

Annual Report 2022

Respectfully submitted on behalf of the ABIAC by

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ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE ANNUAL REPORT – January 15, 2023

ABIAC OFFICERS AND MEMBERS 2022

Council members are appointed by the Department of Health and Human Services Commissioner.

PROVIDERS

Jennifer Jello, Incoming Co-Chair, Standish Scott Mayo, Outgoing Co-Chair, Deer Isle Matthew Hickey, Outgoing Secretary, Yarmouth Austin Errico, Freeport Sharlene Adams, Manchester

ADVOCATES

Lee Glynn, Co-Chair, Skowhegan Courtney Michalec, Incoming Secretary, Brunswick Sarah Gaffney, Vassalboro Violet Nalley, Augusta The seat formerly held in 2022 by Trish Thorsen of the Maine Ombudsman Program is pending a Council vote and a new recommendation for appointment will be forthcoming in 2023

FAMILIES

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

SURVIVORS

Nitzana Aufiero, Newport Ted Brackett, Westbrook Anthony Barresi, Presque Isle Thomas Broussard, Brunswick

STATE LIAISONS

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

PURPOSE & OVERVIEW

Every 9 seconds, someone in the United States sustains a brain injury.¹

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 3.5 million children and adults sustain an ABI each year², but the total incidence is unknown. New data

¹ & ² Center for Neurological Studies, March 1, 2019

available from the Maine Center for Disease Control (CDC) in 2022 indicated that an estimated 5,000 ³ Mainers experience a traumatic brain injury every year, but this does not include acquired brain injuries caused by non-traumatic events, such as stroke, opioid toxicity, or brain tumors. In other words, this does not reflect the full scope of the number of brain injuries in Maine. The CDC slide deck can be referenced here. The same information is included in two different formats, PowerPoint and PDF, for ease of viewing for readers with different electronic devices or applications.



Maine Traumatic Maine Traumatic Brain Injuries 2016-2(Brain Injuries 2016-2(

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ABIAC RESPONSIBILITIES AND HISTORY

- Formed in 2002 to support a federal grant
- Established in statute in 2007 to provide oversight and advice to the Department of Health and Human Services (DHHS) and Legislature
- Meets at least four times per year and holds at least two public hearings annually. Over the past 16 years, the ABIAC has held more than 53 public hearings throughout the state.
- Over the past 16 years, the ABIAC has served as the mandated Advisory Board for four Federal Traumatic Brain Injury (TBI) Partnership grants to improve 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 organizations to provide training for hundreds of professionals and paraprofessionals.
- In 2022, the Council met eight times and held three public hearings.
- In 2022, the Council moved to a subcommittee structure to more efficiently and effectively manage published priorities.
- Statutory requirements of the ABIAC are included here in two formats for reference.



CURRENT SERVICE SYSTEMS

Operated by provider organizations under contract with Maine DHHS or Maine Department of Labor (DOL).

Specialized Nursing Care – MaineCare Section 67

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

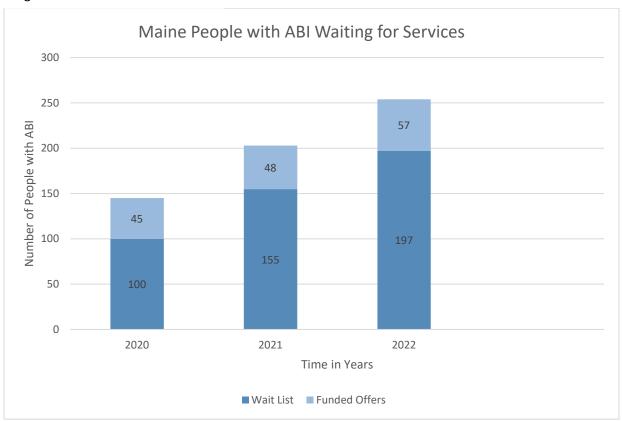
Brain Injury Home and Community Waiver – MaineCare Section 18

• 194 Section 18 recipients, 57 Section 18 funded offers, 197 on Section 18 waitlist. See Figure 1.

