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BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE



ANNUAL REPORT

January 15, 2020

The Acquired Brain Injury Advisory ABIAC of Maine

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Mathew Hickey, Secretary	Providers
Lewis Lamont	Families
Gary Wolcott	Families
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Appointed by Commissioner of DHHS

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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, combat-related brain injuries and health problems such as strokes, brain tumors and other diseases can cause acquired brain injuries, which result in significant thinking, emotional, behavioral and physical changes that alter lives.

Acquired Brain Injury

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graph TD; A[Acquired Brain Injury] --> B[Traumatic Brain Injury]; A --> C[Other Acquired Brain Injury]
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Traumatic Brain Injury

- Falls
- Motor Vehicle Crashes
- Sports Injuries
- Other Injuries Caused by Trauma

Other Acquired 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 (including stroke, TBI, and epilepsy combined). 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 1,920.00 dollars while Occupational Therapy is capped at 1,920.00 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 for these people, condemning them to costly nursing homes or 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 expert assistance. 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 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 ABIAC 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 ABIAC believes could be

accomplished in 2020 and have the potential to significantly impact quality of care. Future work of the ABIAC 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, workforce shortage challenges, expanded care coordination/neuronavigation, 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.

2020 Legislative Recommended Action:

1. Appropriate funding for a Neurobehavioral Treatment Center, LD 408. Currently, individuals requiring this level of care are stuck in hospitals or out-of-state institutional placements and correctional facilities 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.
2. Appropriate funding for the brain injury waiver to address the waitlist and anticipated needs across the State.
3. Support legislation that revises the membership composition of the ABIAC. Explore adding representation from the Legislature.
4. Support legislation that authorizes the promulgation of rights of recipients of brain injury services.

2020 Recommendations to DHHS & Commissioner:

1. The ABIAC recommends updated rules that allow for flexibility of the current assistive technology (AT) funds. This would allow for equipment acquisition and effective training and education for users, support staff, and caregivers. In addition, the ABIAC supports re-establishment of the Assistive Technology user-group to foster communication and collaboration between providers, stakeholders and DHHS. DHHS should conduct a survey regarding AT use, outcomes report data, flexibility related to AT credential to increase providers.
2. The ABIAC recommends and supports DHHS' continued prevention initiatives, including those supporting the opioid epidemic and domestic violence.
3. Support the creation of an ABI trust fund to be used within Maine to support underserved or unserved adults and children, families, and caregivers.
4. Monitor transportation and study the impact of missed rides resulting in missed treatment for individuals with brain injury receiving services and non-medical transportation to provide greater opportunities for individuals to have access to the community.
5. DHHS should appoint a representative from the Office of Child and Family Services who will actively participate on the ABIAC.
6. The ABIAC supports continued training, treatment, and support services to address the opioid crisis and the impact it has on brain injury prevalence in Maine.
7. The ABIAC seeks monthly reporting from the Department on the number of children and adults with ABI and their service needs. This reporting should include the number of individuals served, the types of services they receive, the utilization rate of authorized services, waiting list for services, and the number of out of state placements for both adults and children, this will allow for an ongoing review of the current service delivery system and also evaluate how the current system meets or fails to meet the needs within Maine. The Department should evaluate the current services available for both adults and children in Maine, adding services to allow for least restrictive community based settings, including

increases in assistive technology services, addition of consumer directed services, and specific services to address the needs of children with brain injuries.

ABIAC 2020-Priorities

1. Create a protocol that will assist the ABIAC to evaluate the effectiveness of brain injury services in Maine.
2. Ensure implementation of (Center for Medicaid Services) CMS recommendations from quality review report within the brain injury waiver. The ABIAC will review annual performance measures that report on waiver services and ensure system corrections as appropriate.
3. Evaluate the Section 18 OADS rate study results and potential impact on services. The ABIAC will make recommendations based on the rate study to (Office of Aging Disability Services) OADS. ABIAC should be granted status to participate as a stakeholder in the upcoming review of MaineCare services and rates.
4. Create a sub-committee on establishing different modes of gathering stakeholder input. Create a community needs survey in collaboration with the Brain Injury Association of America Maine Chapter.
5. Develop a survey with the Department of Education (DOE) to evaluate the effectiveness of services provided to students and families related to brain injury education, awareness, and training in school systems.
6. Pursue representation on DOE's concussion work group.
7. Review ABIAC membership composition. Implement statutory changes as needed.
8. Establish an orientation program for all new ABIAC members.
9. Finalize recommendations relating to trust fund program in the state of Maine for brain injury survivors.
10. Recommends that DHHS/OADS add Licensed Substance Abuse Counselors to the rehabilitative services program Section 102 of the MaineCare manual.
11. Increase public awareness of the role of the ABIAC.
12. Encourage full implementation of Maine's Employment First Statute and review how the state is promoting increased access to competitive integrated employment throughout the state of Maine, such as customized employment opportunities.
13. Explore opportunities for the ABIAC to have representation on Maine CDC appropriate prevention committees and initiatives.
14. Create an assistive technology sub-committee to review current options for the assessment, acquisition and procurement of assistive technology.
15. Form a sub-committee to establish a pathway for implementing rules to secure the Rights of Recipients of Brain Injury Services and Programs as afforded in Maine Statute Title 22 MRSA Sec.3089.
16. Partner with the Maine Developmental Disabilities ABIAC on their committee to study and review the self-directed options available to individuals.

