ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE

ANNUAL REPORT 2025

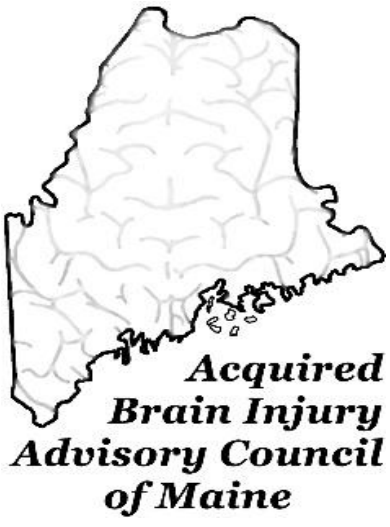

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TABLE OF CONTENTS

About the ABIAC ____ 3

- History & Purpose ____ 3
- Responsibilities ____ 3
- Composition ____ 3

Brain Injury Overview ____ 4

- Incidence in Maine ____ 4
- Prevalence in Maine ____ 5

Maine's System of Services ____ 6

- Specialized Nursing Care – MaineCare Section 67 ____ 6
- Brain Injury Home and Community Waiver – MaineCare Section 18 ____ 6
- Brain Injury Outpatient Services – MaineCare Section 102 ____ 8
- Private Duty Nursing and Personal Care Services – MaineCare Section 96 ____ 8
- Department of Labor ____ 8
- Core State Brain Injury Services (CSBIS) for Vulnerable Populations ____ 10
- ACL Federal Partnership Grant ____ 11

ABIAC Priorities ____ 12

- A Year in Review 2025 ____ 12
- Priorities for 2026 ____ 13

Brain Injury Advocacy Award ____ 15
Summary ____ 16
Recommendations ____ 168
Appendix A ____ 20

- Brain Injury Prevalence Data in Maine 2023 ____ 20
- Brain Injury Prevalence Data 2022 by Maine County ____ 20

Appendix B ____ 21

- Emergency Department Visits in Maine Due to TBI ____ 21
- Hospitalizations in Maine Due to TBI ____ 22
- Annual Maine Deaths Due to TBI ____ 23

Appendix C ____ 24

- National Incidence ____ 24
- Maine Incidence ____ 24
- Expanding Resources for Patients with ABI Due to Cardiac Arrest in Maine ____ 25

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 2025, the Council met six times, excluding subcommittee meetings, and held three public hearings. Over the past 19 years, the ABIAC has held more than 62 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 2025 follows.

Providers
Jennifer Jello, Co-chair, Standish
Matthew Hickey, Yarmouth
Austin Errico, Freeport
Brian Hurd, Orrington
Pamela Searles, Caribou

Families
Suzanne Morneault, Eagle Lake
Ed Russell, Winterport
Fran White, Oxford
Randy Bliss, Madison
Adam Mumm, Saco

State Liaisons
Derek Fales, Office of Aging and Disability Services
Kate Mcilhenny, Vocational Rehabilitation
Cassie Antonelli, Office of Behavioral Health
Tammy Diaz, Department of Education

Advocates
Sarah Gaffney, Secretary, Vassalboro
Danielle Malcolm, Augusta
Mary Le Blanc, South Berwick
Lucas Cuéllar, South Portland
Becky Hadiaris, Saco (outgoing)

Survivors
Jim Beaudry, Co-chair, Rockland
Anthony Barresi, Caribou
Trish Shorey, Saco
Blythe Edwards, Gardiner

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 2025 indicated that an estimated 6,000[2] Mainers experience a traumatic brain injury (TBI) resulting in an emergency room visit every year and 4,448 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.

Top Causes of TBI Death in Maine

- Firearms
- Falls
- Motor Vehicle Accidents

Data provided from the Maine CDC indicates that the top three causes of death for the last five years, 2020-2024, related to TBI are firearms, falls and motor vehicle accidents.

[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 2020-2024, Center for Disease Control

Prevalence in Maine

United States census data from 2022[3] 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% of people who have a stroke, an example of a non-traumatic injury, become disabled as a result.

