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# Brain Injury in Maine: A Needs Assessment

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**Brain Injury in Maine  
A Needs Assessment**

**January 2010**



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**SOUTHERN MAINE**



# Brain Injury in Maine

## A Needs Assessment

January 2010

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For:

Brain Injury Services  
Office of Adults with Cognitive and Physical Disability Services  
Maine Department of Health and Human Services

and

The Maine Acquired Brain Injury Advisory Council

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# Brain Injury in Maine

## A Needs Assessment

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# Executive Summary

“I said to him, ‘You have a head injury. That does not mean you are a forgotten creature.’”

Mother of 44-year old man with brain injury

A brain injury can impact cognitive, physical and behavioral functioning, may have lifelong consequences for health, and, when associated with a permanent disability, can have a profound impact on an individual’s economic and social well-being. An estimated 37% of the people hospitalized with a brain injury each year, or 80,000 to 90,000 people, will end up with a permanent disability as a result of that injury; current estimates indicate that 6 million people in the United States live with permanent disability resulting from a traumatic brain injury. (McMorrow 2007). Of those, an estimated 6%, or 360,000 people in the United States, are in need of intensive and ongoing behavioral supports. (McMorrow 2007).

The cost of brain injury includes not only the cost of medical and rehabilitative services, but the cost of long term services and supports for those with a permanent disability, and the economic and social costs associated with lost productivity, reduced quality of life, strain on family relationships, and other related outcomes. The needs of a person with brain injury cross into employment and schools. Brain injury can impose hidden costs on the system by undermining the effectiveness of treatment and services for other conditions. In some cases, homeless shelters and prisons pick up the costs of brain injury by housing those who have not been successfully served elsewhere. The younger a person is when a brain injury is acquired, the greater the cost to both the individual and society.

The full cost of brain injury is largely unquantified. However, the data that does exist demonstrates its significance in terms of both individual and societal costs. One study estimated the economic burden (direct medical costs and lost productivity) of brain injury in the United States to be over \$60 billion annually. (Finkelstein et al. 2006). Qualitative data and public testimony (some of which is interspersed throughout this document) document the personal costs of a brain injury in Maine, for both the injured and those that care for them.

Brain injury is a public policy issues because many of the costs borne by the public are avoidable. Preventing brain injury in the first place would eliminate the costs of recovery and long term disability. Less than optimal treatment means that maximum recovery may be delayed or denied. For people with a lifelong disability, less than optimal long term supports can mean people are served in unnecessarily restrictive and expensive settings. Inadequate services may mean that costs are shifted onto others, including the mental health system, the substance abuse treatment system, homeless shelters or the criminal justice system.

## FINDINGS

This document reviews existing Maine policy and programs to evaluate how well they meet the needs of persons with brain injury. Based on this analysis, the following findings are made:

- People with brain injury have uneven access to financing for needed services. No health plan covers the full range of needed services.
- It’s possible that the MaineCare program is bearing a greater burden than necessary because private insurers and the Medicare program limit access to needed rehabilitative services.
- The MaineCare program offers a limited array of needed services for persons with brain injury. Notable gaps include in-home services and supports, psychosocial rehabilitation, and service coordination services.
- Maine’s supply of specialized service providers is unevenly distributed geographically and service.

- Providers in general often do not have the training and awareness they need to identify and effectively treat people with brain injury.
- Unidentified and untreated brain injury is a major cause of social failure and has cost implications for schools, the mental health system, the substance abuse treatment system, the criminal justice system, and other publicly administered programs.
- The under-identification of brain injury perpetuates the lack of investment in brain injury services; without supporting data its relative importance is obscured.
- Addressing the full range of issues raised by brain injury requires collaboration across multiple state agencies, an investment in gathering better data, and tools and mechanisms for improving awareness and treatment of brain injury.

## STRATEGIES AND POLICY OPTIONS

Based on the analysis in this assessment, the following strategies and policy options are offered for consideration.

### CLOSING THE INFORMATION GAP

In a number of areas this assessment only identifies potential need without data to define the dimensions of that need. Better data is needed to understand:

- The prevalence of brain injury in the mental health system, among those receiving substance abuse services or protective services, in schools, homeless and domestic violence shelters, and in prisons and jails.
- The prevalence of those with complex, co-occurring conditions, including those having a need for mental health services or substance abuse treatment
- The hidden costs of untreated brain injury for the mental health system, the substance abuse system, for safety net providers (*e.g.*, homeless shelters), and for the criminal justice system.
- Whether and to what degree the cost of care is shifted from private insurers onto the MaineCare program.
- The number of people currently cared for by aging parents and the expected demand for services when those parents are no longer able to provide care.

### CLOSING THE AWARENESS GAP

There is evidence to suggest that brain injury is under-identified in Maine's schools, jails and prisons, and the mental health and substance abuse service systems. If brain injury is under-identified, services are likely to be less effective and resources misallocated. Maine has an opportunity to improve the identification of brain injury. Strategies might include:

- Developing and disseminating tools and educational resources to enable screening for brain injury.
- Coordinating policy and provider education across programs to ensure that, once identified, there is an appropriate system response: services are modified to accommodate the person's brain injury; the person is referred to needed brain injury services; or services are coordinated or integrated across multiple providers.

This strategy might be piloted in certain areas, including protective services, or the mental health and substance abuse services systems.

#### CLOSING THE SERVICE GAP

An inadequate array of service options and uneven access to needed services mean that resources are misallocated and costs are shifted. To improve access to services, the following strategies might be considered:

- Evaluate the costs and benefits of mandating coverage for rehabilitation services and modifying the definition of “medical necessity” under private health plans.
- Expand the specialized brain injury services covered under MaineCare to develop a more graduated array of service options across settings and levels of care; evaluate the impact of expanded service options on demand for existing services and providers and develop strategies for promoting the appropriate supply of service providers.
- Expand the use of the Aging and Disability Resource Centers to facilitate the MaineCare eligibility determination process.
- Explore regulatory and financial barriers to telemedicine and other web-based strategies for extending neurorehabilitative expertise to rural areas.

# Introduction

Publicity on the debilitating impact of brain injury among retired professional football players has brought attention to the risk of sports-related brain injury. The 2009 death of the actress Natasha Richardson showed how a seemingly minor accident can have tragic consequences when a brain injury is untreated. Bob Woodruff, the ABC news anchor injured by a roadside bomb has helped to highlight the high rate of brain injury among soldiers returning home from Iraq and Afghanistan. These events and others have shined a light on an injury that, while growing ever more common over the last several decades, remains largely invisible to most of us.

“Sometimes I look around and think someone stole my car because it’s not where I thought I parked. But what was stolen was that part of my brain that was damaged.”

Woman with a brain injury

## What is a “Brain Injury?”

How brain injury is defined has significant public policy implications. At a macro level, the definition of brain injury is important because it is used to define the dimensions of the population of persons with brain injury, which is in turn used as the basis for assessing the needs of the population group, and can then become the basis for allocating resources to address those needs. On a micro level, the definition of brain injury is important because it can serve as the gateway through which access to, or eligibility for, services is limited.

The Maine Legislature has adopted a broad definition of brain injury, “Acquired Brain Injury,” which it defines as “An insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which:

- Is not of a degenerative or congenital nature;
- Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities and physical functioning;
- Can result in the disturbance of behavioral or emotional functioning;
- Can be either temporary or permanent; and
- Can cause partial or total functional disability or psychosocial maladjustment.”<sup>1</sup>

Brain injuries induced by birth are not included under this definition.<sup>2</sup>

Traumatic Brain Injury (TBI) is a subcategory of Acquired Brain Injury. In Maine, special education is limited to children with TBI, which is defined as:

“Traumatic brain injury means an acquired injury to the brain caused by an external physical force resulting in total or partial functional disability or psychosocial impairment or both that adversely affects a child’s educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem-solving, sensory, perceptual and motor abilities, psychosocial behavior, physical functions, information processing and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.”<sup>3</sup>

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<sup>1</sup> 22 MRSA §3086(1).

<sup>2</sup> 10-144 CMR Chapter 101 MaineCare Benefits Manual, Chapter II, Section 102.

<sup>3</sup> 05-071 CMR Chapter 101, Maine Unified Special Education Regulation, Section VII(2)(M).

A brain injury can impact cognitive, physical and behavioral functioning, may have lifelong consequences for health, and, when associated with a permanent disability, can have a profound impact on an individual's economic and social well-being. An estimated 37% of the people hospitalized with a brain injury each year, or 80,000 to 90,000 people, will end up with a permanent disability as a result of that injury; current estimates indicate that 6 million people in the United States live with permanent disability resulting from a traumatic brain injury. (McMorrow 2007). Of those, an estimated 6%, or 360,000 people in the United States, are in need of intensive and ongoing behavioral supports. (McMorrow 2007).

The severity of a brain injury is categorized as mild, moderate or severe based on the severity of the injury to the brain, not its resulting impact on function and health. The impact of a mild brain injury can sometimes be as severe as those brain injuries classified as moderate or severe. A mild brain injury is often more related to a dysfunction of brain metabolism rather than an anatomic or structural injury to the brain, which is commonly associated with moderate or severe brain injury. (US CDC). Between 75 to 90 percent of all TBI-related deaths, hospitalizations and emergency room visits are some form of mild TBI. (US CDC).

“Steven had an infection that went to his brain... his and our lives are forever changed.”

Mother of man with brain injury

## Who Has a Brain Injury and Why?

Each year 1.4 million American children and adults seek treatment for identifiable brain injuries from falls, motor vehicle crashes and other external blows: 50,000 die, 235,000 are hospitalized and 1.1 million are treated and released from the emergency room. (Langlois 2006). These numbers do not include those who do not seek treatment or do so at a doctor's office. Another 1 million brain injuries are the results of strokes, infections, tumors, toxins, and metabolic causes. At least 5.3 million people, or two percent of the population, have long-term or a lifelong need for help performing activities of daily living as a result of a traumatic brain injury. (Thurman et al.) In Maine, in 2007, there was an average of 5 deaths and 20 hospital discharges related to traumatic brain injury each week. (Maine CDC 2009).

The leading causes of traumatic brain injury are falls, motor vehicle accidents, and assaults. CDC estimates show that the rate and causes of traumatic brain injury vary by age and gender:

- In almost every age group the rate of traumatic brain injury is higher among males than females; on average males are 1.5 times more likely to sustain a traumatic brain injury than females. (Langlois et al. 2006).
- Falls are the leading cause of traumatic brain injury and are highest among children ages 0 to 4 and adults ages 75 years and older. (Langlois et al. 2006). In Maine, 7 of 10 deaths due to unintentional falls (73.8%) and one of every 10 unintentional fall related hospital discharges (11.8%) involved a traumatic brain injury. (Maine CDC 2009)
- Among persons sustaining a traumatic brain injury, adults age 75 years or older have the highest rates of hospitalizations and death. (Langlois et al. 2006).
- Older adolescents, ages 15 to 19, are the most likely to acquire a brain injury from a motor vehicle accident or an assault; brain injuries caused by a motor vehicle accident or assault are more likely to result in death. (Langlois et al. 2006).
- In Maine, 40.2% of unintentional motor vehicle traffic deaths and 33.5% of unintentional motor vehicle traffic hospital discharges involved a traumatic brain injury. (Maine CDC 2009)

“I hit the passenger side of the car at 60 miles an hour and the next thing I remembered was five weeks later getting ready to go home from rehab.”

Man with brain injury, injured in motorcycle accident

## Why is Brain Injury a Public Policy Issue?

The cost of brain injury includes not only the cost of medical and rehabilitative services, but the cost of long term services and supports for those with a permanent disability, and the economic and social costs associated with lost productivity, reduced quality of life, strain on family relationships, increased drug use, suicide, and other related outcomes. The needs of a person with brain injury cross into employment and schools. Brain injury can impose hidden costs on the system, by undermining the effectiveness of treatment and services for other conditions. In some cases, homeless shelters and prisons pick up the costs of brain injury by housing those who have not been successfully served elsewhere. The younger a person is when a brain injury is acquired, the greater the cost to both the individual and society.

The full cost of brain injury is largely unquantified. However, the data that does exist demonstrates its significance in terms of both individual and societal costs. One study estimated the economic burden of brain injury (direct medical costs and lost productivity) to be over \$60 billion annually. (Finkelstein et al. 2006). Qualitative data and public testimony (some of which is interspersed throughout this document) documents the personal costs of a brain injury in Maine, for both the injured and those that care for them.

