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ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE

ANNUAL REPORT 2024



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ABOUT THE ABIAC

History & Purpose

The Acquired Brain Injury Advisory Council of Maine (ABIAC) formed in 2002 to support a federal grant. Formally established in statute in 2007, the ABIAC provides oversight and advice to the Department of Health and Human Services (DHHS) and Legislature.

Responsibilities

The ABIAC meets at a minimum of four times per year and holds at least two public hearings annually. In 2024, the Council met six times, excluding subcommittee meetings, and held three public hearings. Over the past 18 years, the ABIAC has held more than 59 public hearings throughout the state to help inform the Council's priorities.

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 collaborated with multiple organizations to provide training for hundreds of professionals and paraprofessionals. The ABIAC also monitors progress on the Acquired Brain Injury in Maine State Action Plan 2023-2028.

Composition

The Department of Health and Human Services Commissioner appoints Council members. There are a total of 25 member seats, which includes brain injury survivors, family members of survivors, advocates, providers of services and state liaisons. The ABIAC's composition in 2024 follows.

Providers

Jennifer Jello, Co-chair, Standish
Matthew Hickey, Yarmouth
Austin Errico, Freeport
Brian Hurd, Orrington
Kathy Despres, Fayette (incoming)

Families

Suzanne Morneault, Eagle Lake
Ed Russell, Winterport
Fran White, Oxford
Randy Bliss, Madison

State Liaisons

Derek Fales, Office of Aging and Disability Services
Jessica Gartland, Vocational Rehabilitation
Aaron Burke, Maine Center for Disease Control
Cassie Antonelli, Office of Behavioral Health

Advocates

Leland Glynn, Co-chair, Skowhegan
Sarah Gaffney, Secretary, Vassalboro
Danielle Malcolm, Augusta
Becky Hadjaris, Saco
Jennifer Greslick, Windham

Survivors

Jim Beaudry, Rockland
Anthony Barresi, Caribou
Peter Kenyon, Kennebunk (outgoing)

BRAIN INJURY OVERVIEW

Approximately 5.3 million Americans are living with a disability that results from 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. Falls, motor vehicle accidents and assaults are examples of traumatic injuries; strokes, brain tumors, and anoxic injuries are examples of non-traumatic events. ABIs can affect every aspect of an individual's being: physical, emotional, cognitive and communication impacts are common.

*20% of Mainers
have experienced a
traumatic brain injury*

Incidence in Maine

Data available from the Maine Center for Disease Control (CDC) in 2022 indicated that an estimated 5,500² Mainers experience a traumatic brain injury (TBI) resulting in an emergency room visit every year and another 1,100 have an in-patient hospitalization, 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 new brain injuries in Maine. The total incidence is unknown.

Prevalence in Maine

United States census data from 2022³ reveals that the prevalence of people with traumatic brain injury, including new cases and pre-existing cases, in Maine is approximately 20% of the population. Of Maine's nearly 1.4 million people, 2% are disabled as a result of a TBI and 50% disabled as a result of a stroke, an example of a non-traumatic injury.

¹ Traumatic Brain Injury: A "silent epidemic," Center for Brain Injury and Repair, Perelman School of Medicine, University of Pennsylvania

² Maine Traumatic Brain Injuries 2016-2019, Center for Disease Control

³ Overall estimates based on BIAA analysis of national census data, <https://www.census.gov/data/tables/time-series/demo/popest/2020s-counties-total.html> and Corrigan JD, Yang J., Singichetti B. et al Lifetime Prevalence of Traumatic Brain Injury with Loss of Consciousness

Disabled from Brain Injury



Figure 1

MAINE'S SYSTEM OF SERVICES

Maine's system of care is operated by provider organizations under contract with Maine DHHS or Maine Department of Labor.

Specialized Nursing Care – MaineCare Section 67

- Two (2) specialized skilled nursing/rehabilitation facilities
- A total of 36 specialized nursing beds for persons with ABI, representing a decrease in capacity from last year's 44 beds. See Figure 2.