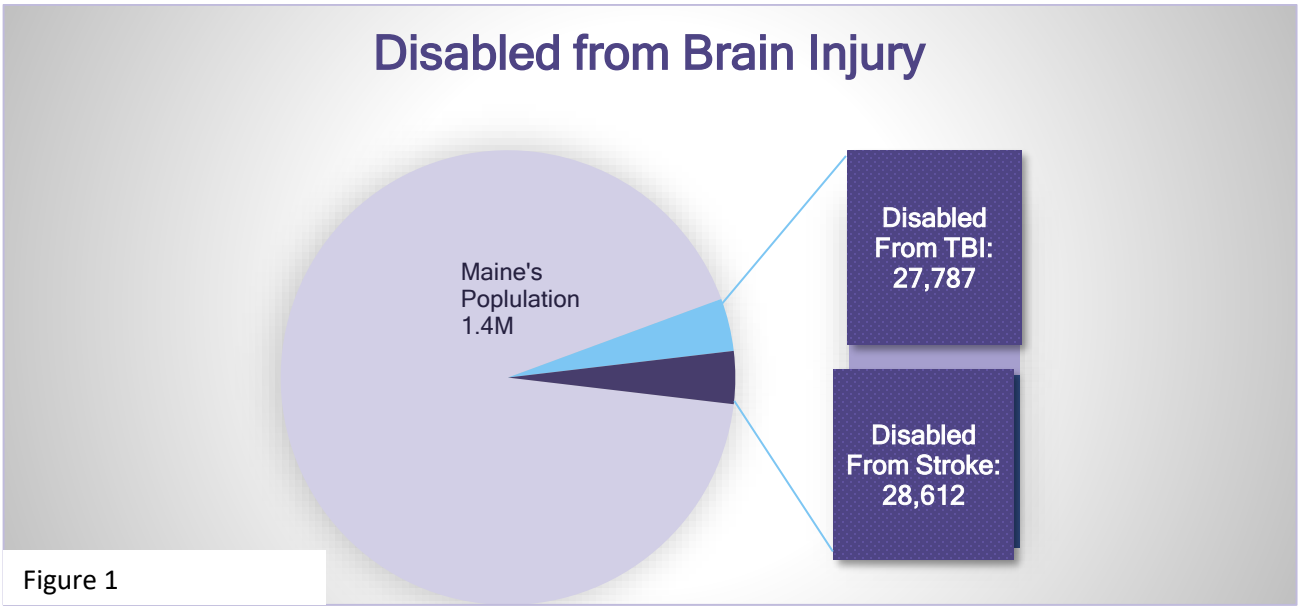


Figure 1

[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

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. See Figure 2.

Brain Injury Home and Community Waiver – MaineCare Section 18

- Section 18 recipients: 213; Section 18 funded offers: 37; Section 18 waitlist: 281. 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 4.6 years[4]. An Office of Aging and Disabilities representative reported to the Council that the wait for priority 1 may be less, estimating 1-2 years.
- Maine residents placed out-of-state due to lack of specialized services available within the state: 45
- Four (4) providers of care coordination services, though one provider has stopped accepting new referrals and two providers are at capacity and looking to hire additional care coordinators.
- Two (2) in-home support programs
- Section 18 recipients receiving participant directed services: 46
- Forty-one (41) community residential programs with 174 beds. Although not all of the beds are filled, this still represents an increase in capacity compared to the previous year.
- Two (2) providers of Financial Management Service to support the service delivery option of self-direction