Brain injury is a public policy issue because many of the costs borne by the public are avoidable. Preventing brain injury in the first place would eliminate the costs of recovery and long term disability. Less than optimal treatment means that maximum recovery may be delayed or denied. For people with a lifelong disability, less than optimal long term supports can mean people are served in unnecessarily restrictive and expensive settings. Inadequate services may mean costs are shifted onto others, including the mental health system, the substance abuse treatment, homeless shelters or the criminal justice system.

## This Needs Assessment

This needs assessment is funded under a grant from the Health Resources and Services Administration, within the U.S. Department of Health and Human Services, which administers the federal Traumatic Brain Injury Program. It reviews brain injury service needs, service options and the existing policymaking infrastructure in Maine, as it relates to prevention, treatment & long term supportive services for all age groups. For the purposes of this analysis, brain injury is defined as Acquired Brain Injury. It is organized as follows:

**BRAIN INJURY SERVICES IN MAINE.** This section defines the types of services and supports often needed by persons with brain injury, beginning first with an overview of the health, functional, and economic and social consequences potentially resulting from a brain injury; assesses the array of services available to Maine residents under available insurance and other programs; and the array of available service providers.

**BRAIN INJURY AND STATE GOVERNMENT.** This section reviews the role of state government agencies in responding to the needs of persons with brain injury, looking at the distribution of responsibility and authority for effecting policy change.

**CONCLUSIONS.** This section identifies some of the policy options and strategies available to address the gaps in services and infrastructure.

This analysis builds on the findings of the *The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine*, an earlier needs assessment which provided a window into the life experiences and needs of people with brain injury living in Maine. That report captured the perspective of those experiencing a brain injury, family members, and providers. It highlighted the need for improved understanding of brain injury for the person experiencing the brain injury, for family members, for medical professionals and service providers, and for the public generally; improved access to housing, transportation, education and employment;

“She is hanging out there one step away from homelessness and feels guilty for having a college degree and not being able to contribute to society, never mind support her child or herself.”

Mother of 29-year old woman recovering from brain tumor

“People that have a medically diagnosed illness or injury of the brain should not fill our jail cells. Yet, right now they do.”

Mother of 35-year old that died from a brain tumor

and access to information, peer support, case management services and needed care. This report shifts the focus to the policies that impede or facilitate improvement to services in Maine.

## MAINE DATA SOURCES

The analysis in this report relies primarily on data sources already existing and gathered for other purposes. These data sources include:

**PUBLIC TESTIMONY.** Public testimony in the form of transcripts and summaries from public hearings and written public testimony submitted by interested parties were reviewed. This testimony is a valuable resource for illustrating individual experiences and identifying issues and needs that may be shared with others. Although public testimony about an individual's experience may not be used to generalize about the experiences of others, it may indicate areas requiring closer investigation or corroborate other sources of information.

**POLICY REVIEW.** Maine statutes and regulations governing brain injury, MaineCare, and other policy programs were reviewed. A policy review can identify the general parameters within which a program may operate. However, a policy review may not provide an adequate picture for how a program is implemented. Often policies provide a range of discretion in how they may be implemented. Often, also, there can be a difference between policy and practice, depending on how clear the policy is or how effectively it has been reinforced or adhered to.

**STATE PROFILE TOOL STUDY.** *A Cross System Profile of Maine's Long Term Support System: A New View of Maine's Long Term Services and Supports and the People Served* is a report produced by the Muskie School of Public Service in partnership with the Maine Department of Health and Human Services (DHHS), under a grant from the Centers for Medicare and Medicaid Services (CMS) to DHHS. (Muskie School 2009). The State Profile Tool provides a cross system view of Maine's MaineCare-funded long term supports and services and the utilization and expenditures of services by those with a continuing need for services.

**MAPPING STUDY.** Completed under a System Transformation grant from CMS to DHHS, this study mapped access to services across multiple population groups, including access to specialized services for persons with brain injury. (Griffin 2009).

**REPORTS AND STUDIES.** A number of reports produced by or for the Maine Department of Health and Human Services or the Maine Acquired Brain Injury Advisory Council were reviewed. These include: the Acquired Brain Injury Advisory Councils annual reports and meeting notes from their public forums and the Maine Department of Health and Human Services 2008-2009 plan for Brain Injury Services and other reports to the Legislature.

## OTHER DATA SOURCES

This document also relies on literature and other general sources. Many of these sources have their own limitations, worthy of note here.

**POPULATION ESTIMATES.** Maine does not have its own count of the number of people with brain injury. Maine statute requires the Maine CDC to create a voluntary registry, which encourages but does not require hospitals, physicians and neuropsychologists to report on persons with brain injury seeking treatment.<sup>4</sup> Because the registry is voluntary, it is not comprehensive.

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<sup>4</sup> 22 MRSA §3087.

For its state population estimates, Maine relies on the population estimates produced by the U.S. Centers for Disease Control and Prevention (CDC). The CDC identifies a number of limitations on its population estimates, including the fact that the number of people with brain injury is underestimated because some people with brain injury are misdiagnosed or missed, or because their brain injury was secondary to other urgent or severe injuries. (U.S. CDC 2005).

While no population estimates were developed for this needs assessment, it's important to recognize the limited information available about the number of people with a brain injury and their needs. From a public policy perspective, the lack of accurate population estimates means policy decisions about resource allocation are made without benefit of a complete understanding of the full scope of need.

**NATIONAL STUDIES and ACQUIRED v. TRAUMATIC BRAIN INJURY.** Maine's definition of brain injury is used to define the scope of this report. However, federal and state research dollars have focused on traumatic brain injury, which is only a subcategory within the expanded definition of Acquired Brain Injury. As a result many of the studies cited in this report relate to traumatic brain injury rather than acquired brain injury.

The lack of adequate financing for needed services has major public policy implications: when access to needed rehabilitative services is delayed or denied, there are long term consequences for recovery and restoration of maximum function. Accordingly, there are long term consequences for the overall cost of caring for an individual, costs borne by the individual and family, and by public programs.

# Brain Injury Services in Maine

The range of available service options are a product of the financing systems that pay for them and provider capacity: from the perspective of the person in need of services, the range of available service options is largely determined by an individual's ability to access and pay for services from services providers with the needed expertise and in reasonable geographic proximity.

This section reviews:

- The range of services often needed by persons with brain injury;
- Access to needed services under health plans and other funding sources; and
- The availability and needed expertise of service providers

Based on this analysis, there is evidence to suggest that people with brain injury have uneven access to financing for needed services and that no health plan covers the full range of needed services. In addition, Maine's supply of specialized service providers is unevenly distributed geographically and service providers in general often do not have the training and awareness they need to identify and treat people with brain injury.

## Brain Injury and Needed Services

To understand what services might be needed, it's important to understand the potential long term consequences of a brain injury for both an individual's health and functioning, as well as the resulting negative impact on economic and social well-being.

A brain injury is best viewed not as a single event, but as the beginning of an ongoing process (Masel 2009), often involving stop and start progress toward recovery, chronic health conditions, and permanent functional impairment. The range of service needs depends on the individual, the severity and nature of the brain injury and its impact, and the individual's pace of recovery. Because the need for treatment and services varies widely across people and over time, the array of needed treatment and support services is less a continuum than a menu.

## IMPACT ON FUNCTIONAL ABILITIES AND RELATED SERVICES

The functional impact of a brain injury can vary depending on what part of the brain is injured, as well as the unique characteristics of the individual experiencing the injury; the ability to "remodel" a brain after an injury will depend on how a person's brain was "wired" before the injury. That means that, for example, children sustaining a brain injury at a younger age tend to have poorer outcomes than children experiencing an injury at later stages of development. (Mayfield 2005).

While the severity of a brain injury is categorized as mild, moderate and severe, the severity of the injury is not always indicative of the severity of its long term impact. In fact, an injury categorized as mild can have just as severe consequences for functional abilities as some moderate or severe injuries.

To address functional impairments, a person may have a short term or an ongoing need for both rehabilitative services to help restore functional abilities, and supportive services to assist with daily living tasks that the individual cannot perform for him or herself. Both rehabilitative services and daily living supports may be provided in a nursing facility, in a residential setting, at home, or on an outpatient or community service, depending on the needs of the individual.

Severity of Injury	Potential Impact on Functioning
<p><b>Mild.</b> The person experiences a change in mental status at the time of injury (e.g., is dazed, confused, or loses consciousness). A mild brain injury often may not appear in diagnostic imaging.</p>	<p>A person with a <i>mild, moderate or severe</i> brain injury can experience any of the following as lifelong consequences of a brain injury:</p> <p><b>Cognitive Functioning.</b> Impaired memory, decision making, judgment, communication, reading &amp; writing skills, planning, problem solving, and other limitations on cognitive functioning.</p>
<p><b>Moderate.</b> The person loses consciousness for minutes to hours. Confusion can last from days to weeks.</p>	<p><b>Physical Functioning.</b> Impaired muscle movement &amp; coordination, sleep, speech, hearing, vision, fatigue, balance, and other limitations on physical functioning.</p>
<p><b>Severe.</b> The person experiences a prolonged unconscious state or coma lasting days, weeks or months.</p>	<p><b>Behavioral Functioning.</b> Impaired social skills, motivation, self-monitoring, anger management; increased depression, anxiety, frustration, irritability, agitation, and other limitations on behavioral functioning.</p>

**REHABILITATIVE SERVICES.** When a brain injury occurs, the damage done to the neural structures of the brain can't be repaired with surgery or medication. Instead, a brain needs to be "remodeled" through structured and consistent interventions involving external stimulation. Through the rehabilitation process, the brain learns how to use new pathways and learns to compensate for abilities that have been permanently changed because of the injury. This process of recovery does not occur at a steady pace or in a predictable orderly fashion. Instead there are periods of plateau, when the rate of recovery is slowed, interspersed with periods of progress.

For the purposes of this document, rehabilitative services are broadly grouped as follows:

**NEUROPSYCHOLOGICAL ASSESSMENT.** A neuropsychological assessment identifies the resulting physiological, psychological and cognitive impact of the brain injury; other conditions such as pain, individual personality traits, and pre-injury conditions that contribute to the individual's current functional status; and resources and factors that will contribute to or impede recovery. (Swiercinksy) This assessment becomes the basis for developing a rehabilitative treatment plan.

**COGNITIVE REHABILITATION.** Cognitive rehabilitation may be process specific, focusing on attention, memory, language or executive functions; or it may be skill-based, focusing on the performance of particular activities. (Katz et al. 2006). The goal may be to restore function or develop strategies to compensate for abilities that have been lost. (American Brain Tumor Association).

**NEUROBEHAVIORAL REHABILITATION.** Neurobehavioral health services address the loss of behavioral and emotional control that some people with brain injury experience. Again, the strategies may be to restore or build functional ability, or develop skills and strategies for self-management.

**THERAPIES.** To address physical, speech and other impairments, part of rehabilitation may include physical therapy, occupational therapy and speech pathology.

**PSYCHOSOCIAL REHABILITATION.** Psychosocial rehabilitation is a service designed to

"I had 700 clients when I went out of work. I can't even do for myself now... I just wanted to crawl in a hole because I couldn't do anything that I'd done...I lost everything basically."

54-year old woman with brain injury

“Early on, I realized that knowledge is power. The more I understood Kym’s circumstances, the more in control of her care I was.”

**Mother of 14-year old girl with brain injury**

“I was first of all Jody’s Mom and then his Caregiver, Homemaker, Advocate, Protector, Medication Manager, Scheduling Manager for his many, many medical appointments, Spokesperson at each appointment, Transportation Provider, Secretary, and his emotional, spiritual advisor and support. That’s a lot of hats to have to wear in addition to my own emotional state knowing how very sick Jody was....”

**Mother of 35-year old man who died from brain tumor**

facilitate a person’s adjustment to their new life after an injury. Psychosocial rehabilitation can improve the chances of a successful return to living in the community by helping a person to adjust to their injury and by addressing the loss of confidence and self-esteem that come with an injury. For example, psychosocial rehabilitation can take the form of a “clubhouse” where people with brain injury can relearn the social and other skills they need to reenter the workforce and community living.

**DAILY LIVING SERVICES.** Some people need “daily living supports” that compensate for a functional impairment caused by a brain injury. For example, some people might need help getting dressed in the morning, assistance selecting groceries from the shelf, or extra support in school or on the job. Daily living services can be provided in many settings, including an institution or residential facility, or in a person’s home or another community setting. In a community setting, personal support services might take the form of:

**IN-HOME PERSONAL SUPPORTS.** A person may also need supportive services on a daily basis. For some people, family members will provide those supportive services. However, a person’s needs may exceed what can be provided by a family member or there is no family member that can provide the needed level of support over time.