³ Maine Traumatic Brain Injuries 2016-2019, Center for Disease Control

- 44 Maine residents placed out-of-state due to lack of specialized services available within the state
- 3 Providers of care coordination services with 194 individuals served in 2022
- 2 In-home support programs
- 23 Section 18 recipients are receiving attendant care services
- 32 Community residential programs with 136 beds, which represents fewer programs and beds available than in 2021. See Figure 2.
- 2 group homes have permanently closed and 3 group homes have closed temporarily
- 1 provider of Financial Management Service to support the newly created service delivery option of self-direction under the temporary authority of an Appendix K amendment to the Brain Injury Waiver, Section 18 of the MaineCare Benefits Manual.

To help stabilize the workforce and improve a home and community-based service system that has been strained by the COVID-19 pandemic, the Appendix K amendment provided flexibilities and increases in service caps for select services. Despite this temporary emergency response, there is still a workforce crisis across the state impeding provider capacity, adversely impacting the wait list and ability of people with funded offers to find placement and contributing to group home closures.







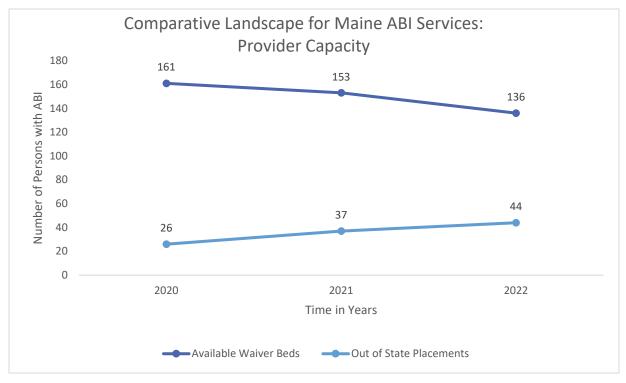
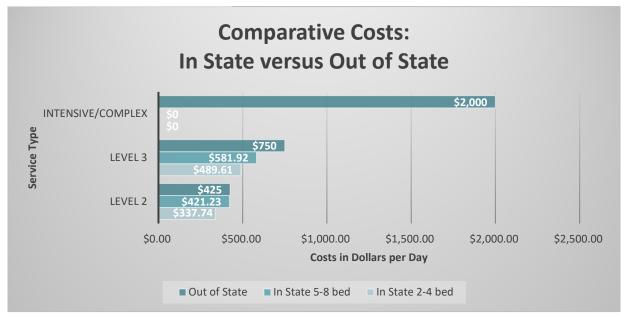


Figure 3



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. By comparison, the 2022 rate for Level 3 neurobehavioral services in

Maine was \$489.61 for 5-8 beds and \$581.92 for 2-4 beds per day. See Figure 3. Bed rates are scheduled to increase on January 1, 2023.

BI Outpatient Services

- 8 Outpatient neurorehabilitation clinics served 367 individuals in 2022 with MaineCare Section 102 funding; more individuals were served with a different payer.
- 1 Work-ordered day club house, serving 28. Note that the club house was initially closed in 2021 due to the Governor's indoor gathering limits, and remained temporarily closed in 2022 due to workforce shortages.

Department of Labor Funding

- 8 Division of Vocational Rehabilitation (DVR) providers served 136 individuals in 2022.
- The Division of the Blind and Visually Impaired (DBVI) served 7 individuals in 2022. •

DVR and DBVI demographics on TBI are included here in two formats, Microsoft Word and PDF, for ease of viewing.

