BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE

ANNUAL REPORT

January 15, 2017

The Acquired Brain Injury Advisory Council of Maine*

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**Appointed by Mary Mayhew, 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.

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 result in inpatient care. Many will make meaningful recoveries, especially if they access needed rehabilitative care. Unfortunately, private health insurance continues to impose limits for rehabilitative care based solely on financial costs rather than based on functional goals or treatment outcomes. 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 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 outside of institutions with the right support. 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 support. 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.

LEGISLATIVE ACTION

The Acquired Brain Injury Advisory Council commends and thanks the Governor, the Legislature, and DHHS for continuing to support brain injury services and future initiatives.

2017 Recommended Action –

DHHS should continue to support home and community based services for individuals with Brain Injury 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.)

DHHS should continue their work to address the needs of individuals who are unable to safely reside in the community without post-injury comprehensive clinical services in the form of a Neurobehavioral Treatment Center.

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 2017 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, workforce shortage challenges, expanded care coordination/neuronavigation, increase 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.

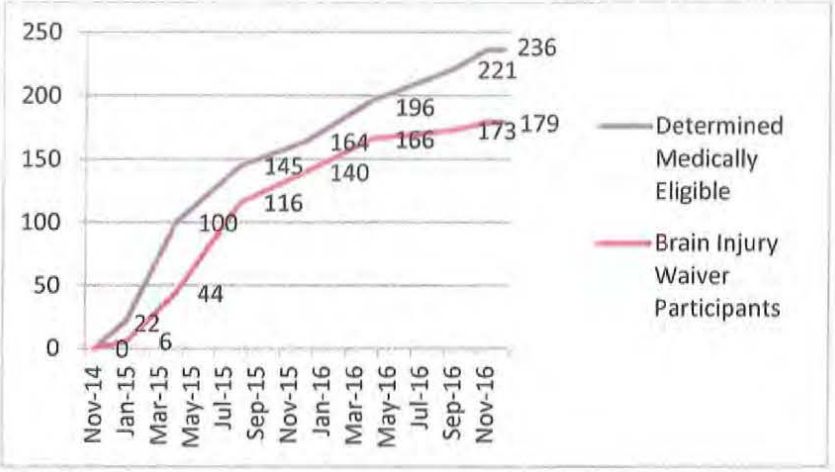
PRIORITY ONE – Enhance Maine's brain injury neurorehabilitation system to respond to current needs.

The current system has improved tremendously over the past few years with the implementation of the brain injury waiver. We now have a continuum of care which includes brain injury services within nursing neurorehabilitation treatment centers, brain injury waiver group homes, individuals' own homes, outpatient neurorehabilitation settings, and also care coordination amongst other waiver services.

Although services for individuals with brain injury have improved significantly, there remain several critical shortfalls, including limited transportation that meets the needs of this specialized population, limited use of technology services, limited affordable housing options and the lack of a Neurobehavioral Treatment Center.

The addition of a Neurobehavioral Treatment Center to our existing continuum of care would allow access to services for persons with significant neurobehavioral behavioral challenges who cannot yet be appropriately served in the community. For instance, persons with brain injury have shown to be at increased risk for repeated law violations due to impulsivity and behavioral dysregulation. These people are often unjustly blamed because there is not a good understanding of their diagnosed condition. Research and best practice show that prevention and early intervention are likely to mitigate these problems.

Current Status of Waiver Participants Currently Served and Those Deemed Medically Eligible



2017 Recommended Action –

DHHS should expand allowable assistive technology services and telehealth throughout the state.

DHHS should open the Section 18 & Section 102 rules and engage stakeholders for innovative improvements.

DHHS should improve access to specialized transportation and continue to hold transportation providers accountable for quality of service including reliability and accessibility throughout Maine, including rural areas.

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

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 continue to explore affordable housing options including rent vouchers and other disability specific options.

