

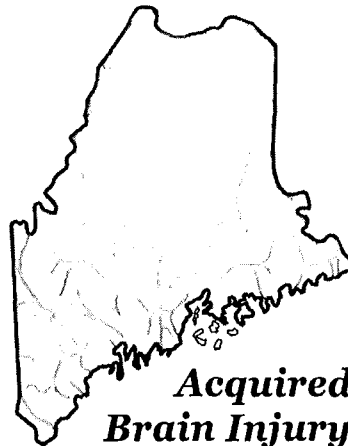
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BRAIN INJURY IN MAINE: A GROWING PUBLIC HEALTH ISSUE



**Acquired
Brain Injury
Advisory Council
of Maine**

2010 REPORT

January 15, 2011

Our goal is to achieve better understanding and identification of brain injury, access to care and overall improvement in the efficiency and quality of services for persons with brain injuries, their families and caregivers.

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The Acquired Brain Injury Advisory Council of Maine

	<i>Representing</i>
Kelley McTague, Co-Chair	Providers
Stacie Linkel, Co-Chair	Persons with Brain Injuries
Matt Hickey, Secretary	Providers
Beverly Bryant	Persons with Brain Injuries
Lewis Lamont	Families
James Feverston, Ph.D.	Families
Marcia Cooper	Advocates
Peter Rice	Advocates
Penny McGonagle	Providers
Richard Brown	Providers
Austin Errico, Ph.D.	Providers
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The Acquired Brain Injury Advisory Council

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The Council was originally established in April 2002 to support a federal grant. It was established in 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.

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) .]

Over the past three years the Council has held 11 public hearings (Bangor, Portland, Caribou, Lewiston, Sanford, Houlton, Calais, Farmington, Fort Kent, Dover-Foxcroft, Biddeford) receiving testimony of hundreds of Maine citizens with brain injuries and their families. The Council has also sponsored five, 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

The Council has examined a broad base of information and experience gathered through these Public Hearings and Forums over the past 39 months in order to formulate its recommendations. The Council met eight times in 2010 and conducted a day-long review of DHHS brain injury initiatives and follow-up on action plans developed at the forums.

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, 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 brain injury died. Today, with the advances in medicine, the vast majority of individuals survive. Each year doctors are able to save many more individuals who have severe injuries. More than 10,000 Mainers experience brain injuries each year. Many will make good recoveries, especially if they can access needed rehabilitative care. Unfortunately, private health insurance pays less and less for rehabilitative care. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities..

Providing 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. With the right support these individuals can live outside of institutions. 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 the problems of individuals with brain injury are dismissed or misdiagnosed; treatments are provided that are not only ineffective but create greater problems leaving individuals and clinicians with feelings of failure and frustration. This creates a significant misuse of valuable resources, dysfunctional interactions with family, employers and problems in the community.

We can do better, by providing the right services and support at the right time. And when we do the “right thing” we create efficiencies that allow our tax dollars to be used effectively.

RECOMMENDED LEGISLATIVE ACTION

The Council recommends streamlining and updating the four statutes that define brain injury and the responsibilities of the Department of Health and Human Services for maintaining a safety net for persons with significant disabilities due to brain injuries. These revisions will clarify and update the statutes to reflect the wholesale changes in medical and rehabilitation science over the twenty years since the last revisions. The Council believes that the proposed revisions will:

1. Produce a clearer understanding and access to appropriate treatment and supports of brain injury
2. Make better use of State and Federal resources
3. Increase the accountability and efficiency of DHHS

The Council looks forward to working with the Legislature on these changes.

PRIORITIES

This report reflects the highest priority areas the Council has identified. The needs of Maine citizens with brain injuries are very broad and complex. Future work of the Council will address the many other areas identified through needs assessments, public hearings, and forums.

1 – PREVENT BRAIN INJURIES

The only cure for brain injury is prevention. Injuries are predictable and preventable. Brain injury frequently kills or threatens the life and well-being of individuals of all ages. Many brain injuries are preventable. Taxpayers often foot the bill for medical and rehabilitation costs through MaineCare and Medicare, to say nothing of the lost economic productivity that comes from a catastrophic brain injury. Prevention of brain injuries is a proven method to reduce our health care costs.

Sports Concussions – The efforts of the Maine Concussion Management Initiative at Colby 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 loss of potential when pressured to return to play before the brain has had time to heal. The Maine Concussion Management Initiative at Colby is working with more than 60 high schools in Maine 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 across the state should have the benefit of this type of support.

Abusive Head Trauma – Maine’s Abusive Head Trauma workgroup has been working on training hospital staff and community based agencies on a **Period of Purple Crying**, a shaken baby prevention program that offers information on normal infant crying.

2011 Recommended Action – DHHS should support the Youth Sports Concussion Initiative in cooperation with the Department of Education and youth sports stakeholders. Support should continue for prevention of abusive head trauma initiatives within Maine CDC.

