

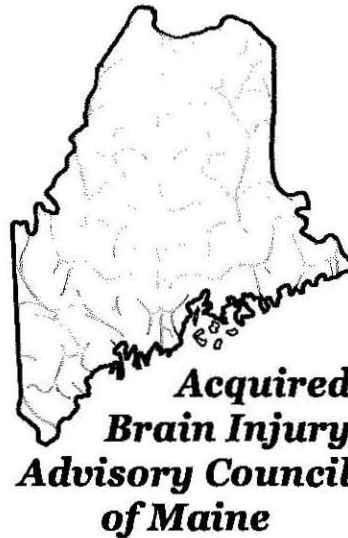
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BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE



ANNUAL REPORT

January 15, 2014

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**Appointed by Mary Mayhew, Commissioner of DHHS*

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OVERVIEW

Brain Injury is a growing 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, combat related brain injuries, and violence represent real risks to every Maine citizen. In addition, 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.

Thirty years ago most people who experienced a severe brain injury died and those who sustained a mild or moderate brain injury went unrecognized. Today, with the advances in medicine, the vast majority of individuals survive. Each year doctors are able to save many more individuals who acquire severe brain injuries. More than 10,000 Mainers experience brain injuries each year. Many will make good recoveries, especially if they access needed rehabilitative care. Unfortunately, private health insurance continues to impose limits for rehabilitative care based on financial and not clinical needs. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. Over 6,000 Maine citizens are living with long-term disabilities due to brain injuries. Immediate access to information and education, care coordination and rehabilitation is crucial for a good outcome. Sometimes the system of care gives up prematurely on these people, condemning them to costly nursing homes or institutions, cutting off options for the person to return home. History shows, these individuals can live outside of institutions with the right support. At the other end of the spectrum are those individuals who appear uninjured but have significant cognitive and behavioral disabilities, which can improve with expert assistance. Too many times issues related to brain injury are dismissed or misdiagnosed; treatments provided are not only ineffective but leave individuals and clinicians with feelings of failure and frustration. This creates a significant misuse of valuable resources, poor interactions with family, employers and problems in the community.

We can do better, by providing the right services and support at the right time. When we do the “right thing” we create efficiencies that allow our tax dollars to be used effectively and results in improved treatment outcomes. 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 systems.

LEGISLATIVE ACTION

The Acquired Brain Injury Advisory Council commends and thanks the Legislature and the Governor for passing the 2014 budget to include funds for a brain injury waiver.

The four statutes that the 125th Legislature “first session” established that define brain injury and the responsibilities of Department of Health and Human Services (DHHS) for maintaining a safety net for persons with significant disabilities due to brain injuries are being implemented. The Council continues to look forward to working with DHHS on the process of implementing these changes including development of specific DHHS policies.

2014 Recommended Action – DHHS should work with the Centers for Medicaid and Medicare Systems (CMS) to get an approved waiver for the brain injury services in Maine. DHHS should complete the work of writing and putting new policies into practice that reflect the direction of the Legislature in these statutory revisions (22 MRSA §3086.)

ACCOMPLISHMENTS

- The State of Maine has approved funding for the implementation of the Brain Injury Waiver
- Increased participation and widened the scope of expertise of the voting members and advisory members of the ABIAC
- Held five public hearings including Ft. Kent, Machias, Waterville, Lewiston, and Effingham, NH with 131 people in attendance, 65 of whom provided testimony
- ABIAC provided testimony to the Joint Committee of Appropriations of Health and Human Services in support of the Brain Injury Waiver
- Presented information and input to the Private Non-Medical Institution (PNMI) Committee advocating for the unique needs of individuals with brain injury with regards to Brain Injury Services and the Brain Injury Waiver
- Supported conferences on Acquired Brain Injury in Ft. Kent and two in South Portland with over 450 people attending these conferences
- 148 professionals in Maine are currently accredited as Certified Brain Injury Specialists
- 90 high schools are now participating in the Maine Concussion Management Initiative
- ABIAC is taking a lead role along with the State to develop state rule to protect the rights for individuals with brain injury
- ABIAC is participating on the DOE workgroup for Concussion Management in the Schools as a result of LD 1873 the Youth Concussion Bill that was passed to work toward better protection of our youth state wide
- ABIAC collaborated with the Disability Rights Center in the development of a new statewide information and referral system and website
- ABIAC advocated in Washington, DC about clinical services for individuals with brain injury
- ABIAC collaborated with the State to accomplish many successes that were recognized nationally by HRSA's Big Strides Awards which is given to a state that does not receive HRSA grant money
- ABIAC increased collaboration with veterans services with VA participation on the Council and ABIAC representation on Maine Military Family Coalition
- ABIAC provides representation on Employment First Committee to advocate for creation of employment opportunities for individuals with brain injury and other disabilities
- Through ABIAC encouragement, the State created an online training for Acquired Brain Injury
- In previous years, DHHS has returned all nursing level patients to Maine from out-of-state placements resulting in improved independence and decreased costs. DHHS has created a complex case team and instituted internal efforts to better coordinate in-state placements. DHHS has continued to meet the needs of Maine citizens through instate providers in the past year.
- Annual measures of effectiveness of neurorehabilitation in Maine demonstrate ongoing improvement and increased functional independence for recently injured as well as long term survivors of brain injury.
- The Council has supported Maine Center for Disease Control (CDC) Injury Program as it continues to support abusive head trauma/shaken baby syndrome prevention education in Maine birthing hospitals and at one of Maine's correctional facilities. Maine CDC's Injury Prevention Program is also supporting falls prevention in older adults' activities, bicycle and pedestrian safety, teen and older adult driver safety, suicide prevention and unintentional poison prevention activities. The CDC works with the MCMC to raise awareness, provide education, and link people to the DOE and their website. The CDC worked with USM to gather and prepare information for publication on sports concussions and pediatric head trauma in Maine.

