3-1-2007

Establishing the Acquired Brain Injury Trust Fund in Maine: Background Information, Experiences in Other States, and The Needs of Maine Individuals and Their Families

Judith B. Tupper DHEd, CHES, CPPS
University of Southern Maine, Muskie School of Public Service

Establishing the Acquired Brain Injury Trust Fund in Maine:

Background information, experiences in other states, and the needs of Maine individuals and their families

March 2007

Report for the
Acquired Brain Injury Advisory Council

Prepared by

Judy Tupper, MS, CHES
Institute for Health Policy
Muskie School of Public Service
University of Southern Maine

This document was developed under Grant No. 11P-92023/1-011 from the U.S. Department of Health and Human Services (HHS), Centers for Medicare and Medicaid Services. This grant was made to the Maine Department of Behavioral and Developmental Services, which has contracted with the Edmund S. Muskie School of Public Service at the University of Southern Maine. However, the contents herein do not necessarily represent the policy of HHS or the Maine State DHHS and you should not infer any endorsement by the Federal or Maine State government. Please include this disclaimer whenever copying or using all or any part of this document in dissemination activities.

Table of Contents

Tables and Figures

Forward

The Muskie School of Public Service has been participating in the program management of a federal Real Choice Systems Change – Money Follows the Person grant. The goal has been to examine community options for persons living with brain injury by redirecting resources toward more person-centered, consumer driven services. It is has become clear through our work with grant pilot activities that current regulations and funding sources are not aligned with optimal rehabilitation and reintegration for those who have acquired a brain injury in the State of Maine. Transition to a less-restrictive and less expensive, person-centered housing option is rarely an option for Maine residents with an acquired brain injury. Key services such as case management and other personal and community supports are not funded through traditional MaineCare or private sources. The Grant Resource Team began to explore other possible funding streams through the history of trust fund development in other states and conducted a best practice review. This information was presented to the Acquired Brain Injury Advisory Committee for further action. This report is a compilation of information gained in the review of trust funds and needs in the State of Maine.

Acquired Brain Injury (ABI) or Traumatic Brain Injury (TBI)?

The proposal to create a Trust Fund in the State of Maine refers to the use of the funds to support services for Maine residents with Acquired Brain Injury. Use of the term ABI applies to a broader range of consumers than TBI and is more inclusive than the vaguer term “brain injury”. It has become clear over the years that the TBI definition needlessly excluded people with other injuries that resulted in similar disability and prognosis and best practices applied to both. Additionally, it has been demonstrated that creating a more unified and inclusive system to serve people with the same needs is more efficient and effective.

Executive Summary

The Acquired Brain Injury Advisory Committee requested this report to inform members of its committee, consumers, service providers, legislators, and state agencies as legislation to create the Acquired Brain Injury Fund is considered. Contained in the report is a review of the development of trust funds as a funding stream to provide services to individuals with brain injury with unmet needs. There are currently 19 active state trust funds. Trust fund revenue sources and the uses of those funds vary from state-to-state. Revenues from trust funds generally support the access and delivery of cognitive rehabilitation, registries, education, community supports and case management. Cognitive rehabilitation is recognized as central to the treatment and long-term recovery of individuals with a brain injury, yet private and public healthcare coverage of this service remains under-funded across states. Case management for individuals with brain injury is not a usual covered benefit for MaineCare members and coverage of cognitive rehabilitation is limited.

The unmet needs and barriers of Maine residents with brain injury and their service providers were detailed in a recent state-wide needs assessment. In particular, case management, supported housing, vocational, and education are identified as high priority areas for resource development. The needs assessment recommendations include policy development, collaboration and coalition building to strengthen the service delivery system, coordination of services and supports, and the development of educational opportunities for clinicians, service providers, employers and general public. The Department of Health and Human Services was recently designated as the Lead State Agency for the coordination of brain injury services in Maine and the new position of Director of Brain Injury Services was created. Recent developments in Maine such as a decreasing number of brain injury service providers, the implementation of a new medical model of reimbursement under MaineCare, and an expected return of recent military veterans with brain injury have prompted the Acquired Brain Injury Advisory Committee to renew focus on the development of a new funding stream to support unmet needs.

