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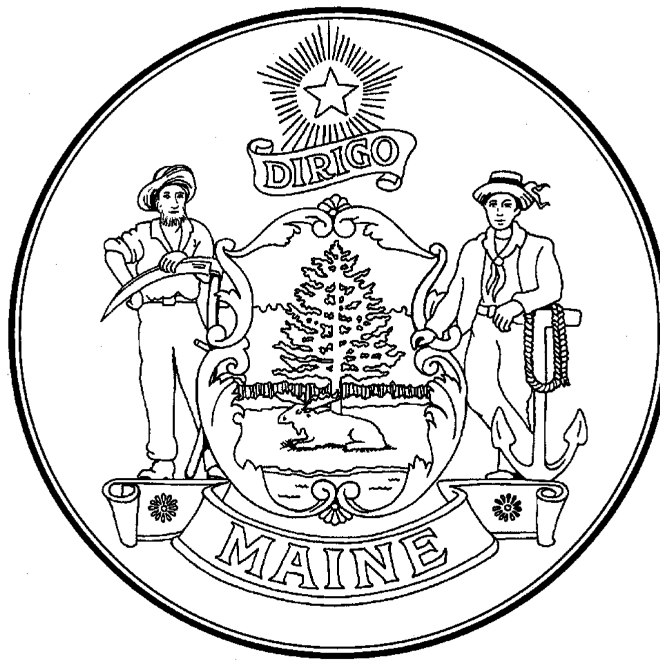

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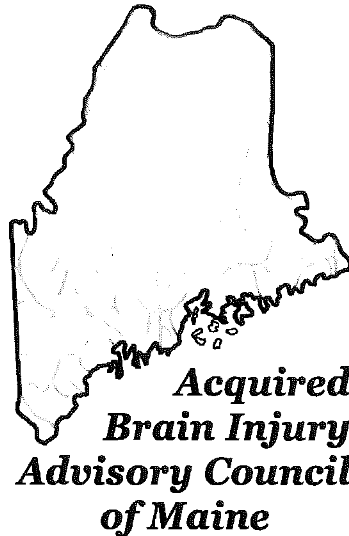
BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE



ANNUAL REPORT

January 15, 2016

The Acquired Brain Injury Advisory Council of Maine*

	Representing
Kelley McTague, Co-Chair	Providers
Richard Brown, Co-Chair	Providers
Matt Hickey, Secretary	Providers
Kitty Chadbourne	Persons with Brain Injuries
Lewis Lamont	Families
Ted Bracket	Persons with Brain Injuries
Joann Beaudoin	Families
Sarah Gaffney	Advocates
Rick Langley	Advocates
Scott Mayo	Providers
Austin Errico, Ph.D.	Providers
open	Maine CDC Injury Prevention
Wendy Warren	Vocational Rehabilitation
open	Maine CDC – Children with Special Health Needs

