must represent advocates for persons with acquired brain injuries; [PL 2007, c. 239, §2 (NEW).]
 - D. Five members must represent providers of services to persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]
 - E. Five members must represent state agencies with expertise in the areas of education, employment, prevention of brain injuries, homelessness, corrections and services to veterans. Members of the council who represent state agencies serve ex officio, without the right to vote, and shall provide data, information and expertise to the council; [PL 2019, c. 566, §1 (AMD).]
 - F. One member must represent an aging and disability resource center; [PL 2019, c. 566, §1 (NEW).]
 - G. One member must represent a center for independent living; and [PL 2019, c. 566, §1 (NEW).]
 - H. One member must be the long-term care ombudsman under Title 22, section 5107 A or a representative of the long-term care ombudsman. [PL 2019, c. 566, §1 (NEW).]
- [PL 2019, c. 566, §1 (AMD).]

5. Expenses. Members of the council serve without compensation but are entitled to reimbursement of reasonable expenses for attending meetings of and serving on the council.

Title 22: HEALTH AND WELFARE

Subtitle 2: HEALTH

Part 7: PUBLIC REHABILITATION SERVICES

Chapter 715-A: ASSISTANCE FOR SURVIVORS OF ACQUIRED BRAIN INJURY

§3087

§3086.

Definitions

As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings. [PL 1987, c. 494 (NEW).]

1. Acquired brain injury. "Acquired brain injury" means an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which:

- A. Is not of a degenerative or congenital nature; [PL 1989, c. 501, Pt. P, §26 (NEW).]
- B. Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]
- C. Can result in the disturbance of behavioral or emotional functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]
- D. Can be either temporary or permanent; and [PL 1989, c. 501, Pt. P, §26 (NEW).]
- E. Can cause partial or total functional disability or psychosocial maladjustment. [PL 1989, c. 501, Pt. P, §26 (NEW).]

§3088. Comprehensive neurorehabilitation service system

The department shall, within the limits of its available resources, develop a comprehensive neurorehabilitation service system designed to assist, educate and rehabilitate the person with an acquired brain injury to attain and sustain the highest function and self-sufficiency possible using home-based and community-based treatments, services and resources to the greatest possible degree. The comprehensive neurorehabilitation service system must include, but is not limited to, care management and coordination, crisis stabilization services, physical

therapy, occupational therapy, speech therapy, neuropsychology, neurocognitive retraining, positive neurobehavioral supports and teaching, social skills retraining, counseling, vocational rehabilitation and independent living skills and supports. The comprehensive neurorehabilitation service system may include a posthospital system of nursing, community residential facilities and community residential support programs designed to meet the needs of persons who have sustained an acquired brain injury and assist in the reintegration of those persons into their communities. [PL 2011, c. 293, §3 (RPR).]

SECTION HISTORY

PL 1987, c. 494 (NEW). PL 2011, c. 293, §3 (RPR).

§3088-A. Support for underserved populations

Within the limits of its available resources, the department may enter into contracts with organizations representing individuals with a brain injury and their families, bringing together state and national expertise to provide core brain injury support for underserved populations of individuals with an acquired brain injury, including, but not limited to, individuals who experienced an opioid drug overdose resulting in anoxic or hypoxic brain injury, who are veterans, who are victims of domestic violence, who are experiencing homelessness, who are ineligible for MaineCare and who have a newly acquired brain injury. For the purposes of this section, "core brain injury support" includes, but is not limited to, resource facilitation, brain injury support groups, outreach designed for individuals who have a newly acquired brain injury, access to a joint state and national helpline, information and resource education and family caregiver training. The department may adopt rules to implement this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2 A. [PL 2019, c. 488, §1 (NEW).]

SECTION HISTORY

PL 2019, c. 488, §1 (NEW).

§3089. Acquired brain injury assessments and interventions; protection of rights

The department is designated as the official state agency responsible for acquired brain injury services and programs. [PL 2005, c. 229, §1 (NEW).]

1. Assessments and interventions. In addition to developing the comprehensive neurorehabilitation service system under section 3088, the department may undertake, within the limits of available resources, appropriate identification and medical and rehabilitative interventions for persons who sustain acquired brain injuries, including, but not limited to, establishing services:

A. To assess the needs of persons who sustain acquired brain injuries and to facilitate effective and efficient medical care, neurorehabilitation planning and reintegration; and [PL 2011, c. 293, §4 (NEW).]

B. To improve the knowledge and skills of the medical community, including, but not limited to, emergency room physicians, psychiatrists, neurologists, neurosurgeons, neuropsychologists and other professionals who diagnose, evaluate and treat acquired brain injuries. [PL 2011, c. 293, §4 (NEW).]

[PL 2011, c. 293, §4 (NEW).]

2. Rights of patients and responsibility of department to protect those rights. To the extent possible within the limits of available resources and except to the extent that a patient with an acquired brain injury's rights have been suspended as the result of court-ordered guardianship, the department shall:

A. Protect the health and safety of that patient; [PL 2011, c. 293, §4 (NEW).]

B. Ensure that the patient has access to treatment, individualized planning and services and positive behavioral interventions and protections; and [PL 2011, c. 293, §4 (NEW).]

