January 15th, 2019

Senator Geoff Gratwick, Chair
Representative Patricia Hymanson, Chair
Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta ME 04333-0100

Dear Senator Gratwick, Representative Hymanson, and Members of the Joint Standing Committee on Health and Human Services:

I am pleased to present you with the Acquired Brain Injury Advisory Council of Maine's annual 2019 report. The Council was originally established in April 2002 to support a federal grant. It was established into law in September 2007 to address the needs of persons with brain injuries and their families, and to raise awareness of those needs to promote systemic change.

Brain Injury is a continuing public health issue that can impact each of us and our families; it affects all communities in Maine. Falls, motor vehicle crashes, sports-related concussions, and violence represent real risks to every Maine citizen. In addition, other sources of brain injury include combat related non-fatalities, anoxia due to opioid overdose, chronic alcoholism and recreational drug abuse, stroke, brain tumor, epilepsy, and infection. These can result in significant thinking, emotional, behavioral and physical changes that alter lives.

With Warmest Regards,

On Behalf of the Members of the Acquired Brain Injury Advisory Council
Scott Mayo, Chair
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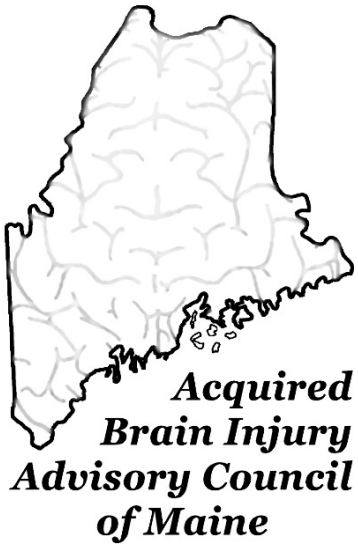
BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE



ANNUAL REPORT

January 15, 2019

The Acquired Brain Injury Advisory Council of Maine

	Representing
Scott Mayo, Chair	Providers
Mathew Hickey, Secretary	Providers
Lewis Lamont	Families
Ted Brackett	Persons with Brain Injuries
Joann Beaudoin	Families
Sarah Gaffney	Advocates
Rick Langley	Advocates
Sharlene Adams	Providers
Austin Errico, Ph.D.	Providers
Lorrie Winslow	Providers
Sheila Nelson	Maine CDC Injury Prevention
Derek Fales	OADS Liaison
Jessica Gartland	Vocational Rehabilitation
Ellie Larrabee	OCFS
Lorrie Winslow	Providers

Appointed by Commissioner of DHHS

CONTENTS

OVERVIEW

Brain Injury is a continuing public health issue that can impact each of us and our families; it affects all communities in Maine. Falls, motor vehicle crashes, sports-related concussions, and violence represent real risks to every Maine citizen. In addition, other sources of brain injury include combat related non-fatalities, anoxia due to opioid overdose, chronic alcoholism and recreational drug abuse, stroke, brain tumor, epilepsy, and infection. These can result in significant thinking, emotional, behavioral and physical changes that alter lives.

Traumatic Brain Injury
- Falls
- Motor Vehicle Crashes
- Sports Injuries
- Other Injuries Caused by Trauma

Non-Traumatic Brain Injury
- Strokes
- Loss of Oxygen
- Brain Tumors
- Other Internal Assaults to the Brain

The Center for Disease Control and Prevention (CDC) reports that Traumatic Brain Injury (TBI) is the leading cause of death and disability in children and young adults in the United States. Per the National Center for Health Statistics in 2012: the prevalence rates of acquired brain injury are as follows: TBI (5.3 million), stroke (6.2 million), and epilepsy (2.0 million), adding up to 13.5 million Americans, making acquired brain injury the second most prevalent disability in the United States. Overall, the number of persons currently living with disability due to acquired brain injury represents 4.5 percent of the U.S population. Many will make meaningful recoveries, especially if they access needed rehabilitative care. 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. Legislation such as the Medicare Post-Acute Care Value Based Purchase Legislation and Medicare Part B caps on outpatient therapy potentially shorten the treatment periods for people with brain injury to obtain needed therapy services. Medicare combines Physical Therapy and Speech Therapy under one annual financial cap of 2,040.00 dollars while Occupational Therapy is capped at 2,040.00 dollars as well. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. Immediate access to specialized neurorehabilitation information, education, and care coordination is crucial for a positive outcome.