**EDUCATIONAL SUPPORTS.** In the educational setting, a child and his or her family may need a different set of educational strategies to help the child get the most out of school. Some of these strategies might include organizational adjustments for memory impairments, accommodations for physical impairments, and more structure and routine but flexible expectations to accommodate behavioral needs. (Lash et al. 2005).

**EMPLOYMENT SERVICES AND SUPPORTS.** After a brain injury, returning to work can be challenging. Depending on the injury and the work, returning to an old job might not be possible. Employment supports might include assistance with physical tasks, cueing or other supports that would enable the individual to maintain a job.

**OTHER COMMUNITY SUPPORTS.** Other community supports might facilitate navigation through community interactions, including social and recreational activities. In some cases, community supports might include transportation services. The inability to drive is a common barrier to employment for persons with a brain injury.

**INFORMATION AND ASSISTANCE AND SERVICE COORDINATION.** Because few are prepared for the changes that come with a brain injury, information and educational resources will be needed. The individual with brain injury and family caregivers need information about what to expect and how to find services. For people with a complex range of needs, navigating a complicated maze of social service programs can require more intensive assistance, especially for persons with significant cognitive impairment or family members under stress. Service coordination supports person or family centered planning and coordination of services across life domains, including social services and financial and material assistance.

## IMPACT ON HEALTH

In the short term, when a person is hospitalized for a brain injury, there are often a variety of other medical issues. Some are related to other injuries resulting from the same trauma that caused the brain injury, such as a motor vehicle accident. Others are conditions connected to the brain injury itself, including seizures, hydrocephalus (the build-up of fluids inside the skull), fevers and infections, and deep vein thrombosis (blood clots). (Masel 2009). In the long term, moderate and severe brain injuries are also associated with a certain health conditions that may not become evident until later. For example, brain injury is associated with a higher incidence of a number of chronic health conditions, including seizures,

<b>SERVICES NEEDED BY PERSONS WITH BRAIN INJURY</b>	
<b>Rehabilitation Services</b>	
Cognitive	Cognitive and neurobehavioral rehabilitation, physical and occupational therapies and speech pathology. Rehabilitative services may be provided in institutional and residential settings, on an outpatient basis or as a home health service.
Neurobehavioral	
Therapies	
Psychosocial	A service designed to facilitate a person's adjustment to life in the community and work after a brain injury.
<b>Other Clinical Services</b>	
Mental Health	Persons with brain injury have a higher incidence of mental illness, substance abuse problems and neurological disorders. To be effective, mental health and substance abuse services need to be tailored to the needs of people with brain injury.
Substance Abuse	
Neurological Services	
<b>Daily Living Services</b>	
In-home Supports	Assistance with "activities of daily living" that compensate for a physical, behavioral, or cognitive functional impairment caused by a brain injury. For example, some people might need help getting dressed in the morning, assistance with driving, or selecting groceries from the shelf, or extra support in school or on the job. These services may be provided in a person's home, on the job, in school, or in another community setting. Daily living services may also be provided in a nursing or residential facility.
Educational Supports	
Employment Supports	
Community Supports	
<b>Coordination Services</b>	
Service Coordination	Coordinating social and other services across life domains, including long term supportive services, housing, and income supports.
Care Management	Managing medical conditions and related psychosocial conditions to improve health status and reduce the need for services.
<b>Financial and Material Supports</b>	
Housing Supports	Environmental modifications or assistive technology, and rental subsidies.
Income Supports	Financial or food assistance or other in-kind supports.
<b>Other</b>	
Information & Assistance	Information and referral, and benefits counseling.
Family Supports	Education, skill building, psychological supportive services, and respite.

Alzheimer's and Parkinson's. (Masel 2009). A brain injury can increase the risk for a mental illness. (McAllister 2005). Brain injury significantly increases the risk of developing a psychotic syndrome. Veterans returning from Iraq and Afghanistan may have post-traumatic stress disorder or major depression, in addition to their brain injury. (Tanielian et al. 2008).

**HEALTH SERVICES.** People with brain injury may need a variety of health services. Neurological, mental health and substance abuse treatment services can be of particular importance to this population group.

**CARE MANAGEMENT.** Many people with complex conditions would benefit from care management services. Care management focuses on helping patients and their families to manage medical conditions and related psychosocial conditions, more effectively to improve health status and reduce the need for services. (Bodenheimer & Barry-Millet 2009).

"I put myself through school after this... I had to take a step down... But then to me it really doesn't matter because I'm doing a job and I'm working with people."

Woman with brain injury

## IMPACT ON ECONOMIC AND SOCIAL WELLBEING

Persons suffering a brain injury are at high risk for significant decreases in friendships and social support. In some cases, personal relationships might be altered when a brain injury results in a personality change or a behavioral issue. The caretaking role can also put a strain on relationships with family and friends. Economic wellbeing is also threatened if the ability to work is impacted; for example, if a person can no longer drive or has memory problems, returning to an old job may no longer be an option. The younger a person is at the time of injury, the longer the life span to cope with the resulting impairments, and the greater the potential impact on educational and vocational goals and achievements. (Kim et al. 2007).

**FAMILY SUPPORTS.** People in supportive family relationships fare better than those in unstable relationships. (Tanielian et al. 2008). Supports and services to bolster the role of the family in turn benefit the person with the injury. Family caregivers need educational supports and skills to understand how best to support a person with a brain injury. In addition, caregivers and other family members need psychological support services to help with the adjustment with new roles and relationships, stress management, and the social isolation and depression that can come with caregiving. Respite services, which provide time away, are also critical for sustaining the family caregiver role.

**INCOME SUPPORTS.** For people who can no longer work, income supports might include financial or food assistance, or other in-kind supports.

**HOUSING SUPPORTS.** In some cases physical adjustments to a home are necessary to accommodate certain functional disabilities. In these cases, preserving a person's independence may depend on housing supports to fund environmental modifications or assistive technology. In other cases, when a brain injury results in lost income, housing supports might take the form of a rental subsidy.

"I need someone I can speak with that knows what resources are available and how to get them....I do not need more paperwork!"

Mother of 14-year old girl with brain injury

## Access to Financing for Needed Services

In Maine, most people have access to some kind of health insurance. However, people with brain injury may face higher barriers to accessing health insurance than others. In addition, no financing option available covers the full array of needed services. In particular, the lack of coverage for rehabilitative services means that maximum recovery may be delayed or denied. The lack of coverage for home and community based supports and services means that people are served in unnecessarily restrictive and expensive settings, or not served at all.

## ACCESS TO HEALTH INSURANCE

Just over 90% of Maine’s population has one kind of health insurance or another. People with brain injury will experience different barriers to coverage depending on the program.

INSURANCE COVERAGE IN MAINE		
TYPE OF COVERAGE	NUMBER	PERCENT
Employer	661,400	50.4
Individual	58,800	4.5
Medicaid	260,900	19.9
Medicare	183,100	14.0
Other Public	21,100	1.6
Uninsured	126,000	9.6
<b>TOTAL</b>	<b>1,311,400</b>	<b>100.0</b>

Health Insurance Coverage of the Total Population. (The Kaiser Family Foundation.)

**PRIVATE INSURANCE.** Access to private insurance is based on the ability to pay, either as a benefit made available through an employer or as a purchase made individually. Many people who suffer a brain injury lose their ability to return to work, meaning they may also lose their private health coverage. For the same reason, the cost of purchasing an individual policy can also be out of reach.

**MAINECARE.** Of 300,000 in the MaineCare population in 2004, 3,323 were persons with brain injury. (Muskie School). MaineCare covers people who are financially eligible, with the financial eligibility threshold tied to other criteria (e.g., age or disability). A person with a brain injury could fall into any of the eligibility categories, but persons in need of the long term supports and services are most likely to qualify because they fall into the elderly or disabled categories.

For those persons with brain injury who might be eligible for MaineCare based on their disability, the eligibility criteria and the eligibility determination process both pose barriers to access. First, a person can be caught in a “Catch 22,” needing a medical diagnosis in order to obtain a disability determination and eligibility for MaineCare, but needing eligibility for MaineCare in order to obtain the services necessary to diagnosis and document the brain injury. (Griffin 2008). The application process itself, including compilation of documentation, is also perceived to be too complicated for persons with cognitive impairment. In addition, for those that do successfully submit an application, barriers remain. Persons with brain injury are perceived to have a greater challenge proving their disability, partly because of the challenges associated with diagnosing a brain injury. (Griffin 2009). Persons receiving a monthly Social Security Disability Insurance payment (SSDI) may be ineligible for MaineCare because their income is too high.

**MEDICARE.** The Medicare program provides coverage primarily to those who are elderly or people with a disability: Almost 80% of Maine’s Medicare population is age 65 and older; the remaining 20% are persons qualifying based on their disability. (Kaiser Family Foundation Medicare Beneficiaries). For those under age 65, many of the same eligibility barriers that apply under MaineCare apply to Medicare as well since the disability determination process used for the Medicare is also used for MaineCare. In addition, eligibility for Medicare is not effective until two years after the date of entitlement to SSDI.

“I have medical coverage through my work but I pay \$2,000 a year medical out of pocket.”

Woman with brain injury

“They said if I need any help call this number.... So I called the number and the lady answered the phone. I said, ‘Could you just help me to kind of walk through it?’ ‘Well, it’s pretty self-explanatory,’ that’s what she said.... And I’m thinking, ‘Well, it said on the form that...if I needed any help....’ Sometime I just need to be guided through it.”

Woman with brain injury

“[Our insurer] assigned a case manager that was very helpful throughout this process. However, they released Kym from [her rehabilitation provider] after only 34 visits.”

Mother of 14-year old girl with brain injury

**OTHER PUBLIC.** Another 1.6 percent has other types of public insurance, including TRICARE (formerly known as CHAMPUS) which provides civilian health benefits for active duty military personnel, military retirees, and their dependents, including members of the reserves and national guards. Maine veterans also have access to health services provided through the Veterans Administration’s health care system for service-connected conditions and, for qualifying low-income veterans, for non-service related conditions.

**THE UNINSURED.** Just under 10% of Maine’s population is uninsured. Of those, the vast majority are age 19-64. (Kaiser Family Foundation Health). Given the challenges of accessing private insurance, MaineCare and Medicare, it’s possible that people with brain injury are disproportionately represented among the uninsured.

## COVERED SERVICES

For those people that do have health insurance, access to needed services is still limited by the degree to which those services are covered under their policy. Many people needing prolonged rehabilitative services or lifelong supportive services will find that needed services are not covered under their insurance plan. (Brain Injury Association of America).

**PRIVATE INSURANCE.** It’s difficult to generalize about covered services under a private insurance policy since the scope of covered services, while regulated by the state, is defined by individual contract. As a general matter, however, private health insurance typically does not cover the full range of services needed by persons with brain injury. (Brain Injury Association of America). In Maine, the Maine Bureau of Insurance defines the minimum requirements and breadth of coverage for particular types of insurance contracts. The **TABLE: MINIMUM REQUIREMENTS FOR SELECT TYPES OF PRIVATE INSURANCE CONTRACTS** describes the minimum level of coverage required for Major and Basic Medical plans under Bureau of Insurance rules. While most insurance plans may go significantly beyond these minimum requirements, in general, private health insurance are likely to exclude coverage for “custodial care” (*i.e.*, care the primary purpose of which is to provide assistance with the activities of daily living) and many of the other needed long term supports and services. In addition, covered services can run out when the costs of recovery exceeds the lifetime maximum benefit.

“It’s so frustrating sometimes I just feel like I just want to give up...”

Wife of 43-year old man with brain injury

Minimum Requirements For Select Types of Private Insurance Contracts	
Major Medical	Basic Medical
Must cover hospital services, out-of-hospital physician services, prescriptions.	Must cover hospital services, out-of-hospital physician services.
May cover nursing facility care, etc.	May cover prescriptions, nursing facility care, etc.
Life time maximum benefit may be no less than \$1 million; co-insurance out-of-pocket maximum of \$10,000/year.	Life time maximum benefit may be no less than \$250,000; co-insurance out-of-pocket maximum of \$25,000/year.

03-031 CMR Chapter 755, Section 6(F) & (G).