Brain Injury Home and Community Waiver – MaineCare Section 18

- Section 18 recipients: 217; Section 18 funded offers: 33; Section 18 waitlist: 222. There are now more people on the wait list for services than are being served by the waiver.
- The average wait for brain injury waiver services is 3.6 years⁴.
- Maine residents placed out-of-state due to lack of specialized services available within the state: 46
- Three (3) providers of care coordination services, though one provider has stopped accepting new referrals
- Two (2) in-home support programs
- Section 18 recipients receiving attendant care services: 46
- Forty (40) community residential programs with 168 beds. Although not all of the beds are filled, this still represents an increase in capacity compared to the previous year.
- Two (2) new group homes have opened with plans for more homes in 2025
- Two (2) providers of Financial Management Service to support the service delivery option of self-direction

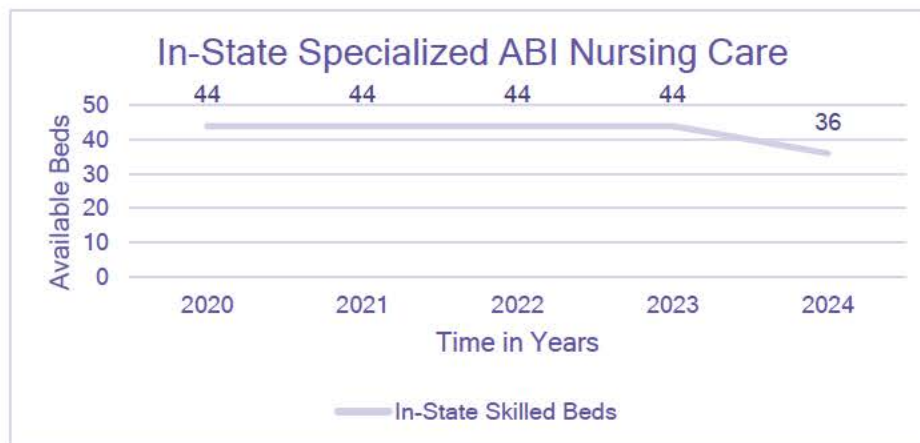


Figure 2

⁴ Maine Department of Health and Human Services HCBS Access Measures, <https://www.maine.gov/dhhs/oads/about-us/data-reports/hcbs-access-measures>