PRIORITIES & RECOMMENDATIONS

This report reflects the highest priority areas identified by the Council. 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 2014 and have the potential to significantly impact quality of care and cost savings. 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 housing, transportation, professional training, improve access to services, employment opportunities, support groups, and increased public awareness and education.

PRIORITY ONE – Enhance Maine’s brain injury neurorehabilitation system to respond to current needs in a cost neutral manner.

The current system including in-patient acute care and rehabilitation, specialized skilled nursing services, and the Private Non-Medical Institution (PNMI) residential programs is not adequately meeting the needs of individuals with brain injuries and their families. Too many individuals “get stuck” in a service despite making improvements in their health and functional capacity. Instead of moving on to greater independence, their improvement slows and unnecessary costs are incurred. Each year many individuals with significant brain injuries are stuck in hospitals awaiting placement in the next appropriate level of rehabilitation care. Pressure to move these people to out-of-state placements to free up hospital beds is intense. Once out-of-state the quality of care cannot be assured and costs are dramatically increased.

Last year, an average of 80 known persons waited to receive residential support services in one of the 125 specialized brain injury PNMI beds. More than 20 persons living in those specialized brain injury PNMI are ready to move to less expensive, more independent settings, closer to their original homes. However, there is no current MaineCare option to provide “less than 24/7 support” for these individuals (unlike for persons with developmental disabilities or serious mental illness.)

The lack of care coordination once the individual moves home is yet another barrier to greater independence. Individuals have challenges navigating the current residential and outpatient systems as there is not care coordination available.

2014 Recommended Action – DHHS should apply for a 1915(c) Medicaid waiver from the Federal government to allow for a cost-efficient system of community-based care. This waiver should include care coordination, community-based residential support, cost-effective technology support, and services to support return to work. This waiver can be accomplished with existing funds and provide more services for the same investment.

PRIORITY TWO – Train professionals, direct care workers, and educate the community as a whole to improve outcomes.

A lack of sufficient knowledge, training and skill among Maine’s healthcare, mental health and educational professionals were the leading issues identified by stakeholders attending the Council’s hearings and forums over the past five years. Testimony cited misdiagnosis of brain injuries, inappropriate treatment, denial of services, and poor quality of care. The knowledge and evidence based practices in neuroscience have dramatically increased over the past decade. Maine’s educators, healthcare professionals and community service providers lack sufficient access to this new information. In-service training and continuing education budgets continue to shrink. Maine does not mandate specific brain injury training, (other than specialized brain injury programs) which inhibits early identification, effective treatment and appropriate referrals to specialized neuro-rehabilitation resources in the community.

The demand on professionals and direct care staff to take on an increasing workload has created a serious gap in Maine's ability to provide quality care and services to persons with brain injuries being served in both the private and public sectors. Many direct care workers, providing day-to-day care in clinics, residential programs, nursing homes and hospitals are not properly trained to work with persons with brain injuries. The Council received reports from various stakeholders, which raise significant concerns for the safety of service providers, other program participants and the individual with brain injury who presents challenging behaviors. If staff is not adequately trained, individuals with brain injury do not learn how to manage behavior effectively. Improperly trained staff leads to increased risks for all involved. Training should include Departments of Labor, Education, Public Safety, Corrections and others who support persons with brain injuries including family care givers and others.