2 – PROVIDE CARE COORDINATION FOR PERSONS WITH BRAIN INJURIES

Individuals, families, educators, providers and medical professionals consistently cite case management and care coordination as areas of critical need. A brain injury diagnosis often eliminates access to this essential service due to regulatory barriers. Brain injury is the only long-term disability that has limited or no access to case management. The complex medical, legal and community service resources are sparse and require expertise to access and navigate.

Persons with a brain injury can continue to improve for many years if provided the support and services necessary to facilitate progress. However, an individual may decompensate medically and/or cognitively, if there are not supports to help navigate and cope with some of life’s demands and changes: i.e. return to work, paying bills, ordinary self-care or caring for family.

The effectiveness of providing case management/care coordination services for individuals and families dealing with other disabilities or chronic illness can be demonstrated in Maine and other states. A case management system, which is flexible and directly meets needs that change over time, could provide persons with brain injuries the needed care and enable them to avoid unnecessary health and safety risks. This would result in a highly efficient use of taxpayer resources.

There are no case management services for adults with brain injuries except for those participating in a rehabilitation program or receiving services under another system (Mental Health, Developmental Services or Adult Protective Services). Case management and other brain injury services for children are severely restricted and limited.

2011 Recommended Action - Provide care coordination /case management under MaineCare regulations by removing the discriminatory exclusion of adults with a diagnosis of brain injury. DHHS should seek alternative approaches to the existing Targeted Case Management services when designing services for children and adults with brain injuries in order to provide effective care coordination and be cost effective.

3 – TRAIN PROFESSIONALS AND DIRECT CARE WORKERS TO IMPROVE OUTCOMES

A lack of sufficient knowledge, training and skill among Maine’s healthcare, mental health and educational professionals was the leading issue identified by stakeholders attending the ABIAC’s hearings and forums over the past three years. Testimony cited misidentification of brain injuries, inappropriate treatment, denial of services, and poor quality of care. The knowledge and best practices in neuroscience have exploded 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. 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 of the “hands-on” 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. Reports received from various stakeholders by the ABIAC, raise significant concerns for the safety of service providers, other program participants and the individual with the challenging behaviors. Improperly trained staff leads to increased risk for all involved. Improperly trained staff often results persons with the brain injury not learning how to manage their behavior effectively. This training should reach across all State departments, including DHHS, DOL, Public Safety, Corrections and others who work with persons with brain injuries. Physicians, emergency room personnel, primary care, mental health and other healthcare professionals have not received adequate education and resources to diagnosis and treat the acute and long-term effects of brain injury. With adequately trained healthcare professionals the result will be more efficient and effective outcomes.

2011 Recommended Action - 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.

4 – IMPROVE SERVICES FOR CHILDREN WITH BRAIN INJURIES

The Office of Special Education and Child Development, within the Maine Department of Education (DOE), collects data on school age children designated as having special needs. In 2007, only 81 children in the State of Maine were specifically identified as having a brain injury. In contrast, a 2004 study of MaineCare members under the age of 18 identified 1,631 children and youth with a diagnosis of a brain injury. This apparently widespread under-identification leads to significant problems for each child with a brain injury and for the parents and the school staff, since appropriate education may not be provided. As the Council heard in testimony, misidentification can result in long-term school failure and social adjustment issues as the child moves into adulthood. On the larger scale, misidentification of large numbers of children results in the inefficient use of special education funds.

2011 Recommended Action – DHHS should promote annual health screening of all children and youth to include a standardized set of questions to identify possible brain injury. DHHS and the Department of Education should collaborate and establish an approach to better identify, educate and coordinate services for students in special education with brain injuries.

5 – IMPROVE OUTCOMES THROUGH IDENTIFICATION OF BRAIN INJURIES

The effects of brain injury can often look like other health issues; learning disabilities, dementia, or mental illness. The care and treatments provided as a result of misdiagnosis are ineffective and can sometimes do harm. At the very least, additional costs and great frustration occur for the individual who has a brain injury and for the person’s family. Healthcare and long-term care providers are burdened and use precious resources ineffectively. Sometimes the individual and family give up, resulting in long-term dependence. Sometimes the patient is passed around to other providers or services. And the cycle is repeated.

2011 Recommended Action – Require screening for brain injury upon admission to any healthcare, long-term care or rehabilitation program funded by DHHS. DHHS contracts should

require the use of consistent, standardized screening protocols to insure that all individuals with brain injuries are identified and their needs are adequately addressed in their plans of treatment and care.

6 – SUPPORT SERVICE MEMBERS AND VETERANS WITH BRAIN INJURIES

Traumatic Brain Injury is the signature injury of the wars in Afghanistan and Iraq. Diagnosis is a critical area in question since often times the impact of mild traumatic brain injury is not immediately apparent. 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 astonishing 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 ABIAC 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, access to neurorehabilitation and the array of support services over time are critical to assist our service men and women with the opportunity to return to their full potential.

As a result of the ABIAC-sponsored forum on veterans and brain injuries in June 2007, a collaborative effort was established between the Maine National Guard and the Dartmouth Medical School. With the help of a Maine Health Access Foundation grant all Maine National Guard troops going into combat zones are now screened before deployment and upon their return to better monitor for post-concussive disabilities. Maine is one of the few states in the US to support its National Guard troops in screening for brain injuries.