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DVR TBI Data 2022.docx



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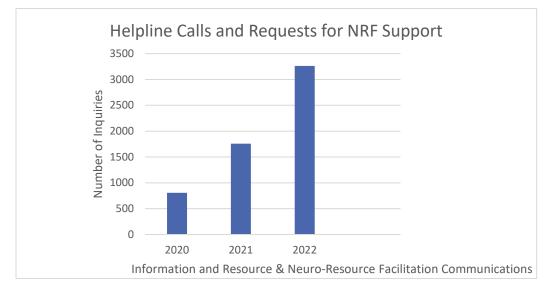


Core State Brain Injury Supports (CSBIS) for Vulnerable Populations

DHHS contract funding with the Brain Injury Association of America – Maine Chapter to provide core support services.

- Neuro-Resource Facilitation (NRF) 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.
- 3262 Neuro-Resource Facilitation and Information & Resource communications in 2022. See • Figure 4.
- 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 19 Support Groups for survivors and families that engaged more than 2100 • participants in 2022

In 2019, LD 297, An Act to Strengthen Brain Injury Resources for Underserved Populations, Including Opioid Overdose Brain Injury Survivors, became law. In order to sustain the above listed core supports and services, it may make sense to add a budget line item in the Department of Health and Human Service's Brain Injury Services for sustainable funding for these essential services in the future. The Council acknowledges the growing need and increased use of these services, and believes the availability of core supports and services for vulnerable populations attends to the priorities established by the ABIAC.





CURRENT ACL FEDERAL PARTNERSHIP GRANT

In 2021, the Office of Aging and Disability Services (OADS), in partnership with the Brain Injury Association of America's Maine Chapter (BIAA-ME) and key stakeholders, received a TBI State Partnership Grant through the Administration for Community Living (ACL). Building upon the successes and lessons learned from the previous partnership project, the focus of the current five-year grant is to strengthen and enhance Maine's system of services and supports to maximize the independence, wellbeing and health of persons with ABI and to strengthen ABI systems of services and supports for three identified underserved populations: Maine's two state psychiatric hospitals, rural Maine communities and persons with co-occurring disorders. Anticipated outcomes include 1) a strengthened ABI Advisory Council, 2) an updated State Plan for ABI services, 3) increased resource facilitation capacity, 4) strengthened person-centeredness and cultural competence, 5) increased capacity in state psychiatric hospitals, 6) increased infrastructure in rural Maine and 7) recognition of ABI as an outcome of Maine's opioid epidemic.

ABIAC PRIORITIES FOR 2022 and OUTCOMES

 Support brain injury prevention strategies and campaigns for the state to address Outcomes: Although there is currently no funding for prevention efforts, a representative from the CDC participates in the Council in a resource and advisory capacity. The CDC has incorporated traumatic brain injury and concussion information on their <u>web page</u>, which serves as both a prevention and public awareness resource.

The ABIAC is encouraged by the recent passage of the federal Omnibus Package which includes the following.

- \$1.5 million secured for the Federal CDC National Concussion Surveillance
 System. This is an increase of \$1 million. The ABIAC is confident that these dollars can support the work of the Maine CDC.
- For the first time ever, \$1 million for the Federal CDC to collect data on the connection between brain injuries and domestic and sexual violence. The ABIAC encourages the Maine CDC to benefit from these dollars by means of data collection here in Maine.

Also note that the ABIAC is overseeing the five-year TBI grant, and one component of the grant is drug overdose prevention.

The ABIAC co-sponsored an educational webinar entitled: "TBI in Childhood: Conceptualizing Social & Behavioral Challenges" on October 6, 2022 with Dr. Jonathan Lichtenstein.

The ABIAC received a brief report on an initiative related to concussion in schools and welcomes continued updates. The synopsis provided by the Concussion Workgroup is included here:

The BIAA-ME is a member of the Concussion Workgroup empaneled by the Department of Education to evaluate schools' implementation of concussion safety protocols and determine how to improve the health and safety of students as it relates to mild TBI. Following the passage of LD 104, An Act to Protect the Health of Student Athletes by Requiring the Department of Education to Report on the Incidence of Concussions, the past year has been spent identifying how concussion data would be tracked, identifying schools in the study, and planning trainings on how to use the tracking platform. The work of collecting and analyzing the data to make recommendations for improved management of concussions in schools is ongoing.