**MAINECARE.** MaineCare is a safety net program, designed to cover people who cannot afford health insurance, including persons with disabilities and chronic conditions. As a result, the MaineCare program has a more comprehensive array of services than other insurers. In addition to medical services, MaineCare covers three types of specialized brain injury services:

**SPECIALIZED NURSING FACILITY SERVICES.** MaineCare covers intensive rehabilitation nursing facility services for persons with a brain injury.<sup>5</sup> The nursing facility is responsible for providing “goal-oriented, comprehensive, interdisciplinary and coordinated services directed at restoring an individual to the optimal level of physical, cognitive and behavioral functioning.” Services include medical, rehabilitative and social services.

**SPECIALIZED RESIDENTIAL SERVICES.** Residential services with intensive rehabilitative and community support services for persons with acquired brain injury.<sup>6</sup> These services are not available to children.

**SPECIALIZED NEUROREHABILITATIVE SERVICES.** Outpatient neurorehabilitation services are provided under the direction of a neuropsychologist or physician and delivered by a neuropsychologist, physician, occupational therapist, physical therapist, registered nurse, speech-language pathologist, or other qualified staff.<sup>7</sup> Under new rules, expected to be effective in April 2010, a person will be able to access one of three levels of rehabilitation services: intensive rehabilitation; neurobehavioral rehabilitation; and self, home, community and work re-integration. Each individual may use up to 18 hours of any combination of these services, as built into a person centered rehabilitation plan when medically necessary.

While the MaineCare program covers the most services, it still has major gaps, especially with respect to services for persons with brain injury:

**IN HOME AND COMMUNITY DAILY LIVING SERVICES.** MaineCare covers daily living services in a nursing facility and in residential settings. However, MaineCare does not provide in-home personal support services, employment supports or other community-based personal support services that are specialized for brain injury services. In-home personal care services are available under programs, if the person meets the eligibility criteria for those programs. Because those services are designed primarily for other population groups, they do not necessarily meet the needs of persons with brain injury. For example, in home services for older adults or persons with physical disabilities are designed to provide assistance with physical needs; they are inadequate for persons with cognitive and behavioral needs.

**SPECIALIZED RESIDENTIAL SERVICES FOR CHILDREN.** Children do not have access to specialized residential services.

**SERVICE COORDINATION.** Service coordination services are not available unless the individual is eligible under another program (e.g., public guardianship, community support for persons with serious and persistent mental illness, or a case manager in the developmental services system). MaineCare does not cover information and referral services for persons with brain injury.

**PSYCHOSOCIAL REHABILITATION.** MaineCare does not cover psychosocial rehabilitation services for people with brain injury. In some cases, psychosocial rehabilitation services may be accessed by those who are also diagnosed with serious and persistent mental illness or developmental disabilities.

**ENVIRONMENTAL MODIFICATIONS AND ASSISTIVE TECHNOLOGIES.** Those population groups having access to waiver services may have access to funding for environmental

“If you are in the hospital for 30 days all the [MaineCare in-home] services you had going while you were home end. You are signed off, you are discharged, and you have to start over from scratch. And...Goold will not reassess him while he is in the hospital. They want you to be home.... That means I have to stay out of work because I have no one to stay with Pete because Goold hasn’t done the reassessment yet.”

**Wife of 43-year old man with brain injury**

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<sup>5</sup> 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter 2, Section 67.02-5.

<sup>6</sup> 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter 2, Section 97 and Chapter 3, Section 97, Appendix F.

<sup>7</sup> 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter 2, Section 102.

modifications and assistive technology. However, persons with brain injury do not have access to those services.

**FAMILY SUPPORTS.** The MaineCare program does not cover family support services for persons with brain injury. Persons qualifying under other programs may have access to respite services.

A survey of brain injury programs across the nation shows that 23 states offer home and community based waiver services to persons with brain injury. All of these waiver programs offer case management and in home services. Many of these waiver programs also offer behavioral services, environmental adaptations, family and caregiver training, and respite. (Hendrikson & Blume 2008).

“Supervision SHOULD be a covered service....What would have happened when he overdosed on his meds if I hadn’t been here? What would have happened when he refused to take any meds if I hadn’t been right here? What would have happened when he left the burners on the stove on and forgot them if I wasn’t right here?”

Mother of 35-year old man who died from brain tumor

**MEDICARE.** Part A of the Medicare program covers hospital and hospital-related services and Part B covers physician and other medical services. Neither part is designed to provide long term services and supports; Medicare specifically limits the duration of nursing facility and home health services. Like private health insurance, Medicare does not cover “custodial care.”<sup>8</sup> Home health services are limited to nursing care, physical or occupational therapy or speech language pathology, medical social services, home health aides and medical supplies.<sup>9</sup>

Medicare Covered Services and Select Limitations	
Part A	Part B
Inpatient hospital care, skilled nursing facility care, home health care and hospice care.	Physician services, outpatient hospital care, and laboratory services. Includes durable medical services, physical therapy, home health, etc.
Up to 100 days per benefit period in a hospital or skilled nursing facility. Up to 100 home health visits per benefit period.	Up to 35 hours per week of home health services when a person is “home bound.”

In a study of MaineCare members in need of long term services and supports, 73 percent of the 392 are dually eligible for Medicare. (Fralich & Griffin 2010). For persons who are dually eligible, Medicare is the primary insurer with MaineCare providing supplemental coverage for services not covered under Medicare.

## MEDICAL NECESSITY AND REHABILITATIVE SERVICES

Even if a particular service is covered under a policy, insurers will often reserve the right to determine whether or not it is “medically necessary” care for a particular individual. Depending on how that term is defined, it may be difficult for persons with brain injury to establish the medical necessity of rehabilitative services.

As a practical matter, reviewing the medically necessity of treatment decisions makes sense in certain cases, when a provider and patient’s treatment decisions are paid for by a third party. The third party may choose to have a say in determining the medical necessity of that service.

<sup>8</sup> 42 USC §1395y(a)(9).

<sup>9</sup> 42 USC §1395x(m).

However, the criteria used for reviewing treatment decisions can have significant implications for access to services for persons with brain injury. The definition of medical necessity is often predicated on expected improvement resulting from the treatment. This approach works well for many injuries or illnesses. For example, a broken bone usually heals in a predictable and straightforward way; maximum “recovery” can be easily marked by the healing of the bone. However, for persons with brain injury it may be difficult to demonstrate that improvement is expected. Because each brain injury is unique and the characteristics of each individual are unique, the pathway to recovery is much less linear and predictable. Progress can plateau because of fatigue, because the brain is healing, or because the rehabilitative needs of the individual exceed the skills and abilities of the person serving them. At a different point in time, or with different services and treatment, progress may resume.

In addition, if care is “medically necessary” only when there is expected improvement, people may be denied access to services needed to maintain function or prevent its further deterioration. (Gottlich 2003).

In Maine, the approach to medical necessity varies across types of coverage. The MaineCare program applies a definition of medical necessity that best supports a long term or chronic need for services. Under MaineCare, medically necessary services are reasonably necessary medical and remedial services that are:

- Provided in an appropriate setting;
- Recognized as standard medical care, based on national standards for best practices and safe, effective, quality care;
- Required for the diagnosis, prevention and/or treatment of illness, disability, infirmity or impairment and which are necessary to improve, restore or maintain health and well-being....<sup>10</sup>

The private insurance market has a narrower definition of medical necessity. Maine insurance law defines “medically necessary health care” as health care services or products provided for the purpose of preventing, diagnosing or treating an illness, injury or disease or the symptoms of an illness, injury or disease in a manner that is:

- Consistent with generally accepted standards of medical practice;
- Clinically appropriate in terms of type, frequency, extent, site and duration;
- Demonstrated through scientific evidence to be effective in improving health outcomes;
- Representative of “best practices” in the medical profession; and
- Not primarily for the convenience of the patient, physician or other practitioner.<sup>11</sup>

The Medicare program by statute may not pay for “items and services...not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member.”<sup>12</sup> In practice, although the requirement for improvement is limited to the functioning of a “body member,” the Medicare program also often requires that a treatment or service be expected to result in improvement. (Gottlich 2003).

In addition to the definition of medical necessity, utilization review criteria and service eligibility criteria are also used to manage service use. For example, in the MaineCare program, access to certain services is limited based on a diagnosis or other eligibility criteria: access to certain home and community based services are available to people with

“They put us in a one size fits all box and we don’t fit the box....I just live within the confines of the laws that were made and that’s where my unmet needs are.”

Woman with brain injury

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“The neural and cognitive mechanisms of injury and recovery are myriad, complex, and interrelated. Different underlying mechanisms are active at different times during recovery; consequently, specific interventions might have beneficial effects at certain times and not others. Although certain rehabilitative interventions probably should be started immediately, others probably should be delayed to maximize effectiveness and minimize adverse effect.” (NIH 1999).

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<sup>10</sup> 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter I, Section 1.02-4(D).

<sup>11</sup> 24-A MRS §4301-A(10-A).

<sup>12</sup> 42 USC §1395y(a)(1)(A).

developmental disabilities; people with a diagnosis of severe and persistent mental illness have access to psychosocial rehabilitation services; others do not.

It's not known how much of an impact medical necessity and other criteria have on limiting access to services. Its importance as an issue merits further inquiry.

## OTHER SOURCES OF FUNDING

In addition to services that might be covered under a health plan, other privately or publicly financed services may be available. These include:

**WORKERS' COMPENSATION AND LIABILITY INSURANCE.** Depending on the cause of injury, coverage may also be available through workers' compensation or liability insurance. In these cases, the carrier is often liable for long term costs, as well as short term care and treatment. As a result, it's believed these carriers have an incentive to promote full recovery faster, so access to rehabilitative services tends to be more comprehensive in scope. (Brain Injury Association of America).

**VOCATIONAL REHABILITATION SERVICES.** The Division of Vocational Rehabilitation Services (DVR) provides vocational rehabilitation services, including individual counseling and guidance, vocational assessment and supported employment. Supported employment funded under this program ends after two years. DHHS continues supported employment after DVR services end for adults with severe and persistent mental illness and adults with mental retardation or autism. Persons with brain injury do not have access to supported employment when the two years are over.

**INDEPENDENT LIVING SERVICES.** Independent living services include information and referral, individual independent living skills training, peer counseling, and individual and systems advocacy. The program can purchase products and services, including home modifications, hand controls and lifts for vehicles, augmentative communication devices, telecommunication devices for the deaf (TTYs), counseling services, and mobility training. Purchases are capped by a maximum lifetime expenditure of \$5,000 for each eligible individual. Separately, the Bureau of Rehabilitation Services administers Independent Living services for people who are blind or visually impaired. These services include individual counseling, guidance related to adjusting to blindness, use of adaptive technology, adaptive skill training, orientation and mobility instruction, etc.

**CHILD DEVELOPMENT AND SPECIAL EDUCATION SERVICES.** The Department of Education contracts with 16 regional sites to provide early intervention for children from birth to two, and special educational services to children from three to five years-old. Each CDS provides case management and direct instruction to address gross and fine motor skills, cognitive abilities, communication, social and emotional abilities, and adaptive skills. Special education services can include case management, transportation, technological aids, communication services, mental health services, physical restoration services, family services, independent living services, residential living services, vocational training, etc.

**HOUSING SUPPORTS.** Rental assistance is available through public housing programs for those who qualify. Rental assistance comes in the form of tenant based subsidies (e.g., housing vouchers) and subsidized housing units. The Maine State Housing Authority also finances homeless shelters.

**INCOME SUPPORTS.** For people who qualify, income supports are available through Supplemental Security Income (SSI) (totaling \$674 per month for an individual or \$1,011 per month for a couple) or Social Security Disability Insurance (SSDI). (SSDI payments are based on the worker's lifetime average income.) Food assistance, general assistance and other programs may also be available depending on individual eligibility.