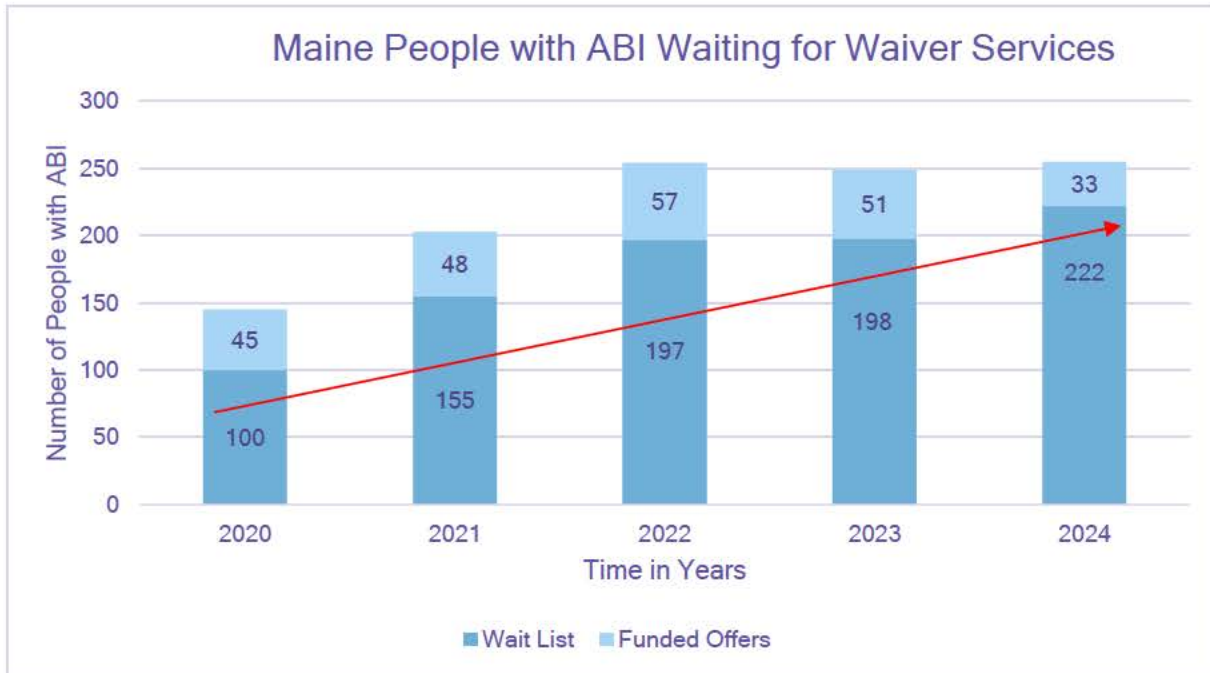


Figure 3

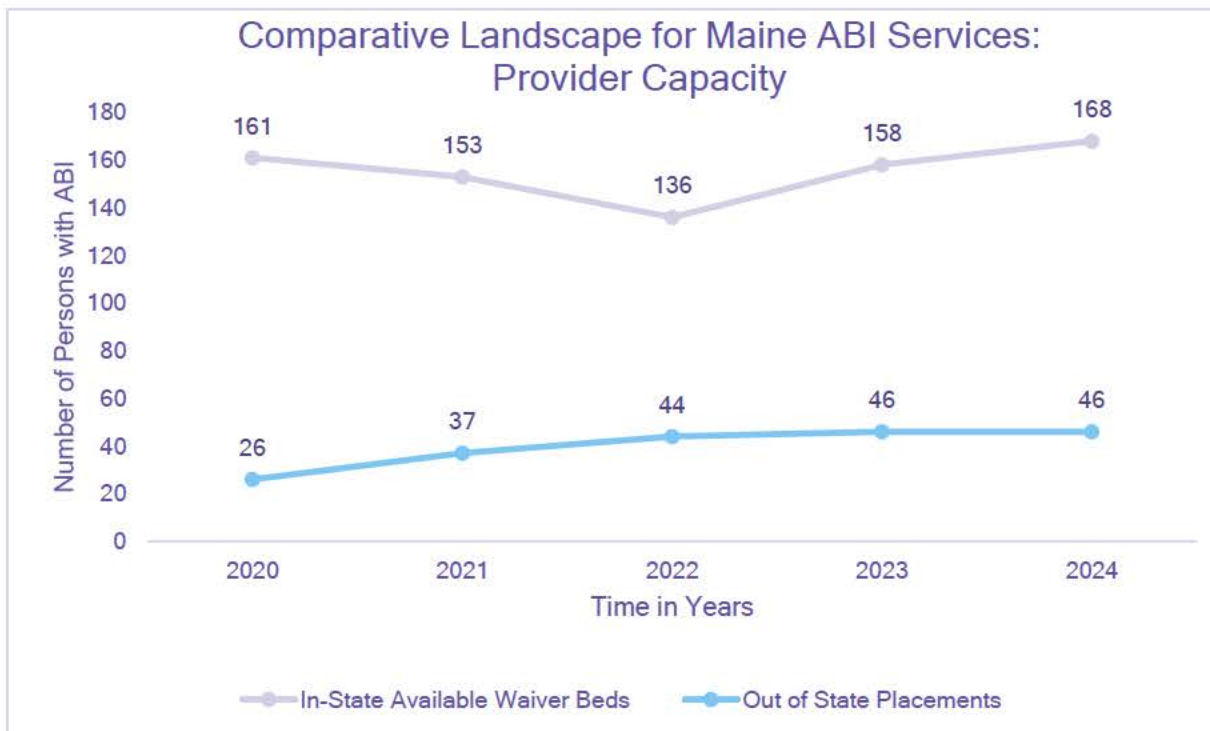


Figure 4

Brain Injury Outpatient Services – MaineCare Section 102

- Eight (8) outpatient neurorehabilitation clinics
- A total of 313 individuals were served in 2024 with MaineCare Section 102 funding; however, more individuals were served by the eight clinics through different payers.