The Concussion Workgroup chose to use the Head Injury Tracker (HIT) developed by the Maine Concussion Management Initiative. HIT provides schools with an easy, confidential, and secure method of collecting concussion data, and it is available at no cost. HIT has been utilized by a number of high schools and colleges as an effective injury surveillance tool for concussions.

As reported through HIT, for the concussions sustained, on average student athletes missed 9 days of academics and 16 days of athletics.

It is important to note that all students in schools are at risk for concussion regardless of how it is sustained. When a student sustains a concussion, it impacts their education. With that in mind, the Workgroup's continuing efforts will work to expand policies and practices related to concussion for all students in a school.

The Concussion Workgroup continues to work with schools in this effort of monitoring concussions. In addition, workgroup members hope to shift the focus to include all students who sustain a mild TBI. Regardless of where the injury occurs, there will be lost academic time and there must be a gradual return to pre-concussion activity. Improved recognition and management of concussion can result in less academic time lost.

 Through the Efficacy and Data Subcommittee of the ABIAC, identify transportation barriers and make recommendations for improvement. Outcome: The ABIAC is monitoring efforts through updates provided by state partners. The Council notes that there is a joint venture between the Department of Health and Human Services and the Department of Transportation currently exploring what other states have done to address transportation access and service delivery.

- Assistance in the Federal TBI grant steering as well as state plan development. Outcome: The ABIAC Executive Committee assists in grant steering. Moreover, a number of Council members participated in a series of workgroups for the development of the state plan. These efforts will continue, as facilitated by Koné Consulting, in 2023.
- Advocate for ongoing coordination for services to address the confluence of persons with substance use disorder and acquired brain injury. Advocate for Section 102 State Plan Amendment and MaineCare rule change to allow this service in neurorehabilitation clinics. *Outcome: On March 4, 2022, a non-voting member of the ABIAC moderated one of the Governor's Opioid Response Seminars entitled: "Invisible Disability: Overdose, Brain Injury, and the Impact of Cognitive Impairment on Service Delivery and Treatment Outcomes" with presenter Dr. Carolyn Lemsky. Over 600 people registered for the seminar.*

Also notable, the ABIAC has included a member of the Office of Behavioral Health to participate in Council meetings and to provide guidance and updates as needed.

The Brain Injury Association of America Maine Chapter has made the Council aware of discussions with all eight neurorehabilitation clinics in Maine on the subject of reinstating substance use disorder (SUD) counseling. The ABIAC also serves on the steering committee for the five-year TBI grant, and one of the deliverables of the grant is the reinstatement of SUD counseling in outpatient clinics.

- Advocate for the development and funding of neurobehavioral 24/7 treatment services. Explore collaboration with New Hampshire/Vermont mobile assessment, treatment and consultation. *Outcome: The ABIAC has continued to converse with state partners on the need for neurobehavioral services, in part to address the growing number of Mainers getting sent out-of-state for these services. The Council continues to advocate for and monitor the state's efforts to hire a project coordinator, initiate a request for information, conduct a rate study or rate determination, research program design and potentially submit a budget to the Maine Legislature in 2024. A tri-state meeting on mobile assessment did not occur, but mobile assessment research and collaboration is a possibility for the upcoming year.*
- Assist the rights task force.

