



# ADVANCING CALIFORNIA'S TRAUMATIC BRAIN INJURY SERVICE SYSTEM:

## NEXT STEPS

In Collaboration with the  
California Traumatic Brain Injury Advisory Board

## FINAL REPORT

May 2010



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On behalf of the California Department of Mental Health (DMH), I would like to express my gratitude to members of the California Traumatic Brain Injury (TBI) Advisory Board and stakeholders across the state for their hard work and commitment to developing a more accessible and comprehensive TBI system in California. We also extend our gratitude to the state departments listed on the following pages for their valuable contributions to this report.

The TBI Advisory Board met several times with the DMH project team to develop a consumer-focused plan to solicit TBI stakeholder feedback through a series of regional stakeholder meetings and a statewide conference call in October and November 2009. At these stakeholder meetings, persons with TBI, family members and other caregivers, advocates, and providers shared critical information, compelling stories, and thoughtful suggestions that informed the development of the recommendations included in this report.

We deeply appreciate the TBI Advisory Board's hard work and acknowledge the personal commitment and many contributions of the individuals listed on the following pages.

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## EXECUTIVE SUMMARY

It is very likely that a person with traumatic brain injury (TBI) resides in every community in California. Persons with TBI are infants, children, youth, young and middle-aged adults – including veterans from the Iraq and Afghanistan wars, and older adults. There are multiple causes of TBI; however, the most common include falls, motor vehicle accidents, and assaults. Persons with TBI may suffer physical impairments, interruptions in cognitive functioning, significant personality changes, and psychological disturbances. A common denominator for many living with TBI is the experience of loss – loss of independence, previous levels of functioning, social and intimate relationships, jobs, and professions.

National and state reported TBI statistics are staggering. Approximately 1.4 million Americans sustain a TBI each year in the United States resulting in 50,000 deaths, 235,000 hospitalizations, and 1.1 million emergency department visits<sup>1</sup>. Of the 29,354 patients hospitalized with a TBI in California in 2007, 7 percent died, and 25 percent were sent to another facility<sup>2</sup>. The peak ages for TBI in California are infancy, the early 20's, and over 80. Yet, no one knows exactly how many people live with TBI, because symptoms and resulting disabilities range from mild to severe and not everyone with a TBI is hospitalized or seen by a medical provider.

***I got released from the hospital and did not feel any different, but when I went to rehabilitation I could hardly manage five minutes on the treadmill. That's when I realized that something was wrong and I understood I needed rehabilitation. Persons with TBI need support from the State and someone to oversee the private insurance carrier right after a TBI, so we can get into rehabilitation as quickly as possible – the sooner the better.***

***Individual living with TBI***

TBI has been defined as a public health concern and a priority of the Centers for Disease Control and Prevention. For those significantly or profoundly impacted by this injury, reintegration into the community is overwhelming due in part to limited services and insurance coverage for critical medical and social rehabilitation. Moreover, persons with TBI often need help with community reintegration multiple times and at different junctures, because of the complexity of their injury and changes in their medical condition, living arrangement, or caregiving situation.

In 2006, the California Department of Mental Health (DMH) was awarded a three-year Traumatic Brain Injury (TBI) State Implementation Grant from the Health Resources and Services Administration, US Department of Health and Human Services to focus on the needs of California residents with acquired traumatic brain injury<sup>3</sup>. This report summarizes two principal grant objectives: 1) findings from an interactive stakeholder process with members of the TBI Advisory Board and other TBI stakeholders (persons with TBI, family members and other caregivers, and providers) addressing key TBI issues and needs; and 2) an evaluation of Medicaid (Medi-Cal) waiver and/or State Plan Amendment options to enhance TBI services with additional federal support.

<sup>1</sup> Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2006.

<sup>2</sup> California Department of Public Health, Safe and Active Communities Branch. Inpatient Discharge Files, Office of Statewide Health Planning and Development. Includes patients hospitalized with any diagnosis of TBI in California in 2007.

<sup>3</sup> Note: For the purposes of this report, the term Acquired Traumatic Brain Injury which 1) is used in the TBI State Implementation Grant definition of traumatic brain injury, and 2) references a California community college program for TBI students is interchangeable with the term Traumatic Brain Injury (TBI).

California's current traumatic brain injury service system includes seven state-funded traumatic brain injury program sites (the California Traumatic Brain Injury Program), services provided by several state departments (California Department of Rehabilitation, California Department of Developmental Services, etc.), and a host of other public and private providers. The objectives of the State Implementation Grant addressed in this report support meeting the legislative mandate, under Assembly Bill 1410, Feuer, Chapter 676, Statutes of 2007, requiring California to apply to the federal Centers for Medicare & Medicaid Services (CMS) for a Home and Community-Based Services (HCBS) waiver application or amendment of the State Plan (Medi-Cal) for HCBS to serve Medicaid (Medi-Cal) eligible adults with traumatic brain injury who otherwise would require care in an institution such as a nursing facility, through the seven state-funded traumatic brain injury program sites. Note: another recent bill affecting persons with traumatic brain injury, Assembly Bill 398, Monning, Chapter 439, Statutes of 2009, transfers the administrative duties and oversight of the California Traumatic Brain Injury Program, effective January 1, 2010, from California Department of Mental Health to the California Department of Rehabilitation.

Regional stakeholder meetings organized through the TBI State Implementation Grant provided TBI stakeholders with an opportunity to share their experiences with California's TBI service system, and give input on what is missing and what is needed for persons living with TBI to manage their injury and maximize their ability to function independently in the community. Four goals, critical to advancing a more accessible and comprehensive TBI service system in California, emerged from the stakeholder meeting process:

- Provide long-term support and insurance coverage for a host of community reintegration services and activities;
- Establish accessible and affordable supported living options;
- Coordinate TBI services at the state and local level; and,
- Improve TBI data collection and reporting to enhance TBI program effectiveness and system accountability.

Not surprisingly, each goal involves a public or private funding challenge. To achieve these goals and address their inherent funding challenges, TBI stakeholders and representatives from multiple state departments must continue to work together. A collaborative approach will allow California to take advantage of the current momentum generated by this grant effort and other state level TBI-related projects, programs, and endeavors. The State will also move forward with exploring three potential Medi-Cal program options (i.e., a Medicaid (Medi-Cal) waiver and/or State Plan Amendment) to enhance TBI services through leveraging state and federal resources. Through these dedicated partnerships and collaboration, the quality of life for persons with TBI can truly be improved in all communities.

As we embark upon the new decade, 2010 marks a milestone in efforts to enhance the development and implementation of a comprehensive TBI service system that reaches all Californians.

*As a family member, I often felt bad that I couldn't help my loved one [with traumatic brain injury] more. Once I started talking with other family members in a caregiver support group, I learned that caregivers need help coping with traumatic brain injury too. Now, I don't feel so alone.*

*Parent of a child with traumatic brain injury*

# TABLE OF CONTENTS

Executive Summary .....	i
I. Introduction .....	1
II. Background. ....	3
A. Traumatic Brain Injury National Data .....	3
B. Traumatic Brain Injury in California .....	5
C. Service System .....	8
D. TBI State Implementation Grant .....	11
E. Recent California TBI Legislation .....	12
III. Stakeholder Meetings .....	13
A. Meeting Dates and Locations .....	13
B. Key Feedback by Core Service Area .....	14
C. Goals and Summary Themes .....	21
IV. Next Steps .....	23
A. State Waiver/State Plan Amendment Options: Overview .....	23
B. Waiver/State Plan Amendment Side-by-Side Charts .....	26
C. Other Avenues to Action .....	29
V. Conclusion .....	31

## Tables and Graphs

Section II: Table 1: Hospitalized Non-Fatal Traumatic Brain Injury, California Residents, 2006 .....	6
Section II: Graph 1: Hospitalized Traumatic Brain Injuries, by Age, California, 2007 .....	7
Section II: Graph 2: Emergency Department Treatments for Traumatic Brain Injuries, By Age, California, 2007. ....	7
Section IV: Table 1: 1915 (c) Waiver Option .....	26
Section IV: Table 2: 1915 (i) State Plan Amendment Option .....	27
Section IV: Table 3: 1915 (j) Self-Directed State Plan Amendment Option ....	28

## Appendices

Appendix A: Acronyms .....	A-1
Appendix B: Department of Defense Numbers for Traumatic Brain Injury. ....	B-1
Appendix C: Schematic – California TBI Service System .....	C-1
Appendix D: Assembly Bill 1410. ....	D-1
Appendix E: Assembly Bill 398. ....	E-1
Appendix F: SWOT Analysis .....	F-1



# I. INTRODUCTION

Traumatic Brain Injury (TBI) is a complex injury that affects individuals in myriad ways. For some, the effect may be minimal, but for others profound with far-reaching and long lasting repercussions. Persons with TBI may suffer physical impairments, interruptions in cognitive functioning, significant personality changes, and psychological disturbances. A common denominator for many persons living with TBI is the experience of loss – loss of independence, previous levels of functioning, social and intimate relationships, jobs, and professions. Several additional characteristics distinguish TBI from other injuries.<sup>4</sup> First, while males between the ages 16 to 24 years are the most vulnerable group to sustain a TBI, all age groups experience TBI from children to the elderly. Second, the causes of TBI are many: national data indicate the most common are falls (28%) and car accidents (20%). Other causes include physical assaults, sporting accidents, and work place injuries. These characteristics and statistics indicate that TBI is a significant injury that touches all communities.

Recent attention given to military men and women returning from Iraq and Afghanistan with TBI has expanded Americans awareness of the injury. Still, meeting the short- and long-term needs of persons with TBI, whether they are military or civilian remains a challenge at all levels of society - local, state, and national.<sup>5</sup> California began focusing on TBI over twenty years ago. In 2006, the California Department of Mental Health (DMH) was awarded a three-year Traumatic Brain Injury (TBI) State Implementation Grant from the Health Resources and Services Administration (HRSA), US Department of Health and Human Services (DHHS).<sup>6</sup> The primary purposes of the grant were to establish a TBI Advisory Board; advance awareness and understanding of TBI in California to promote systems change through public policy and education; and, strengthen TBI partnerships. Prior to concluding the grant, DMH was provided a one year no-cost extension to conduct multiple stakeholder meetings around the state and develop a project report to assist with the development of a Medicaid (Medi-Cal) waiver and/or State Plan Amendment to enhance TBI services.

This report is organized as follows:

- **Background** - provides descriptive summaries of national and California TBI data, California's current TBI service system, and the TBI State Implementation Grant and no-cost extension;
- **Stakeholder Meetings** - summarizes six in-person regional stakeholder meetings and one conference call held throughout the state, highlighting key findings and summary themes;
- **Next Steps** - presents an overview of waiver options, with side-by-side charts identifying key elements of waiver and State Plan Amendment options matched with stakeholder needs and opportunities for state-level TBI collaboration; and,
- **Conclusion** - summarizes the project's key findings.

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<sup>4</sup> Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2006.

<sup>5</sup> The word long-term is used throughout this report to reference an extended period of time, typically longer than several months.

<sup>6</sup> For a list of acronyms used in this report, see Appendix A: Acronyms.



## II. BACKGROUND

Understanding the challenges and needs of persons with TBI and their families is essential to building a responsive and coordinated TBI service system. This section presents the following: a brief introduction to TBI with national and California data; an overview of California's current TBI service system; and, a description of the TBI State Implementation Grant and no-cost extension.

### A. Traumatic Brain Injury National Data

According to the Brain Injury Association of America (BIAA), a "Traumatic Brain Injury" is typically defined as "a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain."<sup>7</sup> The collection of accurate and detailed statistics on TBI is challenging because symptoms and resulting disabilities range from mild to severe. Still, the data that is reported is revealing. In a 2006 report, the Centers for Disease Control and Prevention (CDC) analyzed population-based data on TBI (emergency department visits, hospitalizations and deaths) for the years 1995-2001. Approximately 1.4 million Americans sustain a TBI each year in the United States resulting in 50,000 deaths, 235,000 hospitalizations, and 1.1 million emergency department visits.<sup>8</sup> The numbers of people with TBI who are not seen in an emergency department, or who receive no care, is unknown. The report also provides data on the leading causes of TBI: falls (28%); motor vehicle-traffic crashes (20%); struck by/against events (19%); and assaults (11%). According to the report, the average annual TBI rates per 100,000 population in the following categories are as follows:

- An average of 835,000 TBIs occurred each year among males compared to 561,000 among females. Males are about 1.5 times as likely as females to sustain a TBI.
- The two age groups at highest risk for TBI are 0 to 4 year olds (1,035.0 per 100,000 population) and 15 to 19 year olds (661.1 per 100,000); adults age 75 years or older have the highest rates of TBI-related hospitalization and death (272.1 per 100,000 and 50.6 per 100,000 respectively).
- African Americans have the highest death rate from TBI (19.9 per 100,000 compared to 18.1 per 100,000 for Whites).

Additional statistics indicate the depth and breadth of TBI. Among older adults, falls are the leading cause of injury and deaths. In 2005, 15,800 people ages 65 and older died from injuries related to unintentional falls, approximately 1.8 million people 65 and older were treated in emergency departments for nonfatal injuries from falls, and more than 433,000 of these patients were hospitalized.<sup>9</sup> In the military, the leading causes of TBI are: bullets, fragments, and blasts; falls; motor vehicle-traffic crashes, and assaults (see Appendix B: Department of Defense Numbers for Traumatic Brain Injury).<sup>10</sup> The U.S. Department of Veteran's Affairs (VA), which established a TBI Administration after the Gulf War, noted that while 14 percent of previous war veterans had TBI, the number of brain-injured veterans from the Iraq and Afghanistan wars "is much higher." Some providers estimate that as many as 60 percent of injured veterans from these wars have TBI.<sup>11</sup>

<sup>7</sup> Brain Injury Association of America. About brain injury. Available at <http://www.biausa.org/aboutbi.htm>. Accessed November 6, 2009.

<sup>8</sup> Langlois JA, et al., loc.cit, 2006.

<sup>9</sup> Thomas, KE, Stevens, JA, Sarmiento, K, Wald, MM. (2008). Traumatic Brain Injuries can Result from Senior Falls. *Journal of Safety Research*. 39:3, 269-272. Atlanta, (GA). Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. [http://www.cdc.gov/ncipc/tbi/elder\\_fall.htm](http://www.cdc.gov/ncipc/tbi/elder_fall.htm). Accessed January 2, 2010.

<sup>10</sup> Defense and Veterans Brain Injury Center (DVBIC) Washington (DC): U.S. Department of Defense. Available at: <http://www.dvbic.org/TBI--The-Military/TBI-Facts.aspx>. Accessed January 3, 2010.

<sup>11</sup> United States Department of Veterans Affairs. <http://www.va.gov/> Accessed January 29, 2010.