**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, 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

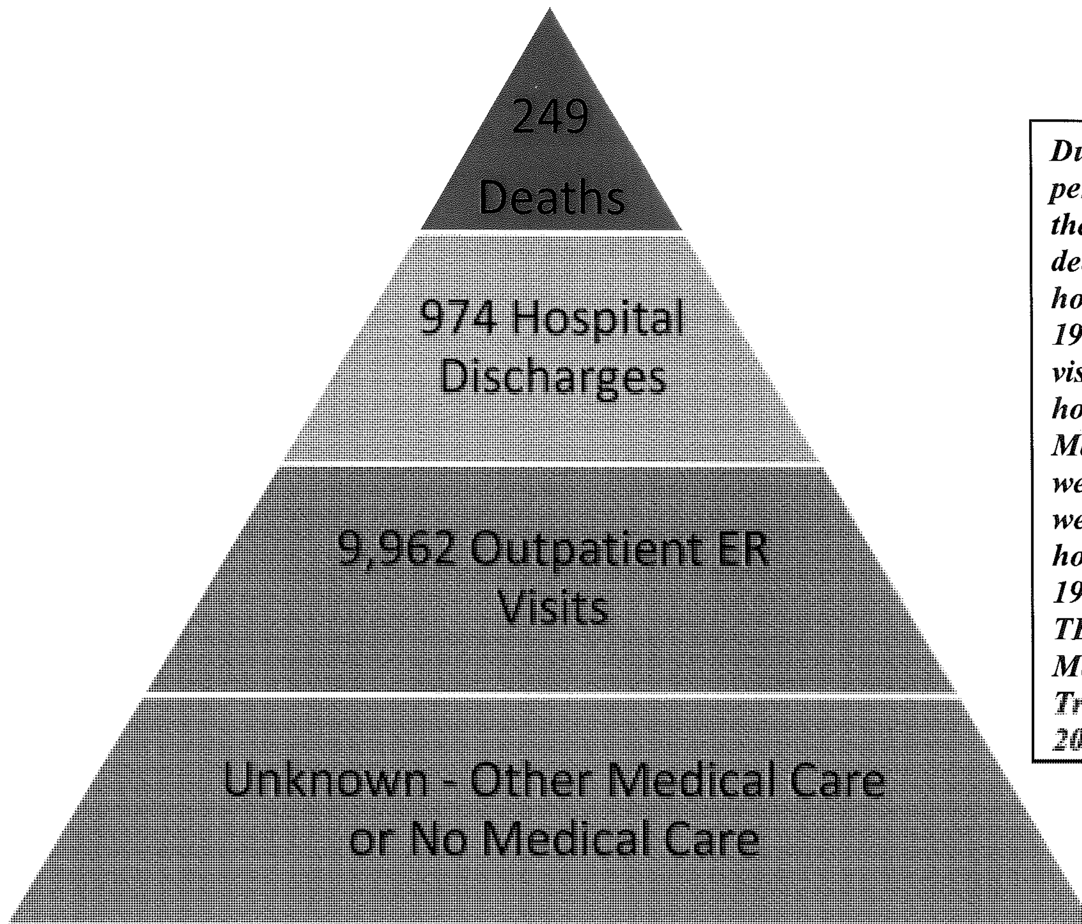
Traumatic Brain Injury
- Falls
- Motor Vehicle Crashes
- Sports Injuries
- Other Injuries Caused by Trauma

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

On average, yearly there are nearly 250 TBI-related deaths, 1,000 TBI-related hospital discharges, and 10,000 TBI-related emergency department visits that did not end with the person being admitted to that hospital as an inpatient. Many will make good recoveries, especially if they access needed rehabilitative care. Unfortunately, private health insurance continues to impose limits for rehabilitative care based solely on financial costs. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. 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 that 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. Year after year public hearings in Maine have demonstrated individuals continue to have issues related to brain injuries which 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 misdirection of valuable resources, poor interactions with family, employers and the community. Additionally, communication between providers is lacking. Care Coordination is a new service that is partially meeting this need but is not available to all of the people.

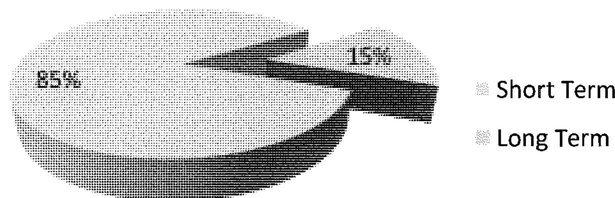
2010 and 2011 Yearly Average Outcomes Related To Traumatic Brain Injuries in Maine



During the two year time period from 2010-2011, there were 497 TBI related deaths, 1,948 TBI related hospital discharges, and 19,923 TBI related ED visits that did not end in hospitalization among Maine residents. Every week, on average, there were five deaths, 19 hospital discharges, and 192 ED visits that were TBI related.
Maine CDC, Injury Trends Data Book Maine, 2002-2011

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 which 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.