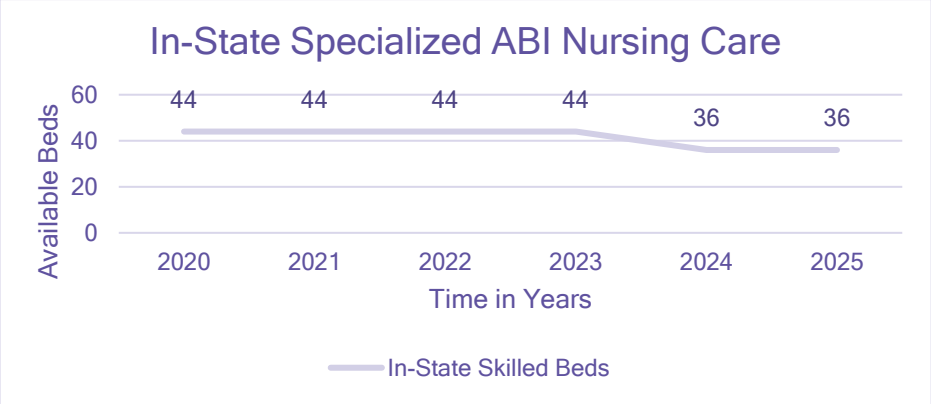


Figure 2

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

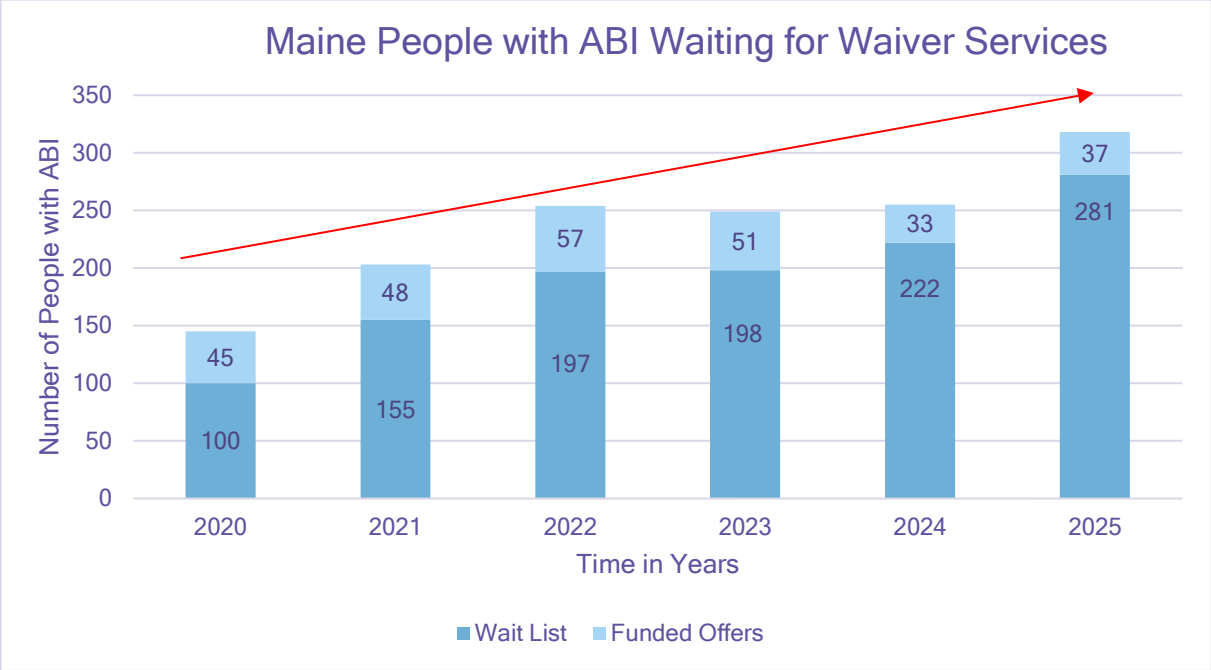


Figure 3

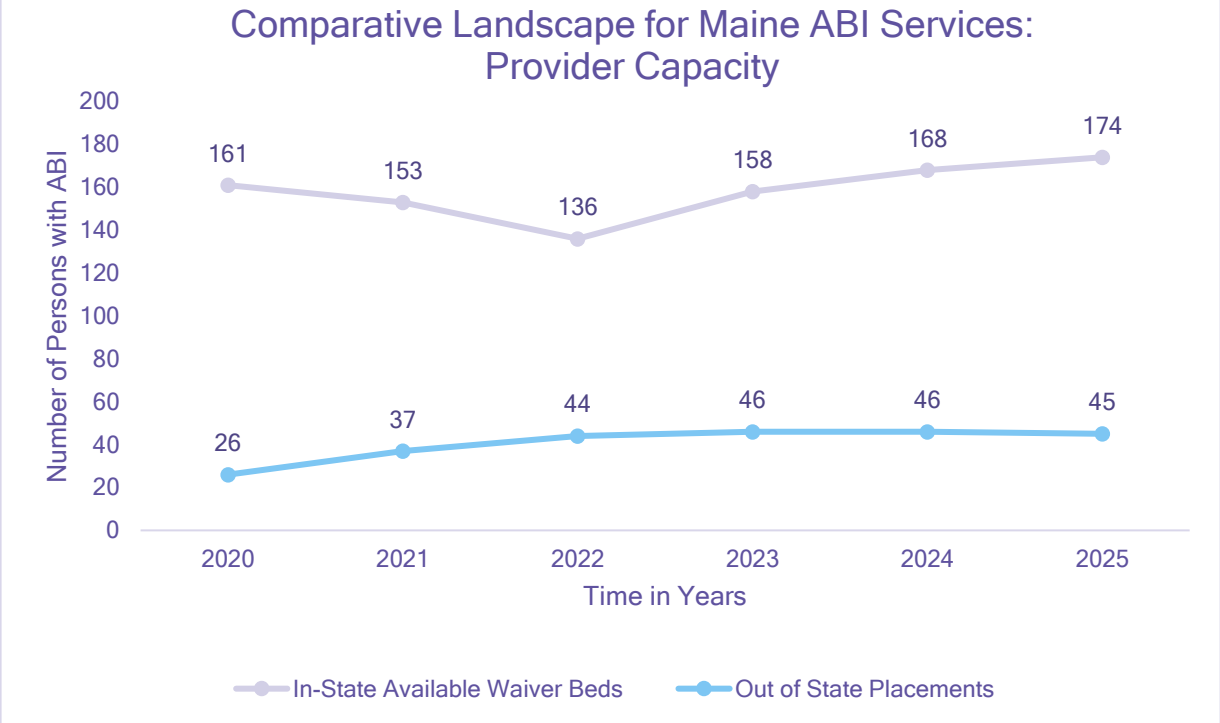


Figure 4

Brain Injury Outpatient Services – MaineCare Section 102

- Eight (8) outpatient neurorehabilitation clinics
- A total of 448 individuals were served in 2025 with MaineCare Section 102 funding; however, more individuals were served by the eight clinics through different payers.

Private Duty Nursing and Personal Care Services – MaineCare Section 96

Although MaineCare Section 96 does not exclusively serve individuals with brain injury, reports this year to the ABIAC highlighted that there are access concerns for individuals needing in-home care. Due to a service coordination agency ending their contract to provide Section 96 services, there have been individuals who are not able to access services, and the state has had to implement a referral management process to attend to basic needs. According to the state's access measures website, there are 2,069[5] participants in this service section. While there is officially no wait list, there is a reportedly large number of people who are not able to receive services under this section due to limited service coordination capacity. The Council has requested metrics from various representatives from the Department of Human Services and is awaiting data. The ABIAC voted to highlight the issue here as a concern.

Department of Labor

- Division of Vocational Rehabilitation (DVR) providers served 236 individuals in 2025, which represents an increase from the previous year. In 2024, DVR served 155 individuals.
- The Division of the Blind and Visually Impaired (DBVI) served 19 individuals in 2025, also representing an increase from eight (8) individuals in 2024.

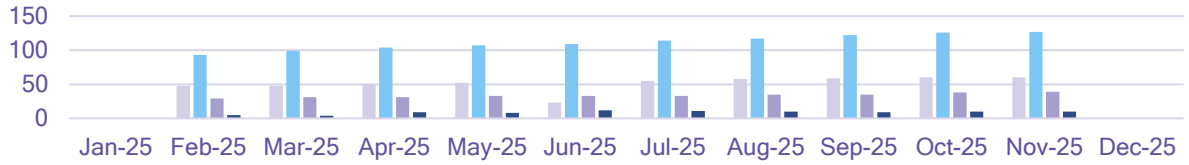
In 2025, the Central region served the highest number of TBI clients statewide, with 127 participants, followed by the South region with 60 clients. The North region served 39 clients, while intake accounted for 10 clients. The data for January 2025 is unavailable. Overall, the Central region clearly had the largest share of participants served throughout the year.