2014 Recommended Actions

DHHS should establish in regulation, minimum staff training standards for all healthcare, rehabilitation, and long-term care residential programs that serve individuals with brain injuries.

DHHS should adapt existing training programs to include specific modules on brain injury and offer information and technical assistance to other state departments in their training efforts.

DHHS should collaborate with statewide brain injury advocacy organizations to increase public awareness about brain injury, accurate screening of brain injury, provide training for families, and set best practice for service providers working with individuals with brain injuries.

PRIORITY THREE – Improve reliability and access to transportation.

The second highest individual need identified during the public hearings held in 2013 was the need for accessible, consistent, and reliable transportation. Many individuals testified that the change in the transportation system has affected them negatively and highly impacted their lives with regards to access to services, work, and stress of not knowing whether their schedule ride would show up.

2014 Recommended Actions

DHHS should continue to hold transportation providers accountable for quality of service including reliability and accessibility of transportation services.

DHHS should continue to update the ABIAC and other stakeholder groups of the status of the transportation services.

PRIORITY FOUR – Strengthen Family and Peer Supports.

The primary support system for Maine citizens with brain injuries is family members and friends, not the healthcare system. Family and friend support is vital for improving outcomes for persons with brain injuries.

During the acute-care phase of a brain injury, family members are concerned with the survival and immediate needs of their loved one. Once the person with the brain injury is home, the family may feel it is time to 'get over it' and 'move on', resulting in frustration and impatience. Often they do not acknowledge or understand the long-term problems resulting from the injury.

Family members often describe a sense of loss, grief and denial. They recognize that their loved one is not the same person and may feel they are living with a stranger. For children, the impact of having a 'different' parent can be significant. The entire family requires time and education to learn about the effects of a brain injury. Families that become primary caregivers for persons with a brain injury are often ill prepared for the personality

and behavior changes that may occur. Individuals and caregivers report that physical problems cause the least amount of stress, since routines are created and needs anticipated. Cognitive problems cause intermediate stress, while the changes in personality and behavior are the most stressful, since these changes are unpredictable and perhaps embarrassing. This can result in increased isolation for the family and individual. Caregiving can often overwhelm the caregiver emotionally, economically and physically. The combination of these pressures frequently results in loss of jobs, shattered marriages, bankruptcies, or institutionalization of the individual with the brain injury.

2014 Recommended Actions

DHHS should recognize and continue to work with the Disability Rights Center, Alpha One, the Brain Injury Association of America, brain injury support groups throughout the state, and the Brain Injury Voices group. DHHS should facilitate improved access to information and referral, resource facilitation, peer-to-peer support, and family support initiatives through collaborative partnerships with these and other organizations.

DHHS should work with providers to establish enhanced family training and counseling programs and maximize available services in place to support this activity financially.

PRIORITY FIVE – Improve employment opportunities.

One of the most devastating impacts of disability due to a brain injury is the loss of work. The employment outlook for individuals with brain injuries has remained unchanged over the past 20 years. During rehabilitation and recovery an individual is often unable to work due to the cognitive, social, behavioral and physical consequences of the injury. This unemployment affects the entire family either through direct loss of income or through the need for a family member to give up a job and stay home to care for their loved one.

The Council heard repeatedly that persons with brain injuries have an intense desire and motivation to return to work. At forums focused on employment and brain injury we have learned from national and local experts of effective program models for return to work. Combinations of intensive, focused rehabilitation coupled with peer support, psycho-social interventions and reliable, accessible transportation can improve outcomes and lead to successful employment. Employers and job counselors also need more information to better accommodate and support persons with brain injuries on the job.

Data from the Department of Labor doesn't always include specific causes of a person's disability and, as a result, a clear picture of the person's brain injury and related needs is not available. Long term work support funds are available from the Department of Labor, but not always accessed by persons with brain injuries, due to the lack of understanding and identification.

2014 Recommended Actions

DHHS should include specialized employment focused rehabilitation services in a 1915(c) Medicaid waiver program serving persons with brain injuries.

DHHS should enhance its partnership with the Department of Labor to better coordinate vocational rehabilitation and long-term job supports and provide additional training on brain injury rehabilitation to all vocational rehabilitation staff and their contracted providers.

DHHS should engage ABIAC representation in the Employment First workgroups.

PRIORITY SIX – Prevent brain injury.