Recovery: Possible Impact of Injury
Short & Long Term



Recovery:
Over Course of a Few Years

- Return to Life before Injury (w/some adjustment)
- Resume Family Role
- Resume Work/Career
- Resume Leisure Activities

Recovery:
A Life Long Process with Long Term Disabilities
Individual often Experiences:

- Loss of Job/Career
- Loss of Family Role
- Loss of Leisure Activities
- Loss of Independence (Ability to Self-Care, Manage Finances, Drive a Car)

LEGISLATIVE ACTION

The Acquired Brain Injury Advisory Council commends and thanks the Legislature and the Governor for continuing to support brain injury services, including the brain injury waiver and also adding additional funds to address the waiting list.

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.

2016 Recommended Action –
DHHS should continue to work to implement the Brain Injury Waiver in Maine.

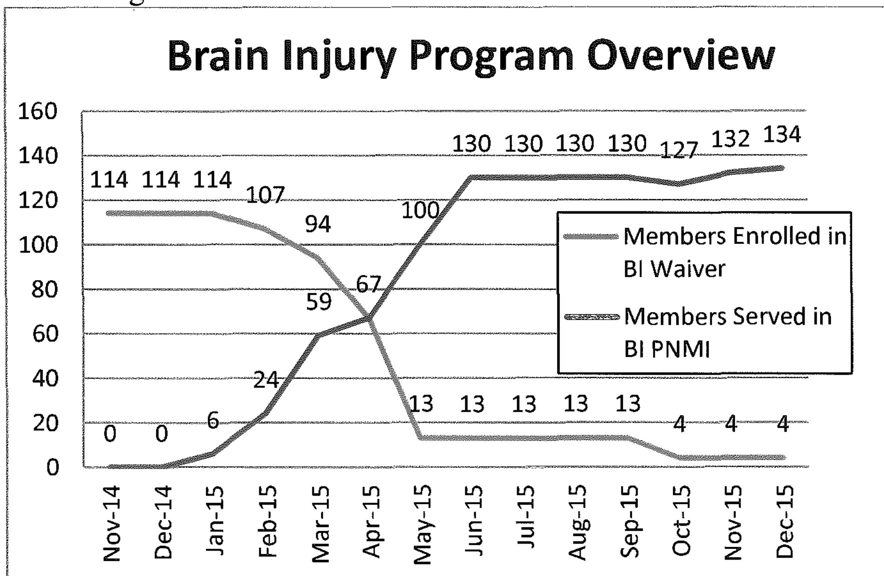
DHHS should complete the work of writing and putting new policies into practice that reflect the direction of the Legislature in these statutory revisions (22 MRSA §3086.)

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 2016 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, increasing care giver capacity, care coordination/neuronavigation, increase public awareness on prevention and education, family and peer supports, transportation, employment opportunities, and addressing the complex needs of individuals with challenging behaviors.

PRIORITY ONE –Enhance Maine's brain injury neurorehabilitation system to respond to current needs.

The current system has improved tremendously over the past year with the implementation of the brain injury waiver. We now have a continuum of care which includes brain injury services within nursing facility treatment centers, brain injury waiver group homes, individuals' own homes, outpatient neurorehabilitation settings, and also care coordination amongst other waiver services. We have almost completed the process of phasing out of Private Non-Medical Institution (PNMI) brain injury beds in order to comply with CMS feedback given in 2010.



2015 Accomplishments:

- The Brain Injury Waiver received CMS approval to begin on November 1, 2014; the first person began receiving service in January 2015. Currently the Waiver is serving approximately 140 members with 30 members awaiting services.
- ABIAC provided testimony to the Joint Committee of Appropriations of Health and Human Services in support of the brain injury waiver.
- ABIAC in collaboration with BIAA Maine advocated for additional funding to increase capacity within the waiver.
- Assistive technology services have been implemented in the brain injury waiver and have helped individuals reach a higher level of independence in home and community based settings.

