

# MAINE STATE LEGISLATURE

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# Annual Report 2023

Respectfully submitted on behalf of the ABIAC by

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# ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE

## ANNUAL REPORT – January 15, 2024

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### ABIAC OFFICERS AND MEMBERS 2023

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

#### PROVIDERS

Jennifer Jello, Co-Chair, Standish  
Scott Mayo, Deer Isle  
Matthew Hickey, Yarmouth  
Austin Errico, Freeport

#### FAMILIES

Lewis Lamont, Mapleton  
Suzanne Morneault, Eagle Lake  
Ed Russell, Winterport  
Fran White, Oxford

#### ADVOCATES

Lee Glynn, Co-Chair, Skowhegan  
Sarah Gaffney, Secretary, Vassalboro  
Danielle Malcolm, Augusta  
Becky Hadiaris, Saco

#### SURVIVORS

Anthony Barresi, Caribou  
Thomas Broussard, Brunswick  
Courtney Michalec, Brunswick  
Jim Beaudry, Rockland  
Peter Kenyon, Kennebunk

#### STATE LIAISONS

Derek Fales, OADS Liaison  
Jessica Gartland, Vocational Rehabilitation  
Aaron Burke, Maine CDC Injury Prevention

### PURPOSE & OVERVIEW

Every 9 seconds, someone in the United States sustains a brain injury.<sup>1</sup>

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, cognitive and communication (e.g. aphasia) impacts are common. More than 3.5 million children and adults sustain an ABI each year<sup>2</sup>, but the total incidence is unknown. Data available from the Maine Center for Disease Control (CDC) in 2022 indicated that an estimated 5,000<sup>3</sup> 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,

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<sup>1</sup> & <sup>2</sup> Center for Neurological Studies, March 1, 2019

<sup>3</sup> Maine Traumatic Brain Injuries 2016-2019, Center for Disease Control

or brain tumors. In other words, this does not reflect the full scope of the number of brain injuries in Maine.

## **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 17 years, the ABIAC has held more than 56 public hearings throughout the state.
- Over the past 17 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 2023, the Council met seven times and held three public hearings.

## **CURRENT SERVICE SYSTEMS**

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

### **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**

- 199 Section 18 recipients, 51 Section 18 funded offers, 198 on Section 18 waitlist. See Figure 1.
- 46 Maine residents placed out-of-state due to lack of specialized services available within the state
- 3 providers of care coordination services with 199 individuals served in 2023
- 2 in-home support programs
- 25 Section 18 recipients are receiving attendant care services
- 38 community residential programs with 158 beds. Although not all of the 158 beds are filled, this still represents an increase in capacity compared to the previous year. See Figure 2.
- 3 new group homes have opened, including one 3-bed home with a new provider agency.
- 2 out of 3 group homes that closed temporarily during the pandemic have re-opened
- 2 providers of Financial Management Service to support the service delivery option of self-direction

