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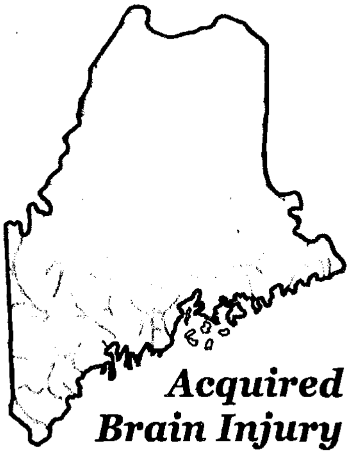
BRAIN INJURY IN MAINE:
A GROWING PUBLIC HEALTH ISSUE



Acquired Brain Injury Advisory Council of Maine

2009 REPORT

January 15, 2010

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.

The Acquired Brain Injury Advisory Council of Maine

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Marcia Cooper, Secretary	Persons with Brain Injuries
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We can no longer deny the impact brain injury has on Maine's citizens and the economy. We literally cannot afford to ignore these issues or "shoehorn" people into the wrong diagnosis and treatment. It is our responsibility, even in times of economic downturn to use this new knowledge to create access and greater efficiencies that lead to improved outcomes for individuals, their families, and our communities.

The Acquired Brain Injury Advisory Council

The Council was established in April 2002 and became a formal state advisory council in September of 2007 to address the needs/challenges of persons with brain injury and their families and to raise awareness of those needs to promote systemic change. The original mission of the Council continues to speak directly to the issues today: *To plan and promote a statewide system of services and supports that is driven by the needs of individuals with brain injury and their families.*

Throughout 2007, 2008 and 2009 the Council held 8 public hearings (Bangor, Portland, Caribou, Lewiston, Sanford, Houlton, Calais, and Farmington) receiving testimony focused on the experiences of Maine citizens with brain injuries and their families. More than 100 Maine citizens submitted formal testimony. The Council sponsored four, one-day forums for in-depth exploration of critical public health challenges. In June 2007 a forum on military service members and veterans with brain injuries was held in Augusta. In October 2008 another forum focused on children and adolescents with brain injuries. Two forums were held in 2009: a forum on brain injury in domestic violence was held in March and in October 2009 a broad-based forum covering the experiences of persons with brain injury in employment, homelessness, and incarceration resulted in identifying critical action steps. The Council has studied and prioritized its recommendations based upon a broad base of information and experience gathered through these Public Hearings and Forums over the past 25 months.

OVERVIEW

Brain Injury is a growing public health issue that can impact each of us, our families and our communities. 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 that 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 8,000 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. And some who experience a brain injury will live with very difficult, life-altering disabilities. More than 6,000 Maine citizens live with these long-term disabilities due to brain injuries. Providing immediate access to information and education, care coordination and rehabilitation is crucial. Unfortunately, the system of care sometimes gives up prematurely on these people condemning them to nursing homes or institutions that are costly, and often times ineffective and unnecessary. At the other end of the injury spectrum are those individuals who appear uninjured but have significant cognitive and behavioral disabilities that 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, 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. And when we do the "right thing" we create efficiencies that allow our State tax dollars to be used effectively.

PRIORITIES

This report reflects the highest priority areas the Council has identified that will begin to lead to substantive improvements. 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 traditionally regarded as random, unavoidable accidents. However, the nature of injuries is predictable and preventable. Brain injury frequently kills or threatens the life and well-being of individuals of all ages. Many brain injuries are preventable.

The Council is very encouraged by the action of the 124th Legislature and the Governor in raising the mandatory helmet motorcycle helmet age to 18. Helmets are highly effective in preventing brain injuries, which often require extensive treatment and may result in lifelong disability. In the event of a crash, motorcycle riders without helmets are three times more likely than helmeted riders to suffer traumatic brain injuries. Additionally, taxpayers often foot the bill for higher medical costs through MaineCare and Medicare. Riders without helmets have higher health care costs as a result of their crash injuries, and many lack health insurance. The government at taxpayer's expense pays a majority of medical costs for those without private insurance.

Abusive Head Trauma – Maine's Abusive Head Trauma workgroup has been working with training hospital staff and community based agencies on a **Period of Purple Crying**, a promising-practices shaken baby prevention program that offers information on normal infant crying. Currently, 90% of all birthing facilities in Maine are delivering the materials to families, with the remaining 10% in the process of implementation.

Sports Concussions – **The Council is very encouraged by the action of the 124th Legislature and the Governor in adopting LD1300 to evaluate options for sports concussion management for high school athletes.** Unfortunately, at this point, the Department of Education has not convened the work group. Failure to identify 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 pressured to return to play before the brain has had time to heal. The efforts of the Maine Concussion Management Initiative at Colby are to be praised and supported. More than 30 high schools in Maine are participating. All sports programs across the state should have the benefit of trained coaches, a statewide safety standard and access to computerized concussion screening.