2016 Recommended Action –

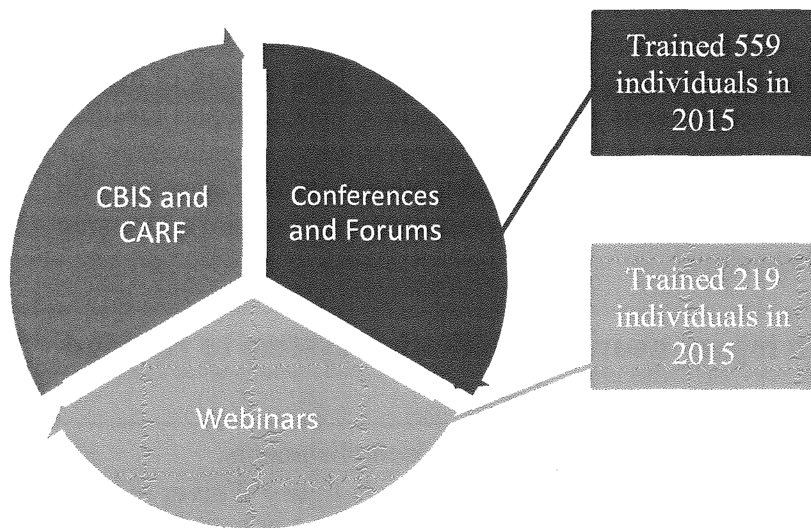
DHHS should continue to meet the needs of individuals with brain injury through the brain injury waiver, outpatient neurorehabilitation, and nursing facilities care.

DHHS should also continue to explore affordable housing options including rent vouchers.

DHHS should collaborate with advocacy and stakeholder groups to explore avenues for meeting the needs of non-MaineCare citizens with brain injuries and the needs of children with brain injury.

DHHS should continue to build the assistive technology services and telehealth throughout the state.

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



2015 Accomplishments:

- 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).
- ABIAC is collaborating with the State of Maine Brain Injury Services to create a certificate course for professional training in Acquired Brain Injury.
- The Traumatic Brain Injury State Partnership grant managed by DHHS BI Services funded forums, webinars, and conferences to train professionals and staff throughout Maine.

2016 Recommended Actions
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. In particular, DHHS and/or Brain Injury Association of America Maine Chapter should provide training to law enforcement entities, correctional facilities, educational systems, first responders, emergency medical services staff (EMS), the Department of Public Safety, transportation providers, vocational rehabilitation providers, and Riverview Psychiatric Center and Dorothea Dix Psychiatric Center staff.

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.

DHHS should continue with current training programs as well as address additional training needs as they arise.

PRIORITY THREE– Address the workforce shortage.

Currently today, we have a staffing shortage across the state of Maine of qualified direct care professionals. This has resulted in individuals who have approved funding waiting for services as the provider community recruits, hires, and trains members of their workforce.

2016 Recommended Actions
DHHS should explore options for workforce development.

DHHS should engage Stakeholders in discussion on solutions including the use of telehealth and assistive technology to meet the needs of the individuals and the staffing demands in the home and community based setting.

PRIORITY FOUR– Expand care coordination and neuronavigation in order to meet the needs of all individuals with brain injuries in Maine.

Care Coordination and neuronavigation are essential components of aiding individuals in the process of obtaining services. Similar to case management, the neuronavigator assists the individual with obtaining MaineCare and Non-MaineCare services to meet his or her needs in the least restrictive environment. Without this assistance, the system can feel very complex and insurmountable.