Recent data reported by the Traumatic Brain Injury Model Systems National Database, based on their database of 8,775 persons with TBI, reflect different statistical outcomes than the national data in several areas: they report that males are 2.8 times as likely to sustain a TBI than females; and, the primary causes of TBI (n=8749) are vehicular 55%, falls 21%; violence 13%; and other 11%.<sup>12</sup> While the differences may or may not be predictive of future trends, behind all the numbers are individuals whose lives have been profoundly altered.

After sustaining a TBI, many persons with a moderate to severe injury follow a common trajectory – admission to the emergency department and then acute care hospital. After stabilization, a period of time that varies from individual to individual depending on the severity of the injury, persons with TBI may be transferred to inpatient or outpatient rehabilitation for rehabilitative services. Both may include medical and nursing care, neuropsychological services, speech therapy, physical therapy, occupational therapy, and social work support. Persons with TBI may also transfer from the acute care hospital to a skilled nursing facility or, in California, to a congregate living health facility, if their injuries and impairments require intensive care and the individual has insurance or private funds to cover the costs.<sup>13</sup> Insurance coverage, the availability of services, and the specific medical, physical, cognitive, and emotional needs of the injured individual primarily define the path to community reintegration for many persons with TBI.

The impact of TBI on an individual, his or her family, and society is difficult to quantify. Economically, direct medical costs together with indirect costs such as lost productivity associated with a TBI totaled an estimated \$60 billion in the United States in 1995.<sup>14</sup> From the human perspective, persons with TBI can experience difficulties with everyday tasks such as eating, bathing, dressing, transferring - getting in and out of bed/shower, and toileting (referred to as Activities of Daily Living or ADLs), as well as short- and long-term disruption in thinking, memory, language, emotions, and behavior. The CDC estimates that at least 3.17 million Americans currently have a long-term or lifelong need for help to perform ADLs, as a result of a TBI.<sup>15</sup>

Below are some of the more common short- and long-term effects of a TBI:<sup>16</sup>

- Memory loss
- Difficulty understanding others
- Loss of self-control
- Physical aggression & flash anger
- Difficulty expressing thoughts
- Inability to recognize or accept limitations
- Depression
- Apathy
- Poor judgment and reasoning
- Seizures
- Inappropriate sexual behavior
- Physical disabilities
- Impaired social skills
- Heightened risk of Alzheimer's disease

<sup>12</sup> Traumatic Brain Injury Model Systems National Data and Statistical Center, Englewood, CO. Traumatic Brain Injury Model Systems National Database Update. <http://www.tbinsc.org/Documents/2009%20TBIMS%20National%20Database%20Update.pdf>. Accessed December 30, 2009.

<sup>13</sup> Congregate living health facilities, in California, provide 24-hour skilled nursing and supportive care in small facility settings for persons suffering from, among other conditions, catastrophic illness or injury including traumatic brain injury, resulting in severed disability.

<sup>14</sup> Finkelstein E, Corso P, Miller T and associates. The Incidence and Economic Burden of Injuries in the United States. New York: Oxford University Press, 2006.

<sup>15</sup> Thurman D, Alverson C, Dunn K, Guerrero J, Sniezek J. Traumatic brain injury in the United States: a public health perspective. *Journal of Head Trauma Rehabilitation* 1999;14(6):602-15.

<sup>16</sup> Traumatic Brain Injury Association of California. About traumatic brain injury (TBI). Available at: <http://www.tbisca.org/about/tbi.asp>. Accessed November 6, 2009.

## B. Traumatic Brain Injury in California

An estimated 350,000 Californians are living with a TBI.<sup>17</sup> Over 100,000 Californians visit emergency rooms annually due to head injuries and an estimated 25 percent of these individuals never return to work.<sup>18</sup> The California Department of Public Health reports the following TBI data involving emergency department visits, hospitalizations, costs to public programs, and causes:<sup>19</sup>

- In 2007, patients with any diagnosis of TBI treated in California emergency departments totaled 142,139. Of these, 5 percent were transferred to another care facility. Government programs were billed for the costs in 65 percent of the cases.
- Of the 29,354 patients hospitalized with any diagnosis TBI in California in 2007, 7 percent died, and 25 percent were sent to another facility. Government programs were billed for the costs in 56 percent of the cases. The main government payers were Medi-Cal and Medicare.
- In 2006, 19,415 California residents were hospitalized with a non-fatal principal diagnosis of traumatic brain injury - 43 percent were caused by falls, 22 percent by motor vehicle accidents, and, 17 percent by assaults (Table 1: Hospitalized Non-Fatal Traumatic Brain Injury California Residents, 2006).

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<sup>17</sup> Estimates from the Centers for Disease Control TBI Surveillance Grant Program and National Center for Health Statistics data, compiled by the Brain Injury Association of America. Cited in *California Traumatic Brain Injury State Grant Program Fact Sheet*, September 2002.

<sup>18</sup> Centers for Disease Control and Prevention, *The Injury Fact Book, 2001 – 2002*.

<sup>19</sup> California Department of Public Health, Safe and Active Communities Branch. Inpatient Discharge Files, Office of Statewide Health Planning and Development. Source: Inpatient Discharge Files (2007), Office of Statewide Health Planning and Development. 2009-2010.

**TABLE 1: HOSPITALIZED NON-FATAL TRAUMATIC BRAIN INJURY  
CALIFORNIA RESIDENTS, 2006**

<b>Unintentional</b>		<b>10,423</b>
Fall	8,387	
Transport, Non-traffic	689	
Struck By Or Against Object	676	
Bicyclist, Non-traffic	625	
Firearms	23	
Cut/Pierce	11	
Drowning/Submersion	6	
Suffocation	3	
Burn, Fire/Flame	2	
Burn, Hot Object/Substance	1	
<b>Motor Vehicle Traffic</b>		<b>6,399</b>
Occupant	4,231	
Pedestrian	940	
Motorcyclist	667	
Bicyclist	357	
Unspecified	143	
Other	61	
<b>Assault</b>		<b>2,277</b>
Fight, Unarmed	713	
Blunt Object	703	
Other	585	
Firearm	164	
Cut/Pierce	74	
Abuse and Neglect	38	
<b>Other</b>		<b>211</b>
Late Effects	135	
Legal Intervention/War*	27	
Other		
<b>Self-Inflicted/Suicidal</b>		<b>105</b>
Other	53	
Firearm	24	
Jump	18	
Cut/Pierce	7	
Hanging/Suffocation	3	

Notes: This table presents hospitalized cases with a principal diagnosis of TBI; it does not include hospitalized cases where TBI was a secondary diagnosis or other sources of TBI incidence data. TBI is defined according to standards used by the Center for Disease Control and Prevention.

Prepared by: Safe and Active Communities Branch, California Department of Public Health. Source: Inpatient Discharge Files, Office of Statewide Health Planning and Development.

\*Legal Intervention refers to TBI sustained through interactions with police, prison guards, etc. War refers to individuals with war-related TBI who receive treatment at a CA hospital. Note: this category is not intended to be a measure of war TBI soldiers in CA who are typically treated by the military.

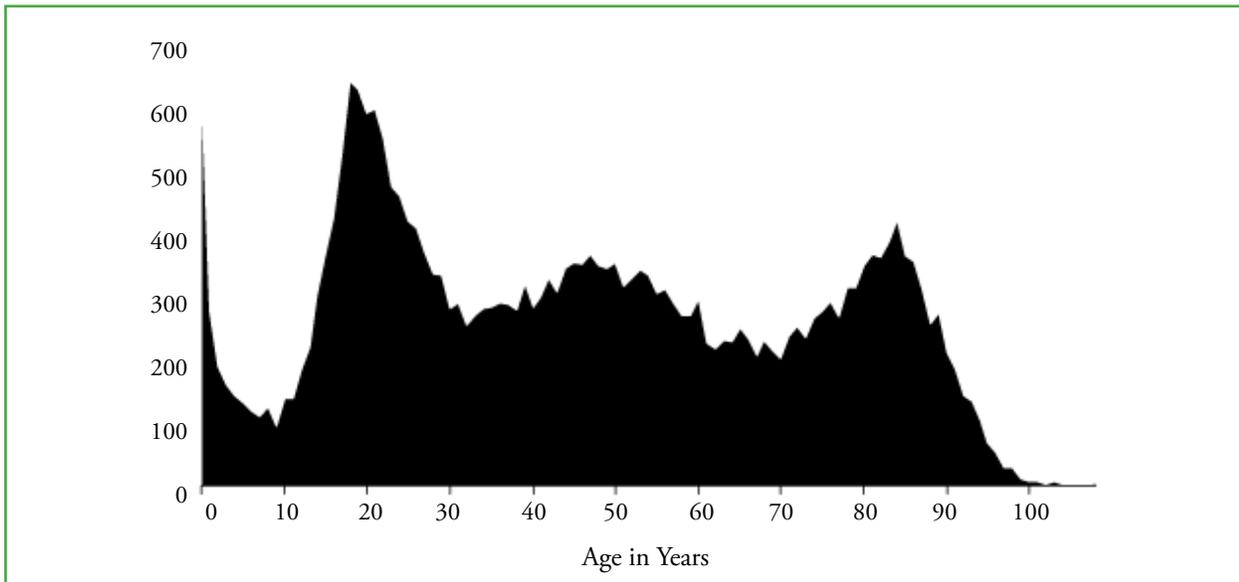
The causes of TBI vary by age:<sup>20</sup>

- Among children under 10, the two main causes are falls (55 percent) and traffic accidents (20 percent);
- Among adolescents and adults, from age 10 to 40, the main causes are traffic accidents (49 percent) followed by violence (18 percent); and,
- Among adults over age 40, falls predominate (59 percent) followed by traffic accidents (23 percent).

Peak ages for TBI are infancy, the early 20's, and over 80. The following graphs show that most people who experience a TBI do so during their years of growth and development, and productive work.<sup>21</sup>

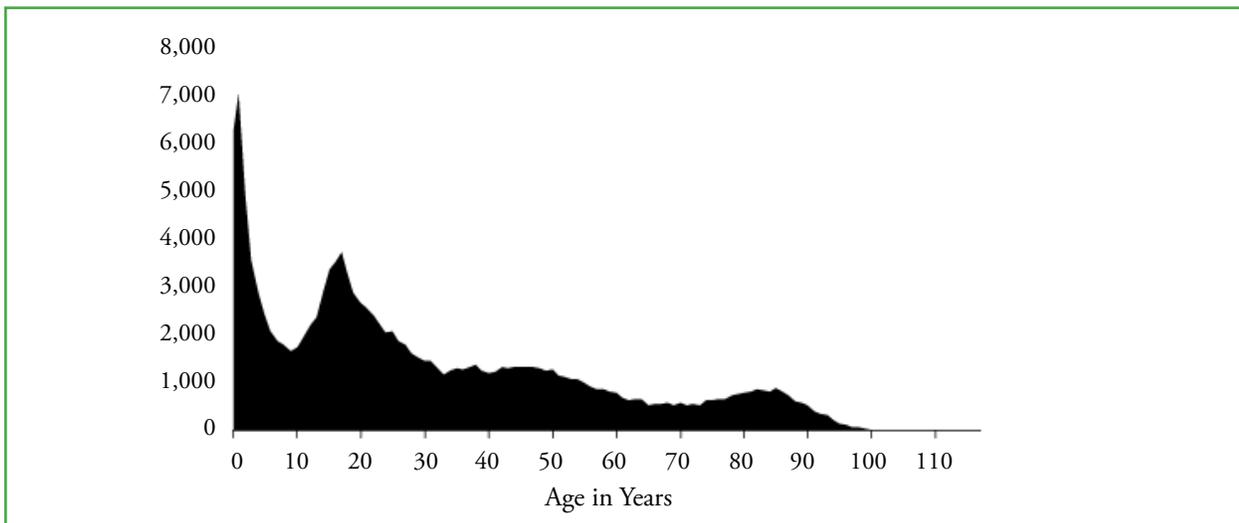
**GRAPH 1: HOSPITALIZED TRAUMATIC BRAIN INJURIES, BY AGE, CALIFORNIA 2007**

Average age = 46



**GRAPH 2: EMERGENCY DEPARTMENT TREATMENTS FOR TRAUMATIC BRAIN INJURIES, BY AGE, CALIFORNIA, 2007**

Average Age = 31



<sup>20</sup> California Department of Public Health, Safe and Active Communities Branch. Inpatient Discharge Files, Office of Statewide Health Planning and Development. Source: Inpatient Discharge Files (2007), Office of Statewide Health Planning and Development. 2009-2010.

<sup>21</sup> Ibid.

The number of persons treated in emergency departments or hospitalized for a TBI provides critical incidence information; however, it is very difficult to predict and accurately capture detailed information regarding the long-term impact of a TBI. Persons with moderate to severe TBI can experience ongoing and sometimes permanent functional challenges in the areas of activities of daily living, work and school, and interpersonal relationships; hence, their needs for medical care, rehabilitative services, vocational and employment training, and social and psychological supports may fluctuate as well as reoccur.

It is important to note that the above reported data on Californians with TBI does not include a summary number of veterans living with TBI. The VA reports that close to 5,000 California veterans are currently living with TBI, the majority with a diagnosis of mild TBI classified medically as “exposure to blast.”<sup>22</sup>

### C. Service System

In 1988 the California Legislature passed Senate Bill 2232 (Chapter 1292, Statutes of 1988), which authorized initial funding (\$500,000) for a four-site TBI pilot project, the California Traumatic Brain Injury (TBI) Program. The program was administered by DMH and dedicated to providing a continuum of services for persons with TBI and their families.<sup>23</sup> The intent of the law was to “demonstrate the effectiveness of a coordinated service approach which furthers the goal of assisting individuals with TBI to attain productive, independent lives which may include paid employment.” The legislation was amended in 1999 to support three additional TBI sites to the TBI Program: one in 2001, and two in 2003. The following is a brief overview of California’s TBI service system (see Appendix C: Schematic – California TBI Service System). Note: recent legislation, (addressed in Section II, Subsection D: Recent California TBI Legislation) transfers the administrative duties and oversight of the TBI Program from DMH to Department of Rehabilitation (DOR), effective January 1, 2010.

The seven TBI sites form the basis for the state’s formal TBI service system. All seven sites receive funding from the California Traumatic Brain Injury (TBI) Fund, established by Section 1464 of the Penal Code.<sup>24</sup> The legislation stipulates that 0.66% of the state penalty funds imposed upon every fine, penalty, or forfeiture collected by the courts throughout the state for criminal and vehicular offenses be contributed to the TBI Fund. Fines collected for violation of California’s seat belt law also support the TBI Program. A cap on the TBI Fund was lifted in 2000, after Senate Bill 2232 was amended. In FY 2009-2010, the Fund total was \$1.05 million (approximately \$150,000 per site). Below are the seven sites, and the counties they serve.