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

DVR TBI Statewide Participants in Calendar Year 2025
Number TBI by Month

South - Portland
Central - Lewiston & Augusta
North - Bangor, Machias, Presque Isle, & Houlton

Please note that January 2025 data is unavailable due to issues with Aware layout



	Jan-25	Feb-25	Mar-25	Apr-25	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25
South	0	48	48	50	52	23	55	58	59	60	60	
Central	0	93	99	104	107	109	114	117	122	126	127	
North	0	29	31	31	33	33	33	35	35	38	39	
Intake	0	5	4	9	8	12	11	10	9	10	10	

Figure 5

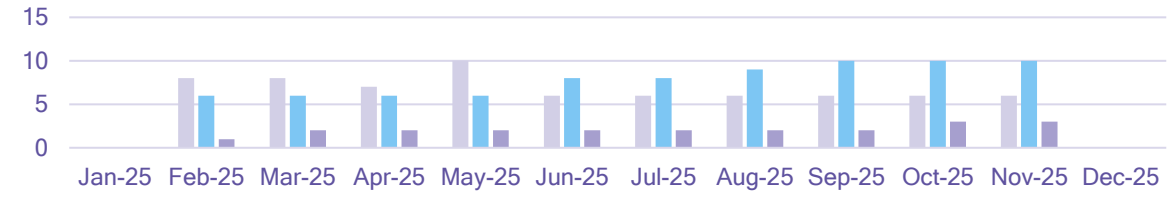
Figure 6 shows the number of TBI participants served by DBVI statewide in 2025 across three regions: South (Portland & Lewiston), Central (Augusta & Rockland), and North (Bangor & Presque Isle). The Central region consistently served the most clients each month, reaching 10 participants by November. The South region had a steady count, fluctuating between 6 and 10 participants, while the North region served the fewest clients, ranging from 1 to 3 participants monthly. January data is missing due to layout issues. Overall, the Central region is the primary service area with the highest client numbers. These number have more than doubled from 2024.

Figure 6

DBVI TBI Statewide Participants in Calendar Year 2025
Number TBI by Month

South - Portland & Lewiston
Central - Augusta & Rockland
North - Bangor & Presque Isle

Please note that January 2025 data is unavailable due to issue with Aware layout



	Jan-25	Feb-25	Mar-25	Apr-25	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25
South	0	8	8	7	10	6	6	6	6	6	6	
Central	0	6	6	6	6	8	8	9	10	10	10	
North	0	1	2	2	2	2	2	2	2	3	3	

Core State Brain Injury Services (CSBIS) for Vulnerable Populations

The Department of Health and Human Services 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.

NRF & HELPLINE

8,300

inquiries and requests for support

2021-2025

- 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.
- NRF and HELPLINE calls and requests for support and outreach of newly injured totaled 8,300 unique inquiries/requests for support from 2021 to 2025
- Outreach to newly injured/diagnosed persons with ABI.

- Education and training initiatives.
    - Annual state brain injury conference. In 2025, there were 207 attendees at the 16th annual conference on September 15, 2025, with two plenary and 11 breakout sessions.
    - The first northern brain injury conference was held in Presque Isle on May 20, 2025.
    - The Brain Injury Resource Fair took place on Thursday, March 20, 2025 at the Augusta Armory, with over 50 exhibitors and more than 250 attendees.
    - Maine-based resource directory and family caregiver training. 1,200 copies of the new 2025 resource directory distributed.
- 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 2,500 participants in 2025.

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 2025

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.

- Select Council members met with 2 out of 4 of Maine's delegates on Brain Injury Advocacy Day on March 5, 2025 in Washington D.C. and engaged in continued advocacy to Maine's full delegation through letters. Focuses included advocacy for renewal and increased funding for the TBI Act, support for a Brain Injury National Action Plan, concern about proposed cuts to Medicaid funding and advocacy for Maine representation on the Congressional Brain Injury Task Force.
- Representation in national ACL brain injury advisory board workgroup.
- Council members lead a panel discussion on advocacy and active brain injury councils on October 29, 2025 at the National Association of State Head Injury Administrators (NASHIA) State of the State Conference.

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

- Testified on LD 209, the supplemental budget, promoting restoration of cost-of-living adjustments (COLAs) and to express concern for impact to Maine's workforce.
- Testified on LD 210, the Governor's biennial budget, to advocate for restoration of COLAs, inclusion of funds to address MaineCare Sections 18 and 102 rate determinations, and advocate that language not be changed to allow for available allocations.
- Testified on LD 623, An Act to Enhance Support Services for Individuals with an Acquired Brain Injury, on March 18, 2025.
- Participated in the state's person-centered planning project, organized through NASHIA.
- Submitted a written appeal to support LR 2792, An Act to Respond to the Emergent Epidemic of Co-occurring Brain Injury and Overdose and Substance Use Disorder.

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 2025 included the following.