BRAIN INJURY SERVICES	COVERAGE FOR BRAIN INJURY SERVICES			
	PRIVATE INSURERS <sup>13</sup>	MEDICARE	MAINECARE	OTHER
<b>Rehabilitation Services</b>				
Nursing Facility	√ L, MN	√ L, MN	√ MN	When applicable, workers' compensation and liability carriers also pay for rehabilitation services.
Residential	-	-	√ MN	
Outpatient	√ L, MN	√ L, MN	√ L, MN	
Home Health	√ L, MN	√ L, MN	√ L, MN	
Psychosocial	-	-	-	
<b>Other Clinical Services</b>				
Mental Health	√ L, MN	√ L, MN	√ L, MN	-
Substance Abuse	√ L, MN	√ L, MN	√ L, MN	-
Neurological Disorders	√ L, MN	√ L, MN	√	-
<b>Daily Living Services</b>				
Nursing Facility	-	-	√	-
Residential	-	-	√	-
In-home Supports	-	-	-	-
Educational Supports	-	-	-	Child Development Services & Special Education
Employment Supports	-	-	-	Vocational Rehabilitation
Community Supports	-	-	-	-
Respite	-	-	-	-
<b>Coordination Services</b>				
Service Coordination	-	-	-	-
Care Management	-	-	-	-
<b>Financial and Material</b>				
Income Supports	-	-	-	Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), food assistance, general assistance
Housing Supports	-	-	-	Rental assistance, independent living
<b>Other</b>				
Information & Assistance	-	-	-	Brain Injury Information Network
Family Supports	-	-	-	-

KEY

- √ = Covered service
- L = Limitations on duration or benefit amount
- MN = Medical Necessity and other qualifying criteria apply

<sup>13</sup> Summary conclusions about covered services under private plans are based on a review of regulations governing major and basic medical health plans, and related materials. It is not based on a survey of actual policies.

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Gaps in MaineCare covered services put Maine significantly behind a number of other states. A 2008 survey of Medicaid-funded brain injury programs across the nation shows that 23 states offer home and community based waiver services to persons with brain injury. All of these waiver programs offer case management and in-home services. Many also offer behavioral services, environmental adaptations, family and caregiver training, and respite. (Hendrikson & Blume 2008).

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## GAPS IN COVERED SERVICES

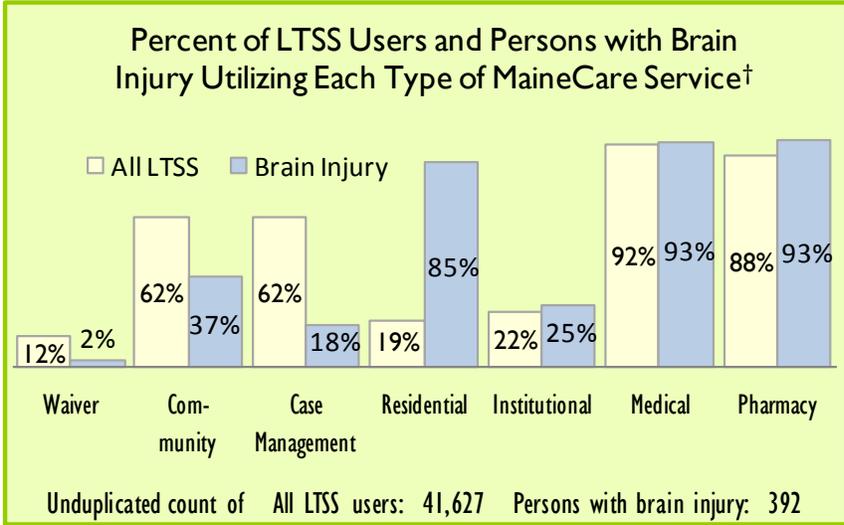
Separately or together, no health insurance plan covers the full range of needed brain injury services. Other sources of funding fill in some of the blanks but eligibility or funding for these can also be limited. The TABLE: COVERAGE FOR BRAIN INJURY SERVICES on page 17 highlights the gaps in covered services.

The lack of adequate financing for needed services has major public policy implications. When a person is unable to access needed rehabilitative services – because it’s not a covered service, or it doesn’t meet the insurer’s definition of medical necessity or because the cost of services exceeds the maximum benefit under the policy – there are long term consequences for recovery and restoration of maximum function. (Ashley et al. 2009). When access to rehabilitation or supportive services could make it possible for a person to hold down a job or stay in school, live in one’s own home, and control impulses and aggression that might otherwise result in criminal behavior, the public policy implications become clearer. The lack of access to needed services means poorer outcomes for the individual and higher costs shifted on to the individual and his or her family caregiver. Or, when those resources are inadequate or exhausted, costs are shifted onto the MaineCare program, homeless shelters, protective services, and other safety nets. In some cases, the costs might be transferred to the criminal justice system, when cognitive and behavioral impairments lead people to activities that result in incarceration.

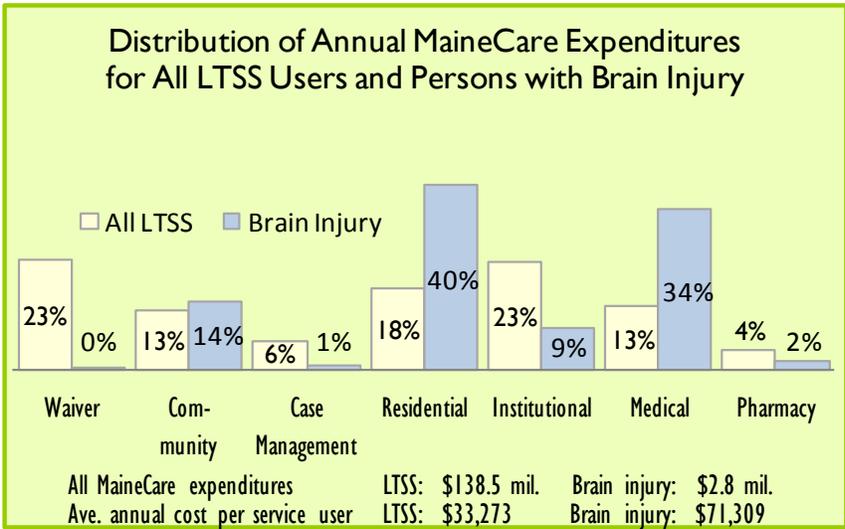
With only the MaineCare program covering long term supportive service, the pool of eligible individuals is very slim. If it’s accurate that two percent of the population has a permanent disability (Thurman 1999), applied to Maine, that would mean over 26,000 people in Maine are living with a permanent disability resulting from a brain injury. Currently, preliminary analysis has identified 392 people in the MaineCare program who have a continuing need for long term supports and services, begging the question of how the needs of the remaining population are being met. The lack of financing for a less intensive array of service options also means that people with brain injury are served in unnecessarily restrictive (and expensive) settings.

A comparison of utilization and expenditures for MaineCare members with a continuing need for long term services and supports shows that adults with brain injury have a very different pattern of utilization and expenditures. In this report, adults with brain injury comprised a small proportion of all long term service users (392 of a total of 41,627). However, as a subset their average annual costs were more than twice as much as that of all users of long term services and supports (\$71,309 compared to \$33,273). Some of this difference can be attributed to higher inpatient medical costs. However, the greatest proportion can be attributed to the cost of residential services. While only 19% of all MaineCare long term service users are served in a residential setting, 85% of MaineCare adults with brain injury are served in that kind of setting (including both specialized brain injury residences and other types of residential services). The cost of residential services accounts for 40% of all expenditures for adults with brain injury.

While these different patterns of utilization and expenditures are driven by the different needs and characteristics of this population group, they are also at least partially explained by the different service options available.



<sup>†</sup> The percent of long term services and supports (LTSS) users adds up to well over 100%, because nearly all LTSS users accessed more than one type of MaineCare service during the year. Muskie School of Public Service (2009).



<sup>†</sup> The percent of expenditures add up to 100% because each MaineCare dollar was attributed to a single service category. Muskie School of Public Service (2009).

NOTE: This presentation of data uses new definitions and formats, representing a new way of aggregating and analyzing long term service users and expenditures in Maine. The results are not easily compared to national data commonly referenced or to other presentations of data that have historically been used in Maine. See APPENDIX: EXPLANATION AND DEFINITIONS FOR EXPENDITURE AND UTILIZATION CHARTS for more on how services and the populations are defined.

A lack of financing for community service options exacerbates a shortage of specialized residential services for persons with brain injury.

## Service Providers In Maine

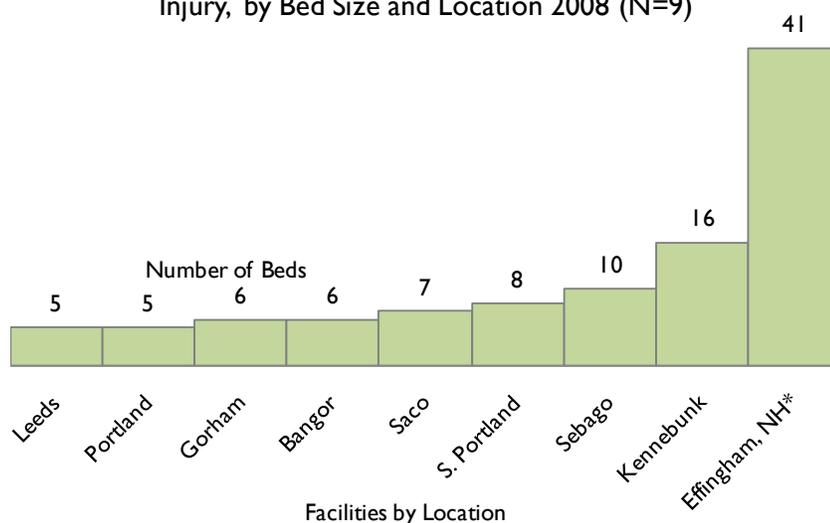
The adequacy of the supply of providers is a function of the number and geographic distribution of specialized service providers as well as the awareness and training for other types of providers. In Maine, access to specialized brain injury service providers is limited geographically. There is evidence that other types of service providers are not adequately trained to identify brain injury or tailor their services to the needs of persons with brain injury.

### SPECIALIZED BRAIN INJURY SERVICE PROVIDERS

There are three types of specialized brain injury service providers: the specialized nursing facility, the specialized residential provider and the neurorehabilitation provider. Geographically, the distribution of Maine's specialized brain injury services is heavily skewed toward southern Maine.

**SPECIALIZED NURSING FACILITY SERVICES.** Maine has two nursing facilities that provide specialized services for persons with brain injury, one in Brewer and one in Kennebunk.

Maine In-State Providers of Specialized Brain Injury Services to Persons with Brain Injury, by Bed Size and Location 2008 (N=9)



A new six bed residential facility in Aroostook County is expected to be in operation by July 2010.

Otherwise, all existing specialized residential facilities serving persons with brain injury are located in the southern half of the state.

There are currently 67 people on the waiting list for residential services.

\*The Lakeview facility in Effingham, New Hampshire located 15 miles from Maine, is considered an in-state provider. *Source:* Maine Department of Health and Human Services, Brain Injury Services. 2008. Plan for Brain Injury Services: 2008-2009. Report to the Legislature.

**SPECIALIZED RESIDENTIAL SERVICES.** There are eight residential service providers who provide intensive rehabilitation services to persons with brain injury. The geographic distribution of these providers is skewed toward the southern half of the state and increasing the supply is controlled: no new specialized residential facilities may be built without an appropriation of funding from the Legislature.<sup>14</sup> In the last legislative session, the Legislature

<sup>14</sup> 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter III, Section 97, Appendix F, Section 3050.

approved a plan to build a new six-bed residential facility in Aroostook County; this facility is scheduled to be in operation by July 2010.

**NEUROREHABILITATION PROVIDERS.** There are eight neurorehabilitation providers distributed across the state and just over the border in New Hampshire: Bangor, Brewer, Caribou, Fairfield, Kennebunk, Lewiston, Portland, and Effingham, New Hampshire. People who do not have easy access to specialized neurorehabilitation services may access their local physician or other providers to obtain needed services.

Public testimony and prior studies have identified the geographic distribution of specialized providers as a barrier to access for people in rural areas. Some forego ongoing treatment because travel time is too great. For those in need of residential services, travel can be even greater, with a significant number of people with brain injury in out-of-state placements.

Maine has documented that an inadequate array of service options has resulted in avoidable out-of-state placements, waiting lists for services, and bottlenecks for people who could live in more integrated environments but do not have the supports to do so. In a 2007 two-part study, 81 of the 103 individuals then living in Maine's specialized residential settings were assessed to determine their readiness for a more independent setting. According to the study, a minimum of 16, and as many as 29, people were ready to move to a less restrictive, less supervised level of care. (Maine DHHS 2008a). However, those supportive housing services were not available.

Another study looking at out-of-state placements identified a similar mismatch in service options and service need. Under the Medicaid program, DHHS is allowed to pay higher reimbursement rates for out-of-state placements than they can for in-state services. As a result, those people whose needs cannot be met at in-state rates must go out of state to obtain services. In 2007, DHHS' care management contractor conducted case reviews for 45 Maine residents being served in out-of-state placements. (Schaller Anderson 2007). Their findings showed that:

- 90% of the people served out of state had traumatic brain injuries.
- The majority are appropriate for community placement.
- No evidence was found that complex medical needs alone were the reason for out-of-state placement.