- **Betty Clooney Foundation**  
Los Angeles County
- **Central Coast Center For Independent Living “New Options”**  
Santa Cruz County & Monterey Counties
- **Janet Pomeroy Center “San Francisco TBI Network”**  
San Francisco County
- **Making Headway Center**  
Humboldt, Mendocino & Del Norte Counties
- **Mercy General Hospital “Coordinated Care Project”**  
Sacramento, Placer & El Dorado Counties

<sup>22</sup> United States Department of Veterans Affairs. Palo Alto Polytrauma Rehabilitation Center. April 2010.

<sup>23</sup> California Welfare and Institutions Code §§ 4353-4359: Traumatic Brain Injury Program.

<sup>24</sup> California Penal Code, Section 1464. Available at: <http://www.leginfo.ca.gov/cgi-bin/waisgate?WAISSdocID=1217717283+12+0+0&WAISSaction=retrieve>. Accessed December 29, 2009.

- **Options Family Services**  
San Luis Obispo & Santa Barbara Counties
- **St. Jude Medical Center “St. Jude Brain Injury Network”**  
Orange County

The core services provided by the TBI sites (outlined in Senate Bill 2232 and further detailed in the sites contract project objectives) include the following:

- **Community Reintegration Services** - services needed by participants that are designed to develop, maintain, increase, or maximize independent functioning, with the goal of living in the community and participating in community life;
- **Family and Community Education** - provision of information designed to improve overall understanding of the nature and consequences of TBI, including public and professional education designed to facilitate early identification of persons with TBI, prompt referral of these persons to appropriate services, and improvement of the system of services available to them;
- **Service Coordination Services** - may include provision of information and resources for participants, advocacy, participant and family education about options, liaison for participants among service providers, problem-solving with participants, and monitoring and following-up on well-being and progress;
- **Vocational Supportive Services** - a method of providing vocational rehabilitation and related services to targeted individuals not served or underserved by existing vocational rehabilitation services; and,
- **Supported Living Services** - services designed to increase a participant’s independent living skills, includes supervision, support, and training in the participant’s place of residence or other settings.

Despite site-by-site variation in the provision and delivery of core services, influenced by each site’s unique organizational-funding structure and geographic location, all sites provide similar core services, employing a coordinated continuum-of-care model that focuses on case management and service coordination services. In 2008-2009, the seven sites served a total of 975 participants, of which 160 were new intakes.<sup>25</sup> Although the sites primarily focus their staff time and resources on persons with TBI, each site also provides information and assistance services and addresses the needs of caregivers. Several have contracts or Memoranda of Understanding (MOUs) with local Caregiver Resource Centers to provide supportive services to family members and other caregivers.

In addition to this state-sponsored TBI service system, persons with TBI may receive services through other state departments such as DOR and the California Department of Developmental Services (DDS). The DOR primarily serves people of working age with all types and categories of disability, including TBI, through two service areas - the Vocational Rehabilitation Program and Independent Living Section. The DOR develops, purchases, provides, and advocates for programs and services in both areas with a priority on services for persons with the most significant disabilities and for persons with significant disabilities. The Vocational Rehabilitation Program assists Californians with disabilities to obtain and retain employment and maximizes their ability to live independently in their communities. DOR offers a range of services through this program, from counseling and vocational training to assistive technology and supported employment services. The DOR contracts for vocational services with two of the seven TBI sites: Mercy General Hospital and Options Family Services. In 2008-2009 (state fiscal year - 7/1/08 to 6/30/09), the DOR vocational rehabilitation program provided services to 1,726 consumers with disability code 37 (TBI) statewide.

<sup>25</sup> California Department of Mental Health. (2009). TBI Project Site Data.

The Independent Living Section of DOR is one part of California's independent living network, which includes 29 independent living centers (ILCs) and the State Independent Living Council (SILC). The DOR administers and provides technical assistance and financial support for the ILCs. An independent living center is a consumer controlled, community based, cross disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities. Independent living services are services that maximize a person's ability to live independently in the environment of their own choosing. All ILCs provide six core services: housing referrals; information and referral; peer counseling; personal assistant services; independent living skills training; and, individual and systems change advocacy. In 2008-2009 (federal fiscal year - 10/1/08 to 9/30/09), the ILCs provided services to 733 consumers with TBI statewide.

The DDS also serves persons with TBI. To be eligible for DDS services, a person must have a disability that begins before the person's 18th birthday, be expected to continue indefinitely and present a substantial disability.<sup>26</sup> Eligibility is established through diagnosis and assessment performed by regional centers. Regional centers help plan, access, coordinate and monitor the services and supports that are needed because of a developmental disability. Some of the services and supports provided by the regional centers include: information and referral; assessment and diagnosis; counseling; lifelong individualized planning and service coordination; advocacy for the protection of legal, civil and service rights; family support; planning, placement, and monitoring for 24-hour out-of-home care.

Complementing California's formal TBI service system is a host of other providers. These providers include hospitals, community colleges, a wide spectrum of public and private nonprofit and for-profit organizations, and the VA. Hospitals are often the first point of contact for a TBI survivor. Treatment is provided in hospital emergency departments, inpatient acute medical, surgical and rehabilitation units, and outpatient rehabilitation clinics. Community colleges represent another vital component of the informal TBI service system.<sup>27</sup> They provide a range of educational and training programs as well as life skills training, counseling, and support services. All 109 California community colleges provide legally required "academic adjustments" such as alternate media and test accommodations through their Disabled Students Programs and Services (DSPS) for qualified individuals with disabilities, including those with TBI.<sup>28</sup> Title 5 of the California Education Code authorizes categorically funded services for students with acquired brain injuries, including those with TBI. A small percentage of California's community colleges have developed specific Acquired Traumatic Brain Injury (ABI) Programs.<sup>29</sup> Albeit a vital component of California's postsecondary education system, the California Community College System is facing significant funding challenges. In addition to serving students with disabilities including TBI, community colleges are increasingly expected to meet the needs of the growing numbers of returning veterans with TBI who want to use their G.I. Bill Education Benefits.<sup>30</sup> This increased demand for service however is coupled with a reduction in funding for all categorical programs, including DSPS during fiscal year 2009-2010, and a continuation of reduced funding projected for 2010- 2011.<sup>31</sup>

<sup>26</sup> California Welfare and Institutions Code §§ 4.5. Services for the Developmentally Disabled Chapter 1. General Provisions.

<sup>27</sup> Burnett, Sandi. Acquired Brain Injury Program Faculty Leader, Santa Monica College. Submitted by November 11, 2009.

<sup>28</sup> California Department of Education. Title 5, California Code of Regulations.

Available at: <http://www.cde.ca.gov/LS/fals/title5regs.asp>. Accessed November 15, 2009.

<sup>29</sup> Note: For the purposes of this report, the term *Acquired Traumatic Brain Injury* (ABI), which 1) references a California community college program for TBI students and 2) is used in the TBI State Implementation Grant definition of traumatic brain injury, is interchangeable with the term *Traumatic Brain Injury* (TBI).

<sup>30</sup> Grossman PD: Foreword, Challenge: Leading Our Campuses Away from the Perfect Storm, *Journal of Postsecondary Education and Disability*, Vol. 22, No.1; 2009.

<sup>31</sup> California Community Colleges 2009-2010 Cuts: [http://fa.fhda.edu/fanews/Sept-9-FA\\_NEWS.pdf](http://fa.fhda.edu/fanews/Sept-9-FA_NEWS.pdf).

2010-1011 Proposed Budget: [www.cccco.edu/Portals/4/News/press\\_releases/2010/Chancellor%20Scott%20on%20Gov%20%20Proposed%20Budget%20for%202010-11%20FINAL%20%281-8-10%29.pdf](http://www.cccco.edu/Portals/4/News/press_releases/2010/Chancellor%20Scott%20on%20Gov%20%20Proposed%20Budget%20for%202010-11%20FINAL%20%281-8-10%29.pdf). Accessed February 4, 2010.

Public and private providers in the informal TBI service system include for-profit freestanding rehabilitation facilities and residential treatment programs to local and statewide nonprofit advocacy and service agencies, such as the Brain Injury Resource Center of the Redwood Empire, the California Brain Injury Association, the California Foundation of Independent Living Centers, Disability Rights California, Easter Seals, and the San Diego Brain Injury Foundation. One additional significant stakeholder and service provider is the California Department of Veterans Affairs, serving veterans with TBI. Over 20,000 military service men and women have sustained TBIs each year for the past few years.<sup>32</sup> In response, the VA has been developing the Polytrauma/Traumatic Brain Injury System of Care (PSC). The PSC initiative addresses the needs of the new generation of veterans and service members - the mission of the PSC is to ensure that veterans and service members with polytrauma and TBI have access to the full continuum of rehabilitation services, case management, family education and support, psychosocial services, and community re-integration assistance.

#### **D. TBI State Implementation Grant**

In 2006, DMH was awarded a three-year Health Resources and Services Administration (HRSA), US Department of Health and Human Services, TBI State Implementation Grant (#H21MC06761), to focus on the needs of California residents with acquired TBI. The definition of TBI used for the State Implementation Grant - Acquired traumatic brain injury is an injury that is sustained after birth from an external force to the brain or any of its parts, resulting in cognitive, psychological, neurological, or anatomical changes in brain function - is slightly different from that used by BIAA. The primary purposes of the grant were to establish a statewide TBI Advisory Board; advance awareness and understanding of TBI in California to promote systems change through public policy and education; and, strengthen TBI partnerships. Core project objectives included:

1. Raising the visibility of traumatic brain injury among state and local policy makers and program administrators;
2. Promoting innovative and successful services and systems to meet the diverse needs of persons with traumatic brain injury;
3. Promoting collaboration among stakeholders to address challenges faced by individuals with traumatic brain injury and their families; and,
4. Promoting coordination of resources, services and information to individuals with traumatic brain injury and their families.

At the conclusion of the project period (March 31, 2009), DMH requested a no-cost extension to the HRSA grant through March 31, 2010. The purposes of the no-cost extension were to continue to work toward meeting the original goals and objectives of the grant, in coordination with the TBI Advisory Board; to conduct multiple stakeholder meetings around the state; and, to develop a project report to assist with the development of a Medicaid (Medi-Cal) waiver and/or State Plan Amendment to enhance TBI services with additional federal support. The no-cost extension project activities included:

1. Conducting a gap analysis of TBI services in California that includes the Advisory Board; federal, state and local government partners; and, local stakeholders;
2. Through regional stakeholder meetings and other advisory bodies, soliciting and summarizing stakeholder recommendations and feedback on enhancing the comprehensive TBI service system in California; based on stakeholder recommendations and feedback, prepare a report to inform development of a draft Medicaid (Medi-Cal) Home and Community-Based Services (HCBS) Waiver Application designed to secure support for TBI services in California, consistent with recently enacted legislation Assembly Bill 1410, Feuer, Chapter 676, Statutes of 2007.

<sup>32</sup> Defense and Veterans Brain Injury Center (DVBIC). Armed Forces Health Surveillance Center. (2009). <http://www.dvbic.org/TBI-Numbers.aspx>. Accessed January 3, 2010.

## E. Recent California TBI Legislation

In October 2007, the California Legislature passed **Assembly Bill 1410** informally referred to as the TBI Bill.<sup>33</sup> The TBI Bill (Appendix D) details the following:

1. Requires the Department of Health Care Services (DHCS) to apply to the federal Centers for Medicare & Medicaid Services (CMS) for a Home and Community-Based Services (HCBS) waiver application or amendment of the state plan (Medi-Cal) for HCBS, to serve at least 100 Medicaid (Medi-Cal) eligible adults with TBI who otherwise would require care in an institution such as a nursing facility.
2. Allows the seven TBI sites in California to offer services to more people and to offer new services with the additional federal support. The services include various kinds of assessments and rehabilitative therapies, supported living, and case management services, including supported employment. Uses existing funds – from the TBI Fund – to serve as the state match for the federal money (thus no state general funds are needed for this match to pay for TBI services). General funds would only be needed to administer the program.<sup>34</sup>

The state's economic challenges and related factors altered the state's capacity to meet AB 1410's requirement to submit a HCBS waiver application or amendment of the state plan.

A second bill affecting persons with TBI was recently signed into law. On October 12, 2009, Governor Schwarzenegger signed **Assembly Bill 398**, (Appendix E) which impacts TBI services and programs.<sup>35</sup> One of the significant changes outlined in the bill is the transfer of the administrative duties and oversight of the California TBI Program, effective January 1, 2010, from DMH to DOR. The bill requires DHCS to submit a HCBS waiver application or amendment of the state plan by March 1, 2011, an extension of the original due date.

<sup>33</sup> Assembly Bill 1410, Feuer, Chapter 676, Statutes of 2007. Available at: [http://info.sen.ca.gov/pub/07-08/billasm/ab\\_1401-1450/ab\\_1410\\_bill\\_20071014\\_chaptered.pdf](http://info.sen.ca.gov/pub/07-08/billasm/ab_1401-1450/ab_1410_bill_20071014_chaptered.pdf). Accessed November 7, 2009.

<sup>34</sup> Disability Rights California. Summary: AB 1410 (Feuer): Traumatic Brain Injury. Available at: <http://www.cce.csus.edu/conferences/cdmh/ctbi09/docs/AB%201410%20summary%20Final%20v2.pdf>. Accessed November 15, 2009.

<sup>35</sup> Assembly Bill 398, Monning, Chapter 439, Statutes of 2009. Available at: [http://info.sen.ca.gov/pub/09-10/billasm/ab\\_0351-0400/ab\\_398\\_bill\\_20091011\\_chaptered.pdf](http://info.sen.ca.gov/pub/09-10/billasm/ab_0351-0400/ab_398_bill_20091011_chaptered.pdf). Accessed November 8, 2009.

### III. STAKEHOLDER MEETINGS

A key activity of the TBI State Implementation Grant's no-cost extension was to develop a project report to assist with the development of a Medicaid (Medi-Cal) waiver and/or State Plan Amendment to enhance TBI services with additional federal support. A critical element of this activity was engaging TBI stakeholders. Persons with TBI, family members and other caregivers, advocates, and providers provided critical information, compelling stories, and thoughtful recommendations on how best to develop and increase access to a more comprehensive and coordinated TBI service system. Key to the success of the stakeholder meetings was the active participation of the TBI Advisory Board. The Board met several times with the DMH project team to develop a consumer-driven plan to solicit TBI stakeholder feedback through a series of regional meetings.

To develop the discussion areas and questions for the stakeholder meetings, Board members reviewed the foundational report, California Traumatic Brain Injury Planning Project: Needs and Resource Assessment (2002), presented by members of California's previous TBI Advisory Board.<sup>36</sup> The report was a core component of an earlier TBI Planning Grant awarded to DMH in 1999 by HRSA. Members of the current Board also participated in a Strengths, Weaknesses, Opportunities, and Threats Analysis (see Appendix F: SWOT Analysis), to understand the current environment with regard to enhancing California's TBI service system. The Board and DMH project team developed the stakeholder meeting agenda using findings from the Needs and Resource Assessment report and SWOT Analysis.