What are Brain Injury Trust Funds?[1]

Trust funds are accounts established by law and earmarked for specific purposes. As State revenue sources become more difficult to obtain, TBI trust funds offer an additional way to serve individuals who have sustained an acquired brain injury.

The earliest brain injury trust fund legislation occurred in 1985 in Pennsylvania. Today, there are 19 fully operational trust fund programs throughout the United States, ten of which also benefit individuals with spinal cord injuries. Two additional programs are under development in Montana and Connecticut.

While not all the programs are specifically called "trust funds," they share these similarities:

- They are established by legislation and are dedicated for activities benefiting individuals with brain injury.
- They are supported by revenues from a fee, fine, or surcharge.
- Revenue is placed in an interest-bearing, non-reverting account.

How do they work?

Despite the fact that a trust fund is an account dedicated for a specific purpose, many states require legislative approval to use brain injury funds. Gaining this approval involves establishing an annual budget and presenting it before a budget or finance committee in the legislature.

Estimated revenue varies widely for established programs, from less than $1 million to $17 million. The average is between $1 million and $4 million annually. The sources of revenue also vary but are most often tied to traffic offenses – a leading cause of car crashes and brain injury.

Just as revenues for trust funds vary, so do their uses. Many programs provide funding for individual consumer needs while others devote funds to projects selected through a request for proposal (RFP) process. Some combine trust fund monies with general revenue or other sources to support new or existing programs, promote research, or help fund registries, information and referral, education, prevention, resource coordination, grants, or waivers.

A summary table of the 19 state trust funds can be found on the next page.

[1] Excerpted from: *A Look at TBI Trust Fund Programs, Possible Funding Sources for Helping Individuals and Their Families Cope with Traumatic Brain Injury,* March 2006. Department of Health and Human Services (DHHS) Health Resources and Services Administration (HRSA), Maternal Child and Health Bureau (MCHB) Contract No. 240-03-0014.

Table 1. Trust Fund Development At-A-Glance.

Date Ratified	State	Revenue Sources	Estimated Revenue	Program Focus
1985	PA	All traffic violations	$3 million	Assessment, short-term community-based rehab services, transition case management
1988	CA	.066 of state penalty fund	$1 million	7 regionally based projects addressing community support needs
1988	FL	DWI, BWI, moving violations motorcycle tag, temp license tag	$17 million	Acute care, rehab, community integration, nursing home transition, case management, Medicaid match, prevention, registry, special project grants
1991	MA	Speeding, DUI	$6.8 million	Non-recurring, short-term community support services
1991	MN	DUI	$1 million	Registry, resource and service coordination
1991	TX	Felonies and misdemeanor	$10.5 million	Inpatient, outpatient, and post-acute rehab services
1992	AZ	Civil & criminal	$2 million	Public information, prevention, education, community rehabilitation, transitional living, surveillance
1993	AL	DUI	$1.5 million	Registry, resource coordination
1993	LA	DUI, speeding	$1.5 million	Community-based services and supports
1993	TN	Speeding, reckless op., DUI, revoked license	$750-950,000	Registry, grants for 10 community-based projects
1996	MS	DUI moving violations	$3.5 million	Registry, waiver match, services, transitional living, prevention, education, recreation
1997	NM	Moving violations	$1.5 million	Service coordination, life skills training, crisis interim services
1997	VA	License reinstatement	$1.2 million	Grants for community-based rehabilitation projects, applied research projects
1998	GA	DUI	$2.3 million	Community-based services and supports, support groups, AT
1998	KY	Percent of court costs	$3.3 million	Community-based services and supports, surveillance registry
2002	CO	Speeding, DUI	$1.5 million	Care coordination, services, research, education
2002	HI	Traffic offenses	$600,000	Service coordination, education, public awareness, education
2002	MO	Cost of court	$800,000	Counseling, mentoring, education
2002	NJ	Car registration	$3.8 million	Community-based services and supports, public awareness, education
2003	MT	Car registration	$8,117	Advisory Council, grants for public awareness, prevention education
2004	CT	Reckless driving speeding, DUI	$300,000	Undetermined – may focus on resource coordination