Instead the study showed that behavioral issues associated with complex medical needs, which cannot be safely managed at in-state reimbursement rates, are the primary reason people are served out of state. But for the shortage of in-state options and the restriction on in-state reimbursement rates, the same level of service (for possibly less cost) cannot be obtained closer to home.

DHHS reports that, because transitions out of residential facilities are less than 5% per year, few openings are available to support transitions from higher levels of care, foreclosing options for those ready for discharge from acute care and institutional settings. DHHS currently has a list of 67 people waiting to access specialized residential services for people with brain injury. Those who are served in unnecessarily restrictive settings have less opportunity to pursue independence and a life in the community. And those on the waiting list for residential services are receiving alternative care that may mean slower or less successful recovery.

## PROVIDER AWARENESS AND TRAINING

Unidentified TBI is a major cause of social failure. (Gordon 2008). Failure to recognize the impact of a brain injury can mean certain behaviors are interpreted as intentionally disruptive when they are actually unintentional byproducts of a brain injury. For example, in school,

"I refuse to have him at the age of 34 go into a nursing home.... I was just hoping there would be something out there that would be appropriate for him.... "

### **Mother of 34-year old man with brain injury**

"[This provider] was the only facility that had experience with TBI, blindness and young children....We began traveling an hour and 15 minutes one way, three days a week."

### **Mother of 14-year old girl with brain injury**

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Unidentified TBI is a major cause of social failure. (Gordon 2008).

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“After several years of watching him suffer from frustration, drinking and drugs, my wife and I began to search for a cause and a solution.... My wife attended a symposium.... She called to inform me that it was our son’s brain injury not mental illness that is his problem! He had every symptom listed on their handouts.”

Father of 32-year old man with traumatic brain injury

“The doctor says...‘I think you’re schizophrenic....’ And then they give me this big label which I carried for a long time. Until a short time ago.... I had another doctor who said ‘You know, I don’t think you’ve been treated for what you should be treated for.’”

Woman with brain injury

children with brain injury may exhibit hyperactivity, distractibility, impulsivity, and temper tantrums. (Mayfield 2005). Older children are more likely to exhibit temper outbursts or inappropriate sexual behavior, and are more likely to drop out of school. Because brain injury is often an “invisible” disability, the need for accommodation is often unrecognized and the individual may be blamed for behaviors that are outside their control. For example, one study showed several stages in the evolution of a family’s reactions to a child that has sustained a traumatic brain injury. When a child fails to recover at the hoped for pace or to the expected level of functioning, the family’s perception of the child deteriorates over time; eventually, the child is viewed as unmotivated, self-centered, irresponsible, irritable, lazy, and difficult. (Mayfield 2005).

In Maine, under-identification in schools may be a significant problem. National estimates indicate that only 11 percent of children with traumatic brain injury receive special education services, meaning that up to 89 percent may be unidentified or misidentified. Of children receiving special education services, only 81 were identified as having a traumatic brain injury in 2007 (Department of Education), significantly less than the expected number of children with a permanent disability. Given these numbers, it’s possible that the majority of children with brain injury are misidentified and inadequately served, possibly blamed for their behaviors rather than helped.

For adults, the failure to recognize the impact of a brain injury may be a contributing factor to the disproportionate number of people with brain injury in jails and prisons. Studies have estimated as much as 25 to 87 percent of the jail and prison population have a history of traumatic brain injury, making the prevalence of TBI for incarcerated adults as high as 10 times that of the general population. (Wald et al. n.d.). In Maine, these findings are consistent with the observation of DHHS staff. (Maine Acquired Brain Injury Advisory Council 2009b). In many cases the brain injury precedes the start of criminal activity. (Gordon 2008). There is evidence to suggest that the higher rate of TBI among the jail and prison population is a consequence of the brain injury. For example, a brain injury can result in impulse control and aggressive behavior. These functional impairments can produce the behaviors that result in imprisonment: among male prisoners, a history of TBI is strongly associated with perpetrating domestic violence; in addition, people with TBI are more likely to experience problems with alcohol or other substance abuse problems. (Wald et al. n.d.). There is anecdotal evidence that in Maine at least some of the people sentenced to prison are there because of cognitive or behavioral issues resulting from their brain injury. For example, a repeat offender who is unable to control certain behaviors or retain earlier admonishments may end up in prison when rehabilitative services would be the optimal response.

The failure to identify brain injury can also mean that services are not as effective as they might otherwise be. The presence of a brain injury can have an impact on treatment strategies. For example, treatment of mental illness may need to be modified for persons with brain injury. In some cases, diagnosis of a mental illness can be problematic when the brain injury and related disabilities interfere with a person’s ability to communicate. (McAllister 2005). The effectiveness and side effects of medications for mental illness are different for people with brain injury; certain medications can worsen neurological symptoms, including tremors, cognition, etc. (McAllister 2005). In Maine, this issue is significant. In a 2004 analysis of MaineCare claims data, almost 80% of the adults with a brain injury had a co-occurring mental health diagnosis. For children, a dual mental diagnosis was found to be less common but, at over 46 percent, still significant.

Similarly, the usual strategies for treating a substance abuse problem are complicated by cognitive and behavioral impairments resulting from the brain injury. For example, a person with a brain injury might have a memory problem that prevents compliance with a prescribed regimen or retention from one counseling session to another. The treatment provider needs to understand the impact of the brain injury to develop a treatment plan to accommodate the individual’s needs.

The training of professionals is considered a major issue in Maine: “A lack of sufficient knowledge, training and skill among Maine’s healthcare, mental health and education professionals” was identified by Maine’s Acquired Brain Injury Advisory Council as a leading issue in its 2007-2008 report. (Maine Acquired Brain Injury Advisory Council 2009a). The misidentification of brain injury and the lack of skills for responding to behavioral needs were among several issues identified. These findings are consistent with the state’s earlier needs assessment, stakeholder forums and public testimony.

# Brain Injury and State Government

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Although Maine's investment has been modest, it has been successful building infrastructure to support brain injury services and policymaking in Maine. The issues raised by brain injury, however, far exceed the sphere of control of Maine's sole staff person dedicated to brain injury policy, requiring investment, collaboration and coordination both within the lead agency, the Department of Health and Human Services and across departments.

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Brain injury reaches across multiple domains and has implications for a number of state government programs that have a role in preventing injuries or better serving those that are injured. This section reviews the capacity of state government to effect change in policy and practice as it relates to:

- Improving awareness of brain injury, to improve the identification and service delivery;
- Improving access to needed services; and
- Improving prevention.

Maine's investment in brain injury at the state policymaking level is modest, but it has made significant progress since assigning a dedicated staff position to brain injury policy. The issues raised by brain injury, however, far exceed the sphere of control of this single staff person, requiring collaboration and coordination both within the lead agency, the Department of Health and Human Services and across departments.

## Overview of Policymaking Roles

The Maine Department of Health and Human Services has been designated by the Legislature as the lead agency for serving people with brain injury since 2005,<sup>15</sup> although dedicated brain injury staffing is new to DHHS. Brain Injury Services was formed only in 2007, when it was given responsibility for coordinating policymaking for brain injury services. (See [CHART: SELECT DHHS OFFICES AND FUNCTIONS IMPACTING PERSONS WITH BRAIN INJURY](#) for a representation of Brain Injury Services relative to other offices and programs within DHHS.) Dedicated resources are modest: Brain Injury Services is staffed by one person, its program manager. Its budget is sufficient to cover the program manager's salary and office expenses. Brain Injury Services has supplemented those resources with a three-year grant from HRSA, of \$100,000 per year. (This grant will end in March 2011.) These funds have been used to build data and analytic capacity within the Department.

Brain Injury Services policymaking is guided by an active and legislatively created advisory committee, the Acquired Brain Injury Advisory Council. The Advisory Council provides independent oversight and advice to DHHS on matters relating to services for people with brain injury.<sup>16</sup> The Brain Injury Advisory Council is a representative body comprising people having a brain injury, family members, advocates, providers, and state agency representatives. The Advisory Council also conducts public hearings, taking testimony from those affected by brain injury; and public forums focusing on specific topics. In the last two years, its forums have focused on veterans, children with brain injury, domestic violence, and strategic planning.

Housed within the Office of Adults with Cognitive and Physical Disabilities, the focus of Brain Injury Services is primarily on adults with brain injury. No office within DHHS is assigned responsibility for policymaking for children's brain injury services. (In general, DHHS does not

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<sup>15</sup> 22 MRS §3089.

<sup>16</sup> 34-B MRS §19001.

have a policymaking home for children not meeting the eligibility criteria for behavioral health services. (Muskie School 2009.)

Also in DHHS, multiple other offices and units have policymaking roles that directly or indirectly impact brain injury. Some of these offices have roles that support prevention of brain injury and others have roles that could influence provider practice when it comes to improving the identification of persons with brain injury, improving access to services, and

Without a budget or other staff resources, the office of Brain Injury Services does not have access to data and analytic capacity, except as funded through its HRSA or under other initiatives. Identified as a valuable resource is the standardized Brain Injury Assessment Tool (BIAT) submitted to DHHS by rehabilitation providers for each person seeking services. In paper format and without the resources to collect or translate in electronic format, the data are untapped and largely inaccessible.

Also in DHHS, multiple other offices and units have policymaking roles that directly or indirectly impact brain injury. Some of these offices have roles that support prevention of brain injury and others have roles that could influence provider practice when it comes to improving the identification of persons with brain injury, improving access to services, and improving treatment and services for people with brain injury. See [ORGANIZATIONAL CHART: SELECT DHHS OFFICES AND FUNCTIONS IMPACTING PERSONS WITH BRAIN INJURY](#) and the [TABLE: ROLES OF SELECT OFFICES WITHIN THE MAINE DEPARTMENT OF HEALTH AND HUMAN SERVICES](#) for more information about these offices.

DHHS operates within the context of multiple other departments also having roles that touch the lives of persons with brain injury. See [ORGANIZATIONAL CHART: SELECT DEPARTMENTS AND AGENCIES WITHIN THE MAINE STATE GOVERNMENT](#) and the [TABLE: ROLES OF SELECT DEPARTMENTS IMPACTING PERSONS WITH BRAIN INJURY](#) for more information about these agencies. Together these offices and departments comprise those public programs most directly impacting brain injury services. DHHS has developed a state action plan for brain injury services. (Maine DHHS 2008b).

## Identifying People with Brain Injury

Better identification would improve the chances of appropriate treatment and better outcomes. Several DHHS offices have the authority to influence provider practice. The Office of MaineCare Services sets reimbursement policy for all MaineCare service providers and the Division of Licensing and Regulatory Services sets regulatory policy for all licensed providers. Program offices also have the ability to influence the practice of frontline service providers by shaping policy for mental health, substance abuse and other services. In addition, because brain injury can be caused by domestic violence, including child abuse, protective services programs should be alert to the possibility that their clients may have suffered a brain injury.

The Maine CDC also plays a role in shaping the health workforce in Maine and could have a voice in influencing medical education on brain injury and recent advances in rehabilitation and prognosis.

External to DHHS, several state agencies oversee programs and services that could play an important role in identifying people with brain injury including schools, vocational rehabilitation providers, homeless shelters, jails and prisons.

Currently, there is no systematic effort to improve provider identification for persons with brain injury. DHHS has not systematically identified those with co-occurring conditions, including mental health or substance abuse conditions. Without that information, there is no basis for assessing the value that might be gained from a concerted effort to coordinate or

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“Social consequences of mild, moderate, and severe TBI are many and serious, including increased risk of suicide, divorce, chronic unemployment, economic strain, and substance abuse. These consequences are tragic to individuals and families and place additional burdens on social service agencies, law enforcement, and courts.” (NIH 1999).