Finally, Board members assumed a critical leadership role in identifying and coordinating the regional stakeholder meeting venues, integrating many of the meetings into existing TBI meetings or other appropriate forums to maximize TBI stakeholder attendance. Many Board members attended as well as helped to facilitate the meetings, further enhancing the stakeholder process with their insight, experience, and expertise.

#### A. Meeting Dates and Locations

Six in-person regional stakeholder meetings and one conference call (listed below) were conducted in October and November 2009 to gather valuable stakeholder feedback. The in-person meetings were held in Sacramento, Burbank, San Diego, San Jose, and Visalia. Information about the meetings was promoted to persons with TBI, caregivers, and providers via phone calls, e-mail, and a TBI Stakeholder Meeting website. In addition, flyers promoting the meetings were translated into five different languages and distributed widely throughout the state.

#### Stakeholder Meetings:

- **Sacramento Head Trauma Support Project (Easter Seals)**  
Sacramento, California  
Thursday, October 8, 2009  
7:00 P.M. – 8:45 P.M.
- **State Independent Living Council Meeting**  
Burbank, California  
Tuesday, October 13, 2009  
1:00 P.M. – 3:00 P.M.

<sup>36</sup> California Department of Mental Health, California Traumatic Brain Injury Planning Project: Needs and Resource Assessment, 2002. [www.dmh.ca.gov/Services\\_and\\_Programs/Adults/docs/TBI\\_docs/TBI\\_needs\\_assessment.pdf](http://www.dmh.ca.gov/Services_and_Programs/Adults/docs/TBI_docs/TBI_needs_assessment.pdf). Accessed December 29, 2009.

- **Traumatic Brain Injury Survivor Support Group (American River College)**  
Sacramento, California  
Wednesday, October 14, 2009  
2:30 P.M. – 4:00 P.M.
- **California Association of Post Secondary Educators of the Disabled Convention**  
San Diego, California  
Monday, October 19, 2009  
1:45 P.M. – 4:30 P.M.
- **Traumatic Brain Injury Survivor Support Group (TBI Matters)**  
San Jose, California  
Wednesday, October 21, 2009  
6:00 P.M. – 8:00 P.M.
- **Traumatic Brain Injury Stakeholder Statewide Conference Call**  
Thursday, October 29, 2009  
3:00 P.M. – 5:00 P.M.
- **Traumatic Brain Injury Survivor Support Group (Jeff Barnes Foundation)**  
Visalia, California  
Thursday, November 12, 2009  
6:00 P.M. – 8:00 P.M.

## **B. Key Feedback by Core Service Area**

The regional stakeholder meetings provided TBI stakeholders - persons with TBI, family members and other caregivers, and providers – with an opportunity to share valuable medical, rehabilitation, community, legal, education, and vocational service experiences and to give input on what is missing and what is needed for persons living with TBI to manage their injury and maximize their ability to function independently in the community. The summary feedback, reflecting diverse stakeholder voices from around the state, directly contributed to and informed the state’s next steps for enhancing TBI services and supports for persons with TBI.

Each meeting was facilitated and opened with background information on the TBI Project and California’s current TBI service system structure. Following the introduction, participants were invited to discuss five core TBI service areas, identified by TBI stakeholders as the most critical core service areas, and respond to the same set of questions for each area. Working definitions for each core area were provided. Note: these core service areas differ slightly from the core services provided by the California TBI sites.

### **TBI Core Service Areas:**

- Community Reintegration Services
- Family and Community Education
- Service Coordination Services
- Vocational Support Services/Extended Supported Employment Services
- Supported Living Services

## Follow-Up Questions for Each Service Area or Type:

- What services are needed and for whom (which specific communities or populations)?
- What are the barriers to existing services and development of new services?
- Who are the providers? Who can be providers – what are their qualifications?
- What opportunities are there at the local level for collaboration to better serve persons, long-term, with TBI?
- What is reimbursed and what is not reimbursed under insurance (Medicare, Medi-Cal, private insurance, etc.)?

Feedback from the meetings was recorded and organized by core TBI service area and follow-up question. Key stakeholder feedback, reflecting repeated comments in each core area and corresponding follow-up question category, was subsequently identified and is presented in italics. The working definition for each core area is also cited. Note: variation in stakeholder feedback by response category is reflected in the findings – not all five follow-up question categories elicited feedback.

### 1. Core TBI Service Area: Community Reintegration Services

#### **Working Definition: *Community Reintegration Services***

Community reintegration consists of “services needed by participants that are designed to develop, maintain, increase, or maximize independent functioning, with the goal of living in the community and participating in community life.” Community reintegration services may include but are not limited to providing or arranging for access to housing, transportation, medical care, rehabilitative therapies, day programs, chemical dependency recovery programs, personal assistance, and education.

#### **Stakeholder Responses:**

##### **Question 1: What services are needed and for whom (which specific communities or populations)?**

- *Early intervention is the best determinant of outcomes for a person with TBI; promote development of early intervention TBI treatment protocols.*
- *There is a big demand for Section 8 (US Department of Housing and Urban Development housing rental program for low-income individuals); however, few actually get it and those who do, don't leave, so opportunities for low-income housing for persons with TBI are limited.*
- *The most important fact about community reintegration is that persons with TBI often need help in this core area multiple times and at different junctures in their recovery because of the complexity of their injury, and changes in their medical condition, living arrangement, or caregiving situation.*
- *Provide more legal, advocacy, and transportation services for persons with TBI and expand the number of support groups for persons with TBI and their family members.*
- *Link community support services for persons with TBI to the network of ILCs.*

**Question 2: What are the barriers to existing services and development of new services?**

- *Comprehensive Community college programs for TBI students are great, but most don't have the counseling and individualized services that students need, and all have had recent cuts in state funding, further limiting services for persons with TBI.*
- *Medi-Cal eligibility is very restrictive and does not take into consideration the cognitive, physical, and emotional complexities associated with a TBI. Recent cutbacks in Medi-Cal additionally challenge opportunities for persons with TBI to receive the medical support they need to address ongoing symptoms.*
- *A significant barrier for persons with TBI is the absence of a robust TBI data collecting and reporting system, which inhibits coordination between agencies and services. Establish a TBI data registry to increase coordination between agencies, improve program effectiveness, and ensure system accountability and improve outcomes.*

**Question 3: Who are the providers? Who can be providers – what are their qualifications?**

- *We need to provide more education about TBI to physicians. They should know the main causes: falls, motor vehicle accidents, assaults, sporting accidents, etc. and how to prevent, assess and treat TBI.*
- *The state needs to understand that TBI providers include a wide range of professionals, paraprofessionals, and lay persons. They range from physicians, rehabilitation therapists, social workers/counselors, and first responders (police, fire, etc.) to community college educators, employers, and volunteers.*
- *Create partnerships between the VA's polytrauma system for veterans with TBI and the state's formal and informal TBI service system.*

**Question 4: What opportunities are there at the local level for collaboration to better serve persons, long-term, with TBI?**

- *Establish community forums or task forces to address TBI – include community colleges, VA Medical Centers, rehabilitation programs, hospitals, community support groups, adult education programs, public schools, and local universities.*
- *Join efforts with dementia service providers – share caregiver and cognitive information and support services.*

**Question 5: What is reimbursed and what is not reimbursed under insurance (Medicare, Medi-Cal, private insurance, etc.)?**

- *Medi-Cal recipients fall through the cracks because there are not enough Medi-Cal service providers offering outpatient rehabilitation (physical therapy, occupational therapy, speech therapy, cognitive training, etc.).*
- *Residential and extended brain injury recovery programs are not available to most persons with TBI unless the individual has deluxe private medical insurance that covers these programs or can use his or her own private funds.*
- *Insurance (all types) provide rehabilitation coverage only to the point where the person with TBI is no longer making progress; however, recovery for many is a lifelong process.*

- *Establish insurance coverage for long-term rehabilitation and community reintegration programs - include case management and counseling, which persons with TBI should be able to access according to their individual recovery needs.*

## 2. Core TBI Service Area: Family and Community Education

### **Working Definition: Family and Community Education**

Family and community education refers to the provision of information designed to improve overall understanding of the nature and consequences of TBI, including public and professional education designed to facilitate early identification of persons with TBI, prompt referral of these persons to appropriate services, and improvement of the system of services available to them.

### **Stakeholder Responses:**

#### **Question 1: What services are needed and for whom (which specific communities or populations)?**

- *Public perceptions and attitudes about TBI need to change – most people don't understand the injury and its impact. We should educate the public about TBI, targeting schools, employers, sports programs, etc.*
- *Families and persons with TBI do not have enough information about TBI after the injury and post-discharge from the acute care hospital. Most don't know where to go for help or who to speak with. More information about state and federal benefits for persons with TBI is needed. Create a website with one-stop shop information for persons with TBI and families.*
- *Advocacy is a huge component of family and community education about TBI. Unless communities are educated about this injury it will remain a fringe issue receiving little public attention.*
- *Provide advanced training about TBI to emergency department personnel, physicians, nurses, and first responders.*

#### **Question 2: What are the barriers to existing services and development of new services?**

- *TBI is both an undiagnosed and under-diagnosed injury. Further educate medical personnel about TBI and ensure that hospitals have designated personnel on staff with knowledge of TBI to educate persons with TBI and their families.*
- *Many staff members working for various state agencies, such as the In-Home Supportive Services (IHSS) program, do not understand TBI and the complex cognitive and emotional needs of persons with TBIs. Individuals maybe assessed as highly functional even when they are not, and consequently receive reduced service support levels. A more coordinated and appropriate educational and collaborative approach to serving persons with TBI needs to be created.*
- *Improve understanding of regulations associated with the Health Insurance Portability and Accountability Act (HIPAA) so volunteers, when appropriate, can connect with persons with TBI and families prior to hospital discharge.*

#### **Question 3: Who are the providers? Who can be providers – what are their qualifications?**

- *TBI educational providers include a wide-range of medical professionals, schools including community colleges, and health and social service agencies.*

- *There needs to be greater coordination among those providing federal benefits (Medicaid, Supplemental Security Income - SSI, or Social Security Disability - SSDI) and state services (all departments sponsoring programs that serve persons with TBI) to persons with TBI.*
- *Providers providing family and community education about TBI can be any of the following: grassroots groups (paid/unpaid, volunteers); emergency personnel and first responders, inpatient and outpatient medical and rehabilitation professionals, schools, human resource departments, the Veterans Administration, senior centers, social service and advocacy organizations.*

### 3. Core TBI Service Area: Service Coordination Services

#### **Working Definition: Service Coordination Services**

Service coordination activities may include provision of the following: information and resources for participants; advocacy; participant and family education about options; liaison for participants among service providers; problem solving with participants; and, monitoring and following-up on well being and progress.

#### **Stakeholder Responses:**

##### **Question 1: What services are needed and for whom (which specific communities or populations)?**

- *The biggest issue is case management. Case management services need to be available long-term and on an as-needed basis to help persons with TBI identify viable housing, vocational training, employment, education, social and recreational activities, and other options.*
- *Families do the majority of the work involved with coordinating services for a loved one with TBI. For those who don't have families, persons with TBI are their own case managers.*
- *ILCs, Aging Disability Resource Centers (ADRCs), and TBI sites can provide valuable service coordination.*

##### **Question 2: What are the barriers to existing services and development of new services?**

- *For many severely injured persons with TBI there may be a social worker helping the individual in the hospital and then in the outpatient rehabilitation setting, but after outpatient care services end so does the case management, yet the needs continue. Expand current service coordination and case management programs provided through the TBI sites, ILCs, and ADRCs.*
- *The state-funded TBI sites are great but they don't provide enough services because of their funding structure and they do not cover the whole state. Develop and train a workforce to provide TBI service coordination; train social workers, community workers, volunteers, etc.*
- *No one-size-fits-all when it comes to services for persons with TBI. All coordination must be provided on an individualized basis for as long as needed.*

##### **Question 3: Who are the providers? Who can be providers – what are their qualifications?**

- *Social workers, community workers, volunteers, and others can be used as case managers/ service coordinators, but they need ongoing training, education, oversight, and support, so they understand TBI and the short- and long-term needs of persons with this injury.*
- *Family members play a central role in service coordination for their loved ones, so there should be education, training, and support for family members who serve in this role.*

#### 4. Core TBI Service Area: Vocational Support Services/Extended Supported Employment Services

##### **Working Definition: Vocational Support Services/Extended Supported Employment Services**

Vocational support services means a method of providing vocational rehabilitation and related services to targeted individuals not served or underserved by existing vocational rehabilitation services. Supported employment is competitive work in integrated work settings, consistent with the capabilities, interests, and informed choice of the consumer with the added provision of ongoing and intensive supports necessary for long-term employment retention. Supported employment is intended for consumers where competitive employment has either not occurred, or is interrupted or intermittent as a result of a significant disability. Extended supported employment services references ongoing support services and other appropriate services needed to support and maintain an individual with TBI in supported employment.

##### **Stakeholder Responses:**

##### **Question 1: What services are needed and for whom (which specific communities or populations)?**

- *The DOR provides vocational rehabilitation, but the services are not extensive and staff from DOR are not always familiar with TBI – they are often more familiar with physical disabilities.*
- *Expand vocational rehabilitation and extended supported employment services - coordinate efforts with DOR, community colleges, and DDS providers.*
- *Create a field of job coaches – a workforce that can assist persons with TBI in the retraining and employment fields.*

##### **Question 2: What are the barriers to existing services and development of new services?**

- *Overall, there are few vocational and employment retraining and support programs, other than Workers' Compensation; for this reason, it is important to initiate simultaneous efforts to coordinate vocational and extended employment at both the state (between departments and systems) and local levels (between providers including community colleges).*
- *It is difficult to access vocational services because of limited transportation or family support (e.g., to bring the person with TBI to the training program). These important factors impact the ability of persons with TBI to attend vocational support services.*
- *It is important to understand that supportive vocational and employment services may be required for an indefinite period of time, depending on the severity of the brain injury.*

##### **Question 3: Who are the providers? Who can be providers – what are their qualifications?**

- *Some providers are private and work with the Workers' Compensation Program; other providers include community colleges, rehabilitation programs, and DOR programs.*

**Question 5: What is reimbursed and what is not reimbursed under insurance (Medicare, Medi-Cal, private insurance, etc.)?**

- *Vocational support and employment support (including extended employment support) are typically only covered for the person with TBI who is injured on the job and receives Workers' Compensation.*
- *Need to establish coverage for vocational support and extended supported employment through private and public insurance policies or state-sponsored programs.*

**5. Core TBI Service Area: Supported Living Services**

**Working Definition: Supported Living Services**

Supported living services are designed to increase a participant's independent living skills and include supervision, support, and training in the participant's place of residence or other setting.