- The Person Centered Planning Initiative, National Association of State Head Injury Administrators

- Maine's Essential Care and Support Workforce Partnership
- Certified Community Behavior Health Clinics and Brain Injury
- Feedback from Maine Parent Federation on Children and Brain Injury
- Nolan's H.E.R.O. (Helping Everyone Realize Opportunity) Foundation and Ellie's Law
- Get On Board Initiative
- Cognitive Mandate Legislation, Brain Injury Association of America
- Maine's Brain Injury State Plan, National Administration for State Head Injury Administrators and Office of Aging and Disability Services

Priorities for 2026

Experience from Council members and testimonials during public forums held across the state, a collaboration between the Office of Aging and Disability Services and the ABIAC, yielded focus areas for the Council's consideration. Many of the same themes arose from past years, such as transportation barriers in a rural state, concerns 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.

54% of respondents said they needed, but could not get medical care in the last 5 years

These reports align with information presented to the ABIAC in 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.[6]

New and revised priorities as well as monitoring activities intended by the Council for 2026 are included here.

- Improve access to care.
  - Advocate for access to care for the uninsured and underinsured.
  - Advocate for brain injury treatment coverage by insurance companies.
  - Improve access to care coordination services as well as access to care for medically complex individuals.
  - Improve awareness that there is not enough bed capacity in state. Advocate for increased capacity of the brain injury waiver.
  - 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.

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

- 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. Improve concussion awareness for adolescents and youth, including return to classroom/return to play.
- 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.
- 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 2026.

- 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.
- Screening and diagnosis of ABI.
- A new activity for 2026: monitor progress on screening related to brain injury and intimate partner violence (IPV), particularly related to the use of the OBISSS (Online Brain Injury Screening and Support System).
- 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. Collaborate with the Maine Stroke Alliance as needed.
- Monitor progress on the TBI and PTSD (post-traumatic stress disorder) Law Enforcement Training Act.
- Monitor outcomes 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. **Leland Glynn**, advocate and former ABIAC member, received the 2024 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
- 2024-Leland Glynn-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 6,000 Mainers will experience a traumatic brain injury in 2026, 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 population[7]. 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[8] 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

[7] Traumatic Brain Injury: A “silent epidemic,” Center for Brain Injury and Repair, Perelman School of Medicine, University of Pennsylvania
[8] About Potential Effects of a Moderate or Severe TBI, Center for Disease Control, May 2024.

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.

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.

RECOMMENDATIONS

The Acquired Brain Injury Advisory Council supports the following recommendations. These recommendations are in alignment with published priorities, have been voted upon by Council members and do not necessarily represent an order of importance.

Recommendation 1: Cognitive Mandate

The ABIAC recommends that Maine consider legislation to require that insurance companies cover brain injury treatment in Maine. In other states this legislation has been coined the "cog mandate." Treatment includes cognitive rehabilitation, communication therapy, neuropsychological assessment, community reintegration and post-acute residential treatment among other components without short time limits, e.g., services do not end after six visits. Two states, Texas and Arkansas, have already passed laws. There are six other states, including Massachusetts, Tennessee, Iowa, Nebraska, Virginia and Pennsylvania currently considering this legislation.

This legislation represents no cost to the state, would expand benefits to an estimated 15% of Maine's population, and ultimately represent a cost-savings to the state, due to early intervention and rehabilitation, for individuals with chronic disability who may ultimately end up receiving Medicaid services. Cost analysis completed in Texas and shared with the Council suggests that the costs to insurance premiums is nominal, increasing premiums $1.37 per policy. Expanded access to services would be a needed win for Maine people navigating the challenge of life after brain injury.

Recommendation 2: Increase Service Capacity

For the comparatively small population of Maine brain injury survivors who eventually qualified for MaineCare services, the wait for Section 18 waiver services is 4.6 years, a stark reality. The wait list for home and community-based services has nearly tripled in the last five years, increasing from 100 in 2020 to 281 in 2025 (or over 300 when funded offers are included). Maine may want to consider legislation to fund additional waiver slots to attend to the growing need. In the interim, the Council recommends that the state consider two changes to increase capacity.

Reserved Capacity

The ABIAC recommends an amendment to MaineCare Section 18 waiver to allow for reserved capacity, a concept already captured in other waiver sections, but not in the brain injury waiver. At present, there are waiver spots reserved for MaineCare members being served out-of-state that are not likely to have an immediate need to return due to medical or behavioral acuity. The idea behind reserved capacity waiver language is that some of those funded offers could be used more quickly by individuals on the growing wait list, but the state

could still reserve some openings for individuals who may need to return from out-of-state placements. The amendment must be considered carefully and not reserve too much capacity (delaying services for some) or reserve too little (delaying repatriation of those individuals ready to return to home and community services in-state).

Time Limits on Funded Offers

At present, an individual who has received a funded offer can hang onto to the offer indefinitely–theoretically for years–without making a choice for placement. By setting reasonable time limits, individuals who receive a funded offer can make an informed choice to accept services, or pass and return to the end of the wait list. The intention here is to have a system for attending to those, in a timely way, who need and are ready for services. Reasonable limit language has been incorporated into other waivers and could be considered for MaineCare Section 18 in an amendment.

