ACQUIRED BRAIN INJURY ADVISORY COUNCIL OF MAINE

ANNUAL REPORT – January 15, 2021

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

PROVIDERS
Scott Mayo, Chair, Deer Isle
Matthew Hickey, Secretary, Yarmouth
Sharlene Adams, Manchester
Austin Errico, Ph.D., Freeport

FAMILIES
Lewis Lamont, Mapleton
Suzanne Morneault, Eagle Lake
Ed Russell, Winterport
Gary Wolcott, Chesterville

ADVOCATE
Sarah Gaffney, Vassalboro
Sara Grant, Augusta
Courtney Michalec, Augusta
Trish Thorsen, Greene

SURVIVOR
Nitzana Aufiero, Newport
Ted Brackett, Portland
Lee Glynn, Skowhegan
Larry Marquis, Turner

STATE LIASONS
Derek Fales, OADS Liaison
Jessica Gartland, Vocational Rehabilitation
Sheila Nelson, Maine CDC Injury Prevention
Emily Poland, Maine DOE

PURPOSE & OVERVIEW

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

An acquired brain injury (ABI) is a brain injury that occurs after birth and is not hereditary, congenital, degenerative, or induced by birth trauma. ABI is the umbrella term for all brain injuries, including traumatic and non-traumatic injuries (e.g., strokes, brain tumors, anoxic injuries). ABIs can affect every aspect of an individual's being: physical, emotional, and cognitive impacts are common. More than 3.5 million children and adults sustain an ABI each year, but the total incidence is unknown (BIAA). It is estimated that 10,000 Mainers experience a brain injury every year.

ABIAC RESPONSIBILITIES AND HISTORY

- Formed in 2002 to support a federal grant
- Established in Statute in 2007 to provide oversight and advice to DHHS & Legislature
- Meets at least five times/year and holds at least two public hearings annually. Over the past 14 years, the ABIAC has held more than 50 public hearings throughout the state.
- Over the past 14 years, the ABIAC has served as the mandated Advisory Board for four Federal Traumatic Brain Injury (TBI) Partnership grants to improve the Maine's system of care for persons living with brain injuries and their families. As part of those grants, the Council has sponsored more than a dozen statewide forums on critical issues and partnered with multiple provider organizations to provide training for hundreds of professionals and paraprofessionals.
- In 2020 the Council met ten times and held two public hearings.

CURRENT SERVICE SYSTEMS

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

Medicaid Funding:

Specialized Nursing Care (Section 67)
2 Specialized Skilled Nursing/Rehabilitation Facilities with **44** licensed specialized beds for persons with ABI

Brain Injury Home and Community Waiver – Section 18 MaineCare Benefits
205 Section 18 recipients, **45** Section 18 funded offers, **100** on Section 18 waitlist
26 Maine residents placed out-of-state due to lack of services
4 Providers of care coordination services with **205** individuals served in 2020
Community residential programs with **161** beds
2 In-home support programs

BI Outpatient Services
7 Outpatient neurorehabilitation clinics served **491** individuals in 2020
1 Work-ordered day vocational clubhouse served **33** individuals in 2020

Vocational Rehabilitation Funding
2 Vocational Rehabilitation providers served **173** individuals in 2020

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

- Neuro-Resource Facilitation to ensure access to brain injury services in Maine for high-risk individuals and support for families
- Outreach to newly injured/diagnosed persons with ABI
- Information and 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. **808** calls in 2020
- Education and training, including the annual state brain injury conference, a Maine brain injury resource fair, a Maine-based resource directory, and family caregiver training
- Support and education for hospitals and agencies working with at-risk ABI populations
- Support for **17** Support Groups for survivors and families that engaged more than **2000** participants in 2020

CURRENT ACL FEDERAL PARTNERSHIP GRANT

Through the Federal TBI Partnership Grant through the Administration for Community Living (ACL), great progress was made in 2020 on tackling the intersection of brain injury and the opioid crisis in Maine. Accomplishments include a webinar on brain injury and substance use disorder (SUD); a forum connecting the mental health, SUD, and brain injury communities; four sessions dedicated to the intersection of brain injury and SUD at BIAA-ME's annual brain injury conference; and outreach and education to Maine SUD providers.