Figure 1

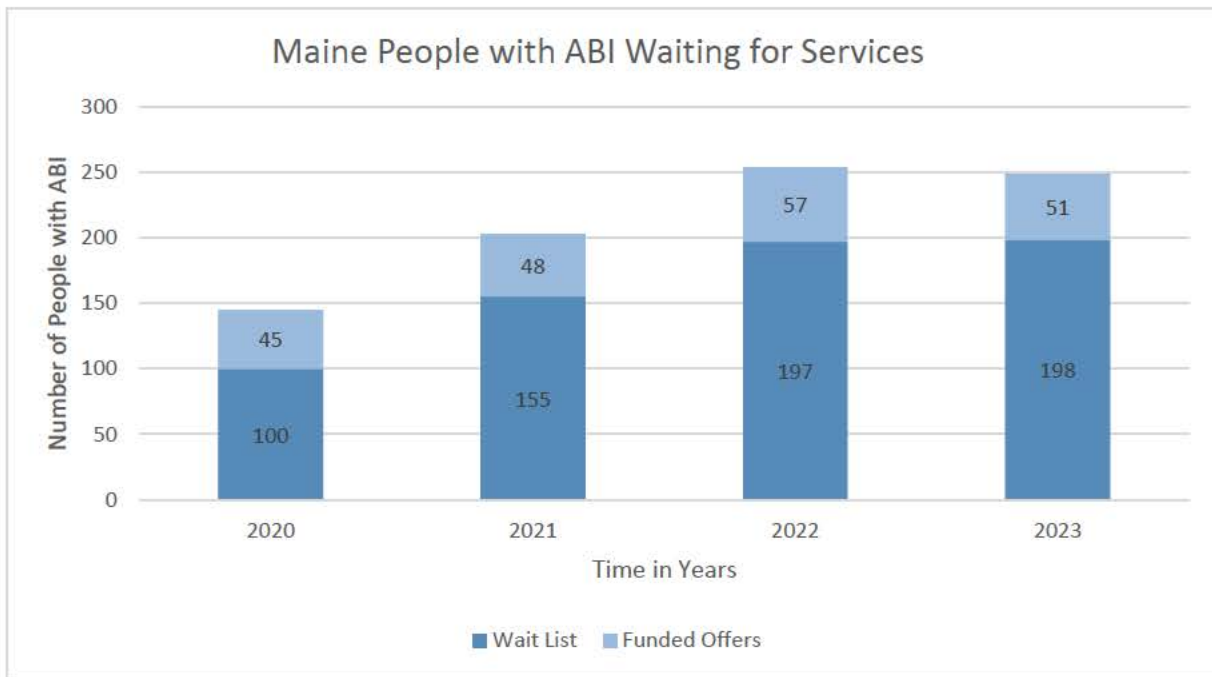


Figure 2

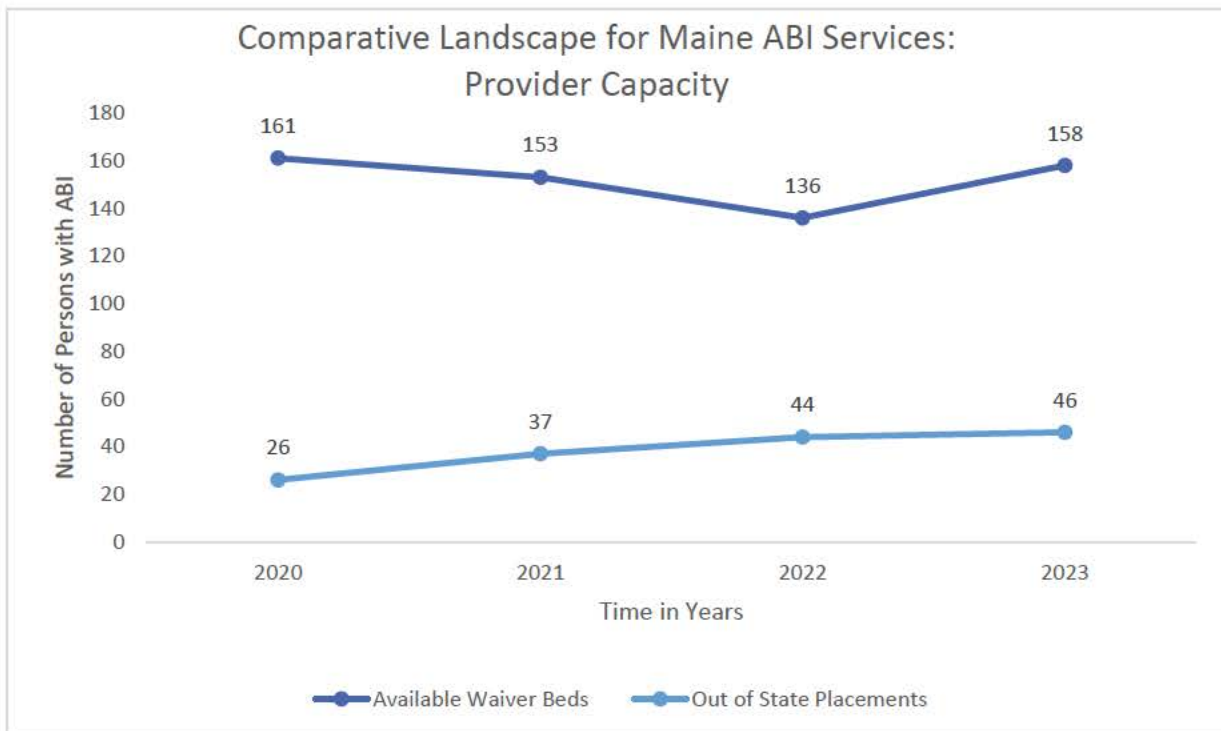
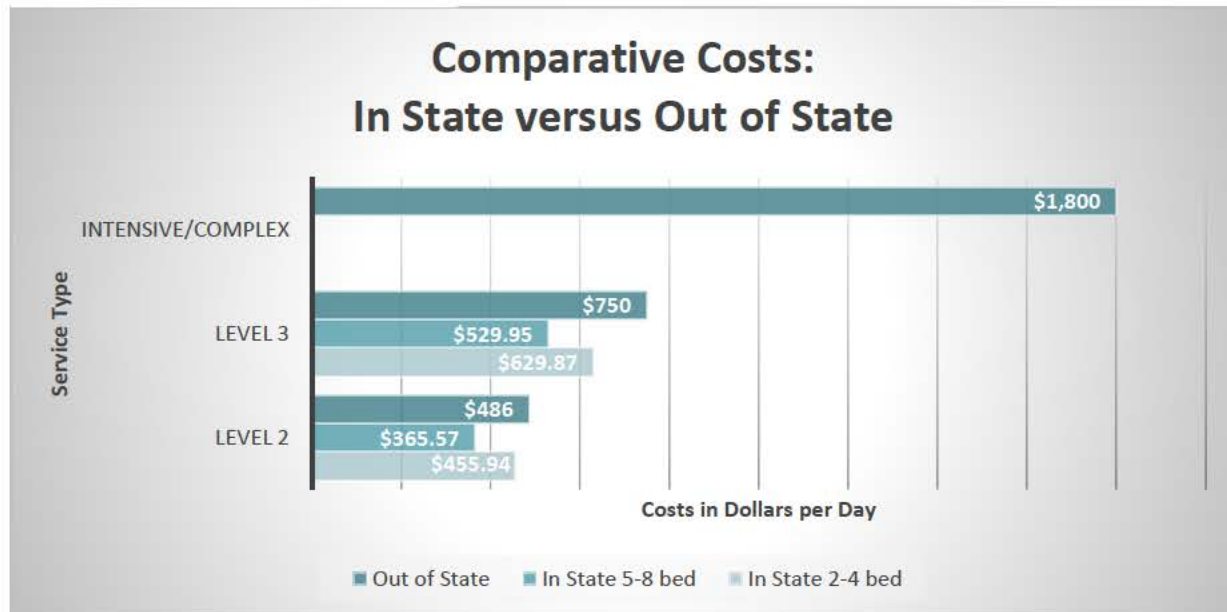


Figure 3



The current rates for skilled neurorehabilitation in an out-of-state nursing facility are up to \$486 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 in combination with complex medical care can be up to \$1,800 a day. By comparison, the 2023 rate for Level 3 neurobehavioral services in Maine was \$529.95 for 5-8 beds and \$629.87 for 2-4 beds per day. See Figure 3. Bed rates will increase by 2.54% on January 1, 2024.


**BI Outpatient Services**

- 8 Outpatient neurorehabilitation clinics served 469 individuals in 2023 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 initially closed in 2021 due to the Governor’s indoor gathering limits, and has remained closed due to workforce shortages.


**Department of Labor Funding**

- 8 Division of Vocational Rehabilitation (DVR) providers served 260 individuals in 2023, nearly doubling the number served from the previous year.
- The Division of the Blind and Visually Impaired (DBVI) served 10 individuals in 2023.

DVR and DBVI demographics on TBI are included here.