Services for Brain Injury – National Perspective

The Centers for Disease Control (CDC) estimates that at least 5.3 million Americans—about 2% of the U.S. population—currently have a long-term or lifelong need for help to perform activities of daily living due to brain injury.[2] Each year at least 1.4 million Americans sustain a brain injury. [3,4] Lifetime costs of brain injury totaled $60 billion in 2000—this includes direct medical and indirect costs such as lost productivity.[5]

The Brain Injury Association of America issued a position paper *Cognitive Rehabilitation: The Evidence, Funding and Case for Advocacy in Brain Injury* in November of 2006.

> Impairments of cognitive function are among the most common and important problems that lead to disability after acquired brain injury. Treatment of cognitive dysfunction is central to the treatment and recovery of individuals with brain injury because of the widespread impact of cognitive rehabilitation deficits on safety, functional independence, productive living, and social interaction.[6]

The report further details the clinical research that supports cognitive rehabilitation and the unmet coverage needs that individuals face through both public and private payers for this evidenced-based care. Most payers, including Medicare and Medicaid restrict scope, duration, timing and intensity of service. Some third party payers even disallow claims or specifically exclude treatment for cognitive rehabilitation in their policies. Lifetime costs for an individual with a severe brain injury are estimated at $600,000 to 1.8 million and most people mistakenly believe that needed services will be covered by employer health plans, individual insurance policies or Medicare/Medicaid. Coverage for treatment during the acute or post-acute time period does not extend to the chronic care needs associated with the injury. Like other chronic illnesses such as diabetes or heart disease, optimal health status and quality-of-life can be attained through ongoing case management, patient education and relapse prevention.[7]

The Brain Injury Association of America offered ten recommendations to reduce the access and delivery barriers for cognitive rehabilitation.[8] Trust fund revenue could be applied to address the recommendation that there be "an increased emphasis on proper

---

[2] Thurman D, Alverson C, Dunn K, Guerrero J, Sniezek J. Traumatic brain injury in the United States: a public health perspective. *J Head Trauma and Rehabil* 1999;14:60215

[3] Thurman et al, 1999.

[4] Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Department of Health and Human Services (US), Centers for Disease Control, and Prevention, National Center for Injury Prevention and Control; 2004.

[5] Finkelstein E, Corso P, Miller T and associates. The incidence and economic burden of Injuries in the United States. New York (NY): Oxford University Press; 2006.

[6] Katz, DI; Ashley MJ, O'Shanick GJ, Connors, SH. *Cognitive Rehabilitation: The Evidence, Funding and Case for Advocacy in Brain Injury.* McLean, VA: Brain Injury Association of America, 2006.

[7] Katz et al, 2006.

[8] Katz et al, 2006.

education, training, certification and continuing education for professionals and support staff involved in cognitive rehabilitation." [9] In addition, the position paper recommends that "cognitive rehabilitation should be integrated into and coordinated with vocational services, special education, and community based programming such as supported living, support networks, and recreation groups so that individuals move seamlessly within a comprehensive, coordinated system of care that is adequately funded." [10] Many states have used trust funds to support these types of services.

Figure 1. Consequences of Brain Injury.

The Consequences of Brain Injury

Cognitive consequences may include:

- Short-term/long-term memory loss.
- Slowed ability to process information.
- Trouble concentrating or paying attention for periods of time.
- Difficulty taking turn in conversation/other communication difficulties such as word retrieval problems.
- Spatial disorientation.
- Organizational problem and impaired judgment.
- Inability to multi-task.
- A lack of initiating activities, or once stared difficulty in completing tasks without reminders.

Physical consequences may include:

- Seizures of all types.
- Muscle spasticity.
- Double vision or low vision, even blindness.
- Speech impairments such as slow or slurred speech.
- Loss of smell or taste.
- Headaches or migraines.
- Fatigue, increased need for sleep.
- Balance problems.

Emotional/Behavioral/Social consequences may include:

- Increased anxiety.
- Depression and mood swings.
- Impulsive behavior.
- Easily agitated.
- Egocentric behaviors.