C. Protect the patient's rights to appeal decisions regarding the person's treatment, access to advocacy services and service quality control standards, monitoring and reporting. [PL 2011, c. 293, §4 (NEW).]

[PL 2011, c. 293, §4 (NEW).]

3. Rules. The department shall establish rules under this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

[PL 2011, c. 293, §4 (NEW).]

SECTION HISTORY

PL 2005, c. 229, §1 (NEW). PL 2011, c. 293, §4 (AMD).

Final Report

Maine Brain Injury Needs Assessment

PREPARED FOR

Brain Injury Association of
America's Maine Chapter



BRAIN INJURY
ASSOCIATION
OF AMERICA - MAINE



GROWING IDEAS INTO SUCCESS

koneconsulting.com

Executive Summary Introduction

The Brain Injury Association of America – Maine Chapter (BIAA-ME) contracted with Koné Consulting to complete this needs assessment of brain injury survivors and their family members, caregivers, and providers in Maine, building off three previous needs assessments. To complete this needs assessment, Koné Consulting conducted a mixed methods assessment that included interviews of 18 people, a survey of 274 survivors, caregivers, and family members, a survey of 177 providers, and 2 focus groups with 14 survivors, caregivers, and family members. The assessment explores brain injury services and unmet needs, training and resource needs of providers, needs of caregivers, and the intersection of brain injury and behavioral health. For brevity, survivors, family members, and caregivers who completed the survey are referred to as “consumers.”

Key Findings and Opportunities for Improvement Awareness

Consumers and providers both ranked increasing awareness of brain injury first among five options when asked what would most positively impact Mainers with brain injury. Limited awareness impacts prevention of brain injury and reinforces stigma at the community level. It also limits identification of brain injury—especially of mild injuries that may go overlooked—and delays intervention. Consumers also indicated the lack of awareness of the services available as a significant barrier to receiving care and therefore slowing the recovery process.

Injury Screening and Diagnosis *There is a need to increase and improve screening for brain injury and improve diagnosis of brain injury*

About 80% of consumers who completed the survey reported that the nature of their injury was a blow to the head or a stroke. The cause of respondents’ injuries were more varied, with auto accident and a fall cited the most often. Diagnosing a brain injury soon after it happens is a critical step in providing care for the survivor. About 73% of consumers were diagnosed between 0 to 3 months of their injury. Awareness of brain injury within the community and among providers is also an important piece of survivors’ healing process. Screening for brain injury is a critical piece of a person’s recovery, but Maine does not have a koneconsulting.com 7 standardized tool. About 26% of providers indicated they do not screen for brain injury. Over half of consumers indicated they use MaineCare to pay for their services.

Health-related services *Primary barriers to services are lack of awareness of services, not having services near where survivors live, and not understanding the process to get services*

Consumers in general have good experiences with rehabilitation services. Three-quarters of the consumers said they were satisfied or very satisfied. The main

rehabilitation service used by consumers is outpatient neuro-rehabilitation, indicating aspects of this service could be incorporated in other parts of the system to improve consumer service experience. Consumers and providers identified unmet needs for three services: brain injury diagnosis and assessment, specialized medical services (neurologist, neuropsychologist), and residential in-home support. *Consumers and providers differ on when services are more difficult to access after an injury* Consumers identified the time immediately after the brain injury as the point when services are most difficult to access. In contrast, providers identified two or more years after the injury as the time period when services are most difficult to access. Over 40% of consumer respondents stated that they are currently receiving mental health services. Consumers indicated that the mental health service they wish they could use more was a peer group (21%). When consumers were turned away by providers, one of the main reasons given was that a brain injury specialist was not available (19%). This survey attempted to capture individuals who were receiving both mental health and substance use services, however in targeted questions about substance use services, only 4% of consumers indicated that they were currently receiving substance use services. The limited number of survey responses is believed to be an underrepresentation of those experiencing brain injury and substance use and therefore prevented an in-depth analysis of substance use services. Additionally, survey results reveal an opportunity to increase awareness of brain injury among police and medics; only 14% of the consumers who had interactions with emergency responders were asked if they had a brain injury. Fortunately, these interactions with emergency responders largely have not resulted in negative impacts on access to services for consumers.

Daily Living *Affordable housing and residential services remain as needs, leading to waiting lists and sending survivors out of state for care* koneconsulting.com 8 Survivors require support services to meet their daily needs and progress towards full recovery. Three support services of interest are education, housing, and employment services. Consumers have education consultation and wrap-around family support or home visiting services at the top of their wish list for education services. Consumers were the least satisfied with employment services. Among the primary limitations for gaining and keeping employment were consumers' changing needs over time (59%) and having a hard time finding a job that will accommodate their brain injury (40%). Close to 60% of the consumers reported living independently in their own homes with modifications, assistive technology or with a personal care provider. When asked to identify [describe?] their challenges with housing, consumers indicated that the cost of housing and having the skills to live safely on their own prevented them from getting or keeping a place to live. Providers indicated the highest needs were for in-home personal care provider services (67%), low-income/subsidized housing (65%), and permanent supportive housing (64%). Just over half (54%) of the providers identified **long-term residential services as an unmet need**, yet this was the highest identified need during stakeholder interviews [because it?] leads to waiting lists.