ABIAC PRIORITIES FOR 2020 and OUTCOMES

- Improve funding for provider rates and eliminate the current waitlist for Home and Community Services (Section 18) for persons with brain injuries.

Outcomes – DHHS conducted rate studies on brain injury services during 2020 in order to develop efficient and sufficient payment rates. Additionally, DHHS requested and received emergency funding for temporary rate increases during the COVID pandemic. No additional funds were available to eliminate the Section 18 waitlist.

- Increase awareness of ABI and improve treatment coordination.

Outcomes – The ABIAC would like to thank the legislature for the passage of LD 297 to provide core brain injury supports to Maine brain injury survivors and families. As a direct result of LD 297, in 2020 brain injury Information and Resource and Neuro-Resource facilitation services were provided to Maine brain injury survivors, families, and professionals; Maine brain injury support groups received support and education; a new Maine Brain Injury & Stroke Resource Directory was produced; and hospitals and community organizations received education and resources, among other core supports.

- Focus efforts on addressing the opioid epidemic and resulting brain injuries.

Outcomes – Through the Federal TBI Partnership Grant through the ACL, great progress was made in 2020 on tackling the intersection of brain injury and the opioid crisis in Maine. Accomplishments include a webinar on brain injury and substance use disorder (SUD); a forum connecting the mental health, SUD, and brain injury communities; four sessions dedicated to the intersection of brain injury and SUD at BIAA-ME's annual brain injury conference; and outreach and education to Maine SUD providers.

- Address transportation issues for service recipients resulting in missed medical appointments and lack of access to services through ongoing monitoring and advocating for improvements.

Outcomes – Specific transportation issues were brought to DHHS by the ABIAC. DHHS held meetings with stakeholders to resolve these issues. Substantial improvement has been reported.

- Improve access to and impact of assistive technologies for service recipients and providers.

Outcomes – Discussions with assistive technology providers were initiated, and DHHS submitted adjustments to assistive technology benefits under the Home and Community services waivers to Federal Medicaid. Further efforts need to continue in 2021.

- Development of Neurobehavioral Services for persons with brain injuries and severe behavioral challenges to ensure effective, Maine-based care.

Outcomes – Due to time limitations caused by the COVID-19 pandemic, progress on this priority did not occur. Efforts will be made to prioritize this issue in 2021.

- Explore creation of ABI trust fund to provide funds for non-MaineCare eligible children and adults.

Outcomes - ABIAC subcommittee was formed and began to explore possible structure of a trust fund and surveyed other states which have trust funds. Further efforts to define specific goals and funding mechanisms will continue in 2021.

- Improve understanding of needs of underserved Mainers with ABI – children, youth sports, substance use disorder, domestic violence, and criminal justice.

Outcomes – ABIAC conducted two public hearings in 2020 where these issues were raised. Testimony from the hearings was incorporated into the ABIAC's priorities. A statewide needs assessment funded by the Federal ACL grant was initiated and will be conducted in 2021.

- Expand survivor, family, and advocacy organization representation on ABIAC.

Outcome - The 129th Legislature passed legislation to enhance the ABIAC membership. It adds 3 survivors, 3 family members, and 3 advocates (one representative each from the Long-Term Care Ombudsman, Aging and Disability Resource Centers, and Center for Independent Living) to membership for a total of 20 voting members. The DHHS Commissioner is reviewing nominations for appointments to fill the new positions.