**Stakeholder Responses:**

**Question 1: What services are needed and for whom (which specific communities or populations)?**

- *There are few housing options for persons with TBI. Those who have mild to moderate injuries live with family, some live alone, and those with severe injuries are typically cared for by family or are placed in a skilled nursing facility.*
- *Many skilled nursing facilities don't want TBI residents because they do not "fit in" – they tend to be younger than most residents and often have accompanying behavioral difficulties.*
- *We should not recommend a single one-size-fits-all supported living model. We need options – transitional housing, group homes, and residential treatment facilities that are covered by insurance.*
- *Create community coalitions to establish accessible and supported living options. Long-term care is needed for persons with TBI with severe emotional and behavioral problems.*

**Question 2: What are the barriers to existing services and development of new services?**

- *The biggest barrier to supported living options is funding. Few private insurers cover supported living and those that do, typically do so only for a short period of time.*
- *Right after discharge, persons with TBI mostly go home with a family member because there are no options for supported living. Persons with TBI without families to help are at increased risk of becoming homeless and vulnerable to additional injury and abuse.*
- *The lack of affordable and organized supported living options lead many family members to quit their jobs to care for their loved one with TBI. Then, even if they are low income, they may not receive IHSS payment for their caregiving because their loved one with TBI may not be eligible for the service.*

## Feedback and Recommendations from Skilled Nursing Facility Operators

An interview conducted with several California skilled nursing facility operators offered additional feedback and recommendations on the subject of supported living options for persons with TBI.<sup>37</sup>

The operators reported that although admitting persons with TBI into nursing facilities poses unique challenges, especially when the person with TBI is young, has no insurance, and presents behavioral difficulties (physical aggression, verbal abuse, disruptive outbursts, etc.), most skilled nursing facilities have a small subpopulation of residents with TBI. Within this population, they noted, the majority either have very severe head injuries, or medical histories that often include multiple TBIs, physical disabilities, past substance abuse, or mental illness, making caring for this particular group of injured individuals in the home setting difficult.

The operators indicated that while some TBI nursing home residents may be eligible to transition back to the community with appropriate support, most would require 24-hour care and support. They suggested that more research be done to explore the feasibility of funding group homes (through waivers or other appropriate funding vehicles) for individuals with severe TBI, where they could receive appropriate health care, rehabilitation services, and behavior management support.

### C. Goals and Summary Themes

After the initial organization of the stakeholder feedback, the findings were further catalogued and analyzed to identify summary themes and emergent goals. Patterned responses reflecting the most common stakeholder concerns, experiences, and recommendations revealed summary themes in each core service area. A subsequent process of synthesizing the themes to explore relationships and interconnectedness across the service areas led to the emergence of four broad long-term goals. The goals represent and address the most significant needs for persons with TBI, as reported by stakeholders. The goals and supporting summary themes are outlined below:

#### Goals

- Provide long-term support and insurance coverage for a host of community reintegration services and activities.
- Establish accessible and affordable supported living options.
- Coordinate TBI services at the state and local level.
- Improve TBI data collection and reporting to enhance TBI program effectiveness and system accountability.

The four goals impact not only TBI stakeholders and the organizations that serve them, but also the five core TBI service areas, either directly or indirectly. They focus on the identified need for support services and insurance coverage to help persons with TBI with long-term community integration, as well as the need for viable housing options, coordinated services at every level, and improved tracking and reporting systems. Together, the goals highlight next step strategic directions for enhancing California's TBI service system.

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<sup>37</sup> Interviews were conducted with representatives from Crestwood Behavioral Health, Inc., Idlywood Care Center, Sunnyvale, CA.

## **Summary Themes by Core Service Area**

### **Community Reintegration Services**

1. Revise Insurance Coverage for Persons with TBI – revise current public and private insurance policies to cover post-hospital medical and rehabilitation services and residential treatment programs on an ongoing, as needed, basis.
2. Promote Early Intervention and Create Community TBI Consortia – promote development of early intervention TBI treatment protocols; educate providers who interact with persons with TBI at every level – local, state, and federal; and, establish TBI consortia, with the full range of community based stakeholder partners (including TBI sites, ILCs, ADRCs, community colleges, public and private service and advocacy organizations, state programs, VA Medical Centers, etc.) to improve coordination of TBI services.
3. Advance TBI Data Collection and Reporting Systems – revise current TBI data tracking and reporting systems to accurately record the incidence, prevalence, and long-term impact of TBI.

### **Family and Community Education**

1. Enhance Public Awareness – expand current TBI public education efforts to address misperceptions, discrimination, and limited understanding of the injury. Target schools, employers, sports programs, etc.
2. Create Statewide TBI Website – organize a website with information for persons with TBI, family members/caregivers, and providers addressing a wide range of TBI issues and needs (support groups, legal services, benefits information, etc.). Include chat rooms, community resources, and instructional videos for persons with TBI and family members.

### **Service Coordination Services**

1. Develop Long-Term Service Coordination/Case Management Services – provide individualized and ongoing (as-needed), service coordination or case management services.
2. Enhance Workforce Capacity for Service Coordination – develop and train a workforce (social workers, community workers, volunteers) to provide TBI service coordination.

### **Vocational Support Services/Extended Supported Employment Services**

1. Expand Vocational Support/Extended Supported Employment Services – increase vocational and extended employment support for persons with TBI; coordinate efforts with DOR, community colleges, and DDS.
2. Establish Job Coaches – create and train job coaches to work with persons with TBI during vocational rehabilitation and in supported employment.

### **Supported Living Services**

1. Create Supported Living Options – provide accessible, affordable, and subsidized supported living options to include independent living, group homes, transitional homes, nursing homes, and residential facilities.
2. Address IHSS Eligibility for Persons with TBI – educate IHSS workers about TBI, so persons with TBI who need IHSS can remain in the community by receiving appropriate levels of care and support.

## IV. NEXT STEPS

Members of the TBI Advisory Board and representatives from the California Health and Human Services Agency (CHHS) and multiple state departments, including DMH, DOR, DHCS, and the Department of Social Services (DSS) reviewed the stakeholder feedback summary themes, responses, and proposed goals. Based on this feedback, they reviewed opportunities to apply for waiver and State Plan Amendment options to further advance California's TBI service system. This final section provides an overview of waiver and State Plan Amendment options; side-by-side charts of potential waiver and State Plan Amendment options, with the primary elements of each option matched with recorded stakeholder needs; and, a summary of opportunities for additional collaboration at the state level to enhance services and supports for persons with TBI.

### A. State Waiver/State Plan Amendment Options: Overview

When a state wants to make significant changes to its Medicaid program, it must take one of two steps: either (1) receive an exemption or “Medicaid waiver” from portions of Title XIX of the Social Security Act by the U.S. Department of Health and Human Services; or (2) amend its State Medicaid Plan – a document approved by the federal government.<sup>38</sup>

#### Waivers

The State has discretion to design its waiver program to address the needs of the waiver's target population within the parameters of Medicaid waivers available through the federal government. Waiver services complement and/or supplement the services that are available to participants through the Medicaid State Plan and other federal, state, and local public programs as well as the supports that families and communities provide. The waiver services however, cannot duplicate state plan services. Two sections of the Social Security Act, Sections 1915 and 1115, allow states to apply to the federal government to obtain an exemption from particular Medicaid statutes. These two sections describe two types of Medicaid waivers:<sup>39</sup>

- **Program Waivers:** These waivers, authorized under Sections 1915(b) or (c) of the Social Security Act, allow exemptions from parts of Section 1902 of the Social Security Act relating to managed care or home and community-based care.<sup>40</sup>
- **Research and Demonstration Waivers:** Section 1115 allows the waiver of a broader scope of Medicaid laws in Section 1902 for the purpose of experimentation or testing pilot programs.<sup>41</sup>

#### Section 1915 (c)

The 1915(c) waiver, or the Home and Community-based Services (HCBS) waiver which allows states to provide services to Medicaid populations in home or other community based settings rather than in institutional or long-term care facilities such as hospitals or nursing homes. The HCBS waiver allows states to cover services beyond the scope of traditional Medicaid benefits to cover additional medical and non-medical services. The Social Security Act specifies services that may be provided under a 1915(c) waiver: case management (service coordination), skilled nursing, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. The array of services

<sup>38</sup> Lewis, V. Medicaid Waivers: *California's Use of a Federal Option*; California HealthCare Foundation, March, 2000,

<sup>39</sup> Sowers, M. Home and Community Based Services 1915(i), 1915(j), 1915(c). Centers for Medicare and Medicaid.

<sup>40</sup> Social Security Act, Section. 1902. [42 U.S.C. 1396a]. Compilation of the Social Security Laws: Available at: [http://www.ssa.gov/OP\\_Home/ssact/title19/1902.htm](http://www.ssa.gov/OP_Home/ssact/title19/1902.htm). Accessed November 21, 2009.

<sup>41</sup> Social Security Act, Section. 1115. [42 U.S.C. 1315]. Compilation of the Social Security Laws: Available at: [http://www.segurosocial.gov/OP\\_Home/ssact/title11/1115.htm](http://www.segurosocial.gov/OP_Home/ssact/title11/1115.htm). Accessed November 21, 2009.

may be expanded when requested by states and approved by CMS to include such services as non-medical transportation, in-home support services, special communication services, and minor home modifications, and adult day care. Some states have used this waiver for persons with TBI. Note: As part of the federal requirements, the state must achieve cost neutrality with HCBS waivers. That is, the HCBS waiver programs must be more cost effective than institutional care, i.e., the cost of the federal match for the waiver must not exceed the amount that would have been paid without the waiver.

### **Section 1115**

Section 1115 of the Social Security Act provides the Secretary of Health and Human Services, United States Department of Health and Human Services, broad authority to authorize experimental, pilot, or demonstration projects likely to assist in promoting the objectives of the Medicaid statute. Flexibility under Section 1115 is sufficiently broad to allow states to test substantially new ideas of policy merit. These projects are intended to demonstrate and evaluate a policy or approach that has not been demonstrated on a widespread basis. Some states expand eligibility to individuals not otherwise eligible under the Medicaid program, provide services that are not typically covered, or use innovative service delivery systems.

### **State Plan Amendment**

A State Plan Amendment is the means by which a state changes its Title XIX Medicaid State Plan. Every proposed plan change is submitted to CMS in a State Plan Amendment. The following are several options for amending the State Plan Amendment. Each state can only have one 1915(i). Currently, one developed by DHCS and DDS has been submitted to CMS.

### **Section 1915(i)**

The Deficit Reduction Act created a new choice with which states may provide home and community based services in their Medicaid plan – a unique type of state plan benefit with similarities to HCBS waivers. It was created under Section 6086 of the Act, which adds a provision to Medicaid under Section 1915(i). As a result, some refer to it as the 1915i State Plan Amendment—or simply as the “i option.” Budget neutrality is not required for this State Plan Amendment. The state must give the federal government the required information on who is being served and the services, but it does not have to include cost information to show budget neutrality. States can write needs-based criteria and define services so they are helpful to a particular population. Eligibility is not based on disability or age but on functional need. This option breaks the “eligibility link” between HCBS and institutional care needs required under 1915 (c) waivers.<sup>42</sup>

Section 1915(i) of the Act allows the provision of specific HCBS under the State plan. These services are listed in section 1915(c)(4)(B) of the Act that governs HCBS waivers. The services listed in section 1915(c)(4)(B) of the Act are: case management services, homemaker/home health aide services, personal care services, adult day health services, habilitation services, and respite care. In addition, the following services may be provided for individuals with chronic mental illness: day treatment, other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility). As with other State plan services, States may impose criteria of medical necessity or requirements for prior authorization and utilization control to ensure the appropriate level of services furnished to an eligible individual. In addition, States may establish a maximum utilization level of a particular service furnished under the State plan HCBS option.

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<sup>42</sup> Social Security Act, Section. 1915. [42 U.S.C. 1396n]. Compilation of the Social Security Laws: Available at: [http://www.ssa.gov/OP\\_Home/ssact/title19/1915.htm](http://www.ssa.gov/OP_Home/ssact/title19/1915.htm). Accessed November 21, 2009.

**Section 1915 (j)**

A State may provide, as “medical assistance”, payment for part or all of the cost of self-directed personal assistance services (other than room and board) under the plan which are provided pursuant to a written plan of care to individuals with respect to whom there has been a determination that, but for the provision of such services, the individuals would require and receive personal care services under the plan, or home and community-based services provided pursuant to a waiver under subsection (c). Self-directed personal assistance services may not be provided under this subsection to individuals who reside in a home or property that is owned, operated, or controlled by a provider of services, not related by blood or marriage.

## B. Waiver/State Plan Amendment Side-by-Side Charts

To inform development of either a state Medi-Cal waiver application and/or State Plan amendment, the following side-by-side charts profile key elements of several potential waiver and State Plan Amendment options matched with identified TBI stakeholder needs.