Satisfaction with Services *Consumers and providers have different perspectives on service barriers* The proportion of consumers who were satisfied to very satisfied with support services (health-related or for daily living) ranged from 69% to 76%. These estimates summarized in

Table 1 show that there is room for improvement in delivery and quality of services. Particular attention could be paid to the demands of consumers regarding employment services, the support service with the lowest satisfaction ratings. Providers were asked to identify the top three barriers they believe prevent people with brain injuries from accessing services. Over half responded that **waiting lists** are an issue, with **limited training for providers** and **location** as the second and third most-selected responses. **Table 1: Percent of Consumers satisfied or very satisfied with support services**

Level of Injury Severity	Rehabilitation (N=214)	Education (N=161)	Employment (N=92)	Housing (N=130)	Provider Communication/ Coordination (N=173)
Mild	68%	77%	69%	69%	72%
Moderate	80%	68%	65%	78%	58%
Severe	71%	64%	56%	70%	84%

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System Coordination and Support for Providers and Caregivers *Consumers and providers have different priorities regarding service coordination needs* Seventy percent (70%) of consumers are satisfied or very satisfied with how their providers communicate and collaborate with one another. Consumers who responded they were dissatisfied or very dissatisfied with communication and collaboration between their providers identified that **having someone to help them navigate services** and **having one case manager who could work across supports** would be most helpful in improving service coordination, while providers overwhelmingly believe that having **more options for services and supports** would be most helpful. *Provider training could be improved—especially cross-training across fields* Providers and caregivers need ongoing support and training to be able to care for survivors. Providers responded they need additional funding for staff to attend trainings and high-quality online training options. There also remains a need to train providers who work outside of healthcare and rehabilitation, including those in the behavioral health, domestic violence, and education fields. Unfortunately, stakeholders report there are **workforce shortages** in Maine, specifically of specialists, such as Neuropsychologists and Psychiatrists, as well as in-home care providers, which worsened during the COVID-19 pandemic. Workforce shortages were also reported as impacting the length and quality of training, especially in settings where staffing shortages are due to high turnover and the need for coverage is prioritized over training procedures. *Caregivers need more support—especially in navigating service systems* Family members and caregivers indicated that support and information are the most important services they need.

Systems Level *There has been progress to improve services for people with brain injury in Maine* Support from the Legislature and Executive leadership have allowed for changes that have increased services to a broader range of people based on the impact of their injury rather than the cause. The Legislature recently funded Neuroresource Facilitation services, brain injury support groups, and a new Brain Injury & Stroke Resource Directory. Maine is also unique due to the community rehabilitation clinics which are based on a trans-disciplinary team model and are known for better outcomes for survivors, reducing the impact on the healthcare system, and increases the state’s ability to serve its very rural communities. *Data on the incidence and prevalence of brain injury is not available statewide or collected within state systems* There is need to improve statewide data collection on brain injury incidence and

prevalence. This need has been identified in previous assessments and emerged again as a theme during this needs assessment. koneconsulting.com 10 Best practices also confirm the importance of data collection not only to identify brain injuries but also to improve connecting people to services and funding support services. Current publicly available data from the Maine Center for Disease Control and Prevention (CDC) is outdated and limited to a narrow scope of information. Data on brain injury is also not available for people receiving services through the Department of Education Special Education Services, the Department of Corrections, or the Office of Behavioral Health. *State silos continue to be a challenge and lead to gaps in services* Stakeholders report that the siloed nature of state services limits the ability to provide whole-person, client-centered care, focusing instead on what the person is eligible to receive funding for. Despite increased efforts to collaborate between state agencies around brain injury, there remain opportunities to advance towards person-centered care determined by needs rather than funding, especially for those with co-occurring brain injury and behavioral health needs.

Next Steps Given the existing initiatives and opportunities for improvement determined through this needs assessment, the recommended next step is to engage in a strategic planning process with key stakeholders, including representatives from DHHS, ABIAC, and BIAA-ME. One strategic planning approach that has been successful with other organizations is called the Knotworking approach, which also uses Ecocycle planning; both from the Liberating Structures method of facilitation.¹ If making a strategic plan were simple, a team would develop a list of tasks, decide who is doing what, what resources are needed, and forge ahead. This assumes resources are predictable, conditions are static, and the future is stable and knowable. That is not reality. Traditional strategic planning approaches start with an analysis of strengths, weaknesses, opportunities, and threats (SWOT analysis), followed by an environmental scan of the political, economic, social, and technological factors (PEST analysis) impacting an organization. These approaches often assume a linear future will unfold, and concentrate design, ownership and implementation in a top-down model and pin hopes on wonderful-but-vague mission statements. Traditional planning frameworks fail to unleash and engage those who must execute and build on data without a sense-making step that would help the group ground factors in the context of how things actually get implemented in their organization. ¹ <https://www.liberatingstructures.com/31-ecocycle-planning/>