Sometimes, the system of community care ends prematurely, condemning survivors to costly nursing facilities or other institutions, cutting off options for the person to return home. History shows that these individuals can live successfully, when treatment and supports are available, outside of institutions. At the other end of the spectrum are those individuals who physically appear uninjured but have significant cognitive and behavioral disabilities, which can improve with professional treatment. This phenomenon is known as the “Silent Epidemic.”

Year after year, public hearings in Maine have demonstrated individuals continue to have issues related to brain injuries which are often dismissed or misdiagnosed leading to the provision of ineffective treatment that leaves individuals and clinicians with feelings of failure and frustration. This creates a significant misdirection of valuable resources, poor interactions with family, employers and the community.

The system in Maine is improving access to the right services and supports. When we do the “right thing” we create efficiencies that allow our tax dollars to be used effectively in the utilization of proper resources to include evidence based treatment and recommendations to increase positive 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 the hospital and criminal justice system.

PRIORITIES & RECOMMENDATIONS

The Acquired Brain Injury Advisory Council (referred to hereafter as “the Council” or ABIAC) commends and thanks the Governor, the Legislature, and DHHS for continuing to support brain injury services and future initiatives.

This report reflects the highest priority areas identified for the Council, as determined through input by the people of Maine during public listening tours across the State. The needs of Maine citizens with brain injuries are very broad and complex. These recommendations speak to actions that the Council believes could be accomplished in 2019 and have the potential to significantly impact quality of care.

Future work of the Council will address the many other areas identified through needs assessments, public hearings, and forums. Public hearing testimony overwhelmingly emphasized the need for improved access to services, education for professionals and para-professionals, workforce shortage challenges, expanded care coordination/neuro-navigation, increased public awareness on prevention and education, family and peer supports, employment opportunities, improved children's services and addressing the complex needs of individuals with challenging behaviors.

2019 Recommended Legislative Action:

1. Appropriate funding to support brain injury survivors, caregivers and families with neuro-resource facilitation, mentor support groups, and information and referral to enable individuals in need who do not have traditional MaineCare funding as well as ensure those without access to case management in lieu of Home and Community Based waiver services, regardless of payer opportunities.
2. Appropriate funds for a system of response and support for brain injury survivors, families, and caregivers resulting from the loss of the Federal Traumatic Brain Injury Partnership Grant.
3. Appropriate additional funding for the brain injury waiver to serve individuals currently on a waitlist.
4. Ensure reimbursement parity for Care Coordination and Home Support Level 1 services.
5. Appropriate funding for a Neurobehavioral Treatment Center. Currently, individuals requiring this level of care are stranded in hospitals or out-of-state institutional placements without the appropriate clinical treatment. Not only is this more costly to the State of Maine, individuals' recovery suffers due to lack of natural supports and family involvement.

2019 Recommendations to DHHS & Commissioner:

1. Streamline the process for individuals to access Assistive Technology through increased spending and integration of assistive technology devices and education to be used by all service providers and caregivers. The Council recommends a waiver amendment to allow for flexibility with the current assistive technology funds that would allow for equipment acquisition and effective training and education for user and support staff/caregivers. The current rules do not allow the ability to shift costs to support individuals in their areas of greatest need. In addition, the Council supports re-establishment of the Assistive Technology user-group to foster communication and collaboration between providers, stakeholders and DHHS.
2. Support the creation of an ABI trust fund to be used within Maine to support underserved or unserved individuals, families, and caregivers.
3. Monitor transportation and study the impact of missed rides resulting in missed treatment for individuals with brain injuries receiving services.
4. Promulgate the Rights of Recipients of Brain Injury Services for Adults.
5. Develop a statewide system for screening and referral for acquired brain injury that ensures screening for acquired brain injury occurs in a timely manner. This screening process will ensure the appropriate treatment approaches are in place to address neurological treatment needs that may otherwise be misdiagnosed.
6. The Council recommends specific steps to be taken to improve the current treatment of children with acquired brain injuries in Maine. A systematic approach that begins with early screening, diagnosis and referral to appropriate brain injury service providers is recommended. The Council recommends screening for every child at each prevention/treatment encounter, educational settings, public health nursing