Outcome: After a decade of advocacy by the ABIAC, LD 559, An Act to Improve the Basic Protections of Persons with Acquired Brain Injury, became law in 2021. The full ABIAC membership collaborated with the members of the Rights Task Force—a group that included select members of the ABIAC among its representatives—and submitted public comments on subsequent rule making process for Proposed Rule Amendment: 14-197 C.M.R. - Office of Aging and Disability Services Policy Manual, Ch. 8, Grievance Process for Persons with an Intellectual Disability, Autism Spectrum Disorder, or an Acquired Brain Injury and for Proposed Rule 14-197 C.M.R. - Office of Aging and Disability Services Policy Manual, Ch. 1, Rights and Basic Protections of Persons with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury. Both rules were listed as adopted on the Secretary of State's website on November 18, 2022.

 Advise/assist with permanent assistive technology policy. Collect data on telehealth practices in Maine.

Outcome: The Policy and Legislation Subcommittee followed national telehealth policy updates and trends through the Center for Connected Health Policy, invited a representative from the Office of MaineCare Services to speak to the subcommittee about state and federal changes to telehealth policy, and ultimately identified no concerns or recommendations related to the state's telehealth policy development.

The Council also noted that the state continues to do work related to assistive technology. Through Section 9817 of the American Rescue Plan Act of 2021 there are funds available to help individuals become assistive technology professionals. The state has proposed a Lifespan Project for individuals with intellectual and Developmental Disabilities (IDD), which includes an assistive technology component. The Council is supportive and encourages ongoing collaboration with the State to ensure people with brain injuries have the same benefits proposed in a Lifespan Project to support greater flexibility to address changing needs, improved in-home services and innovation.

Advocate and support legislation related to stroke response care in Maine.
 Outcome: Although there were no legislative bills identified in 2022 related to Maine's stroke response, the ABIAC developed a relationship with the Maine Stroke Alliance. A representative from the Maine Stroke Alliance spoke with the Council, and continued work with the ABIAC Policy and Legislation Subcommittee. One member of the ABIAC now serves as a member on the Maine Stroke Alliance.

Also notable, the ABIAC acknowledged the allocation by the Brain Injury Association of America Maine Chapter (BIAA-ME) of a Neuro-Resource Facilitator dedicated to Maine Medical Center to serve as an aide to individuals with acquired brain injuries, including strokes, to get connected with community-based resources.

 Advocate for a plan or program designed to increase service recipient awareness of MaineCare benefits.

Outcome: The Council noted the addition of another Neuro-Resource Facilitator to the Brain Injury Association of America-Maine Chapter. The ABIAC acknowledges the need for core support initiatives, especially liaisons to hospitals given that both the 2021 Statewide Brain Injury Needs Assessment and public forums across the state have noted a need to increase awareness of resources following discharge from acute care.

Several Council members served on a panel discussion on Maine Public Radio's Maine Calling, which aired an episode entitled, "Brain Injury Prevention, Symptoms and Treatment—and support for those that have brain injuries" on November 18, 2022.

Improve the effectiveness of the ABIAC by gaining advanced, formal, quarterly status reports
describing critical indicators of brain injury services from the Office of Aging and Disability
Services, MaineCare, Maine Center for Disease Control and Office of Child and Family Services.

Outcome: The ABIAC benefited from regular updates from Office of Aging and Disability Services liaisons, received data from the Maine Center for Disease Control on the prevalence and demographics of traumatic brain injuries in Maine for the period 2016-2019, and welcomed a new representative from the Office of Child and Family Services to the Council.

• Revise by-laws, remote meeting procedures, and new member orientation and development. *Outcome: The Council developed and adopted remote meeting procedures.*

The Membership Subcommittee gained oral feedback about new member orientation, researched practices in other states and solicited new member materials used across the country. The Council implemented a mentor program for new members as well as made adjustments to meeting materials to be more accessible to individuals coming from varied backgrounds. For instance, meeting materials include references to commonly used acronyms and may include hyperlinks to various references so that a reader can gain context about a service or subject prior to discussion at a meeting.