**Table 1: 1915 (c) Waiver Option**

<b>1915 (c) Key Program &amp; Eligibility Requirements</b>	<b>Matched Stakeholder Needs</b>
<p><u>Program Requirements:</u></p> <ul style="list-style-type: none"> <li>• Program must achieve cost neutrality.</li> </ul>	<p><u>Program Recommendation:</u></p> <ul style="list-style-type: none"> <li>• Use the 7 TBI sites to provide designated services under this waiver to eligible persons with TBI.</li> </ul>
<p><u>Eligibility:</u></p> <p>Persons who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities. States are allowed to limit the availability of services geographically, target specific populations or conditions, control the number of people serviced, and cap overall expenditures.</p>	<p><u>Eligibility:</u></p> <p>Medi-Cal beneficiaries with TBI who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities.</p>
<p><u>Key Elements:</u></p> <p>Provide medical assistance to individuals for:</p> <ul style="list-style-type: none"> <li>• Case Management Services</li> <li>• Homemaker/Home Health Aide Services and Personal Care Services</li> <li>• Habilitation Services*</li> <li>• Respite Care</li> <li>• For Chronic Mental Illness:               <ul style="list-style-type: none"> <li>- Day Treatment or Partial Hospitalization</li> <li>- Psychosocial Rehabilitation</li> <li>- Clinic Services.</li> </ul> </li> </ul> <p>* Habilitation Services means services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings; and includes pre-vocational, educational, and supported employment services. As opposed to State Plan services, CMS may waive requirements of statewideness, comparability of services (to the overall Medicaid State Plan beneficiary population) and income and resource rules applicable in the community.</p>	<p><u>Key Needs:</u></p> <ul style="list-style-type: none"> <li>• Case Management Services</li> <li>• Homemaker/Home Health Aide Services and Personal Care Services</li> <li>• Habilitation Services – includes self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings and prevocational, educational, and supported employment services.</li> </ul> <p>Note: AB 1410 required that services provided under the waiver be provided by project sites (7 TBI sites) providing services to adults with acquired traumatic brain injuries, as described by existing law, and would expand the services that these projects would be permitted to provide.</p>

**Table 2: 1915 (i) State Plan Amendment Option**

1915 (i) Key Program & Eligibility Requirements	Matched Stakeholder Needs
<p><u>Program Requirements:</u></p> <ul style="list-style-type: none"> <li>• Only one State Plan amendment under 1915 (i) per state.</li> <li>• 1915 (i) is based on a specific set of functional needs.</li> </ul>	<p><u>Program Recommendation:</u></p> <ul style="list-style-type: none"> <li>• Collaborate with current state efforts exploring the 1915 (i) State Plan Amendment Option – assess the opportunity to integrate extended employment services for persons with TBI into the 1915 (i) State Plan Amendment consistent with the specific set of needs currently being addressed with this option.</li> </ul>
<p><u>Eligibility:</u></p> <ul style="list-style-type: none"> <li>• Must be eligible for medical assistance under the state plan (Medi-Cal).</li> <li>• Must have income that does not exceed 150% of the Federal Poverty Level (FPL).</li> <li>• States must provide needs-based criteria to establish who can receive the benefit.</li> <li>• Must reside in the community.</li> <li>• Eligibility is not based on disability or age but on functional need.</li> </ul> <p>Does not require individuals to be at a nursing facility level of care.</p>	<p><u>Eligibility:</u></p> <ul style="list-style-type: none"> <li>• Medi-Cal beneficiaries</li> <li>• Income that does not exceed 150% of the (FPL).</li> <li>• Meets State’s needs-based criteria</li> <li>• Resides in the community.</li> </ul>
<p><u>Key Elements:</u></p> <p>Any of the statutory 1915(c) services:</p> <ul style="list-style-type: none"> <li>• Case Management</li> <li>• Homemaker</li> <li>• Home Health Aide</li> <li>• Personal Care</li> <li>• Habilitation</li> <li>• Respite Care</li> <li>• For Chronic Mental Illness:               <ul style="list-style-type: none"> <li>- Day Treatment or Partial Hospitalization</li> <li>- Psychosocial Rehabilitation</li> <li>- Clinic Services</li> </ul> </li> </ul>	<p><u>Key Needs:</u></p> <ul style="list-style-type: none"> <li>• Under this option the needs for persons with TBI reflect the services covered by 1915 (i); however, consistent with the specific set of needs currently under consideration for this option, integrating supported employment services for persons with TBI using providers currently offering these services to other designated communities may be an appropriate option.</li> </ul>

**Table 3: 1915 (j) Self-Directed State Plan Amendment Option**

1915 (j) Key Program & Eligibility Requirements	Matched Stakeholder Needs
<p><u>Program Requirements:</u></p> <ul style="list-style-type: none"> <li>California recently converted the ended IHSS Plus 1115 waiver to the 1915 (j) State Plan Option. Under the 1915 (j) State Plan, states may elect to provide self-directed personal assistance services (PAS) in the State Plan, so demonstrations and waivers would not be necessary.</li> <li>States have the option to amend their State plan to provide self-directed PAS to beneficiaries, without regard to the Medicaid requirements of comparability or statewideness.</li> </ul>	<p><u>Program Recommendation:</u></p> <ul style="list-style-type: none"> <li>Collaborate with the current 1915 (j) State Plan Option to address the needs of persons with TBI eligible for PAS under this option.</li> </ul>
<p><u>Eligibility:</u></p> <ul style="list-style-type: none"> <li>Must be eligible for medical assistance under the State plan (Medi-Cal).</li> <li>Self-directed State plan PAS are not available to individuals who reside in a home or property that is owned, operated, or controlled by a provider of services not related to the individuals by blood or marriage.</li> </ul>	<p><u>Eligibility:</u></p> <ul style="list-style-type: none"> <li>Medi-Cal beneficiaries receiving IHSS.</li> <li>Eligible persons with TBI do not reside in a home or property that is owned, operated, or controlled by a provider of services not related to the individuals by blood or marriage.</li> </ul>
<p><u>Key Elements:</u></p> <p>Individuals have an approved self-directed service plan and budget: individuals exercise choice and control over budget, planning, and purchases of PAS; individuals' needs, strengths, preferences for PAS are assessed; and, the plan for services and supports is developed using person-centered planning process. Program characteristics include:</p> <ul style="list-style-type: none"> <li>Advance Pay (cash option)</li> <li>Restaurant Meal Allowance</li> <li>Services Provided by Parent/Spouse</li> <li>Self-Direction of Services</li> </ul>	<p><u>Key Needs:</u></p> <ul style="list-style-type: none"> <li>Persons with TBI receiving IHSS would be eligible for PAS under the 1915 (j) State Plan Option.</li> </ul>

## C. Other Avenues to Action

DHCS will explore opportunities to submit a HCBS waiver application or amendment of the State Plan [Medicaid (Medi-Cal)] for HCBS to serve more persons with TBI; however, neither will solely meet all of the needs of Californians with TBI. Waiver or State Plan Amendment options must be matched with additional dedicated efforts to enhance the TBI service system. The TBI State Implementation Grant yielded important stakeholder recommendations regarding advancing a more accessible and comprehensive TBI service system, and equally provided a foundation for collaboration among diverse stakeholder groups. Following the stakeholder meetings, members of the TBI Advisory Board and representatives from CHHS, DMH, DOR, DHCS, and DSS met to review the recommendations and discuss next steps. The group also identified the following state-level projects, programs, and endeavors to enhance and expand TBI services for persons with TBI. Note: concluding this subsection, are highlights from a hearing on TBI before the California Senate Health Committee on January 13, 2010.

1. DOR, which begins administering the TBI sites January 1, 2010, identified several areas to explore, to better serve persons with TBI:
  - Supported Employment and “On-the-Job Training” (via Vocational Rehabilitation)
  - Independent Living
  - Job Coaching
  - Assistive Technology (cueing/reminder devices)

In addition, DOR recently awarded the Traumatic Brain Injury-Veterans Services Expansion Grant, funded by President Obama’s American Recovery and Reinvestment Act of 2009 (ARRA), to the Central Coast Center for Independent Living (Salinas, CA). This grant will increase independent living service capacity and coordinate existing services and programs for veterans with TBI and other persons with TBI.

2. DHCS is implementing the “California Community Transitions” (CCT) program – a Money Follows the Person Rebalancing Demonstration. CCT allows eligible Medi-Cal beneficiaries, including persons with TBI, who have been receiving services in nursing or other inpatient health care facilities for six months or longer to transition to a community setting, if that is their preference. U.S. Department of Housing and Urban Development (HUD) will release Section 8 Housing vouchers for program participants to local housing authorities that apply.
3. The Ticket to Work (TTW) and Self-Sufficiency Program is a work incentive program for Social Security Administration’s (SSA) SSDI or SSI beneficiaries who are between the ages of 18 and 64 and interested in going to work. The “Ticket” can be used to obtain employment services and support from State Vocational Rehabilitation (VR) Agencies such as the DOR or SSA-approved service providers called Employment Network (EN) under the TTW program. Providers are paid through SSA funds based on individuals’ milestone achievements or reimbursed upon successful employment outcomes.
4. DSS, through the IHSS program, provides personal care, support for activities of daily living (eating, dressing, getting into or out of a bed or chair, taking a bath or shower, and using the toilet), and some support with instrumental activities of daily living related to independent living (eating, dressing, getting into or out of a bed or chair, taking a bath or shower, and using the toilet, and transportation). DSS plans to follow-up on issues raised by stakeholders regarding persons with TBI and the IHSS program.

5. For the past twelve years the State Plan for Independent Living (SPIL) has identified persons surviving traumatic brain injury as an underserved population needing additional independent living services and funding. Efforts to reach and serve persons with TBI will continue through the SILC, DOR, and their partners.

A January 2010 presentation by California's lead TBI researchers, providers, and advocates before the California Senate Health Committee, *New Approaches in the Care and Treatment of Persons with Brain Injury: Overview of Traumatic Brain Injury in California*, highlighted multiple critical TBI issue areas, several of which complement the TBI State Implementation Grant project findings detailed in this report. Underscoring that the CDC defines TBI as a public health concern, the presenters called on the State to improve TBI data collection and surveillance to better understand its prevalence, causes, treatment options, and the long-term medical and social support needs of persons with TBI. They also outlined the following justifications for increasing financial access to treatment for persons with TBI and establishing TBI standards of care.<sup>43</sup>

- Medical rehabilitation is the single most effective treatment following brain injury.
- No other organ [referencing the brain], similarly injured is managed outside major medical benefits provision or with arbitrary time constraints on medical treatment.
- Contract language has not changed to keep pace with the evolution and provision of medical treatment outside traditional hospital settings.
- Substantial variations in treatment of TBI exist across the State. These variations are in part due to facility availability.
- Standards have been developed by national and state organizations and are in place in other parts of the country (e.g. Colorado, Texas).

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<sup>43</sup> California Brain Injury Association. *New Approaches in the Care and Treatment of Persons with Brain Injury*. California Senate Health Committee Hearing. California Senate Committee on Health, Senator Elaine K. Alquist, Chair. January 13, 2010, Sacramento.

## V. CONCLUSION

With input from persons with TBI, caregivers, and providers around the state, this report provides insight into the following goals stakeholders identified as important to advancing a more accessible and comprehensive TBI service system in California:

- Provide long-term support and insurance coverage for a host of community reintegration services and activities;
- Establish accessible and affordable supported living options;
- Coordinate TBI services at the state and local level; and,
- Improve TBI data collection and reporting to enhance TBI program effectiveness and system accountability.

To achieve these goals, and others, addressing the needs of persons with TBI and their caregivers, it is critical for stakeholders and representatives from multiple state departments to continue to work collaboratively. California will also move forward with exploring opportunities to enhance TBI services through leveraging state and federal resources, including a Medicaid (Medi-Cal) waiver and/or State Plan Amendment. At this time, there are three potential Medi-Cal program options for the state to consider:

- 1915 (c) Waiver Option - known as the “home and community-based services waiver” (HCBS) because it allows states to treat certain Medicaid populations in home or other community based settings rather than in institutional or long-term care facilities such as hospitals or nursing homes;
- 1915 (i) State Plan Amendment Option - a unique type of state plan benefit with similarities to HCBS waivers; and,
- 1915 (j) Self-Directed State Plan Amendment Option – an option in which states may provide, as “medical assistance”, payment for part or all of the cost of self-directed personal assistance services (other than room and board) under the State Plan.

Persons with TBI are all ages – infants, children, youth, young and middle-aged adults, including veterans from the Iraq and Afghanistan wars, and older adults. The urgency of addressing TBI as a public health concern is unmistakable. With renewed momentum to address TBI, it is time to look more closely at the incidence and prevalence of this injury in California and its effect on communities. As we embark upon the new decade, 2010 marks a milestone in efforts to develop and implement a comprehensive TBI service system that reaches all Californians.



# APPENDIX A

## ACRONYMS

Reference	Acronym
Acquired Traumatic Brain Injury Programs . . . . .	ABI
Aging and Disability Resource Centers. . . . .	ADRCs
Brain Injury Association of America. . . . .	BIAA
California Community Transitions . . . . .	CCT
California Brain Injury Association . . . . .	CALBIA
California Department of Developmental Services. . . . .	DDS
California Department of Mental Health. . . . .	DMH
California Department of Rehabilitation . . . . .	DOR
California Department of Social Services . . . . .	DSS
California Health and Human Services Agency . . . . .	CHHS
Centers for Disease Control and Prevention . . . . .	CDC
Centers for Medicare & Medicaid Services. . . . .	CMS
Department of Health Care Services . . . . .	DHCS
Department of Veterans Affairs . . . . .	VA
Disabled Students Programs and Services. . . . .	DSPS
Employment Network . . . . .	EN
Home and Community-Based Services . . . . .	HCBS
Independent Living Centers . . . . .	ILCs
In-Home Support Services . . . . .	IHSS
Medicaid . . . . .	Medi-Cal <i>(In California)</i>
Memoranda of Understanding . . . . .	MOUs
Polytrauma/Traumatic Brain Injury System of Care . . . . .	PSC
Social Security Administration . . . . .	SSA
Social Security Disability Insurance . . . . .	SSDI
State Independent Living Council . . . . .	SILC
State Plan Amendment . . . . .	SPA
State Vocational Rehabilitation Agencies . . . . .	VR Agencies
Strengths, Weaknesses, Opportunities, and Threats Analysis. . . . .	SWOT
Supplemental Security Income. . . . .	SSI
Ticket to Work. . . . .	TTW
Traumatic Brain Injury. . . . .	TBI
US Department of Housing and Urban Development . . . . .	HUD



## APPENDIX B

# DEPARTMENT OF DEFENSE NUMBERS FOR TRAUMATIC BRAIN INJURY

### TBI DIAGNOSES BY SEVERITY OF INJURY 2000-2009<sup>44</sup>

Information posted here is collected from medical records and analyzed by the Defense and Veterans Brain Injury Center (DVBIC) in cooperation with the Armed Forces Health Surveillance Center.<sup>45</sup> At this time, DVBIC is unable to provide information regarding cause of injury or location because that information is not available in most medical records. The numbers below represent actual medical diagnoses of TBI within the US Military. Other, larger numbers routinely reported in the media must be considered inaccurate because they do not reflect actual medical diagnoses. Many of these larger numbers are developed utilizing sources such as the Post Deployment Health Assessment (PDHA) or Post Deployment Health Reassessment (PDHRA). However, these documents are assessment tools, with TBI screening questions, and are not diagnostic tools. Using electronic medical records, the Department of Defense has compiled the number of service members diagnosed with TBI and determined the severity of the injury on an annual basis dating back to 2000. The severity of injury was ascertained using ICD-9 codes.

**Concussion/mild TBI (mTBI) is characterized by the following:** A confused or disoriented state which lasts less than 24 hours; loss of consciousness for up to 30 minutes; memory loss lasting less than 24 hours; and structural brain imaging (MRI or CT scan) yielding normal results.

**Moderate TBI is characterized by the following:** A confused or disoriented state which lasts more than 24 hours; loss of consciousness for more than 30 minutes, but less than 24 hours; memory loss lasting greater than 24 hours but less than seven days; and structural brain imaging yielding normal or abnormal results.

**Severe TBI is characterized by the following:** A confused or disoriented state which lasts more than 24 hours; loss of consciousness for more than 24 hours; memory loss for more than seven days; and structural brain imaging yielding normal or abnormal results.