ABIAC PRIORITIES FOR 2021

- Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to ensure humane, cost-effective, evidenced-based treatment in Maine. Explore collaboration with New Hampshire and Vermont on development of mobile neurobehavioral team for assessment, treatment, and consultation for individuals served by community agencies.
- Advocate for a state law clearly describing the Rights of Service Recipients with ABI.
- Advocate for ongoing coordination and funding for services to address the confluence of persons with substance use disorder and a brain injury. Support efforts to increase awareness, professional education, and treatment coordination. Advocate for MaineCare rule changes and funding for Substance Abuse Counseling as a billable service in the Neurorehabilitation Clinics in Section 102.
- Improve access and impact of Assistive Technologies/Telehealth for service recipients and providers through advocacy for DHHS rule changes that provide greater flexibility. Such changes can cause more efficient and effective use of funds and personnel to support service recipients.
- Support the creation of an ABI trust fund to help Maine children and adults with ABI who lack financial resources/eligibility for timely, effective treatment.
- Improve understanding and coordination of services for children with ABI through regular participation of a representative of OCFS on the ABIAC.
- Improve the effectiveness of the ABIAC through providing advanced, formal, quarterly status reports describing critical indicators of brain injury services from OADS, MaineCare, Maine CDC, and OCFS.
- Provide guidance to the ACL Partnership grant efforts including the statewide needs assessment to be conducted in 2021.

REPORT SUMMARY

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

Brain Injury is a significant, on-going public health issue that affects all communities in Maine. More than 10,000 Mainers will experience a brain injury in 2021. Falls, motor vehicle crashes, sports-related concussions, violence, combat-related injuries, opioid overdoses, strokes, brain tumors, infections, and other causes can result in ABIs. The Council is also concerned about brain injuries caused by emerging infectious diseases, including COVID-19, and the resultant impact on Maine citizens. ABIs are often accompanied by significant, long-term cognitive, emotional, behavioral, and physical changes that alter the lives of brain injury survivors and their families. In addition, brain injury survivors are at increased risk of experiencing social, mental health, and substance use disorder challenges.

The Federal Centers for Disease Control and Prevention (CDC) reports that traumatic brain injury (TBI) alone is the leading cause of death and disability in children and young adults in the United States. Overall, the number of persons currently living with disability due to acquired brain injury represents 4.5% of the U.S population (including stroke, TBI, and epilepsy combined). Many will make meaningful recoveries, especially if they get the needed rehabilitative care. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. Immediate access to specialized neurorehabilitation treatment (including information and care coordination) is crucial for positive outcomes. Unfortunately, public and private health insurance continues to impose limits for rehabilitative care based solely on financial costs rather than based on functional goals or treatment outcomes.

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

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

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

The 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.

STATUTORY REQUIREMENTS

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES
Chapter 19: ADVISORY COUNCILS
§19001. Acquired Brain Injury Advisory Council

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

2. Duties. The council shall:

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

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

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

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

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

[PL 2007, c. 239, §2 (NEW).]

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

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

A. Five members with acquired brain injuries must represent persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

B. Five members must represent families of persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

C. Two members must represent advocates for persons with acquired brain injuries; [PL 2007, c. 239, §2 (NEW).]

D. Five members must represent providers of services to persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

E. Five members must represent state agencies with expertise in the areas of education, employment, prevention of brain injuries, homelessness, corrections and services to veterans. Members of the council who represent state agencies serve ex officio, without the right to vote, and shall provide data, information and expertise to the council; [PL 2019, c. 566, §1 (AMD).]

F. One member must represent an aging and disability resource center; [PL 2019, c. 566, §1 (NEW).]

G. One member must represent a center for independent living; and [PL 2019, c. 566, §1 (NEW).]

H. One member must be the long-term care ombudsman under Title 22, section 5107 A or a representative of the long-term care ombudsman. [PL 2019, c. 566, §1 (NEW).]

[PL 2019, c. 566, §1 (AMD).]

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

Title 22: HEALTH AND WELFARE
Subtitle 2: HEALTH
Part 7: PUBLIC REHABILITATION SERVICES
Chapter 715-A: ASSISTANCE FOR SURVIVORS OF ACQUIRED BRAIN INJURY
§3087
§3086.
Definitions
As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings. [PL 1987, c. 494 (NEW).]