Source: *Brain Injury Association of America*, 2001.

[9] Katz et al, p.15.
[10] Katz et al, p. 16.

The Situation in Maine

Acquired brain injury results in a broad range of physical, cognitive, behavioral, emotional and social challenges. Treatment and services are based upon the individualized needs of each patient.

The Department of Health and Human Services was designated by law as the Official State Agency in 2005 and is responsible for programs and services for persons affected by brain injury (L.D. 741) A workgroup of DHHS staff and stakeholders prepared a report for the Maine State Legislature to identify existing systems of support, number of individuals served and the identification of service gaps.[11] Various, but *limited* MaineCare and state-funded services include funding for intensive rehabilitation nursing care, outpatient rehabilitation, residential care, nursing care, personal assistance, behavioral health services, as well as, prevention and surveillance services, intake (informal process), transition services, and case management for individuals with co-occurring mental illness or mental retardation only.

An estimated 3,232 adults with a primary diagnosis of brain injury were served by MaineCare in SFY 2004 at a cost of $87,869,798 according to research presented in the report. The Interim Report lists the following outstanding areas of concern as identified by the stakeholder group:[12]

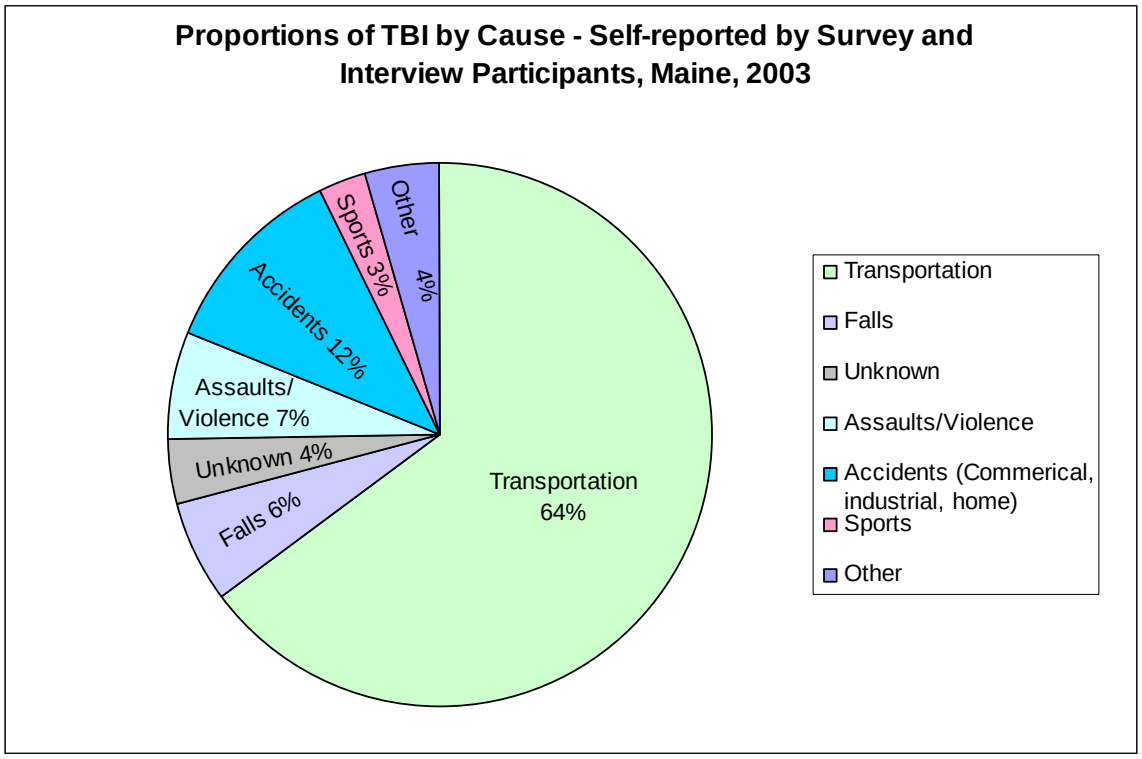
- Access to stand-alone case management (85% of the adults with brain injury covered by MaineCare in FY '05 received no case management services).
- Timely diagnoses of brain injury from knowledgeable clinicians.
- Access to in-home supports for those who are not physically disabled, but who require extensive cueing in order to function independently in the community.
- Access to an array of community residential options.
- Services for individuals with the co-occurring diagnosis of substance abuse
- Employment
- Transportation