**Penetrating TBI**, or open head injury, is a head injury in which the dura mater, the outer layer of the meninges, is penetrated. Penetrating injuries can be caused by high-velocity projectiles or objects of lower velocity such as knives, or bone fragments from a skull fracture that are driven into the brain.

Calendar Year	Incident Diagnoses
2000.....	10,963
2001.....	11,830
2002.....	12,469
2003.....	12,886
2004.....	13,271
2005.....	12,025
2006.....	16,873
2007.....	23,002
2008.....	27,507
2009* .....	27,862

\*Numbers updated as of December 2009.

<sup>44</sup> Defense and Veterans Brain Injury Center (DVBIC). Armed Forces Health Surveillance Center. (2009). <http://www.dvbic.org/TBI-Numbers.aspx>. Accessed January 3, 2010.

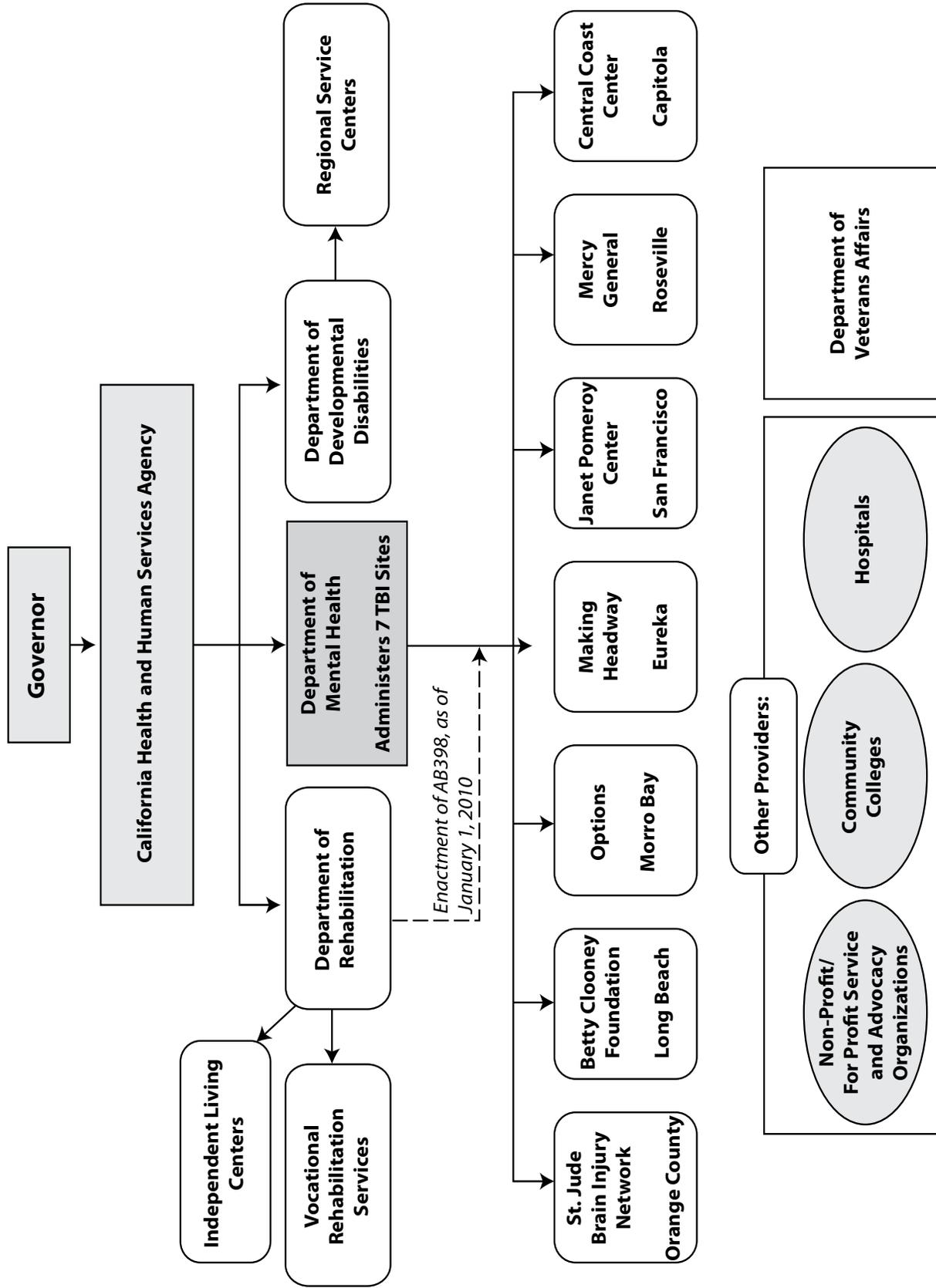
<sup>45</sup> The numbers and severity of injury are updated for the current year on a quarterly basis. Other data will be updated annually.



# APPENDIX C

## SCHEMATIC – CALIFORNIA TBI SERVICE SYSTEM

Schematic of California's Traumatic Brain Injury Service System





# APPENDIX D

## ASSEMBLY BILL 1410

### CHAPTER 676

An act to amend Sections 4354, 4355, and 4358.5 of, and to add Section 14132.992 to, the Welfare and Institutions Code, relating to traumatic brain injury.

[Approved by Governor October 14, 2007. Filed with Secretary of State October 14, 2007.]

### LEGISLATIVE COUNSEL'S DIGEST

AB 1410, Feuer. Traumatic brain injury.

Existing law requires the State Department of Mental Health to designate project sites in order to develop a system of postacute continuum-of-care models for adults 18 years of age or older with acquired traumatic brain injuries. Existing law also establishes the Traumatic Brain Injury Fund, to be used, upon appropriation by the Legislature for these purposes. These provisions are to be repealed as of January 1, 2012.

Existing law provides for the Medi-Cal program, which is administered by the State Department of Health Care Services, pursuant to which medical benefits are provided to public assistance recipients and certain other low-income persons. The Medi-Cal program is partially governed and funded by federal Medicaid provisions.

This bill would require the department, by March 15, 2009, to submit to the federal Centers for Medicare and Medicaid Services a home- and community-based services waiver application or an amendment of the state plan for home- and community-based services, to serve at least 100 adults with acquired traumatic brain injuries who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities. It would specify that the waiver or state plan amendment would be implemented only if certain conditions are met.

The bill would require that services under the waiver be provided by project sites providing services to adults with acquired traumatic brain injuries, as described in existing law, and would expand the services that these projects would be permitted to provide.

*The people of the State of California do enact as follows:*

SECTION 1. Section 4354 of the Welfare and Institutions Code is amended to read:

4354. For purposes of this chapter, the following definitions shall apply:

(a) "Acquired traumatic brain injury" is an injury that is sustained after birth from an external force to the brain or any of its parts, resulting in cognitive, psychological, neurological, or anatomical changes in brain functions.

(b) "Department" means the State Department of Mental Health.

(c) "Director" means the Director of Mental Health.

(d) (1) "Vocational supportive services" means a method of providing vocational rehabilitation and related services that may include prevocational and educational services to individuals who are unserved or underserved by existing vocational rehabilitation services.

(2) "Extended supported employment services" means ongoing support services and other appropriate services that are needed to support and maintain an individual with an acquired traumatic brain injury in supported employment following that individual's transition from support provided as

a vocational rehabilitation service, including job coaching, by the State Department of Rehabilitation, as defined in paragraphs (1) and (5) of subdivision (a) of Section 19150.

(e) The following four characteristics distinguish “vocational supportive services” from traditional methods of providing vocational rehabilitation and day activity services:

(1) Service recipients appear to lack the potential for unassisted competitive employment.

(2) Ongoing training, supervision, and support services must be provided.

(3) The opportunity is designed to provide the same benefits that other persons receive from work, including an adequate income level, quality of working life, security, and mobility.

(4) There is flexibility in the provision of support which is necessary to enable the person to function effectively at the worksite.

(f) “Community reintegration services” means services as needed by clients, designed to develop, maintain, increase, or maximize independent functioning, with the goal of living in the community and participating in community life. These services may include, but are not limited to, providing, or arranging for access to, housing, transportation, medical care, rehabilitative therapies, day programs, chemical dependency recovery programs, personal assistance, and education.

(g) “Fund” means the Traumatic Brain Injury Fund.

(h) “Supported living services” means a range of appropriate supervision, support, and training in the client’s place of residence, designed to maximize independence.

(i) “Functional assessment” means measuring the level or degree of independence, amount of assistance required, and speed and safety considerations for a variety of categories, including activities of daily living, mobility, communication skills, psychosocial adjustment, and cognitive function.

(j) “Residence” means the place where a client makes his or her home, that may include, but is not limited to, a house or apartment where the client lives independently, assistive living arrangements, congregate housing, group homes, residential care facilities, transitional living programs, and nursing facilities.

SEC. 2. Section 4355 of the Welfare and Institutions Code is amended to read:

4355. (a) The department shall designate sites in order to develop a system of postacute continuum-of-care models for adults 18 years of age or older with an acquired traumatic brain injury.

(b) The project sites shall coordinate vocational supportive services, community reintegration services, and supported living services. The purpose of the project is to demonstrate the effectiveness of a coordinated service approach that furthers the goal of assisting those persons to attain productive, independent lives which may include paid employment.

(c) Project sites that are authorized to provide home- and community-based waiver services pursuant to Section 14132.992 shall also provide extended supported employment services, as defined in paragraph (2) of subdivision (d) of Section 4354.

SEC. 3. Section 4358.5 of the Welfare and Institutions Code is amended to read:

4358.5. (a) Funds deposited into the Traumatic Brain Injury Fund pursuant to paragraph (8) of subdivision (f) of Section 1464 of the Penal Code shall be matched by federal vocational rehabilitation services funds for implementation of the Traumatic Brain Injury program pursuant to this chapter. However, this matching of funds shall be required only to the extent it is required by other state and federal law, and to the extent the matching of funds would be consistent with the policies and priorities of the State Department of Rehabilitation regarding funding.

(b) The department shall seek and secure funding from available federal resources, including, but not limited to, Medicaid and drug and alcohol funds, utilizing the Traumatic Brain Injury Fund as the state’s share for obtaining federal financial participation, and shall seek any necessary waiver of federal program requirements to maximize available federal dollars.

SEC. 4. Section 14132.992 is added to the Welfare and Institutions Code, to read:

14132.992. (a) (1) By March 15, 2009, the department shall submit to the federal Centers for Medicare and Medicaid Services a home- and community-based services waiver application pursuant to Section 1396n(c) of Title 42 of the United States Code, or an amendment of the state plan for home-

and community-based services pursuant to Section 1396n(i) of Title 42 of the United States Code, to serve at least 100 adults with acquired traumatic brain injuries who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities or, for the amendment of the state plan, who would meet the eligibility criteria in Section 1396n(i).

(2) As authorized by Section 1396n(c)(3) and 1396n(i)(3) of Title 42 of the United States Code, the waiver or amendment of the state plan shall waive the statewide application of this section as well as comparability of services so that waiver services may be provided by one or more of the sites designated to provide services to persons with acquired traumatic brain injury pursuant to Section 4356.

(3) The waiver services to be provided to eligible Medi-Cal recipients shall include case management services, community reintegration and supported living services, vocational supportive services including prevocational services, neuropsychological assessments, and rehabilitative services provided by project sites currently serving persons with acquired traumatic brain injuries pursuant to Chapter 5 (commencing with Section 4353).

(4) The waiver services to be provided shall include as a habilitation service pursuant to Section 1396n(c)(5) of Title 42 of the United States Code “extended supported employment services” to support and maintain an individual with an acquired traumatic brain injury in supported employment following that individual’s transition from support provided as a vocational rehabilitation service, including job coaching, by the State Department of Rehabilitation pursuant to paragraphs (1) and (5) of subdivision (a) of Section 19150.

(5) The waiver services to be provided shall include rehabilitative therapies, including, but not limited to, occupational therapy, physical therapy, speech therapy, and cognitive therapy, that are different in kind and scope from state plan services.

(6) The waiver shall require an aggregate cost-effectiveness formula be used.

(b) The development process of the home-and community-based services waiver application or state plan amendment shall include the solicitation of the opinions and help of the affected communities, including the working group members pursuant to Section 4357.1 and representatives of project sites currently serving persons with acquired traumatic brain injuries pursuant to Chapter 5 (commencing with Section 4353) of Part 3 of Division 4.

(c) The waiver or state plan amendment shall be implemented only if the following conditions are met:

(1) Federal financial participation is available for the services under the waiver or state plan amendment.

(2) Cost neutrality is achieved in accordance with the terms and conditions of the waiver or state plan amendment and the requirements of the federal Centers for Medicare and Medicaid Services.

(3) State funds are appropriated, otherwise made available, or both, for this waiver or state plan amendment, including funds for staff to develop, implement, administer, monitor, and oversee the waiver or state plan amendment.

(d) It is the intent of the Legislature that the home and community-based services waiver or state plan amendment augment funds available to meet the needs of persons with acquired traumatic brain injuries served by the participating project sites in accordance with subdivision (b) of Section 4358.5.



# APPENDIX E

## ASSEMBLY BILL 398

### CHAPTER 439

An act to amend Sections 4354, 4354.5, 4357, 4357.1, 4358.5, 4359, and 14132.992 of, to repeal Section 4357.2 of, and to repeal and add Sections 4355 and 4356 of, the Welfare and Institutions Code, relating to acquired brain trauma.

[Approved by Governor October 11, 2009. Filed with Secretary of State October 11, 2009.]

### LEGISLATIVE COUNSEL'S DIGEST

AB 398, Monning. Acquired brain trauma: administration.

(1) Existing law establishes the State Department of Mental Health and sets forth its powers and duties relating to the administration of programs for the delivery of mental health services, including, but not limited to, establishing the department as the agency responsible for administering a program of services for persons with acquired traumatic brain injury, as defined. This program provides for a demonstration project for postacute care for adults 18 years of age and older with an acquired traumatic brain injury, including the funding of demonstration project sites, as specified.

Existing law establishes the Department of Rehabilitation and sets forth its powers and duties relating to rehabilitation services, including, but not limited to, duties related to the delivery of services for persons with acquired traumatic brain injury.

This bill would remove the State Department of Mental Health as the agency responsible for administering the program of services for persons with acquired traumatic brain injury and would, instead, establish the Department of Rehabilitation as the responsible agency and would extend the existing July 1, 2012, repeal date for these provisions until July 1, 2019.

This bill would delete references to the program as a demonstration project. It would, instead, dependent upon securing sources of funding for the provision of services, require the Department of Rehabilitation to fund an array of services for adults 18 years of age and older with acquired traumatic brain injury and would require the department to determine the requirements for service delivery, uniform data collection, and other aspects of program administration that service providers participating in the program must meet and to monitor and evaluate the performance of those service providers, as specified.

The bill would require service providers to furnish data to the department and would require service providers wishing to continue to participate in the program after July 1, 2013, to comply with additional eligibility requirements specified by the department.