2015 Accomplishments:

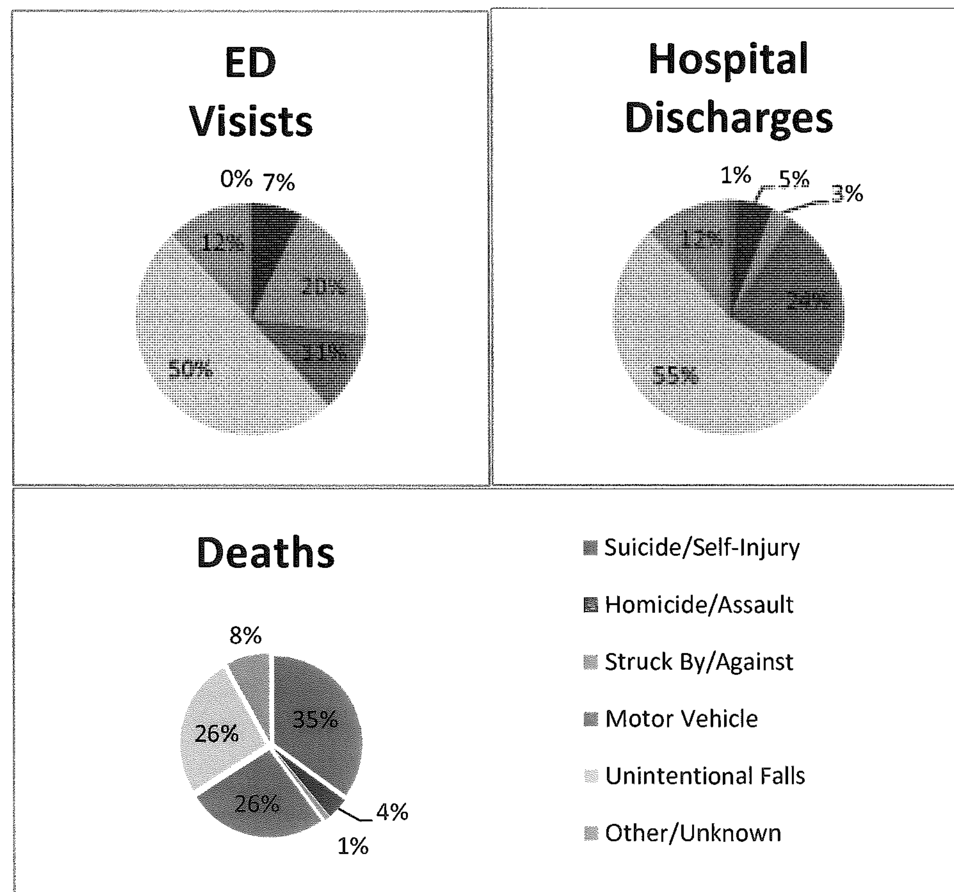
- Care coordination became a funded brain injury waiver service.
- The Brain Injury Association of America Maine Chapter began delivering resource facilitation (served 10 individual to date) and information and referral services (served 83 individuals to date), which are funded by the TBI State Partnership Grant.
- Alpha One began delivering information and referral services for individuals with brain injuries serving a total of 72 individuals.

2016 Recommended Actions

DHHS should explore other models, including models used by other states, to create a sustainable system of neuronavigation outside of the brain injury waiver to meet the unmet needs that still remain.

PRIORITY FIVE – Prevent brain injury through education and public awareness.

To prevent brain injury, we must understand the causes of brain injury in the state of Maine. Below are three graphs that illustrate the three leading causes of TBI related deaths, hospital discharges, and emergency room visits.



2015 Accomplishments:

- The ABIAC supports the Maine CDC Injury Prevention Program as it advocates at the local, state, and national levels and conducts prevention education regarding brain injury.
- The CDC worked with USM epidemiologists in the creation of *Injury Trends Data Book Maine, 2002 – 2011, Maine Special Emphasis Report: Traumatic Brain Injury, 2010-2011,* and *Emergency department visits for sports-related concussions Maine, 2009-2011.*

2016 Recommended Actions

DHHS should appoint a person from the Maine Centers for Disease Control that has the availability to attend meetings and provide updates on the CDC initiatives that related to brain injury prevention.

DHHS should 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 SIX – 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. These realities can lead to increased isolation for the family and individual. Caregiving can often overwhelm the caregiver emotionally, economically and physically. The combination of these pressures can result in loss of jobs, shattered marriages, bankruptcies, or institutionalization of the individual with the brain injury.

2015 Accomplishments:

- The ABIAC acknowledges the creation of the Brain Injury Association of America of Maine Chapter in 2014 which will meet many needs for Maine citizens with acquired brain injuries and their families.
- The BIAA – Maine Chapter representative visited majority of the support groups in Maine.