[11] Defining DHHS as the Lead State Agency for Brain Injury Services to Adults in Maine, March 2006. Interim Report submitted to the Joint Standing Committee for Health and Human Services, 122nd Maine Legislature, Augusta, Maine.
[12] Interim Report, ibid.

Maine Needs Assessment Survey

In 2005, the Maine Department of Health and Human Services, Children with Special Health Needs Program, collated the results of surveys of individuals with brain injury, their families and/or significant others, private service providers and state agency personnel.[13] Through a federal grant program, the agency aimed to identify resources, gaps in services and support for individuals with brain injury across Maine. The survey information provided recommendations to enhance access and services.

Figure 2. Proportions of TBI by Cause.



Source: *The Silent Epidemic*, 2005.

[13] *The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine,* 2005. Brain Injury Association of Maine. Supported in part by grant #P05 MC00061-2 from the Department of Health and Human Services (DHHS), Health Resources and Services Administration, Maternal and Child Health Bureau.

The needs assessment identified the following areas of concern for Maine families:

- **Education**, information and peer support
  - Significant need for awareness, understanding and expertise in the areas of *Prevention, Injury identification,* and *Long-term impact.*
  - Individual and family
  - Clinical education for healthcare professionals particularly for current and optimal diagnosis, short-term and long-term treatment of brain injury
  - Education for school and vocational services professionals
  - Community education to reduce the stigma of brain injury and increase active participation in the community

- **Housing**, transitional and long-term residential services
  - Funding shortfalls, lack of access to in-home supports and regulatory barriers diminish opportunities for independent living and often contribute to adults living in restrictive environments unnecessarily.
  - Community support services such as case management and resource facilitation, uncovered services under current Medicaid and Medicare regulations could be beneficial to aid individuals and their families in navigating a complex and challenging healthcare system.
  - Supported housing options are generally not available in the State due to existing regulatory restrictions and eligibility criteria.

- **Case Management**
  - Navigation of medical, financial and legal systems overwhelms individuals with brain injury and their families. Outcomes could be greatly improved through timely facilitation and coordination of needed services and resources.

- **Transportation**
  - Lack of transportation limits access to rehabilitation, medical services, education, vocational training and employment opportunities, as well as, social and recreational activities.

- **Healthcare barriers**
  - Obstacles were identified that prevent individuals receiving beneficial expert services essential to optimal treatment of brain injury.

Recommendations from the Needs Assessment

The report prepared by the Brain Injury Association of Maine included a number of recommendations to improve and sustain the development and maintenance of coordinated systems of services and supports for individuals with brain injury and their families:

1. A committed State Lead Agency
    a. This state agency should be responsible for providing service needs such as case management and resource facilitation. (*Since the report was issued, the Department of Health and Human Services became the officially designated state agency to coordinate brain injury services in Maine. A Director of Brain Injury Services position was created within the Office of Adults with Cognitive and Physical Disabilities early in 2007.)*

2. Policy development in the areas of:
    a. Advocacy training, especially in the area of legal and insurance issues
    b. Legislation specifically targeted to aid individuals with brain injury
    c. Development of a state-wide care protocol that requires screening and basic head injury care procedures with trauma patients. Also, related to clinical care, monitoring of head injury patients with overnight stay
    d. School sports injury baseline-testing program and "return to play" guidelines
    e. Head trauma follow-up, particularly with mild brain injuries
    f. Funding and policies that reflect the validity and economic value of maintenance programs
    g. Legislation that provides less costly and more appropriate housing options in Maine for individuals who are currently receiving long-term care out-of-state.