programs, and at every child well-being check. Education needs to be provided to medical, educational and other providers of children services related to appropriate referrals to brain injury service providers for treatment and rehabilitation. The Council recommends that Department of Health and Human Services and the Department of Education increase collaboration to address the ongoing needs of children with acquired brain injuries including but not limited to diagnosis and Maine's limited clinical capacity to support, rehabilitate and treat each child effectively.

7. DHHS should appoint a representative from the Department of Education to the ABIAC which has been vacant since the Council's inception.
8. Develop training, treatment, and support services to address the opioid crisis and the impact they have on brain injury prevalence in Maine.
9. Work with the Federal ACL to explore future funding options

Council 2019 Priorities

1. Create a protocol that will assist the Council to evaluate the effectiveness of brain injury services in Maine.
2. Collect and review data regarding opioids and acquired brain injury due to overdoses and misuse.
3. Address children and young adults with brain injury through an in-depth exploration of needs beginning with earlier screening, referral and diagnosis of brain injury.
4. Collect and review available information on brain injury trust funds currently available in other states.
5. Support legislation regarding Maine State Identification cards having a voluntary indicator that a person is a brain injury survivor. The Council will partner with State Legislators, Secretary of State, Brain Injury VOICES, and other service providers to support this effort, along with a partnership for education and training to include criminal justice, all first responders, and mental health providers.
6. Ensure implementation of CMS recommendations from quality review report within the brain injury waiver. The Council will review annual performance measures that report on waiver and ensure system corrections as appropriate.
7. Work with the DHHS & Commissioner to explore future funding options.

COUNCIL ACTIVITIES & HISTORY

The Council was originally established in April 2002 to support a federal grant. It was established into law in September 2007 to address the needs of persons with brain injuries and their families, and to raise awareness of those needs in order to promote systemic change.

Over the past decade, the Council has held 45 public hearings (Bangor, Brewer, Portland, Caribou, Presque Isle, Lewiston, Sanford, Houlton, Calais, Farmington, Fort Kent, Dover-Foxcroft, Biddeford, Kennebunk, Rockport, Machias, Rockland, Standish, Waterville, and Effingham, NH) receiving testimony from hundreds of Maine citizens with brain injuries and their families.

The Council gathered information through these public hearings and forums to formulate its recommendations. The Council met eleven times in 2018 including a day-long review of DHHS' brain injury initiatives and action plans developed at the forums.

The Council has sponsored more than a dozen one-day forums for in-depth exploration of critical public health challenges, including:

- Military service members and Veterans with brain injuries
- Children and adolescents with brain injuries
- Domestic Violence, Corrections, and brain injury
- Public policy challenges in brain injury
- Homelessness and brain injury
- Complex Needs of persons with brain injuries
- Employment and brain injury
- Assessment and Care Coordination
- Substance Abuse
- Assistive Technology
- Caring for the Caregiver

In the four years since the ACL/TBI partnership grant award, the Council has co-sponsored two training forums each year, one held in spring and one held in the fall, to further increase education around brain injury and best practices in supporting and treating individuals with brain injury. The grant ends May 2019.

The Council acknowledges and thanks the DHHS Liaison to the Council: Derek Fales, Neurobehavioral Services, from the Office of Aging & Disability Services.

ABIAC & COLLABORATIVE PARTNERS ACCOMPLISHMENTS:

Since 2007, there have been 45 public hearings across the State. 2018 forums were held in Caribou, Fairfield and Standish, Maine.