2010 Recommended Action – The Legislature and Governor should establish in law a concussion management standard for all student athletes based upon the most current medical knowledge.

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 efficacy of 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 that is flexible and directly meets needs that change over time could provide persons with brain injuries the needed care and avoid unnecessary health and safety risks. This would result in a highly efficient use of taxpayer resources.

The Council is very encouraged by the action of the 124th Legislature and the Governor to include funding for Targeted Case Management services for children with brain injuries under the responsibilities of Children's Behavioral Services.

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).

2010 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 adults with brain injuries in order to provide effective care coordination and remain budget neutral.

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 were the leading issues 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. The demands 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 who receive care and support 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. Of special concern are the insufficient skills of many professionals and direct care staff providing support for persons with challenging behaviors. Maine does not mandate specific brain injury training. 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 can lead to increased risk for all involved, and often results in failure of the person with the brain injury to learn how to manage their behavior effectively. This training should reach across all departments including DHHS (mental health, developmental services, elder services, substance abuse services, Maine CDC, and financial eligibility), DOL, Public Safety, Corrections and others who work with persons with brain injuries.

2010 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 – 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 for this group is over 60 persons for the 112 specialized beds.
The Council is 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 designated for northern Maine, where no such services currently exist.

The Council is also very encouraged by the establishment of a strategic priority within DHHS to address individuals with complex needs. Additionally, the Department's efforts to bring individuals with brain injuries home from out-of state placements have been outstanding. In the past year, more than 12 individuals have returned to Maine and are receiving better care with an estimated savings of more than $500,000/year.

However, individuals with brain injuries have no options for specialized brain injury support in their own home or apartment 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, 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 situation. 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 home. Although many individuals have moved back to Maine from out of state, resulting in cost savings, in some cases the opposite is true. 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 (DHHS) 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-hour a day, seven day a week support and are able to live in less restrictive settings.

2010 Recommended Action – DHHS should establish community living services with less than 24/7 supports that allow individuals to live in their own home with adequate support to maintain health and safety within current budget levels.

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 to address the 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.

2010 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 plan of treatment and care.

6 – 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 apparent 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.

The Council is very encouraged by the action of the 124th Legislature and the Governor in establishing a Resolve (LD866) requiring the Department of Education to establish a working group to consider the widespread misidentification of children with brain injuries in special education. Unfortunately, as of this date, the Department of Education has been unable to begin this effort.

2010 Recommended Action – Require that the annual health screening of all children and youth in schools include a standardized set of questions to identify possible brain injury. The Legislature should mandate the LD866 statewide study group led by Department of Education, educators, pediatricians, and DHHS to evaluate the steps needed to better identify, educate and coordinate services for students in special education with brain injuries.

7 – SUPPORT FAMILIES WHO CARE 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 of 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. The family can experience frustration and impatience when the individual with a brain injury is back at home. The family may feel that it is time to 'get over it' and 'move on' once the acute phase of the injury is passed. Often family and friends do not acknowledge the long term problems resulting from the injury or do not understand the effects of the injury.

Many family members often describe a sense of loss, grief and denial. They recognize that their loved one may not be the same person as they were prior to the injury 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 intermediate stress, while the changes in personality and behavior are the most stressful, increasing over time since they are unpredictable and perhaps embarrassing. This results 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.

2010 Recommended Action – DHHS should establish a study group to evaluate options for addressing family issues.

8 – 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, 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 and mitigate unnecessary consequences.

As a result of the ABIAC sponsored forum on veterans and brain injuries in June of 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.

2010 Recommended Action – Insure that the Maine National Guard can continue the screening and follow-up program for brain injuries when grant funding ends in 2010. Mandate DHHS to enhance ongoing collaborative efforts between State agencies, Veterans Administration, veterans groups, and community-based brain injury providers to improve coordination, care and support for Maine's veterans.

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 to the person's brain. 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) an intense desire and motivation to return to work from persons with brain injuries.

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 (DOL) doesn't always include specific causes of a person's disability and as a result a clear picture of the scope of need is not available. And long term support funds are available from DOL but not always accessed by persons with brain injuries.

2010 Recommended Action – Department of Labor and Department of Health and Human Services should establish a joint task force to better coordinate vocational rehabilitation and long term job supports.

10 – PROVIDE ACCESS TO NEUROREHABILITATION SERVICES IN RURAL MAINE

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

2010 Recommended Action – DHHS should establish a broad-based study to evaluate the needs, barriers, and benefits of providing ongoing neurorehabilitation in rural areas of the state.

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