Recommendation 3: Neurobehavioral Treatment

The Council recommends funding and development of in-state neurobehavioral treatment facilities as well as mobile crisis stabilization. Maine currently has 45 individuals served in out-of-state placements. This is problematic for two reasons: (1) there is a higher cost in serving and transporting individuals out-of-state, and (2) families are unnecessarily separated because no in-state treatment options are available.

The Department of Health and Human Services Neurobehavioral Treatment Services Final Recommendations Report dated March 2025 highlights an approach to attend to service gaps, promote positive outcomes, prevent institutionalization and includes cost analysis. The Council refers readers to this report for additional information. If funded, in-state neurobehavioral treatment services would attend to a service gap and have the potential to reduce costly out-of-state placements.

APPENDIX A

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 County[9]

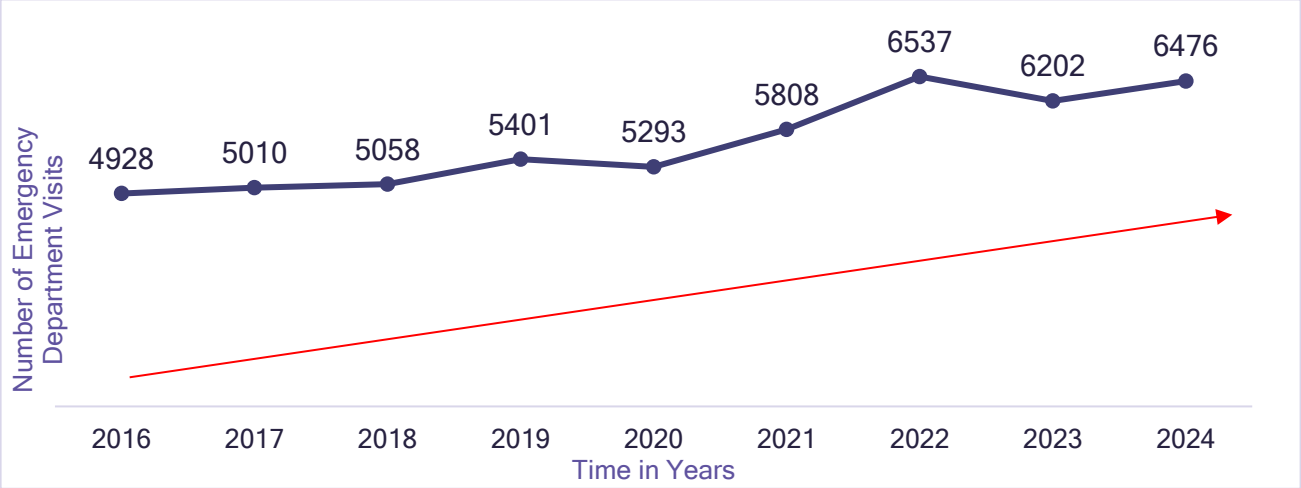
	US Census Estimate July 1, 2022	Prevalence TBI General Population: 20%	Prevalence of Stroke in ME: 3.6%	Prevalence of Brain Injury	Disabled from TBI: 2%	Disabled from Stroke: 50%	Disabled from brain injury
Maine	**1,389,338**	**277,868**	**10,003**	**287,871**	**27,787**	**5,002**	**32,788**
Androscoggin	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

[9] 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

APPENDIX B

Maine Center for Disease Control is credited with data included in Appendix B.

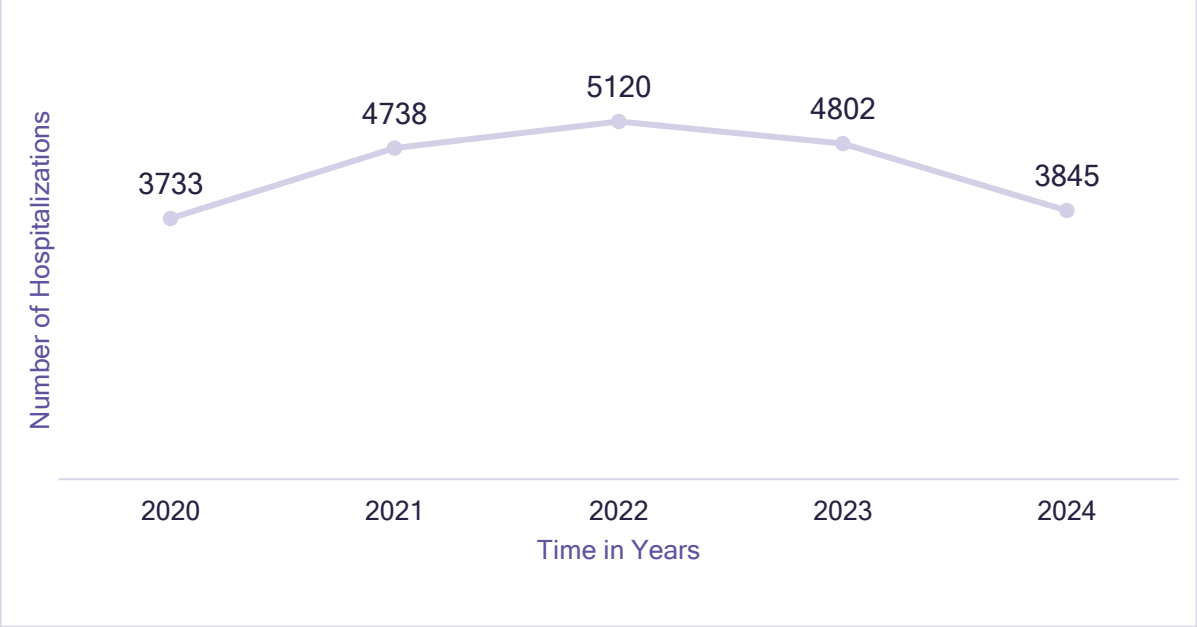
Emergency Department Visits in Maine for Traumatic Brain Injury[10]