Department of Labor

- Five (5) Division of Vocational Rehabilitation (DVR) providers served 155 individuals in 2024, which represents a decrease from the previous year.
- The Division of the Blind and Visually Impaired (DBVI) served eight (8) individuals in 2024.

Core State Brain Injury Services (CSBIS) for Vulnerable Populations

DHHS contracts 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.
- Neuro-Resource Facilitation and Information & Resource communications. Over the last few years, there has been an increasing use of helpline calls and requests; however, the number of communications for 2024 was not yet available at the writing of this report.
- 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 24 Support Groups for survivors and families that engaged more than 2,700 participants in 2024.

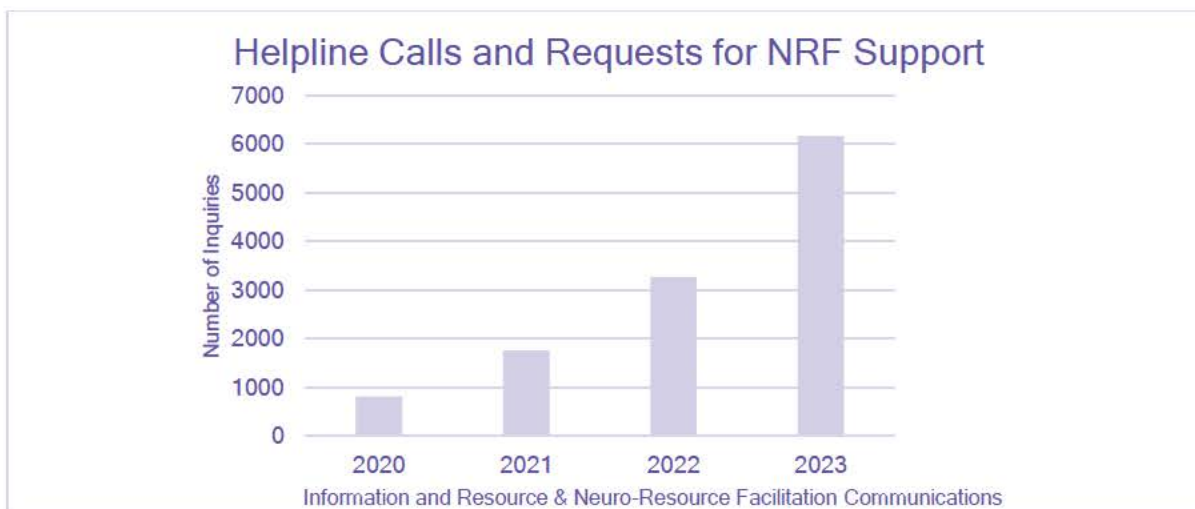


Figure 5

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

A Year in Review 2024

The Acquired Brain Injury Advisory Council of Maine had an active year at both the federal and state levels. While primarily a council dedicated to Maine affairs, note that Maine benefits from federal funding in the form of grants. These grants have been pivotal in the development of Maine's brain injury infrastructure, promoted research and provided protection and advocacy services. The prospect of legislative changes could have the potential to affect Maine citizens adversely. Activities in the federal arena included the following.

- Advocacy for renewal and increased funding for the TBI Act. Select Council members met with 3 out of 4 of Maine's delegates as well as continued advocacy through letters.
- Subsequent advocacy to a congressional representative regarding a bill that would eliminate the Center for Disease Control Injury Center and important brain injury programming like concussion surveillance and core state brain injury prevention.
- Advocacy for Maine representation on the Congressional Brain Injury Task Force.
- Support and recommendations for the Blast Overpressure Safety Act.
- Representation in national ACL brain injury advisory board workgroup.

At the state level, the ABIAC participated in the following.

- Provided public comment on the brain injury waiver renewal application.
- Testified on the Maine State Plan on Aging, particularly on aspects related to brain injury screening and referral to care for older adults.
- Advocated for mobile crisis funding for brain injury survivors and recommended training and brain injury informed care for treatment provided in Certified Behavioral Health Clinics.
- Participated in focus group sessions for the Neurobehavioral Treatment Project.
- Participated in the person-centered planning project.
- Gained DHHS Commissioner approval and officially adopted revised by-laws.