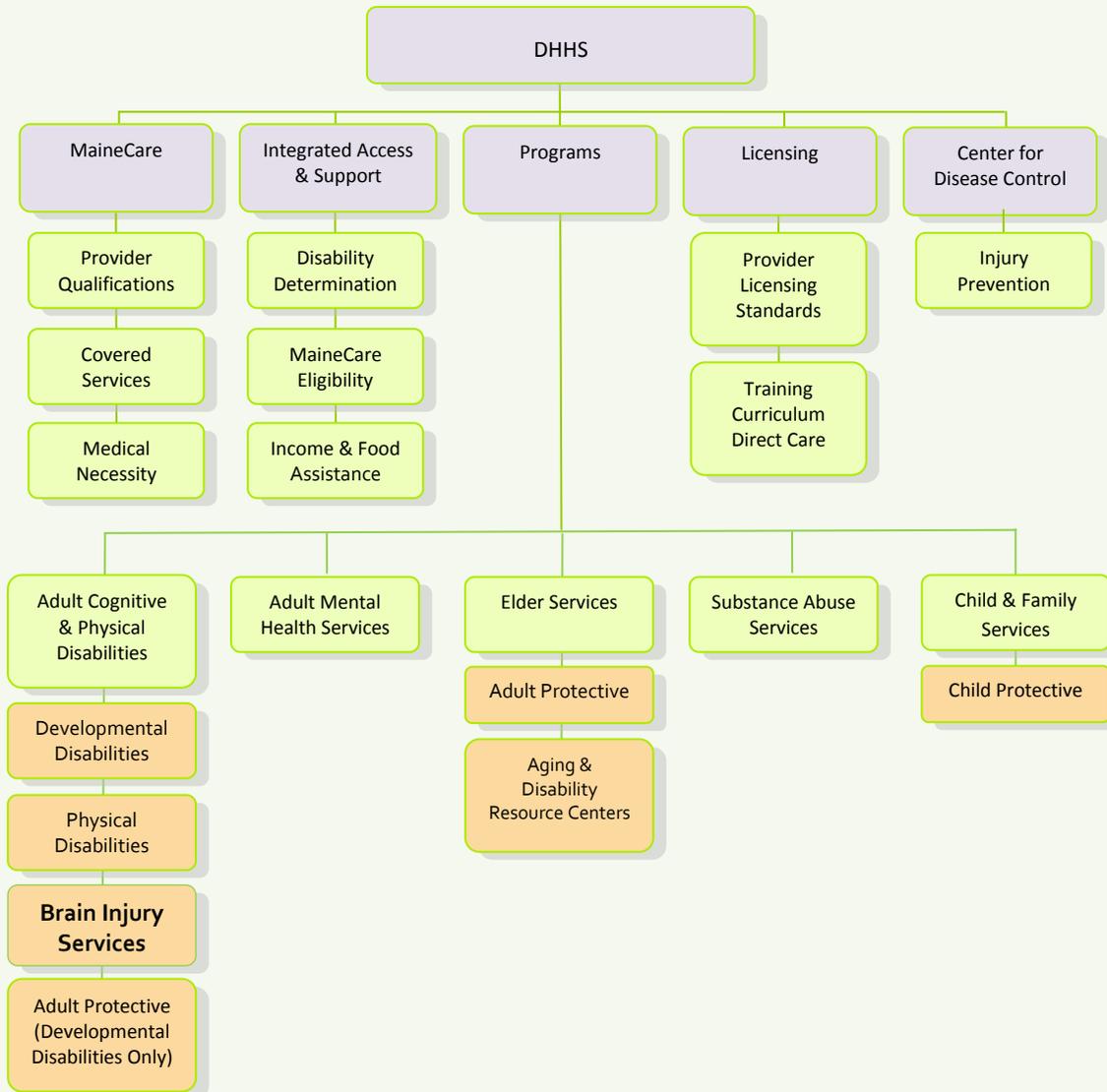
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“In children, surveillance needs to persist over many years, as some problems do not emerge immediately. Unlike adults, children may “grow into” the injury – as they age, their injured brains become unequal to the more-sophisticated learning challenges of later childhood, adolescence and adulthood.” (Gordon 2008).

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## SELECT DHHS OFFICES AND FUNCTIONS IMPACTING PERSONS WITH BRAIN INJURY\*

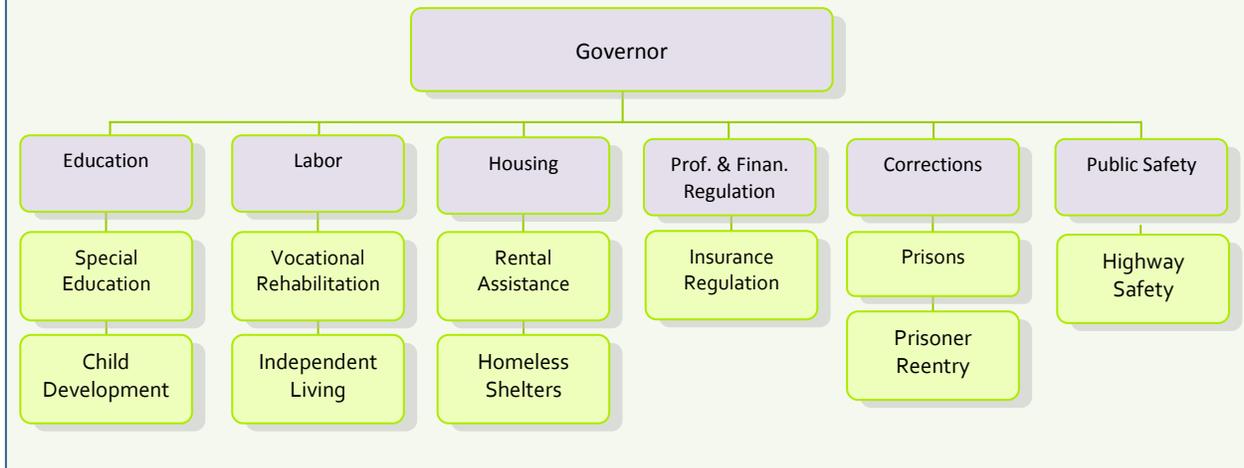


\* This chart is not intended to represent the complete range of offices and programs within DHHS or their place within the organizational structure.

## Roles of Select DHHS Offices Impacting Persons with Brain Injury

Office	Roles
Maine Center for Disease Control and Prevention (Maine CDC)	The Maine Center for Disease Control and Prevention (Maine CDC), under the Maine Injury Prevention Program, is the lead state agency for preventing injury, including brain injury.
Office of MaineCare Services	OMS sets policy for MaineCare services. OMS defines the nature and quality of services, eligibility for services, required provider qualifications in order to be reimbursed for providing services, reimbursement rates, etc.
Office of Integrated Access and Supports	OIAS is the agency responsible for determining eligibility for MaineCare. OIAS is also responsible for the disability determination process which is required for determining eligibility for the Social Security and Supplemental Security Income (SSI) program, as well as some eligibility categories under MaineCare. OIAS also administers food and income assistance programs.
Division of Licensing and Regulatory Services	DLRS sets regulatory policy for the majority of Maine’s licensed health or social service agencies.
Child & Family Services	OCFS administers programs serving children with behavioral health needs and children with developmental disabilities. OCFS administers the Child Protective Services program.
Adult Mental Health Services	AMHS administers programs serving adults with serious and persistent mental illness, including community-based case management and psychosocial rehabilitation, residential programs and hospital-based services.
Adults with Cognitive & Physical Disability Services	Brain Injury Services is housed with OACPDS. OACPDS also houses programs serving adults with developmental disabilities and adults with physical disabilities. OACPDS administers an Adult Protective Services program for persons with developmental disabilities.
Office of Elder Services	OES administers programs serving elders and adults with disabilities. These programs include home and community-based services, nursing facility and residential services, protective services and community services including Aging and Disability Resource Centers.
Office of Substance Abuse	OSA administers programs serving persons with addiction disorders

## SELECT AGENCIES AND FUNCTIONS IMPACTING PERSONS WITH BRAIN INJURY



## Roles of Select Departments Impacting Persons with Brain Injury

Office	Roles
Department of Education.	The Department of Education is the State Educational Agency responsible for carrying out Maine's responsibilities under the Individuals with Disabilities Education Act (IDEA). IDEA governs ChildFind, the process of identifying children with disabilities; early intervention services; and special education.
Department of Labor	The Department of Labor houses the Bureau of Rehabilitation Services which administers the vocational rehabilitation and independent living programs (including an independent living program for persons with are blind or visually impaired).
Maine State Housing Authority	MSHA plays a leading role in addressing homelessness, partnering with DHHS to address mental health, substance abuse, and other service needs of persons who are homeless. MSHA, along with local public housing authorities, also administers rental assistance programs and funds the construction of subsidized housing, including subsidized housing for persons with disabilities.
Department of Professional and Financial Regulation	The Bureau of Insurance, within DPFR, is responsible for regulating insurance companies including health insurers.
Department of Corrections	The Department of Corrections oversees Maine's prisons and prisoners, and the services that are provided to inmates.
Department of Public Safety	The Department of Public Safety administers federal grants to improve highway safety for teen and adult drivers, passengers, including child passengers, pedestrians and cyclists.

possibly integrate services for those with highly complex needs. In contrast, under a grant from the Substance Abuse and Mental Health Services Administration (SAMHSA), Maine has made significant progress in coordinating policy and practice for persons with co-occurring mental health and substance abuse conditions. Similarly, Maine’s jails recently assessed the number of inmates with mental illness. A comparable effort for people with brain injury could produce valuable data for future policymaking discussions.

## Improving Access to Services and Treatment

A number of offices within DHHS and a number of other state agencies can influence access to needed services.

**SERVICES COVERED UNDER PRIVATE INSURANCE.** While the Maine Bureau of Insurance regulates insurance companies, it does not have authority to change the definition of “medically necessary health care,” which is written into statute.<sup>17</sup> Nor can the Bureau of Insurance mandate that certain benefits be covered under a health plan; the Legislature has defined in statute a process for enacting mandated benefits.<sup>18</sup> However, the Bureau of Insurance would have an important role in investigating the issue in order to assess the degree to which private insurance adequately meets the needs of persons with brain injury and to understand better the implications for public programs.

**COVERED SERVICES UNDER MAINECARE.** Over the years, DHHS has explored the feasibility of pursuing a Medicaid home and community based waiver for brain injury services to provide a more graduated array of service options. Constraints imposed by federal law have made this process challenging. However, federal law has been expanded to offer new options. Brain Injury Services is currently working with the Office of MaineCare Services to determine the feasibility of these other options for expanding home and community based services.

**THE ELIGIBILITY DETERMINATION PROCESS.** More than one population has an identified need for assistance with the MaineCare eligibility determination process, and Maine’s Aging and Disability Resource Centers (ADRCs) have been identified as a potential source for that assistance. (Griffin 2009). The ADRCs are funded under grants from the Administration on Aging; their role is to facilitate access to long term supports and services. Maine’s ADRCs have been developed as complementary functions of Maine’s five local area agencies on aging; ADRCs are not limited to older adults and serve people of any type of disability. The Office of Elder Services administers the Administration on Aging grants funding the ADRCs.

**PROVIDER AVAILABILITY.** The demand for services, often driven by the financing for services, is a major driver of provider availability. Currently, Maine’s geographic distribution of providers is skewed to the south and there is a waiting list for specialized residential services. The current MaineCare policy which limits the expansion of residential providers may be an appropriate check on the system’s current dependence on residential services. With a different mix of covered services, including in home services, the shortage of residential services in the north may be less of an issue. However, regional access to outpatient neurorehabilitation services will remain an issue. MaineCare and licensing policy can facilitate the use of telemedicine, which could be a low cost strategy for bringing needed expertise into rural areas.

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Improving access to services and treatment will require the cooperation and participation of several offices within DHHS and a number of state agencies external to the Department.

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<sup>17</sup> 24-A MRS §4301-A(10-A).

<sup>18</sup> 24-A MRS §2752.

## Prevention

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The Maine CDC addresses prevention of brain injury on multiple fronts and in collaboration with a number of partners.

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The Maine Injury Prevention Program within the Maine Center for Disease Control and Prevention's (Maine CDC) is the lead state agency for preventing injury, including brain injury. Because of the multiple ways in which brain injury can occur, Maine CDC works with multiple partners both within DHHS and without.

**FALLS.** Falls are the leading cause of traumatic brain injury and are highest among children ages 0 to 4 and adults ages 75 years and older. (Langlois et al. 2006). In Maine, 7 of 10 deaths due to unintentional falls (73.8%) and one of every 10 unintentional fall related hospital discharge (11.8%) involved a traumatic brain injury. (Maine CDC 2009). Maine CDC and the Office of Elder Services are working with a range of community partners to implement a fall prevention program for older adults.