	2020	2021	2022	2023	2024	Average Annual # of ED Visits for TBI (2020-2024)
Androscoggin	521	562	517	475	553	525.6
Aroostook	237	253	336	339	240	281.0
Cumberland	1,588	1,738	2,217	2,124	1,164	1,766.2
Franklin	112	142	156	168	147	145.0
Hancock	158	174	148	209	143	166.4
Kennebec	407	427	460	545	495	466.8
Knox	221	234	278	247	254	246.8
Lincoln	108	125	119	133	186	134.2
Oxford	186	201	224	227	292	226.0
Penobscot	680	728	670	597	247	584.4
Piscataquis	107	115	141	99	73	107.0
Sagadahoc	149	124	225	158	190	169.2
Somerset	212	283	268	203	210	235.2
Waldo	176	199	258	193	206	206.4
Washington	137	103	121	77	63	100.2
York	443	524	624	566	700	571.4

[10] Data provided by Maine Center for Disease Control. Source data includes Syndromic Surveillance ESSENCE

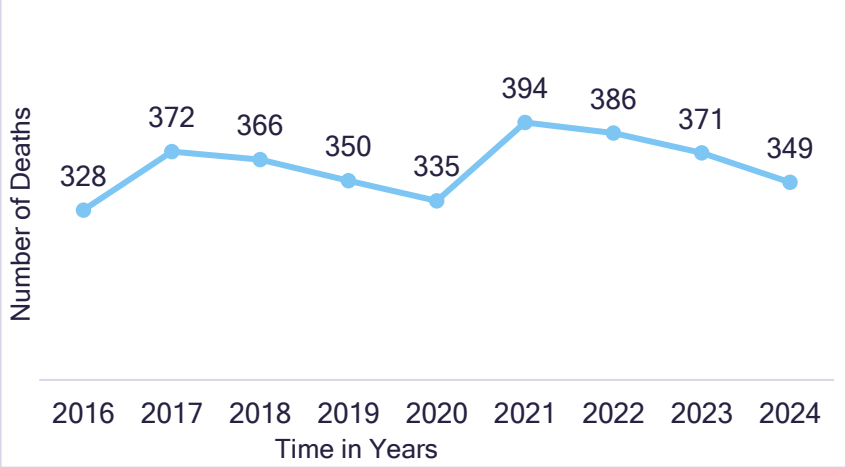
Hospitalizations Due to Traumatic Brain Injury in Maine Each Year[11]



	2020	2021	2022	2023	2024	Average Annual Number of Hospitalizations due to TBI (2020-2024)
Androscoggin	314	366	426	415	441	392.5
Aroostook	214	249	289	290	299	268.1
Cumberland	799	941	1081	1095	1,084	1,000.0
Franklin	81	111	101	106	109	101.5
Hancock	132	173	187	156	176	164.9
Kennebec	312	412	379	430	421	390.7
Knox	155	213	231	168	204	194.1
Lincoln	111	150	149	142	140	138.5
Oxford	160	206	193	219	223	200.3
Penobscot	322	466	426	390	411	403.0
Piscataquis	51	72	86	51	58	63.7
Sagadahoc	115	130	189	129	158	144.3
Somerset	188	263	257	202	264	234.9
Waldo	172	213	262	212	219	215.5
Washington	91	142	127	102	108	114.1
York	516	663	706	650	693	645.7

[11] Data provided by the Maine Center for Disease Control. Source data includes Maine Health Data Organization, Inpatient Hospitalizations

Annual Deaths Due to Traumatic Brain Injury in Maine Each Year



Approximately 1 person will die of a TBI each day in Maine

	2020	2021	2022	2023	2024	Average Annual Deaths due to TBI (2020-2024)
Androscoggin	24	29	25	31	34	28.6
Aroostook	21	25	20	21	17	20.8
Cumberland	54	69	75	62	45	61.0
Franklin	12	17	9	14	12	12.8
Hancock	16	16	11	23	11	15.4
Kennebec	36	28	34	28	40	33.2
Knox	5	15	10	10	6	9.2
Lincoln	9	15	13	16	13	13.2
Oxford	15	23	22	20	16	19.2
Penobscot	46	35	35	37	52	41.0
Piscataquis	10	7	7	2	7	6.6
Sagadahoc	6	10	2	6	7	6.2
Somerset	13	21	18	21	13	17.2
Waldo	9	13	18	16	10	13.2
Washington	14	13	17	10	8	12.4
York	45	58	67	54	58	56.4

APPENDIX C

Acquired Brain Injury Due to Cardiac Arrests in Maine

The Brian Injury Association of America Maine Chapter shared this narrative and data with the Acquired Brain Injury Advisory Council. Credit goes to the Cardiac Arrest Patient and Family Advisory Council.