The ABIAC keeps apprised of the brain injury landscape in part through communication with subject matter experts at the full council meetings or, at times, during more detailed committee work groups. Focus discussions and education in 2024 included the following.

- Wait List Outreach, Brain Injury Association of America Maine Chapter
- Equitable Access to Health Care, Disability Rights Maine
- Community of Practice (children with brain injury), University of Maine
- Brain Injury Self-Assessment Tool, Office of Aging and Disability Services
- Home and Community Based Rehabilitation, Rehab without Walls
- Person Centered Planning Initiative, National Association of State Head Injury Administrators

- Non-emergency Transportation, Department of Health and Human Services
- Substance Use and Brain Injury, Maine Opioid Response
- Service System for Veterans, Maine Veterans Administration

Priorities for 2025

Testimonials during public forums held across the state, a collaboration between the Office of Aging and Disability Services and the ABIAC, yielded new focus areas for the Council's consideration. While many of the same themes arose from past years, such as transportation barriers in a rural state, newer concerns emerged about access to care for the uninsured or underinsured and better education of medical personnel, which may include physicians, nurses, care managers and awareness through medical schools. These reports align with information presented to the ABIAC in March of 2024 by Disability Rights Maine, a protection and advocacy organization. A key finding of the survey revealed that 58% of people with brain injuries said their doctors and medical staff were not trained to treat them. Also notable, 54% of survey respondents indicated that they needed, but could not get, medical care in the last five years.⁵

New and revised priorities as well as monitoring activities intended by the Council for 2025 are included here.

- New priorities for 2025: Advocate for access to care for the uninsured and underinsured. Improve access to care coordination services, access to care for medically complex individuals, and awareness that there is not enough bed capacity in state for the number of people with funded offers. Continue to 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.
- Promote brain injury awareness by our state partners, especially with medical personnel, care managers and through medical schools.
- Advocate for improved identification of children with ABI. Collaborate with state partners regarding this under-identified and underserved population.
- Serve as oversight and steering for both the state's five-year TBI partnership grant as well as the state's five-year plan.
- 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.
- Identify transportation barriers and make recommendations for improvements to DHHS.

⁵ Battis, Jennifer, Equitable Access to Healthcare for Mainers with Disabilities PowerPoint Presentation, Disability Rights Maine, March 2024

- Encourage the development by state partners of brain injury prevention strategies and campaigns.
- Advocate for a budget line item for sustainable funding for Maine-based core supports for vulnerable and underserved brain injury populations, such as neuro-resource facilitation, support groups, state brain injury hotline, education and training programs. To help sustain delivery of these core supports, advocate for the transition of Maine's nonprofit brain injury stakeholder organization from a national chapter, to be an independent, Maine-based or state affiliate association, established and directed by Maine families, caregivers and survivors.

The ABIAC will continue to monitor the following areas in 2025.

- 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 screening and diagnosis of ABI.
- Through collaboration with the Division of Vocational Rehabilitation, advocate for improved access for persons with ABI to competitive employment.
- Monitor assistive technology policy and potential impact to people with ABI.
- Monitor stroke response care in Maine. Collaborate with the Maine Stroke Alliance as needed.
- A new focus in 2025, the ABIAC voted to monitor progress on the TBI and PTSD Law Enforcement Training Act.
- Monitor outcomes, also new for 2025, of the Blast Overpressure Safety Act.

BRAIN INJURY ADVOCACY AWARD

History of the 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. Lewis Lamont, a long-time member of the Council, passed away in May of 2024.

The award is presented every year in the Lamont name to a person or group who has positively influenced the brain injury community. Sarah Gaffney, ABIAC Secretary pictured on left, presented Carole Starr (right), author and advocate, with the 2023 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-ABIAC 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
- 2023-Carole Starr-Author and Advocate

SUMMARY

Brain Injury is a significant, on-going public health issue that affects all communities in Maine; in fact, the prevalence of brain injury in Maine is 20% of the total population. More than 5,500 Mainers will experience a traumatic brain injury in 2025, 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. Brain injuries 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 number of persons currently living with disability due to acquired brain injury represents 2% of the U.S population⁶. 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 disabled⁷ 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.