DHHS should support the need for a Neurobehavioral Treatment Center to serve individuals who are unable to safely reside in the community without post-injury comprehensive clinical services.

DHHS should continue its efforts to appropriate additional funding to assure all Maine residents with brain injury have timely access to the services that they need.

PRIORITY TWO – Address the workforce shortage of qualified brain injury professionals.

Currently today, we have staffing shortages of qualified professionals across the state of Maine. This has resulted in individuals who have approved funding waiting for services as the provider community recruits, hires, and trains members of their workforce. Despite these obstacles, the Maine brain injury support network has made strides in providing individuals with brain injury education.

2017 Recommended Actions

DHHS should continue to 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 continue to collaborate with statewide brain injury and other related 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 explore options for workforce development and convene stakeholders as part of process. Such as rate studies, incentive based systems, supervision and mentorship trainings.

PRIORITY THREE– 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.

2017 Recommended Actions

DHHS should explore other models, including successful 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.

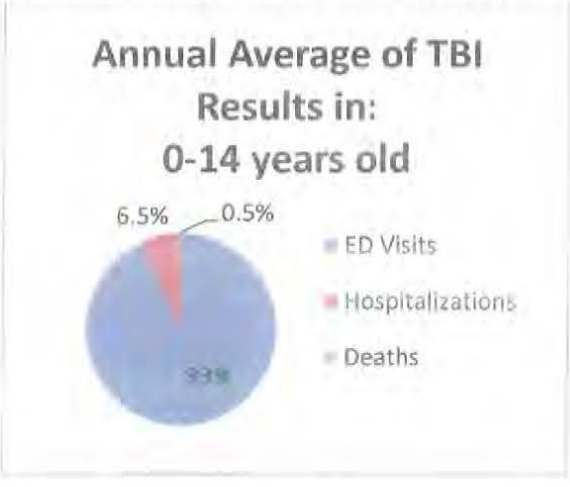
DHHS should explore collaborations with local Community Action Programs and Area Agencies on Aging.

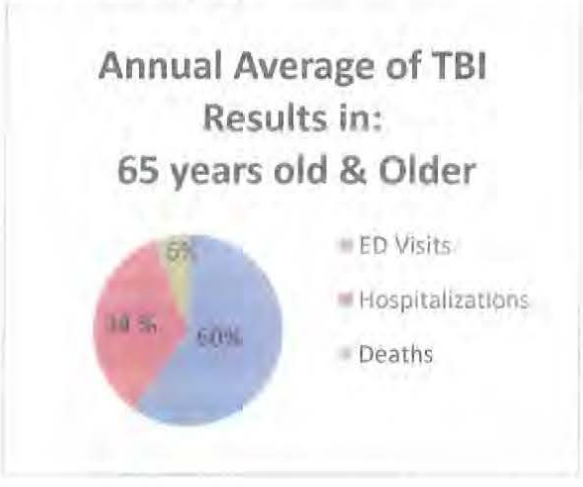
DHHS should open Section 18 rule and examine increasing the available care coordination units and broadening the scope for those receiving this service.

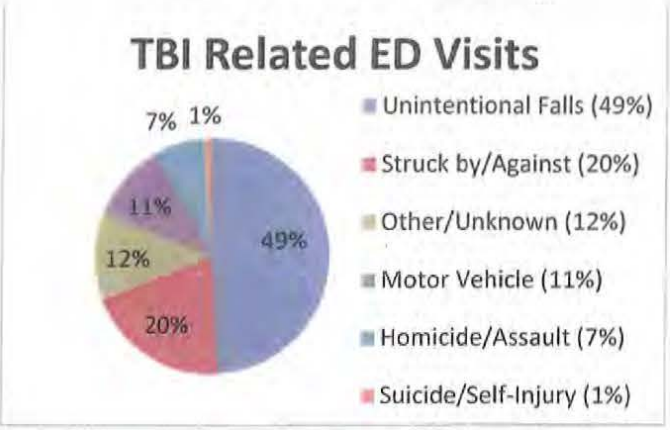
PRIORITY FOUR – Prevent brain injury through education and public awareness.