DVR TBI Data  
Calendar Year 2023 D



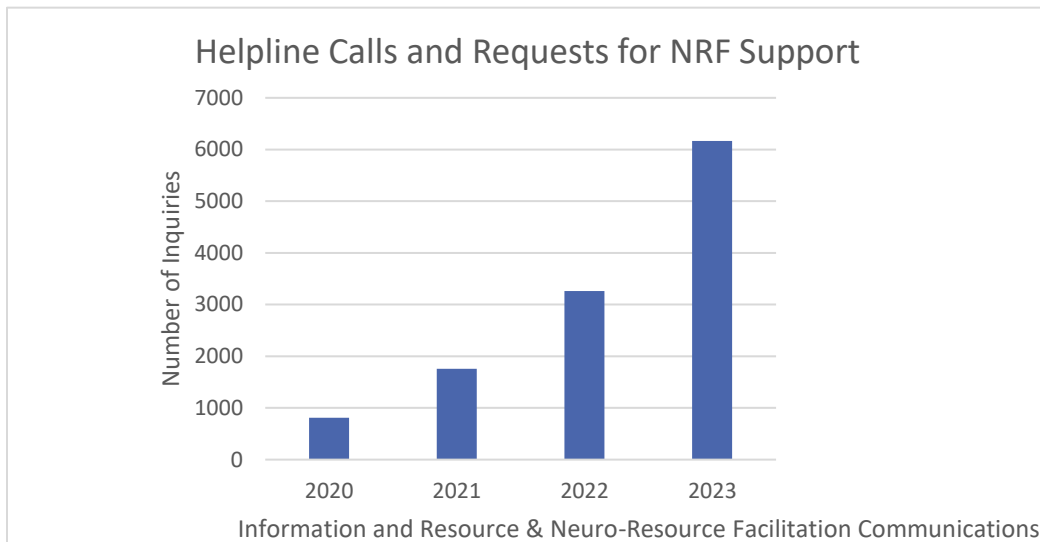
DBVI TBI Stats  
Calendar Year 2023 D

### 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.
- 6,164 Neuro-Resource Facilitation and Information & Resource communications in 2023, representing a significant increase in demand from the previous year. 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 22 Support Groups for survivors and families that engaged more than 2,600 participants in 2023.

Figure 4



### 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, well-being and health of persons with ABI and to strengthen ABI systems of services and supports for three identified underserved populations: children/youth with brain injury, 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) development of a Community of

Practice on the neurobehavioral and educational needs of children/youth with brain injury, 6) increased infrastructure in rural Maine and 7) recognition of ABI as an outcome of Maine's opioid epidemic.

## ABIAC PRIORITIES FOR 2023 AND OUTCOMES

- Advocate for improved services, increased access to services 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.

*The ABIAC received regular updates throughout the year from state liaisons about waitlists, out-of-state placements, and new home openings. Workforce shortages still present barriers to effectively serving Maine's growing brain injury population, but there has been a modest increase in provider capacity. In past years, there had been a steadily increasing list of MaineCare members awaiting brain injury waiver services. That trend has leveled off, though there are more people awaiting services than are actually served through the brain injury waiver.*

*The growing stream of people served out-of-state because there is no in-state option has also slowed, and the state is moving forward with the implementation of neurobehavioral treatment options over the next few years to address this service gap.*

*The ABIAC received a report that the Office of Aging and Disability Services partnered with a Disability Rights Maine attorney to conduct out-of-state site visits to monitor the conditions and quality of services for MaineCare members in Michigan as well as two nursing facilities in Massachusetts.*

- 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.

*Active council members and interested parties reported awareness activities to include the following.*

- *A dedicated BIAA neuro-resource facilitator performing outreach to people on the Section 18 wait list for services*
  - *Neuro-resource facilitators embedded in hospitals*
  - *ABIAC represented with a table and the annual Resource Fair*
  - *BIAA-ME conference*
  - *Sharing information through support groups around state*
  - *BIAA-ME resource directory*
  - *One member of the Council has done numerous articles and speaking events on stroke and aphasia awareness and prevention.*
- Advocate for improved identification of children with ABI. Collaborate with state partners regarding this under-identified and underserved population.

*The ABIAC received a report that the BIAA-ME and a University of Maine clinician and director of the Brain Injury, Education, and Rehabilitation (BEaR) Lab have come together to develop a*



*Community of Practice. This group formed to address a stakeholder needs assessment to attend to the needs of children with brain injury in Maine.*

- Advocate for improved screening and diagnosis of ABI.