2016 Recommended Actions

DHHS should recognize and continue to work with Disability Rights Maine, Alpha One, the Brain Injury Association of America, Brain Injury Association of America Maine Chapter, the Brain Injury Voices group and other brain injury support groups throughout the state. 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.

DHHS should explore a peer support model of service for consideration as a service in the Brain Injury Waiver.

DHHS should create and implement the rules for the Rights of Individuals with Brain Injury.

PRIORITY SEVEN – Improve reliability and access to transportation.

The need for reliable and accessible transportation for individuals was identified during the public hearings held in 2015. This need has been consistently identified each year. Many individuals testified that the change in the transportation system has affected them negatively and highly impacted their lives with regards to having safe transportation that provides them access to services, work, and the stress of not knowing whether their scheduled ride would arrive.

2015 Accomplishments:

- Outpatient neurorehabilitation providers met with the transportation brokers to problem solve transportation needs for their members.
- The ABIAC has received periodic updates from the Office of MaineCare Services transportation staff.
- The ABIAC hosted a presentation on the Independent Transportation Network of America, an alternative transportation model.

2016 Recommended Actions

DHHS should continue to hold transportation providers accountable for quality of service including reliability and accessibility of transportation services. DHHS should monitor the complaints and resolution of those complaints regarding the transportation services.

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

DHHS should consider alternative methods to providing transportation across the state including volunteer and ride sharing systems.

DHHS should educate transportation providers regarding the unique needs of the brain injury population. In addition, DHHS should educate and develop strategies for the individuals using transportation in order for them to be able to respond to their own needs.

DHHS should consider telehealth as an option to meet health care needs of individuals and also lessen the need for transportation.

PRIORITY EIGHT – Improve employment opportunities.

One of the most devastating impacts of disability due to a brain injury is the loss of 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. 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.

2015 Accomplishments:

- Career Planning, Employment Specialist Services, and Work Supports are now funded services offered under the Brain Injury Waiver.
- A representative from Vocational Rehabilitation is attending the ABIAC meetings on a regular basis.
- ABIAC provides representation on Employment First Committee to advocate for creation of employment opportunities for individuals with brain injury and other disabilities.
- ABIAC has received a voting position on the Employment First of Maine Council to represent the needs of individuals with brain injuries.

2016 Recommended Actions
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 implement a training platform for all Department of Labor staff working with individuals with brain injuries to attend training on brain injury.

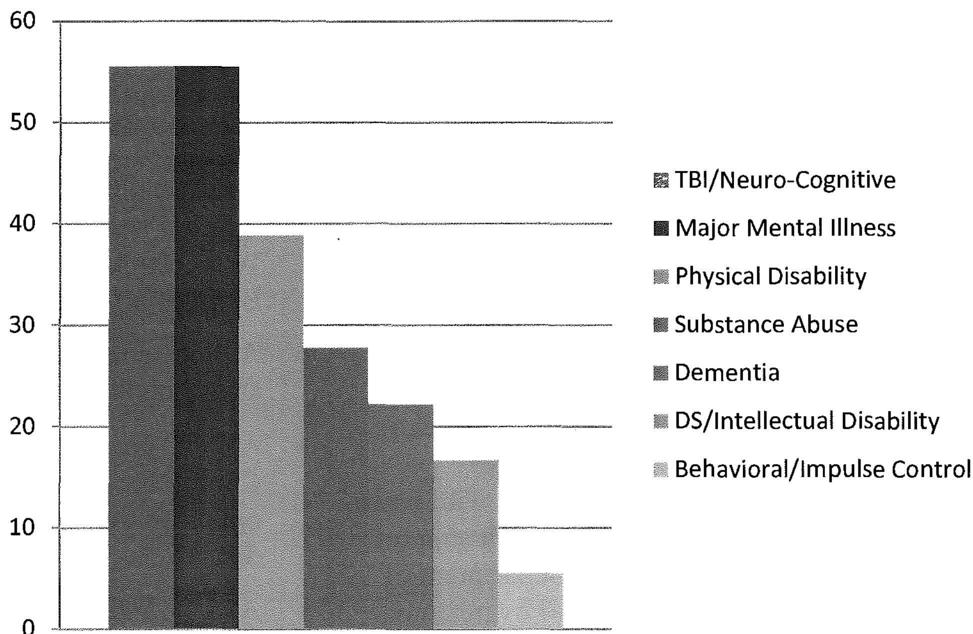
DHHS should continue ABIAC representation in the Employment First workgroups. DHHS should emphasize the needs of individuals with brain injuries and ensure that these needs are addressed in the Employment First initiatives.