3. Expand collaboration and coalition building
    a. Cooperative alliances to maximize service delivery
    b. Collaboration between hospitals and agencies to provide brain injury services in regions that lack rehabilitation services
    c. Collaboration with advocacy groups to promote leadership development and self-advocacy skills

4. Coordinated State system of services and supports
    a. Case management, caregiver supports, peer mentoring, natural supports in the community
    b. Respite care, crisis line, day programs, transportation systems
    c. Increased vocational rehabilitation resources and range of services
    d. Increased housing options that address changing needs through an array of services
    e. Person-centered planning and communication
    f. Services for individuals in remote areas

5. Maximize resources to achieve program sustainability
    a. Benefit counseling
    b. Increased funding for vocational rehabilitation programs to avoid long waits for services
    c. Expanded funding to cover non-medical needs such as case management, socialization, recreation, strategies for daily living, homemaker services, tutoring, and community integration.

6. Development of effective brain injury products
    a. Telemedicine to meet service needs in rural areas
    b. Resource catalogs, tools
    c. Brain injury informational material, lending library, help line, electronic bulletin board

7. Build capacity through maximizing educational opportunities and building awareness of brain injury
    a. Professional education and training for clinical and behavioral health providers
    b. Injury registry to document incidence of brain injury in Maine
    c. Education and support at acute care setting
    d. Public education and awareness of brain injury
    e. Injury prevention education and promotion
    f. Expanded training to law enforcement, school systems, and other groups.
    g. Employer education regarding vocational needs
    h. Development of services that meet needs of individuals and their families through the aging continuum
    i. Development of prevention and awareness programs about the risks of substance abuse, domestic violence, elder safety and risk-taking behavior.

Recent Developments

Since the needs and resource assessment was completed, changes in Maine state policies and regulations concerning rehabilitation services have occurred. Funding for brain injury rehabilitation was reduced from approximately $17 million to approximately $12.5 million. There has been a reduction from nine to seven sites providing outpatient rehabilitation services. The service model as covered under MaineCare has become a medical model that instituted levels of care and caps within those levels. Some individuals were dropped from services under the new model due to new eligibility requirements. Community-based services are not currently available to meet the needs of individuals no longer eligible for state funded services. As previously mentioned, the Department of Health and Human Services has been designated as the Lead State Agency for the coordination of brain injury services in Maine and the Director of Brain Injury Services position was recently filled.

With the recent return of many veterans to Maine from active duty service, there is a new and urgent call to address the needs of individuals with brain injury.

Preliminary research by the Defense and Veterans Brain Injury Center indicates that nearly 10% of all troops in Iraq, and up to 20% of front-line infantry troops, suffer concussions during combat tours. George Zitnay, co-founder of the Center, testified before a Senate subcommittee in May 2006 that body armor saves troops caught in blasts but leaves many with brain damage, stating, "Traumatic brain injury is the signature injury of the war on terrorism."[14] According to a July 2006 report from the Veterans Administration Office of the Inspector General, brain injured veterans often fall through the cracks. The report found that multiple factors lead to suboptimal access to care and services are often very limited in communities where injured veterans live.[15] An increased number of individuals requiring community-based services should be anticipated and part of the preparation and consideration of new programs and funding mechanisms.

Brain injury is a significant public health issue that impacts Maine individuals, families and communities, as well as, human and financial resources. Maine citizens affected by brain injury have unmet needs through existing programs and funds. Brain injury trust funds are proven mechanisms in terms of funding streams and service delivery for 19 other states. The development of a Trust Fund for the State of Maine is expected to provide a new and sustainable revenue source to meet the needs of Maine individuals with acquired brain injury and their families.

[14] USA Today and Zoroya, Gregg. *Center for war-related brain injuries faces budget cut.* [Web Page]. Available at: http://www.usatoday.com/news/washington/2006-08-08-brain-center_x.htm. Accessed March 2, 2007.

[15] Department of Veterans Affairs. Office of Inspector General. *Healthcare inspection: Health status of and services for Operation Enduring Freedom/Operation Iraqi Freedom veterans after traumatic brain injury rehabilitation*. (Report No. 05-01818-165). Washington, DC: VA Office of Inspector General; 2006.