*As one objective of the TBI State Partnership Grant through the Administration for Community Living (ACL), the state has contracted to use the OBISSS, the Online Brain Injury Screening and Support System, screening tool at key pilot sites.*

- Through collaboration with the Division of Vocational Rehabilitation, advocate for improved access for persons with ABI to competitive employment.

*The Council is pleased to note that Vocational Rehabilitation services, despite significant workforce capacity challenges, nearly doubled the number of brain injury survivors who received vocational supports. The State has continued to work on recruitment for work support providers and there are seven (7) new providers offering employment services within the past two years.*

*The ABIAC Needs and Awareness Committee elicited the assistance of the Division of Vocational Rehabilitation to present at the 2023 Defining Moments in Brain Injury Conference.*

- Serve as oversight and steering for the state's five-year TBI partnership grant as well as state plan development.

*The ABIAC Executive Committee assisted in grant steering. The ABIAC will be establishing a dedicated TBI Grant Steering Committee in 2024.*

*The ABIAC voted and approved the state's five-year Acquired Brain Injury in Maine State Action Plan, and continues to monitor progress of goals and objectives.*

- 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.

*The state is moving forward with the implementation of a project to research, review and develop in-state neurobehavioral treatment services as well as a mobile team. The Office of Aging and Disability Services hired a consulting firm. The project launched in December of 2023 and will conclude in March of 2025. Select members of the ABIAC serve on the project task force.*

- 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.

*On March 27, 2023, several ABIAC members provided testimony in support of LD 539, An Act to Provide Substance Use Disorder Counseling for MaineCare Members with Acquired Brain Injury. The bill passed unanimously through the Joint Standing Committee on Health and Human Services, but remained unfunded at the close of the first session of the 131<sup>st</sup> Legislature. On December 21, 2023, prior to the start of the second session, the ABIAC submitted a letter to Commissioner Lambrew requesting support for the bill, possibly through inclusion of substance use disorder counseling for persons with acquired brain injury in the Department’s budget.*

*The Council noted increased awareness in the state related to overdose and brain injury through multiple training opportunities by subject matter experts geared toward professionals, paraprofessionals and caregivers; the use of a new screening tool, the Online Brain Injury Screening and Support System, or OBISSS, which screens for brain injury and substance use; and the Governor’s Opioid Summit. One Council member provided testimony at an opioid settlement hearing on substance use and brain injury.*

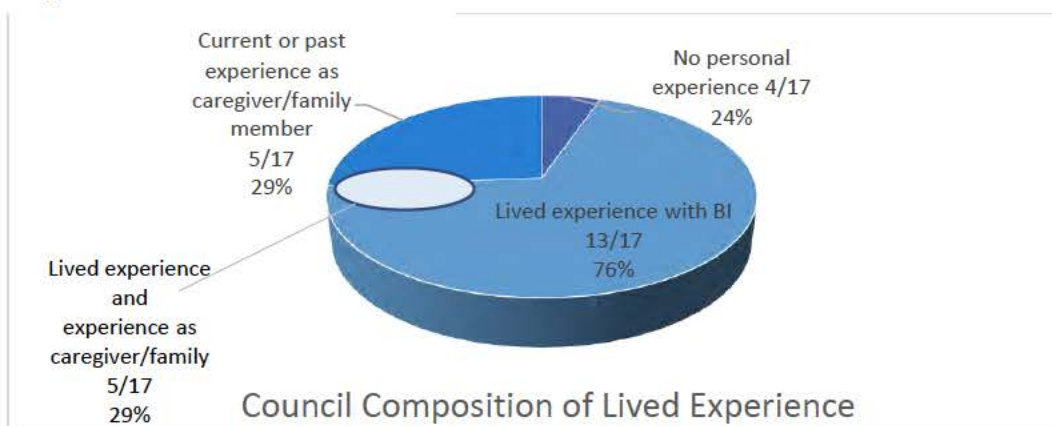
*Also note that the ABIAC is overseeing the five-year TBI grant, and one component of the grant is increased awareness around the intersection of brain injury and substance use disorder as well as better support for individuals impacted by these co-occurring diagnoses.*

- **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.**

*The revised by-laws unanimously passed. The ABIAC will submit the updated version for approval by the Commissioner of the Department of Health and Human Services. The Membership Committee completed an orientation manual and implemented a mentor system for prospective and new members.*

*In 2023, the Membership Committee completed a survey, which revealed that Maine continues to have well over 50% of its Council membership with lived experience with brain injury, as a survivor, a caregiver or family member. See Figure 5. The by-laws changed, in part, to include the lived experience component to align with best practices among brain injury councils at the national level.*

**Figure 5**



- Identify transportation barriers and make recommendations for improvements to DHHS.