1. Acquired brain injury. "Acquired brain injury" means an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which:
A. Is not of a degenerative or congenital nature; [PL 1989, c. 501, Pt. P, §26 (NEW).]
B. Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]
C. Can result in the disturbance of behavioral or emotional functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]
D. Can be either temporary or permanent; and [PL 1989, c. 501, Pt. P, §26 (NEW).]
E. Can cause partial or total functional disability or psychosocial maladjustment. [PL 1989, c. 501, Pt. P, §26 (NEW).]

§3088. Comprehensive neurorehabilitation service system
The department shall, within the limits of its available resources, develop a comprehensive neurorehabilitation service system designed to assist, educate and rehabilitate the person with an acquired brain injury to attain and sustain the highest function and self-sufficiency possible using home-based and community-based treatments, services and resources to the greatest possible degree. The comprehensive neurorehabilitation service system must include, but is not limited to, care management and coordination, crisis stabilization services, physical therapy, occupational therapy, speech therapy, neuropsychology, neurocognitive retraining, positive neurobehavioral supports and teaching, social skills retraining, counseling, vocational rehabilitation and independent living skills and supports. The comprehensive neurorehabilitation service system may include a posthospital system of nursing, community residential facilities and community residential support programs designed to meet the needs of persons who have sustained an acquired brain injury and assist in the reintegration of those persons into their communities. [PL 2011, c. 293, §3 (RPR).]
SECTION HISTORY
PL 1987, c. 494 (NEW). PL 2011, c. 293, §3 (RPR).

§3088-A. Support for underserved populations
Within the limits of its available resources, the department may enter into contracts with organizations representing individuals with a brain injury and their families, bringing together state and national expertise to provide core brain injury support for underserved populations of individuals with an acquired brain injury, including, but not limited to, individuals who experienced an opioid drug overdose resulting in anoxic or hypoxic brain injury, who are veterans, who are victims of domestic violence, who are experiencing homelessness, who are ineligible for MaineCare and who have a newly acquired brain injury. For the purposes of this section, "core brain injury support" includes, but is not limited to, resource facilitation, brain injury support groups, outreach designed for individuals who have a newly acquired brain injury, access to a joint state and national helpline, information and resource education and family caregiver training. The department may adopt rules to

implement this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2 A. [PL 2019, c. 488, §1 (NEW).]
SECTION HISTORY
PL 2019, c. 488, §1 (NEW).

§3089. Acquired brain injury assessments and interventions; protection of rights
The department is designated as the official state agency responsible for acquired brain injury services and programs. [PL 2005, c. 229, §1 (NEW).]
1. Assessments and interventions. In addition to developing the comprehensive neurorehabilitation service system under section 3088, the department may undertake, within the limits of available resources, appropriate identification and medical and rehabilitative interventions for persons who sustain acquired brain injuries, including, but not limited to, establishing services:
A. To assess the needs of persons who sustain acquired brain injuries and to facilitate effective and efficient medical care, neurorehabilitation planning and reintegration; and [PL 2011, c. 293, §4 (NEW).]
B. To improve the knowledge and skills of the medical community, including, but not limited to, emergency room physicians, psychiatrists, neurologists, neurosurgeons, neuropsychologists and other professionals who diagnose, evaluate and treat acquired brain injuries. [PL 2011, c. 293, §4 (NEW).]
[PL 2011, c. 293, §4 (NEW).]

2. Rights of patients and responsibility of department to protect those rights. To the extent possible within the limits of available resources and except to the extent that a patient with an acquired brain injury's rights have been suspended as the result of court-ordered guardianship, the department shall:
A. Protect the health and safety of that patient; [PL 2011, c. 293, §4 (NEW).]
B. Ensure that the patient has access to treatment, individualized planning and services and positive behavioral interventions and protections; and [PL 2011, c. 293, §4 (NEW).]
C. Protect the patient's rights to appeal decisions regarding the person's treatment, access to advocacy services and service quality control standards, monitoring and reporting. [PL 2011, c. 293, §4 (NEW).]
[PL 2011, c. 293, §4 (NEW).]

3. Rules. The department shall establish rules under this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.
[PL 2011, c. 293, §4 (NEW).]
SECTION HISTORY
PL 2005, c. 229, §1 (NEW). PL 2011, c. 293, §4 (AMD).