In 2022, the Membership Subcommittee completed a survey, which revealed that Maine had well over 50% of its Council membership with lived experience with brain injury, either as a survivor, a caregiver or family member. See Figure 5. The goal to update the membership composition component of the by-laws to include 50% members with lived experience, a target regarded as a best practice among brain injury councils at the national level, and to develop a written orientation manual for new members will remain focuses in 2023.

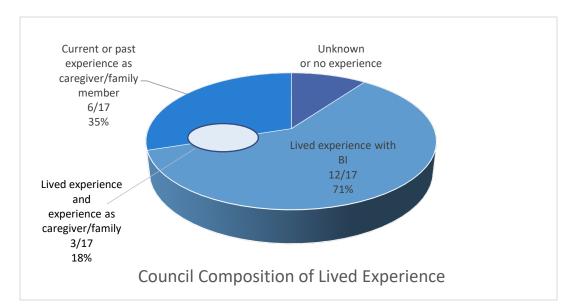


Figure 5

ABIAC PRIORITIES FOR 2023

In 2023, the Council will continue the subcommittee model to address the following priorities.

- Advocate for improved and increased access to and expanded scope of services, which may include exploration of barriers and options related to waitlists, out-of-state placements, work force and provider capacity.
- Increase survivor, family, professional, paraprofessional and community awareness of services, as well as service gaps, within the continuum of care. Advocate for a plan or program designed to increase member awareness of MaineCare benefits.
- Advocate for improved identification of children with ABI. Collaborate with state partners regarding this under-identified and underserved population.
- Advocate for improved screening and diagnosis of ABI.
- Through collaboration with the Division of Vocational Rehabilitation, advocate for improved access for persons with ABI to competitive employment.
- Serve as oversight and steering for the state's five-year TBI partnership grant as well as state plan development.
- Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to
 ensure humane, cost-effective, evidenced-based treatment in Maine. Encourage the
 development of a 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 use counseling as a billable service in the Neurorehabilitation Clinics in Section 102.
- Revise by-laws to include that at least 50% of members have lived experience with brain injury. Continue next phase of member orientation and development, including a written orientation manual.
- Identify transportation barriers and make recommendations for improvements to DHHS.
- Monitor assistive technology policy and potential impact to people with ABI.
- Monitor stroke response care in Maine. Partner with the Maine Stroke Alliance as needed.
- Encourage the development by state partners of brain injury prevention strategies and campaigns.
- Advocate for a budget line item for sustainable funding for LD 297 core supports for vulnerable and underserved brain injury populations.

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. Tim and Mary Crowley received the 2021 Lewis and Clara Lamont Advocacy Award during the September 2022 Defining Moments in Brain Injury Conference.

Award 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
- 2021-Tim and Mary Crowley-Family Members and Advocates

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 5,000 Mainers will experience a traumatic brain injury in 2023; this number does not reflect the full scope of the problem as it does not include all acquired brain injuries. The number of acquired brain injuries, which would also include injuries caused by non-traumatic events, such as stroke, opioid toxicity, brain tumors etc., is currently unknown in Maine. 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) report 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 2% of the U.S population. Many will make meaningful recoveries, especially if they get the needed rehabilitative care. Among those still alive five years following a moderate or severe TBI, 57% are moderately to severely disabled and will live with very difficult, life-altering challenges. Immediate access to specialized neurorehabilitation treatment, access to information and access to 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 have also emphasized the need for greater geographic access to services, education for professionals, addressing workforce shortages, waitlist for services, increased public awareness, access to employment opportunities, improved children's services, and addressing the complex needs of individuals with challenging behaviors.

The past year has revealed alarming trends related to need and resources. The wait list for home and community-based services (MaineCare Section 18 waiver) has nearly doubled, increasing from 100 in 2020 to 197 in 2022. During the last two years, two brain injury group homes have permanently closed, and three more have temporarily closed and not yet reopened. Provider capacity is limited, and has gone from 161 beds in 2020 to 136 in 2022. Increasing numbers of Maine people are being served in more costly out-of-state placements.

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.