Maine Concussion Management Initiative- 6/1/2014 – 5/31/2018

- Delivered 29 trainings for providers of brain injury services and other related services that focused on the topic of understanding and screening for concussions
- Delivered 20 trainings for coaches and other key personnel at the high school level on the topic of understanding and screening for concussions
- Delivered 71 educational outreach programs for the general public and interested stakeholders on the topic of understanding and screening for concussions
- Visited 137 of Maine's public and private high schools to perform concussion policy and management needs assessments
- 603 concussions have been entered during the grant's 4-year cycle

Alpha One, over the course of the grant contacted 86 individuals (78 via phone, 6 via email and 2 'walk-in') regarding brain injury and related information and referral interactions. Alpha One provided information on adapted driving evaluations, personal support services, ramp construction and other home accessibility modifications, adapted loan program information, durable medical equipment resources, personal emergency response systems, visual impairment resources and resources on specialty therapy services for a brain injury.

The **Home Base Program** assists Post-9/11 Service Members, Veterans and their families heal from the Invisible Wounds of War: traumatic brain injury (TBI), post-traumatic stress (PTS) and related conditions. During the reporting period, Home Base launched a targeted social media campaign for Maine clinicians to increase the multi-week TBI course participation for the April 9, 2018 course.
The program reached 30 Maine registrants for the course, of which 24 completed at least one seminar. During the contract period, the online multi-week TBI course was offered twice with a total of 64 unique participants from Maine watching one or more sessions.
Home Base delivered two in-person education sessions and presented to 65 Maine clinicians and first responders during this year's grant period. Home Base participated in two in-person outreach events and used a targeted social media campaign for Maine clinicians to increase Home Base's multi-week TBI course occurring in September 2017 and again in April 2018. The social media campaign generated a reach of more than 42,000 people with over 490 links clicked. This contributed to a successful recruitment of course participants in Maine.

The Brain Injury Association of America – Maine Chapter (BIAA-ME) BIAA-ME's 9th Annual Conference on Defining Moments in Brain Injury was held October 16, 2018. The conference featured five tracks, including a survivor track and a concussion-training track through MCMI. The conference had 275 attendees with 78 of those identifying as survivors and family members. BIAA-ME also hosted the 2018 Maine Brain Injury Resource Fair, which took place on March 29, 2018. The fair is designed as a "one-stop shopping" event for Maine brain injury survivors, family members, and professionals to connect with important resources and supports and is free to attend. This was the third year that BIAA-ME held the fair and, after outgrowing the previous venue, it was held at a new location, the Augusta Armory. The fair had 191 attendees, including 50 survivors and 35 family members/caregivers.

In January 2018, the BIAA-ME began distributing the second edition of *Maine Brain Injury and Stroke Resource Directory* in both digital and hard copy formats. Copies were available at the 2018 Maine Brain Injury Resource Fair and distributed at hospital trainings, outreach events, and other presentations throughout the state. The directory is also available on the BIAA-ME website as a PDF download and in e-reader format.
During this reporting period, the BIAA-ME visited 4 hospitals and provided information and education on brain injury services and resources in Maine. A total of 77 hospital staff attended these presentations. In addition, during this reporting period a total of 183 families, survivors, friends, and professionals received information on brain injury services and referrals. Of those served, 62 were survivors and 53 were family members. All information requests were initiated by phone, email or in-person and support was provided via email, mailings and/or phone. Twelve families/survivors received longer-term one-on-one support through resource facilitation services during this reporting period.

To date, BIAA-ME has provided education and resources to 92% (and offered education to 100%) of Maine's hospitals. BIAA-ME has also provided education to dozens of community organizations, learning institutions, and brain injury support groups. In these educational presentations, BIAA-ME staff provided attendees with information and materials on Maine brain injury resources and supports for professionals, survivors, and family members/caregivers. BIAA-ME provides support and resources to Maine's 18 brain injury support groups. In 2018, Maine brain injury support group meetings were utilized over 2500 times by brain injury survivors, family members, and caregivers.