ABIAC ACTIVITIES AND HISTORY

The ABIAC 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 12 years the ABIAC has held 46 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 ABIAC gathered information through these public hearings and forums to formulate its recommendations. The ABIAC met seven times in 2019 including a day-long review of DHHS' brain injury initiatives and action plans developed from information gathered at the forums.

The ABIAC has sponsored seven, one-day forums for in-depth exploration of critical public health challenges:

- Military service members and Veterans with brain injuries - June 2007
- Children and adolescents with brain injuries - October 2008
- Domestic violence and brain injury - March 2009
- Public policy challenges in brain injury - October 2009
- Homelessness and brain injury - March 2010
- Complex Needs of persons with brain injuries - March 2011
- Employment and brain injury - December 2011
- Assessment and Care Coordination - June 2012

In the three 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.

In 2010 the ABIAC presented an Advocacy Award to Lewis and Clara Lamont for their amazing work with the Brain Injury Association of Maine as well as their strong advocacy for individuals impacted by brain injury. The award is presented every year in their name to someone who has positively influenced the brain injury community.

Past recipients of the Lewis and Clara Lamont Advocacy award are,

2011 Dr. Paul Berkner MCMC Colby

2011 Dr. Joseph Atkins MCMC Colby

2011 Dr. William Heinz MCMC Colby

2012 Beverley Bryant Author and Advocate

2013 Marcia Cooper ABIAC and BINN

2014 Kirsten Capeless Brain Injury Services Manager DHHS

2015 Sarah Gaffney BIAA ME

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

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

ABIAC AND COLLABORATIVE PARTNERS ACCOMPLISHMENTS:

LD 49 passed into law. Beginning January 1, 2020, the Secretary of State shall issue, on the request of a person who elects to receive it, an acquired **brain injury identification card** in accordance with this section.

LD 297 passed into law. This bill authorizes the Department of Health and Human Services to 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.

LD 408 passed into law, an act to **Improve Access to Neurobehavioral Services**. Services shall develop a plan to provide up to 16 new neurobehavioral beds in the state to serve individuals with ABI. DHHS shall submit a report with the plan, together with any necessary legislation, to the Joint Standing Committee on Health and Human Services no later than January 30, 2020. The committee is authorized to report out a bill based on the report to the Second Regular Session of the 129th Legislature.

LD 972 passed into law. This bill directs the **Department of Health and Human Services to increase the rates for services provided to MaineCare members receiving Home Support (Residential Habilitation) Level I under the brain injury waiver, rule Chapter 101: MaineCare Benefits Manual, Chapter III, Section 18**, to no less than \$8.63 per quarter hour. It also allows up to 400 units of care coordination each year rather than only in the first year of receiving services under the waiver. The Department of Health and Human Services is directed to explore opportunities to provide additional telehealth services, including care coordination services, provided by both licensed medical personnel and non-licensed personnel. The Department of Health and Human Services must seek approval from the United States Department of Health and Human Services, Centers for Medicare and Medicaid Services to amend the brain injury waiver to increase rates for Home Support (Residential Habilitation) Level I to no less than \$8.63 per quarter hour. It also requires the department to include any findings from exploring telehealth opportunities for brain injury services to be submitted to the joint standing committee of the Legislature having jurisdiction over health and human services matters as part of the annual telehealth report. The amendment also adds an appropriations and allocations section.

The ABIAC presented information to the Commissioner on this problem and its specific impact on brain injury services. The Council will continue providing data and advocating for increased collaboration with providers and transportation services. The ABIAC is encouraged by the Department's efforts to address this serious barrier to access to healthcare and welcomes further collaboration. **The ABIAC encourages the Department to thoughtfully review individuals' access to reliable transportation for non-emergency and non-medical transportation which continue to be priorities for the ABIAC.**

The ABIAC has supported establishing rights for recipients of brain injury services. The ABIAC presented to the Commissioner of DHHS the current status and advocated for the need to finalize these rights. **The ABIAC is disappointed DHHS is choosing not to promulgate the rights for recipients of brain injury services** approved by the ABIAC. The ABIAC will continue to advocate to the Commissioner of DHHS and provide any

information needed to move this forward.

The ABIAC would like to **thank Commissioner Lambrew** for her efforts with the Department of Education to fill the vacant DOE seat on the ABIAC.

The ABIAC encouraged the DHHS Commissioner to support a new ACL Grant that was awarded to Maine. **The grant work will focus on Maine's opioid crisis relating to brain injury.** In addition, the ABIAC membership composition will include more representation from survivors and family members.

The ABIAC initiated background information related to **Trust Fund development in the State of Maine.** Framework was created based on information from existing Trust Fund programs in other states. The ABIAC will continue to further develop a plan related to recommendations and advocacy for a B.I. Trust Fund program in Maine.

STATUTORY REQUIREMENTS

Title 34-B: Behavioral and Developmental Services

§19001. Acquired Brain Injury Advisory ABIAC

1. ABIAC established. The Acquired Brain Injury Advisory ABIAC, referred to in this section as "the ABIAC," 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 ABIAC 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) .] [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.