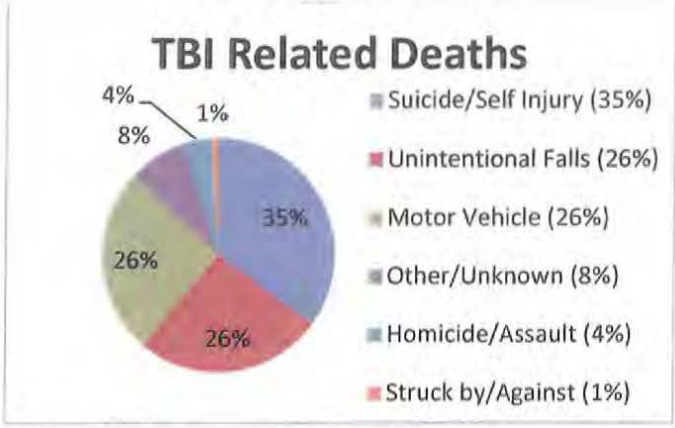
To prevent brain injury, we must understand the causes of brain injury and who is at greatest risk. The populations who are at greatest risk for traumatic brain injury are the very young and the elderly. Both groups have a heightened risk of falls. *(See charts below)*

More education and public awareness is needed to help prevent traumatic brain injury in the United States as a woman is beaten every 12 seconds; most frequently around the head, face and neck. Furthermore, two-thirds of physically abused children under the age of three have traumatic brain injury.









2017 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 strengthen collaboration with NAMI or others as offering qualified Crisis Intervention Training.

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, 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

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

PRIORITY FIVE – 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 a brain injury returns home the family may need continued support to understand the complex medical, behavioral and cognitive changes that manifest themselves on the long-term path to recovery. 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, divorce, bankruptcies, or institutionalization of the individual with the brain injury.

2017 Recommended Actions

DHHS should 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.

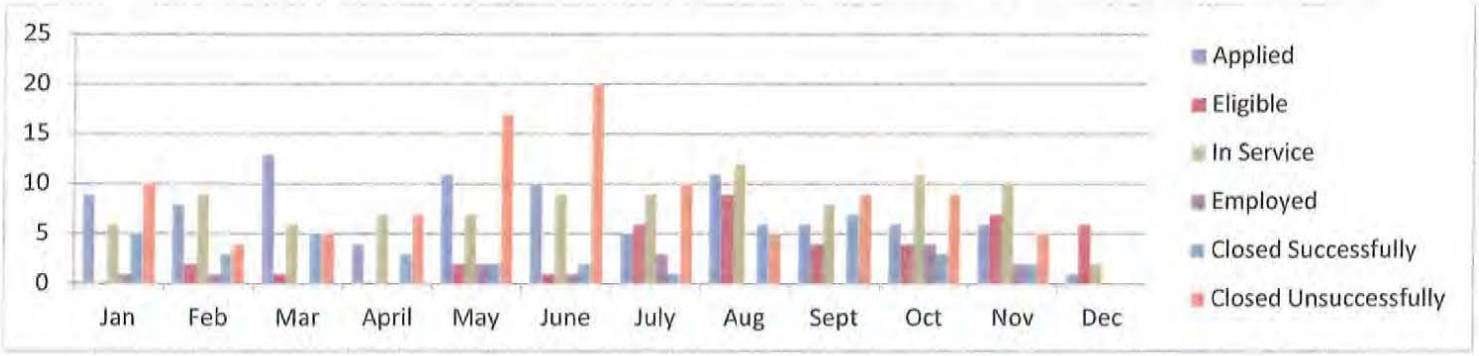
DHHS should facilitate improved access to neuronavigation, information and referral, resource facilitation, peer-to-peer support, and family support initiatives through collaborative partnerships with these and other organizations.