The USM – Muskie School of Public Service completed *Brain Injury Family Training #2.* This training is intended for family members and loved ones in Maine, who are caring for adults who have experienced brain injuries and reside in Maine. Topics covered include: Brain injury refresher and ongoing discovery; becoming a caregiver; journey toward acceptance; navigating complex support systems; and stories of hope, resilience, and small successes. The completed draft was shared with members of the BIAA-ME and other key stakeholders.

Their comments and suggestions were added to the document. The training is available on Maine's Office of Aging and Disability Services website, the Brain Injury Association of America Maine Chapter and other website resources in Maine.

Goodwill Industries of Northern New England delivered trainings for correctional officers on brain injury and other related services that focused on understanding and screening for concussion. The HELPS Brain Injury Screening Tool was given to Kennebec County Jail with no completed tools returned. Goodwill coordinated and hosted Certified Brain Injury Specialist training courses for 95 professionals.
Courses were held in the following locations during this grant period:

Augusta, ME	18 attendees	(21 registered/enrolled)
Saco, ME	21 attendees	(24 registered/enrolled)
Bangor, ME	23 attendees	(24 registered/enrolled)
Hallowell, ME	26 attendees	(26 registered/enrolled)

Goodwill coordinated and hosted a public forum on the topic of acquired brain injury. The conference was held on April 20th, 2018 at the Calumet Club in Augusta, Maine. There were 126 registered/enrolled individuals with actual attendance of 114 individuals. Part I was "Traumatic Brain Injury 101 from Mechanism to Rehabilitation: An overview to Help Guide Care" and Part II was "The Effect of Secondary Trauma and How to Cope for the Caregiver." Goodwill coordinated a stakeholder group for input on and development of a brain injury curriculum course. Two classes were held in Portland. There were 6 attendees from various providers in each class.

SERVICE SYSTEM REPORT

- The Brain Injury Waiver received CMS approval to begin on November 1, 2014; the first person began receiving service in January 2015. There have been 195 members served by the Brain Injury Waiver in 2018.
- The neurorehabilitation clinics (Section 102) have served 498 in 2018 as of October 2018
- Brain Injury VOICES presented brain injury training in February 2018
- Vocational Rehabilitation Services held a brain injury training in June 2018
- All MaineCare Services for brain injury require accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF) and staff who are Certified Brain Injury Specialist (CBIS) or other equivalent qualified brain injury training. This past year, seven providers have either received or renewed their CARF accreditation.
- No cost extension for TBI grant was attained in 2018
- Testimony in support of increased access to brain injury services and neurobehavioral treatment center services was provided.
- A representative from Vocational Rehabilitation is actively attending the ABIAC meetings and reporting data on how many individuals with brain injury are accessing Vocational Rehabilitation services.

STATUTORY REQUIREMENTS

Title 34-B: Behavioral and Developmental Services
§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, the Director of the Office of Adults with Cognitive and Physical Disability Services within the department, the Director of the Maine Center for Disease Control and Prevention within the department and the

Director of the Office of MaineCare Services within the department. [2007, c. 239, §2 (NEW).]

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; [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; [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; [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 [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. [2007, c. 239, §2 (NEW).]

Title 22: Health and Welfare, Ch. 715-A: Assistance for Survivors of Acquired Brain Injury

§3086. Definitions As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings. [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; [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; [1989, c. 501, Pt. P, §26 (NEW).]

C. Can result in the disturbance of behavioral or emotional functioning; [1989, c. 501, Pt. P, §26 (NEW).]

D. Can be either temporary or permanent; and [1989, c. 501, Pt. P, §26 (NEW).]

E. Can cause partial or total functional disability or psychosocial maladjustment. [1989, c. 501, Pt. P, §26 (NEW).] [2011, c. 293, §1 (AMD).]

§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. [2011, c. 293, §3 (RPR).] SECTION HISTORY 1987, c. 494, (NEW). 2011, c. 293, §3 (RPR).

§ 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.

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

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.

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;

B. Ensure that the patient has access to treatment, individualized planning and services and positive behavioral interventions and protections; and

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.

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.