Injury and violence prevention is about saving lives, reducing disabilities, minimizing health care costs and preventing tragedies. The physical, emotional and financial impact of brain injury can be significant and

lifelong. Injuries and their consequences are significant causes of morbidity and are responsible for millions in health care costs each year.

The core elements of injury/violence prevention mirror the essential public health services with a focus on primary prevention in a population-based approach. Decisions and prevention activities are based on data collection and analyses that identify the leading causes of mortality and morbidity, risk and protective factors and high-risk groups and are monitored over time. Conducting training, implementing best practice interventions and evaluating their impact in reducing Maine's injury/violence problems can lead to reduced rates of mortality and morbidity. Implementing effective policies to address the incidence of injury/violence prevention and enhancing collaborations among key systems including public health, health care, education, law enforcement, mental health, social services, substance abuse, recreation, economic development, business, and the public are crucial to achieving a reduced burden of injury/violence.

Healthy Maine 2020 - The Maine CDC's Injury and Violence Prevention Program identified the following injuries and violence topics to be addressed in the Healthy Maine 2020: the suicide rate, nonfatal child maltreatment, bullying among adolescents, motor vehicle crash related deaths, sexual and domestic violence, poisoning deaths and hospitalizations from falls.

Sports Concussions - The efforts of the Maine Concussion Management Initiative (MCMI) at Colby College are to be praised and supported. Failure to identify concussions and provide appropriate care for Maine's school-aged youth is a significant concern. New medical research clearly points to the risk to a young person's long-term health and well-being when not properly assessed and released to return to play and school before the brain has had time to heal. The MCMI works with over 90 Maine high schools to help coaches, trainers, parents and health care providers to recognize concussions and take effective action to assure the health and educational success of all students. All youth sports programs statewide should benefit from this support.

Maine Department of Education: Management of Concussion and Other Head Injuries - The Maine Department of Education's model policy on concussion management is now available on the student health website (<http://www.maine.gov/education/sh/>). Every school district and private schools must adopt a concussion management policy that is consistent with Maine DOE's model policy by Jan. 1, 2013. The model policy was developed by the Maine DOE Concussion Work Group, which includes members from the fields of health care, athletics, school nursing, physical therapy and neuropsychology. By June 2014, every school district and private school has to implement their concussion management plan.

2014 Recommended Actions

Continue to support Maine's CDC initiatives focused on prevention of abusive head trauma and older adult falls.

DHHS should work with stakeholder groups to support efforts to prevent brain injury.

PRIORITY SEVEN— Support service members and veterans with brain injuries.

Traumatic Brain Injury is the signature injury of the wars in Afghanistan and Iraq. Often times the impact of mild traumatic brain injury is not immediately apparent. Proper diagnosis is essential for timely and effective treatment. Many Maine soldiers serving in Iraq and Afghanistan are in the National Guard. These service men and women do not receive the same benefits as active duty soldiers. An astonishingly high percentage of US service members who have returned from these theaters report experiencing some level of brain injury during their deployment. Testimony given during the Council's public hearings indicated a need for more information and training for veteran support organizations and programs. Furthermore, veterans are limited to VA facilities for treatment. Veterans should have access to the full array of brain injury services in Maine. Rapid diagnosis,

rehabilitation and access to that array of support services over time are critical to assist our service men and women with the opportunity to return to their full potential.

2014 Recommended Action

DHHS should enhance the ongoing collaborative efforts between State agencies, Veterans Administration, veterans groups, and community-based brain injury providers to insure optimal screening and identification, coordination, care and support for Maine's service members and veterans.

COUNCIL ACTIVITIES AND 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. The grant ended on September 30, 2011.

Over the past five years the Council has held 22 public hearings (Bangor, Brewer, Portland, Caribou, Presque Isle, Lewiston, Sanford, Houlton, Calais, Farmington, Fort Kent, Dover-Foxcroft, Biddeford, Kennebunk, Rockport, Machias, Waterville, and Effingham, NH) receiving testimony from hundreds of Maine citizens with brain injuries and their families.

The Council 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 2013, the Council co-sponsored two conferences:

- Ft. Kent – September 2013
- South Portland – November 2013

The Council gathered information through these public hearings and forums in order to formulate its recommendations. The Council met eleven times in 2013 including a day-long review of DHHS' brain injury initiatives and action plans developed at the forums.

The Council acknowledges and thanks the DHHS Liaisons to the Council: Toni Wall, Maine Centers for Disease Control, Gary Wolcott, Associate Director, Office of Aging & Disability Services & Kirsten Capeless, Brain Injury Services, and Office of Aging & Disability 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) .] [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.