DHHS should continue to review and finalize the rules for the Rights of Individuals with Brain Injury.

PRIORITY SIX – 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 and education to better accommodate and support persons with brain injuries on the job. Limited 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.

2016 Monthly Summary of Persons' with Brain Injury whom access Vocational Rehabilitation



2017 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 continue to 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 to support Maine as an Employment First state through implementation of final EFM report.

PRIORITY SEVEN– 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.

2017 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 work with the Maine Centers for Disease Control and the Department of Education through Special Education to accurately identify children with brain injury.

DHHS should appoint a representative from the Department of Education to the ABIAC which has been vacant since the Council's inception.

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 eight years the Council has held 35 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 the three years since the ACL/TBI partnership grant award, the Council has co-sponsored the following conferences:

- Orono – March 2014
- South Portland – October 2014, 2015 & 2016
- Augusta – April 2015 & 2016

The Council gathered information through these public hearings and forums in order to formulate its recommendations. The Council met ten times in 2016 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: Derek Fales, Neurobehavioral Services, from the Office of Aging & Disability Services.

ABIAC AND COLLABORATIVE PARTNERS ACCOMPLISHMENTS:

- A statewide needs assessment was funded by the TBI State Partnership Grant. The assessment was finalized and published into a report by the University of Southern Maine Muskie Center. This report was created from 850 surveys that were sent out to individuals with brain injury to identify the ongoing unmet needs of these individuals to then compare /contrast from 5 years ago.
- 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 178 members with an additional 57 individuals deemed medically eligible for services.
- Assistive technology and drop-in home supports services have been implemented in the brain injury waiver and have helped 80 individuals reach a higher level of independence in home and community based settings.
- 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.
- ABIAC collaborated 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 Neurobehavioral Services funded forums, webinars, and conferences to train professionals and staff throughout Maine.
- The ABIAC acknowledges the creation of the Brain Injury Association of America of Maine Chapter (BIAA-ME) in 2014. The Brain Injury Association of America Maine Chapter continued delivering resource facilitation (served 21 individual to date) and information and referral services (served 263 individuals to date), which are funded by the TBI State Partnership Grant.
- The BIAA – ME Chapter representative has visited over 80% of the brain injury support groups in Maine. There are 16 brain injury support groups serving the people of Maine and in 2016 these groups were utilized 1,464 times by brain injury survivors, family members, and caregivers. To date, BIAA-ME has visited 74% of Maine hospitals. At these visits, BIAA-ME provided hospital staff with presentations and materials on Maine brain injury resources and supports for survivors, family members, and professionals.
- Alpha One began delivering information and referral services through the Brain Matters website, by email and phone for individuals with brain injuries, serving a total of 286 individuals.
- 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.*
- 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.
- ABIAC provided representation on the Employment First Committee to advocate for creation of employment opportunities for individuals with brain injury and other disabilities.
- The TBI State Partnership Grant has funded a provider to train correctional staff about brain injuries in adult and juvenile settings. In 2016, the current locations have been visited and trained: Kennebec County Jail, Long Creek Youth Center, York County Jail, Cumberland County Jail, Somerset County Jail, and Oxford County Jail.
- Penquis CAP staff attended TBI training on two different occasions in May 2016 on the topic of understanding and screening for TBI.
- The Maine Concussion Management Initiative (MCMI) through partnership with DHHS with the Traumatic Brain Injury Partnership Grant completed 9 trainings for injury and other related services, completed 10 trainings for coaches and other key personal at the high school level and 12 educational outreach programs for the general public on the topic of understanding and screening for concussion, and visit 137 high schools to offer concussion tracking through the HIT Project.
- The BIAA-ME annual Conference on Defining Moments in Brain Injury has offered a certified training track for individuals to acquire the skills to employ the use of the IMPACT (return to play) Sideline Assessments for athletic events for three years running.

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.