2011 Recommended Action – The Legislature and Governor should establish a “Governor’s Maine Military & Community Leadership Council” to provide oversight and guidance in State government. DHHS should enhance the ongoing collaborative efforts between State agencies, Veterans Administration, veterans groups, and community-based brain injury providers to insure optimal coordination, care and support for Maine’s service members and veterans.

7 – RESPOND TO PERSONS WITH COMPLEX NEEDS DUE TO BRAIN INJURIES

Maine’s system of residential supports for persons with significant disabilities due to brain injuries is not meeting the existing need. The waiting list for existing residential services (124 specialized beds) is over 70 persons.

The Council was very encouraged by the action of the 124th Legislature and the Governor to include funding for six additional beds of 24/7 specialized brain injury residential support. The program opened last year in Eagle Lake and serves six individuals some of whom returned from out-of-state placements.

The Council is also very encouraged by the establishment of a strategic priority within DHHS to address individuals with complex needs. This priority has led to successful efforts to bring individuals with brain injuries home from high cost, out-of-state placements.

However, individuals with brain injuries have no options for specialized support in their own homes or apartments once they have progressed to the point of not needing intensive residential services. Contrary to common understanding, many people with brain injuries, even with severe, life-long disabilities, can make progress over time to greater levels of independence and self-care. Initially, residential systems were designed upon the assumption that living in a group home with

24-hour, seven-day-a-week care was the final destination for an individual with severe disabilities. Over a decade of experience and ongoing brain research indicates that individuals can recover skills and abilities long after the injury. Many people in their current residential settings are ready to move to less intensive, less restrictive, less expensive, more independent living situations. Unfortunately, no alternatives exist, except to move from round-the-clock support to no support. Many people in nursing or assisted living facilities remain there, because there are not adequate supports to insure health and safety in their own homes. Many individuals have moved back to Maine from out of state, resulting in cost savings; however the lack of capacity to serve these individuals leads to new costly out of state placements. The lack of transitional options has forced a few individuals to be moved to costly out-of-state specialized programs, far from their families and communities.

Two studies conducted in the 2007 by the Maine Department of Health and Human Services evaluated the functional capacity for greater independence of persons now in specialized assisted living or out-of-state placements. Studies confirmed that nearly 20% (20 individuals) progressed in their rehabilitation to the point of needing less than 24/7 support and are able to live in less restrictive settings.

2011 Recommended Action – DHHS should establish community living services with less than 24/7 supports, which allow individuals to live in their own homes with adequate support to maintain their health and safety.

8 – STRENGTHEN FAMILY & PEER SUPPORT FOR PERSONS WITH BRAIN INJURIES

The primary support system for Maine citizens with brain injuries is family members and friends – not the healthcare system. There is unanimous agreement that support from families and friends 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 back at home, the family may feel that it is time to ‘get over it’ and ‘move on’, resulting in frustration and impatience. Often family and friends 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 be 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 are rated as causing intermediate stress, while the changes in personality and behavior are the most stressful, increasing over time, since they 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.

2011 Recommended Action – DHHS should recognize and work with the Brain Injury Information Network, brain injury support groups throughout the state, and the Brain Injury

Voices group. DHHS should facilitate improved access to information and referral, peer-to-peer support, and family support initiatives through collaborative partnerships with these organizations.

9 – IMPROVE EMPLOYMENT OPPORTUNITIES FOR PERSONS WITH BRAIN INJURIES

One of the most devastating impacts of disability due to a brain injury is the loss of work. Frequently, during rehabilitation and recovery, the individual is unable to work due to the cognitive and physical consequences of the injury. This loss of work 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 two messages repeatedly from individuals and families in its Hearings and Forums across Maine: 1) the loss of work leads to emotional and economic ruin; and 2) persons with brain injuries have an intense desire and motivation to return to work.

Many factors affect the work opportunities for persons with brain injuries. Lack of awareness and knowledge of methods to support persons with brain injuries is widespread. Employers and job counselors need more information to better accommodate persons with brain injuries on the job. Data from 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 the 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.

2010 Recommended Action – DHHS should partner with the Department of Labor to better coordinate vocational rehabilitation and long-term job supports and provide training on brain injury rehabilitation to all vocational rehabilitation staff.

10 – FOSTER DEVELOPMENT OF MORE EFFECTIVE AND EFFICIENT REHABILITATION PRACTICES

Maine's system of neurorehabilitation programs serves more than 700 individuals each year. Unfortunately, the nine clinics providing these services are clustered in major population centers in the state, leaving citizens who live in rural areas without access to effective rehabilitative treatment.

2011 Recommended Action – DHHS should conduct a broad-based evaluation to identify cost-effective options for the provision of ongoing neurorehabilitation and support services for Maine citizens throughout the State. Emphasis should be placed upon overcoming barriers to self-sufficiency and return to work.

The ABIAC acknowledges and thanks the DHHS Liaisons to the Council:
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