PRIORITY NINE– Neurobehavioral system of care for individuals with complicated behavioral needs both in the community and forensic setting.

People with brain injury often have limited judgment and insight, including impulsivity and are more likely to make mistakes, including committing offences and other involvement with law enforcement. Once an individual with brain injury enters into the criminal justice system they often get stuck. They are unable to receive quality treatment within that system and are unable to make adequate restorative gains as outlined by the legal system. This results in individuals being in the system for years for charges that would typically result in months of jail time. Additionally, there is not an adequate diversion program for individuals with brain injury such as those available for domestic violence and substance abuse.

Individuals with dual diagnosis are at even greater need. Over 50% of the cases reviewed by the DHHS Complex Case Team involved a person with brain injury and/or a major mental illness. This continues to show the complicated nature of effectively and efficiently serving individuals with complex needs.

2015 Achievement:
- The TBI State Partnership Grant has funded a provider to train correctional staff about brain injuries in one adult setting and one juvenile setting. This partner is in the process of training staff and will be implementing a brain injury screening tool to begin to assess home many individuals are affected by brain injuries in each setting.



2016 Recommended Action

DHHS should address the needs of individuals with brain injuries that are Not Criminally Responsible and still within the forensic system and those stuck in other parts of the criminal justice system.

DHHS should create a workgroup to formally assess the needs for statutory changes for civil commitment including research on the best practice approaches throughout the country. This should include consideration of an Assertive Community Treatment (ACT) team style approach for brain injury, upfront training for staff, enhanced provider rates, and least restrictive settings, including alternatives to sentencing, detention, and probation. DHHS should encourage participation from Departments of Corrections and Public Safety, District Attorney's office, the Judiciary and State Forensic services.

PRIORITY TEN– Addressing the needs of children with brain injury.

Proper screening and identification is essential to working effectively with children who have sustained a brain injury. Without proper identification, the school and medical systems are likely to treat the symptoms without fully understanding the core needs. This often results in misdiagnosis and ineffective treatment which impacts learning and treatment progress throughout the child's life.

2015 Accomplishments

- The Maine Concussion Management Initiative (MCMI) through partnership with DHHS with the Traumatic Brain Injury Partnership Grant completed 9,915 baseline neurocognitive tests and 1,994 post-injury cognitive tests.
- MCMI has outreached to high schools across the state for education of school professionals and implementation of the HIT program for concussion tracking. Thus far, they have enrolled 35 high schools.

2016 Recommended Action

DHHS should explore systems of Return to Learn to aide students with brain injuries to return successfully to the educational setting.

DHHS should expand brain injury services, including the brain injury waiver, to children.

DHHS should work with the Maine Centers for Disease Control and the Department of Education to accurately identify children with brain injury.

DHHS should appoint a representative from the Department of Education to the ABIAC.

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.

Over the past seven years the Council has held 31 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 2014, the Council co-sponsored three conferences:

- Orono – March 2014
- South Portland – October 2014
- Augusta - 2015

The Council gathered information through these public hearings and forums in order to formulate its recommendations. The Council met eleven times in 2015 including a day-long review of DHHS' brain injury initiatives and action plans developed at the forums.

The Council acknowledges and thanks the DHHS Liaison to the Council: 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.