National Incidence

The estimated annual incidence of out-of-hospital cardiac arrest (OHCA) treated by emergency medical services (EMS) in the US is ~185,000, (E) and survival to hospital discharge is estimated at ~11% (≈20,000 per year). (EF) For in-hospital cardiac arrest (IHCA), the incidence is estimated at 209,000 individuals, with survival to hospital discharge of 26% (≈54,000 individuals). (GH) Thus, an estimated 75,000 individuals are discharged alive from the hospital after cardiac arrest yearly in the US. (EFGH).

Most sustain an acquired brain injury which may be severe leading to irrecoverable coma, moderate requiring chronic care, or mild yet significant and often undiagnosed at hospital discharge. (A) A 2021 study found that 43% of cardiac arrest survivors discharged alive from the hospital demonstrated cognitive impairment on neuropsychological testing. (D) They receive fragmented care, compounded after hospital discharge when they struggle to access rehabilitation services, find support resources for themselves and family (co-survivors), or try to return to work. (BC) During Patient Family Advisory Council meetings, the group heard from patients and their families that the task of navigating the healthcare system to address these issues is immense and usually not achievable. This is multifaceted and includes general lack of outpatient neurocognitive rehabilitation resources, low awareness of these challenges in primary care provider and outpatient cardiology settings, and poor communication between the hospital teams for what problems might be expected after leaving the hospital.

Maine Incidence

For Maine in 2024, 1366 OHCA were attended by EMS, including 187 (14%) that were drug overdose related (data from Maine EMS & Fire Incident Reporting System - MEFIRS). The majority died in the field (873 - 64%) or the ED (85 - 6%), but 474 (35%) were transported to a hospital (see table on page 25). At Maine Medical Center-Portland in 2024, 132 patients were comatose after their cardiac arrest and treated in the intensive care unit. This includes patients brought directly to MMC and those experiencing an IHCA at MMC (66; 50%) or those transported to MMC from another hospital (66; 50%). Among these 132 patients, 81 (61%) died during their hospital stay; the remainder were discharged, with 10 (8%) having severe cognitive impairments, 21(16%) having moderate impairments, and 20 (15%) having mild cognitive impairments. If the data from MMC Portland are applied to the statewide totals for

the 474 brought to a hospital, 61% (289) would die in hospital, 8% (38) would have severe cognitive impairments, 16% (76) would have moderate impairments, and 15% (71) would have mild cognitive impairments.

Expanding Resources for Patients with Acquired Brain Injury Due to Cardiac Arrest in Maine

At the urging of the Cardiac Arrest Patient and Family Advisory Council, and with the staff at Maine Medical Center- Portland (Neurocritical Care, Cardiology, Social Work, Occupational Therapy, Speech and Language Pathology, Physiatry) and the Brain Injury Association of America - Maine Chapter, there will be a practice improvement effort to increase the number and improve the quality of pre-discharge structured assessments of cardiac arrest survivors, and working to connect them with NeuroResource Facilitators to improve the outpatient care they receive. The BIAA NeuroResource Facilitators will provide structured follow-up for patients and their families and assist in both education and direction to available resources in the community. This pilot includes up to 12 patients referred or 3 months of referrals, whichever originates first. The experience from this pilot will guide future plans and discussions about sustainability to continue improving care for this population.

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D. Byron-Alhassan A, et al. Resuscitation 2021; 165:154-160.
E. de Ferranti SD, et al.Circulation 2017;135:e146-e603.
F. CARES Cardiac Arrest Registry to Enhance Survival. https://mycares.net/.
G. Sunde K, et al. Resuscitation 2007;73:29-39.
H. Elmer J, et al. Resuscitation 2016;108:48-53.

Table 1: Out-of-Hospital Cardiac Arrest Patients in Maine 2024 Transported to Hospital

Hospital	N
MMC Portland	95(19%)
EMMC Bangor	64 (13%)
CMMC Lewiston	53 (11%)
MGMC + Thayer + Inland Waterville	48 (9.8%)
MH Biddeford	28 (5.8%)
Midcoast Brunswick	18 (3.7%)
PenBay Rockland	17 (3.5%)
Franklin Memorial Farmington	12 (2.4%)
Redington Fairview	11 (2.3%)
NL AR Gould	10 (2%)
Rumford Hospital	9 (1.8%)
Sebasticook Valley	9 (1.8%)
MH Sanford	9 (1.8%)
Waldo County	8 (1.6%)

Cary Medical Center	8 (1.6%)
Stephens Memorial	8 (1.6%)
York Hospital	7 (1.4%)
Portsmouth Regional	7 (1.4%)
Lincoln County Miles	6 (1.2%)
Houlton Regional	6 (1.2%)
NL Mayo	6 (1.2%)
Bridgton Hospital	5 (1%)
Calais Community Hospital	5 (1%)
Wentworth Douglass Hospital	5 (1%)

*- remaining 20 patients presented <5 for the year to other hospitals

Table 2: Transported to Hospital by Maine County 2024

Hospital	N
Androscoggin	53 (11%)
Aroostook	26 (5.3%)
Cumberland	118 (24%)
Franklin	12 (2.5%)
Hancock	9 (1.8%)
Kennebec	48 (9.8%)
Knox	17 (3.5%)
Lincoln	6 (1.2%)
Oxford	17 (3.5%)
Penobscot	67 (14)
Piscataquis	7 (1.4%)
Somerset	20 (4.1%)
Waldo	8 (1.6%)
Washington	7 (1.4%)
York	44 (9%)

*Presumably Sagadahoc had no transports in 2024