*Maine citizens have continued to provide feedback at the public forums hosted by the ABIAC in partnership with the Office of Aging and Disability Services about barriers related to transportation. One Council member contacted three non-emergency transportation brokers in order to be included in quarterly meetings and to receive notifications. The member has not yet received an opportunity to participate.*

*The ABIAC received reports that there is a workgroup exploring whether non-medical transportation could be added as a waiver service.*

- Monitor assistive technology policy and potential impact to people with ABI.

*The ABIAC noted that the telehealth rule was updated in the last year, and those benefits continued to be accessible to MaineCare members at the conclusion of the federal public health emergency.*

*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 issued grants to recruit and cover the cost to train prospective assistive technology assessors. Two agencies are currently enrolling to become assistive technology providers, though services have not been made available yet to Section 18 members.*

*There is a new Lifespan Project for individuals with intellectual and Developmental Disabilities (IDD) currently under development and 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.*

- Monitor stroke response care in Maine. Collaborate with the Maine Stroke Alliance as needed.

*Two ABIAC members intermittently participated in Stroke Alliance meetings throughout the year. The embedding of neuro-resource facilitators in key locations, such as New England Rehabilitation Hospital of Portland, have provided opportunities to help brain injury survivors transition to home and community care as well as distribute resources like the [“Brain Injury and Stroke Resource Directory”](#) and [“Moderate to Severe Brain Injury: A Practical Guide for Families”](#) prior to discharge. BIAA-ME intends to have an additional neuro-resource facilitator embedded at Maine Medical Center in the near future for this purpose.*

- Encourage the development by state partners of brain injury prevention strategies and campaigns.

*In the last year, the Council observed additional information and resources added to the Maine Center for Disease Control Prevention Store. The ABIAC also participated in federal outreach to support renewal and funding for the TBI Act.*

- Advocate for a budget line item for sustainable funding for LD 297 core supports for vulnerable and underserved brain injury populations.

*On February 24, 2023, two Council members and one non-voting interested party provided testimony on Governor's budget in support of core supports funding becoming a regular line item, rather than a discretionary consideration, in the Department of Health and Human Services budget. Though no change has been noted, funding has continued for these essential services.*

*The Brain Injury Association of America Maine Chapter has relayed to the Council a hope to use resources to embed a neuro-resource facilitator in Aroostook County in the future, which was also suggested during the ABIAC public forum held in Presque Isle in 2023.*

## **ABIAC PRIORITIES FOR 2024**

The ABIAC will continue with essentially the same focuses for 2024, although the goal around by-law revision and development of an orientation manual will discontinue. Five priorities will move to monitoring status, including focuses pertaining to awareness of services, improved screening and diagnosis of ABI, improved access to competitive employment, assistive technology policy and stroke response care. All other priorities will continue for 2024.

## **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. In 2023, Representative Vickie Doudera presented Steven Wade with the 2022 Lewis and Clara Lamont Advocacy Award during the 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
- 2022-Steven Wade-Brain Injury Association of America Maine Chapter

## REPORT SUMMARY

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 2024, but 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 most 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.

In the last year, Maine has witnessed some improvements related to need and resources. The number of both employment and assistive technology providers has increased, more brain injury survivors have received vocational services, and after a disturbing trend of group home closures during the pandemic, bed capacity in Maine has increased modestly. The wait list for home and community-based services (MaineCare Section 18 waiver) has nearly doubled, increasing from 100 in 2020 to 198 in 2023; however, the exponentially rising demand for services has slowed significantly from the previous year. Increasing numbers of Maine people continue to be served in more costly out-of-state placements, a concern the Council hopes will be addressed with the implementation of neurobehavioral treatment in Maine.

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.