**MOTOR VEHICLE ACCIDENTS.** There were 179 deaths and 877 hospital discharges related to unintentional motor vehicle traffic incidents among Maine residents in 2007. People aged 15 to 24 and 75 to 84 were at significantly higher risk than most other age groups for unintentional motor vehicle traffic hospital discharges. (Maine CDC 2009). The Department of Public Safety has lead responsibility for highway safety. The Maine Legislature has recently passed law regulating the use of hand-held devices by new drivers, distracted drivers, helmet use, pedestrian safety, and other highway safety initiatives.

**DOMESTIC VIOLENCE.** At least 85% of domestic violence victims are women, mostly abused by male partners. The head is a major target of domestic violence assaults. Many victims of domestic violence suffer repetitive injuries. Traumatic brain symptoms also overlap with crisis reactions. For example, domestic violence victims with traumatic brain injury report memory loss, lack of concentration, inability to process information and mental fatigue. (Vaughn & Parry 2004). The Maine Coalition to End Domestic Violence has been participating in a pilot study examining the prevalence and functional deficits among domestic violence victims. (Pearson et al.).

**SPORTS INJURIES.** The CDC estimates that between 1.6 and 3.8 million sports and recreation related concussions occur in the United States each year, most of which are not treated in a hospital or emergency department. (U.S. CDC). For children and youth ages 5 to 18, bicycling, football, basketball, playground activities, and soccer are the five leading sports and recreational activities accounting for concussions. Football accounts for 60% of concussions occurring in high school sports. (Brain Injury Association of America). Through a grant initiative led by Colby College, the Maine Concussion Initiative (MCMCI) is working to enhance the health and safety of Maine high school athletes by educating medical practitioners and school administrators about the dangers of traumatic brain injury and the importance of consistent concussion management.

**ABUSIVE HEAD TRAUMA (OR SHAKEN BABY SYNDROME).** A baby has weak neck muscles and a large, heavy head; shaking causes the brain to bounce back and forth inside the skull, causing bruising, bleeding and swelling and tearing of brain tissue. The result can be permanent severe damage or death. Most children injured this way are under a year old. (Kidshealth). The resulting injuries can include blindness, hearing loss, seizures, intellectual disabilities, cerebral palsy, and other challenges. Thirty-nine Maine residents under the age of two were hospitalized with AHT between 2000 and 2008. The most common perpetrator was the victim's father, stepfather or the mother's boyfriend. (Maine CDC 2009).

Maine's Abusive Head Trauma Prevention Workgroup has been working with and training hospital staff and community based agencies on the shaken baby prevention program that offers new 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.

**STROKES AND CEREBRAL AND VASCULAR EVENTS.** A stroke interrupts the flow of blood to the brain, depriving the brain of oxygen and causing permanent brain damage. Each year, about 795,000 people suffer a stroke in the United States; for 600,000 people these are their first attacks. (Stoke Center). Stroke is the leading cause of serious long term disability in the United States. A cerebral aneurysm is a weak or thin spot on a blood vessel in the brain that balloons out and fills with blood. A ruptured or leaking cerebral aneurysm can damage brain tissue. Each year, about 30,000 people in the United States suffer a ruptured cerebral aneurysm; about half of those surviving a ruptured cerebral aneurysm will suffer permanent neurological deficit. (Brain Aneurysm Resources). Through its Healthy Maine initiatives, Maine CDC is working to reduce several of the major risk factors contributing to these and other cerebral and vascular events, including high blood pressure, heart disease, diabetes, high cholesterol and smoking.

**SUICIDES.** In Maine, there were 188 suicide deaths and 718 self-inflicted injury hospital discharges among Maine residents in 2007. Every week, on average, there were four suicide deaths and 14 self-inflicted injury hospital discharges. Most (83.8%) of the firearm related deaths were suicides; 14.3% were homicides. (Maine CDC 2009). The Maine Youth Suicide Prevention Program enhances the capacity of 11 schools and service providers to provide a culturally competent, sustainable system of prevention, early identification, intervention and referral for families and youth in selected areas of the state.

# Conclusions

This document reviews existing Maine policy and programs to evaluate how well they meet the needs of persons with brain injury. Based on this analysis, the following findings are made:

“Though admittedly I still have deficits, in the darkest times of despair, I knew I was lucky to be alive, and I knew I would get better.”

57-year old man with brain injury

- People with brain injury have uneven access to financing for needed services. No health plan covers the full range of needed services.
- It’s possible that the MaineCare program is bearing a greater burden than necessary because private insurers and the Medicare program limit access to needed rehabilitative services.
- The MaineCare program offers a limited array of needed services for persons with brain injury. Notable gaps include in-home services and supports, psychosocial rehabilitation, and service coordination services.
- Maine’s supply of specialized service providers is unevenly distributed geographically and service.
- Providers in general often do not have the training and awareness they need to identify and effectively treat people with brain injury.
- Unidentified and untreated brain injury has cost implications for schools, the adult mental health system, the substance abuse treatment system, the criminal justice system, and other publicly administered programs.
- The under identification of brain injury perpetuates the lack of investment in brain injury services; without supporting data, its relative importance is obscured.
- Addressing the full range of issues raised by brain injury requires collaboration across multiple state agencies, an investment in gathering better data, and tools and mechanisms for improving awareness and treatment of brain injury.

“He talks in a whisper now and we’re even finding some original thoughts that are coming out. We know that cognitively there is a lot going on that he cannot express, but more and more he is doing that.”

Mother of 43-year old man with brain injury

Based on the analysis in this assessment, the following strategies and policy options are offered for consideration.

## CLOSING THE INFORMATION GAP

In a number of areas this assessment only identifies potential need without data to define the dimensions of that need. Better data is needed to understand:

- The prevalence of brain injury in the mental health system, among those receiving substance abuse services or protective services, in schools, homeless and domestic violence shelters, and in prisons and jails.
- The prevalence of those with complex, co-occurring conditions, including those having a need for mental health services or substance abuse treatment.

- The hidden costs of untreated brain injury for the mental health and substance abuse systems, for safety net providers (*e.g.*, homeless shelters), and the criminal justice system.
- Whether and to what degree the cost of care is shifted from private insurers onto the MaineCare program.
- The number of people currently cared for by aging parents and the expected demand for services when those parents are no longer able to provide care.

“Although Kym still has significant memory loss, she has made remarkable improvements! ...She is now reading at a first grade level, something we were told would be impossible.”

Mother of 14-year old girl with brain injury

## CLOSING THE AWARENESS GAP

There is evidence to suggest that brain injury is under-identified in Maine’s schools, jails and prisons, and the mental health and substance abuse service systems. If brain injury is under-identified, services are likely to be less effective and resources misallocated. Maine has an opportunity to improve the identification of brain injury. Strategies might include:

- Developing and disseminating tools and educational resources to enable screening for brain injury.
- Coordinating policy and provider education across programs to ensure that, once identified, there is an appropriate system response: services are modified to accommodate the person’s brain injury; the person is referred to needed brain injury services; or services are coordinated or integrated across multiple providers.

This strategy might be piloted in certain areas, including protective services, or the mental health and substance abuse services systems.

## CLOSING THE SERVICE GAP

An inadequate array of service options and uneven access to needed services mean that resources are misallocated and costs are shifted. To improve access to services, the following strategies might be considered:

- Evaluate the costs and benefits of mandating coverage for rehabilitation services and modifying the definition of “medical necessity” under private health plans.
- Expand the specialized brain injury services covered under MaineCare to develop a more graduated array of service options across settings and levels of care, evaluate the impact of expanded service options on demand for existing services and providers, and develop strategies for promoting the appropriate supply of service providers.
- Expand the use of the Aging and Disability Resource Centers to facilitate the MaineCare eligibility determination process.
- Explore regulatory and financial barriers to telemedicine and other web-based strategies for extending neurorehabilitative expertise to rural areas.

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## APPENDIX: Explanation and Definitions for Expenditure and Utilization Charts

### DEFINITIONS AND DATA

The utilization and expenditures tables on page 19 are taken from data analysis conducted for *A Cross System Profile of Maine's Long Term Support System: A New View of Maine's Long Term Services and Supports and the People that Use Them* (Muskie 2009). or the unduplicated total of long term service and support users.

*Data Source:* MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data.

This presentation of data uses new definitions and formats, representing a new way of aggregating and analyzing long term service users and expenditures in Maine. The results are not easily compared to national data commonly referenced or to other presentations of data that have historically been used in Maine.

### HIGH LEVEL DESCRIPTION OF POPULATION DEFINITIONS<sup>19</sup>

Adults (Age 18+)	
With Mental Illness	Members receiving mental health case management services (§13), or who are in a residential care facility for people with mental illness (§97), or who have two or more inpatient hospitalizations during the year (§46).
Older Adults and Adults with Disabilities	Members residing in nursing homes (§67), residential care (§97) or housing with assisted living services (§6). Members receiving services under the waiver for older adults and adults with disabilities (§19) or private duty nursing (§96) or day health services (§26).
With Physical Disabilities who Self-Direct	Members receiving consumer directed waiver services (§22) or state plan consumer directed personal assistance services (§12).
With Brain Injuries	Use of rehabilitative services (§102); specialized nursing facilities for persons with brain injury (§67); individuals residing in residential care with diagnoses of brain injury; <sup>20</sup> members with inpatient hospitalization over 30 days or eight or more emergency department visits during the year with a brain injury diagnosis.
With Developmental Disabilities	Members in ICFs-MR (§50) or accessed either waiver serving person with mental retardation or autism (§21 & §29); who have MR case management (§13) or MR residential care facilities (§97) or residing in a nursing facility (§67) with an MR diagnosis.
Children (Age 0-17)	
With Developmental Disabilities	Children receiving day habilitation services (§24) services or with a mental retardation diagnosis.
With Mental Disorders	Children using specific mental disorder services including targeted case management (§13), residential treatment (§97), behavioral health services (§65), and 2 or more inpatient psychiatric stays (§46) or crisis stabilization unit stays in the year.
With Physical Disabilities	Children receiving private duty nursing (§96).

<sup>19</sup> Citations are to sections within 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II.

<sup>20</sup> Brain injury diagnosis listing was developed by the Maine Center for Disease Control and Brain Injury Service Unit. Listing is available on request.

## MAINECARE CLAIMS DATA – SERVICE CATEGORY DEFINITIONS<sup>21</sup>

Service Category	Services Included
Waiver	<p>Maine’s four home and community benefits waivers:</p> <ul style="list-style-type: none"> <li>▪ Comprehensive waiver for adults with mental retardation (§21)</li> <li>▪ Community support waiver for adults with mental retardation (§29)</li> <li>▪ Physically disabled waiver for adults who choose to self-direct (§22)</li> <li>▪ Older adults &amp; adults with disabilities waiver (§19)</li> </ul> <p>Each population group had some claims for services provided through the four waivers. The services grouped under the waiver can include services under the Daily Living category or Treatment category. In the case of the waiver for older adults and adults with disabilities, service coordination is also grouped here.</p>
Community	<p>All in-home support services, population-specific outpatient services, and other services offered in the community that are not waiver or case management services including:</p> <ul style="list-style-type: none"> <li>▪ Daily living supports, skills development, day support services (§17)</li> <li>▪ Assertive community treatment, outpatient psychiatric services, crisis intervention, medication management (§17)</li> <li>▪ Private duty nursing and personal care services (§96), consumer-directed attendant services (§12), day health services (§26)</li> <li>▪ Day habilitation (24), school-based rehabilitation (§41)</li> <li>▪ Rehabilitation for persons with brain injury (§102)</li> <li>▪ Substance abuse treatment services</li> <li>▪ Other services offered in the community</li> </ul> <p>The type and mix of community services varies by population group.</p>
Case Management	<p>Case management is provided by various agencies and billed under certain programs. Case Management includes intensive case management and community integration services (§17), and targeted case management (§13). Case management for the waiver serving older adults and adults with disabilities waiver is included as a waiver cost.</p>
Residential Services	<p>Residential services (§97) for specific population groups including persons with mental illness, mental retardation, medical and remedial needs, and substance abuse disorders. Members in each population group had claims under different types of residential services. Adult family care (§2) and assisted living (§6) are also included here.</p>
Institutional Services	<p>Institutional services are provided by nursing facilities, intermediate care facilities for person with mental retardation (ICFs-MR), and inpatient psychiatric units.</p>
Medical Services	<p>The Medical Services category includes claims for services used by these members that are primarily acute, medical or routine health services. These services are not specific to a particular program or population. This category includes claims for general inpatient, general outpatient, physician, dental, durable medical equipment, lab, medical transportation, general therapies, etc.</p>

<sup>21</sup> Citations are to sections within 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II.