Maine has a relatively robust service system, and integrated neurorehabilitation, access to resources and care coordination is available. 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. Workforce challenges have also created barriers to specialized medical treatment, e.g. neuropsychologists, psychiatrists, professional therapy staff, paraprofessionals and care coordination.

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.

⁶ Traumatic Brain Injury: A “silent epidemic,” Center for Brain Injury and Repair, Perelman School of Medicine, University of Pennsylvania

⁷ About Potential Effects of a Moderate or Severe TBI, Center for Disease Control, May 2024.

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 in 2024 emphasized the need for timely access to care, the high personal and societal costs when survivors and families experience barriers to treatment ranging from underinsurance, losing insurance following an injury and unreasonable transportation hurdles. For those who found their way to specialized care, multiple accounts highlighted a lack of understanding by medical personnel and care managers of brain injury as well as lack of resources.

For the comparatively small population of Maine brain injury survivors who eventually qualified for MaineCare services, the wait for Section 18 waiver services is 3.6 years, a stark reality. The wait list for home and community-based services has more than doubled in the last four years, increasing from 100 in 2020 to 222 in 2024. Improvements in the amount and geographic availability of neuro-resource facilitation has been a helpful intervention for those regardless of insurance coverage. While waiver bed availability has made modest recovery following the COVID pandemic, specialized ABI nursing bed availability has diminished, following an overall trend of dwindling nursing homes in Maine.

Additional public hearing themes as well as the most recent needs assessment have emphasized the need for addressing workforce shortages, increased public awareness, improved children's services, and addressing the complex needs of individuals with challenging behaviors. The Council is hopeful about the latter as the state has undertaken a neurobehavioral treatment project, and if supported, would attend to a service gap and have the potential to reduce 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.

APPENDIX

Brain Injury Prevalence Data in Maine 2023

	US Census Estimate July 1, 2023	Prevalence TBI General Population: 20%	Prevalence of Stroke in ME: 4.1%	Prevalence of Brain Injury	Disabled from TBI: 2%	Disabled from Stroke: 50%	Disabled from Brain Injury
Maine	1,395,722	279,144	57,225	336,369	27,914	28,612	56,527

Brain Injury Prevalence Data 2022 by Maine County⁸

	US Census Estimate July 1, 2022	Prevalence TBI General Population: 20%	Prevalence of Stroke in ME: 3.6%	Prevalence of Brain Injury	Disabled from TBI: 2%	Disabled from Stroke: 50%	Disabled from brain injury
Maine	1,389,338	277,868	10,003	287,871	27,787	5,002	32,788
Androscoggin	113,225	22,645	815	23,460	2,265	408	2,672
Aroostook	67,322	13,464	485	13,949	1,346	242	1,589
Cumberland	308,837	61,767	2224	63,991	6,177	1,112	7,289
Franklin	30,595	6,119	220	6,339	612	110	722
Hancock	56,549	11,310	407	11,717	1,131	204	1,335
Kennebec	126,535	25,307	911	26,218	2,531	456	2,986
Knox	41,179	8,236	296	8,532	824	148	972
Lincoln	36,285	7,257	261	7,518	726	131	856
Oxford	59,458	11,892	428	12,320	1,189	214	1,403
Penobscot	154,728	30,946	1114	32,060	3,095	557	3,652
Piscataquis	17,403	3,481	125	3,606	348	63	411
Sagadahoc	37,372	7,474	269	7,743	747	135	882
Somerset	51,118	10,224	368	10,592	1,022	184	1,206
Waldo	40,255	8,051	290	8,341	805	145	950
Washington	31,527	6,305	227	6,532	631	113	744
York	216,950	43,390	1562	44,952	4,339	781	5,120

⁸ Annual Estimates of the Resident Population for Counties in Maine: April 1, 2020 to July 1, 2023 Source: U.S. Census Bureau, Population Division. Release Date: March 2024