Existing law establishes the Traumatic Brain Injury Fund in the State Treasury, with this fund being available for purposes of the program, upon appropriation by the Legislature. The fund receives moneys from specified fines and penalties.

This bill would allow the department to use the funds in the Traumatic Brain Injury Fund to make grants to service providers for the provision of services, as specified. It would also modify requirements relating to the securing of matching funds.

(2) Existing law provides for the Medi-Cal program, which is administered by the State Department of Health Care Services, pursuant to which medical benefits are provided to public assistance recipients and certain other low-income persons. The Medi-Cal program is partially governed and funded by federal Medicaid provisions.

Existing law requires the department, by March 15, 2009, to submit to the federal Centers for Medicare and Medicaid Services a home- and community-based services waiver application or an amendment of the state plan for home- and community-based services, to serve at least 100 adults with acquired traumatic brain injuries who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities.

This bill would, instead, require this waiver to be submitted by March, 1, 2011.

*The people of the State of California do enact as follows:*

SECTION 1. Section 4354 of the Welfare and Institutions Code is amended to read:

4354. For purposes of this chapter, the following definitions shall apply:

(a) "Acquired traumatic brain injury" is an injury that is sustained after birth from an external force to the brain or any of its parts, resulting in cognitive, psychological, neurological, or anatomical changes in brain functions.

(b) "Department" means the State Department of Rehabilitation.

(c) "Director" means the Director of Rehabilitation.

(d) (1) "Vocational supportive services" means a method of providing vocational rehabilitation and related services that may include prevocational and educational services to individuals who are unserved or underserved by existing vocational rehabilitation services.

(2) "Extended supported employment services" means ongoing support services and other appropriate services that are needed to support and maintain an individual with an acquired traumatic brain injury in supported employment following that individual's transition from support provided as a vocational rehabilitation service, including job coaching, by the department, as defined in paragraphs (1) and (5) of subdivision (a) of Section 19150.

(e) The following four characteristics distinguish "vocational supportive services" from traditional methods of providing vocational rehabilitation and day activity services:

(1) Service recipients appear to lack the potential for unassisted competitive employment.

(2) Ongoing training, supervision, and support services must be provided.

(3) The opportunity is designed to provide the same benefits that other persons receive from work, including an adequate income level, quality of working life, security, and mobility.

(4) There is flexibility in the provision of support which is necessary to enable the person to function effectively at the worksite.

(f) "Community reintegration services" means services as needed by consumers, designed to develop, maintain, increase, or maximize independent functioning, with the goal of living in the community and participating in community life. These services may include, but are not limited to, providing, or arranging for access to, housing, transportation, medical care, rehabilitative therapies, day programs, chemical dependency recovery programs, personal assistance, and education.

(g) "Fund" means the Traumatic Brain Injury Fund.

(h) "Supported living services" means a range of appropriate supervision, support, and training in the consumer's place of residence, designed to maximize independence.

(i) "Functional assessment" means measuring the level or degree of independence, amount of assistance required, and speed and safety considerations for a variety of categories, including activities of daily living, mobility, communication skills, psychosocial adjustment, and cognitive function.

(j) "Residence" means the place where a consumer makes his or her home, that may include, but is not limited to, a house or apartment where the consumer lives independently, assistive living arrangements, congregate housing, group homes, residential care facilities, transitional living programs, and nursing facilities.

(k) "Community rehabilitation program" shall have the same meaning as contained in subdivision (5) of Section 705 of Title 29 of the United States Code.

SEC. 2. Section 4354.5 of the Welfare and Institutions Code is amended to read:

4354.5. The Legislature finds and declares all of the following:

(a) Traumatic brain injuries have a long-term impact on the survivors, their families, caregivers, and support systems.

(b) Long-term care consumers experience great differences in service levels, eligibility criteria, and service availability, resulting in inappropriate and expensive care that fails to be responsive to their needs.

(c) To the maximum extent feasible, the department shall pursue all available sources of federal financial participation, including, but not limited to, the Medicaid home and community-based services waiver program (42 U.S.C. Sec. 1396n(c)) and Part J of Subchapter II of the Public Health Service Act (42 U.S.C. Sec. 280b et seq.).

(d) If new sources of funding are secured which will permit expanding the existing Traumatic Brain Injury Program, the department shall fund an array of appropriate services and assistance to adults 18 years of age and older with traumatic brain injuries in those areas of the state with the greatest need.

(e) Implementation of this chapter shall be consistent with the state's public policy strategy to design a coordinated services delivery system pursuant to Article 4.05 (commencing with Section 14139.05) of Chapter 7 of Part 3 of Division 9.

SEC. 3. Section 4355 of the Welfare and Institutions Code is repealed.

SEC. 4. Section 4355 is added to the Welfare and Institutions Code, to read:

4355. (a) On or before January 1, 2012, the department shall determine requirements related to service delivery, uniform data collection, and other aspects of program administration, in addition to those specified in Section 4357, that service providers participating in the traumatic brain injury program must meet. This may include, but is not limited to, the following:

(1) The department may require that service providers be approved as community rehabilitation programs eligible to serve consumers.

(2) Upon approval of the Medicaid waiver sought pursuant to Section 14132.992, the department may require that all service providers do both of the following:

(A) Satisfy all applicable eligibility requirements for provision of services under the waiver.

(B) Participate in the waiver and provide extended supported employment services, as defined in paragraph (2) of subdivision (d) of Section 4354.

(b) On or before January 1, 2013, the department shall do all of the following:

(1) Determine the level of funding necessary to permit a service provider to meet all applicable requirements and adequately serve its designated service area.

(2) Determine the number of sites that can be supported with available funding.

(3) Solicit applications from organizations interested in and qualified to provide services pursuant to this chapter, and select those best qualified to do so, with priority given to applicants that have proven experience in providing effective services to persons with acquired traumatic brain injuries, including, but not limited to, supported living services, caregiver support, and family and community education.

(c) The department shall meet periodically with traumatic brain injury service providers for discussion of topics, including, but not limited to, the development and implementation of performance standards and data collection processes, eligibility requirements, program administration, pursuit of funding, implementation of the Medicaid waiver, if approved by the federal government, and refinement of the traumatic brain injury continuum of care.

SEC. 5. Section 4356 of the Welfare and Institutions Code is repealed.

SEC. 6. Section 4356 is added to the Welfare and Institutions Code, to read:

4356. Using data collected consistent with requirements established pursuant to subdivision (a) of Section 4355, the department shall monitor and evaluate the performance of service providers.

SEC. 7. Section 4357 of the Welfare and Institutions Code is amended to read:

4357. (a) Service providers shall identify the needs of consumers and deliver services designed to meet those needs.

(b) Service providers shall match not less than 20 percent of the amount granted, with the

exception of funds used for mentoring. The required match may be cash or in-kind contributions, or a combination of both, from the sites or any cooperating agency. In-kind contributions may include, but shall not be limited to, staff and volunteer services.

(c) Service providers shall provide at least 51 percent of their services under the grant to individuals who are Medi-Cal eligible or who have no other identified third-party funding source.

(d) (1) Service providers shall provide, directly or by arrangement, a coordinated service model to include all of the following:

(A) Supported living services.

(B) Community reintegration services.

(C) Vocational supportive services.

(D) Information, referral, and, as needed, assistance in identifying, accessing, utilizing, and coordinating all services needed by individuals with traumatic brain injury and their families.

(E) Public and professional education designed to facilitate early identification of persons with brain injury, prompt referral of these persons to appropriate services, and improvement of the system of services available to them.

(2) The model shall be designed and modified with advice from consumers and their families, and shall be accessible to the population in need, taking into account transportation, linguistic, and cultural factors.

(e) Service providers shall develop and utilize an individual service plan which will allow consumers to move from intensive medical rehabilitation or highly structured living arrangements to increased levels of independence and employment. The goals and priorities of each consumer shall be an integral part of his or her service plan.

(f) Service providers shall seek all third-party reimbursements for which consumers are eligible and shall utilize all services otherwise available to consumers at no cost, including vocational rehabilitation services provided by the department. However, grantees may utilize grant dollars for the purchase of nonreimbursed services or services otherwise unavailable to consumers.

(g) Service providers shall endeavor to serve a population that is broadly representative with regard to race and ethnicity of the population with traumatic brain injury in their geographical service area, undertaking outreach activities as needed to achieve this goal.

(h) Service providers shall maintain a broad network of relationships with local groups of brain injury survivors and families of survivors, as well as local providers of health, social, and vocational services to individuals with traumatic brain injury and their families. The sites shall work cooperatively with these groups and providers to improve and develop needed services and to promote a well-coordinated service system, taking a leadership role as necessary.

(i) Service providers shall furnish uniform data to the department pursuant to subdivision (a) of Section 4355 as necessary to monitor and evaluate the program.

(j) Service providers wishing to continue to participate in the program after July 1, 2013, shall, by that date, be in compliance with additional eligibility requirements established by the department pursuant to Section 4355.

SEC. 8. Section 4357.1 of the Welfare and Institutions Code is amended to read:

4357.1. (a) The department may make grants from the funds in the Traumatic Brain Injury Fund, established in Section 4358, to service providers for the purpose of carrying out the programs detailed in this chapter.

(b) Contracts or grants awarded pursuant to this chapter, including contracts required for administration or ancillary services in support of programs, shall be exempt from the requirements of the Public Contract Code and the State Administrative Manual, and from approval by the Department of General Services.

(c) Grants awarded to service providers pursuant to this chapter shall be subject to open competition every three years, unless the department elects to extend one or more grants and delay competition for those grants by a maximum of two additional years.

SEC. 9. Section 4357.2 of the Welfare and Institutions Code is repealed.

SEC. 10. Section 4358.5 of the Welfare and Institutions Code is amended to read:

4358.5. Funds deposited into the Traumatic Brain Injury Fund pursuant to paragraph (8) of subdivision (f) of Section 1464 of the Penal Code may be matched by federal vocational rehabilitation services funds for implementation of the Traumatic Brain Injury program pursuant to this chapter. However, this matching of funds shall occur only to the extent it is permitted by other state and federal law, and to the extent the matching of funds would be consistent with the policies and priorities of the department.

SEC. 11. Section 4359 of the Welfare and Institutions Code is amended to read:

4359. This chapter shall remain in effect until July 1, 2019, and as of that date is repealed, unless a later enacted statute enacted prior to July 1, 2019, extends or deletes that date.

SEC. 12. Section 14132.992 of the Welfare and Institutions Code is amended to read:

14132.992. (a) (1) By March 15, 2011, the department shall submit to the federal Centers for Medicare and Medicaid Services a home- and community-based services waiver application pursuant to Section 1396n(c) of Title 42 of the United States Code, or an amendment of the state plan for home- and community-based services pursuant to Section 1396n(i) of Title 42 of the United States Code, to serve at least 100 adults with acquired traumatic brain injuries who otherwise would require care in a Medi-Cal funded nursing facility or an intermediate care facility for persons with developmental disabilities or, for the amendment of the state plan, who would meet the eligibility criteria in Section 1396n(i).

(2) As authorized by Section 1396n(c)(3) and 1396n(i)(3) of Title 42 of the United States Code, the waiver or amendment of the state plan shall waive the statewide application of this section as well as comparability of services so that waiver services may be provided by one or more service providers designated to provide services to persons with acquired traumatic brain injury pursuant to Chapter 5 (commencing with Section 4353) of Part 3 of Division 4.

(3) The waiver services to be provided to eligible Medi-Cal recipients shall include case management services, community reintegration and supported living services, vocational supportive services including prevocational services, neuropsychological assessments, and rehabilitative services provided by service providers currently serving persons with acquired traumatic brain injuries pursuant to Chapter 5 (commencing with Section 4353).

(4) The waiver services to be provided shall include as a habilitation service pursuant to Section 1396n(c)(5) of Title 42 of the United States Code “extended supported employment services” to support and maintain an individual with an acquired traumatic brain injury in supported employment following that individual’s transition from support provided as a vocational rehabilitation service, including job coaching, by the State Department of Rehabilitation pursuant to paragraphs (1) and (5) of subdivision (a) of Section 19150.

(5) The waiver services to be provided shall include rehabilitative therapies, including, but not limited to, occupational therapy, physical therapy, speech therapy, and cognitive therapy, that are different in kind and scope from state plan services.

(6) The waiver shall require an aggregate cost-effectiveness formula be used.

(b) The development process of the home and community-based services waiver application or state plan amendment shall include the solicitation of the opinions and help of the affected communities, including representatives of service providers currently serving persons with acquired traumatic brain injuries pursuant to Chapter 5 (commencing with Section 4353) of Part 3 of Division 4.

(c) The waiver or state plan amendment shall be implemented only if the following conditions are met:

(1) Federal financial participation is available for the services under the waiver or state plan amendment.

(2) Cost neutrality is achieved in accordance with the terms and conditions of the waiver or state plan amendment and the requirements of the federal Centers for Medicare and Medicaid Services.

(3) State funds are appropriated, otherwise made available, or both, for this waiver or state plan

amendment, including funds for staff to develop, implement, administer, monitor, and oversee the waiver or state plan amendment.

(d) It is the intent of the Legislature that the home and community-based services waiver or state plan amendment augment funds available to meet the needs of persons with acquired traumatic brain injuries served by the participating service providers in accordance with Chapter 5 (commencing with Section 4353) of Part 3 of Division 4.

## APPENDIX F

### SWOT ANALYSIS

#### Traumatic Brain Injury (TBI) Environmental Scan: SWOT Analysis<sup>46</sup> Based on Feedback from TBI Advisory Board and Other Stakeholders (August 2009)

#### Internal Factors

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Improved communication among and between CA TBI network and stakeholders – e.g., TBI Advisory Board, CALBIA, and the TBI Coalition</li> <li>• Seven TBI sites serving persons with TBI and their families (also the lead in organizing the TBI Coalition and conducting previous TBI stakeholder meetings)</li> <li>• AB 1410 (Assemblymember Feuer’s TBI bill)</li> <li>• Completed TBI Needs Assessment - California Traumatic Brain Injury Planning Project: Needs and Resource Assessment (2002), the California Traumatic Brain Injury Planning Project: Statewide Action Plan (2002)</li> <li>• TBI increasingly acknowledged by the State/ Legislature</li> <li>• Categorical funding for Community Colleges (reference previous levels) to serve TBI students</li> <li>• Existence of Veterans Administration TBI Service Programs – Palo Alto, Los Angeles, Camp Pendleton</li> <li>• Ongoing commitment of TBI Board</li> <li>• Olmstead Advisory Committee has identified TBI as an issue to be addressed</li> <li>• The Department of Rehabilitation (DOR) has issued a Request for Applications (RFA) targeting TBI survivors – to provide services and improve the current TBI system</li> </ul>	<ul style="list-style-type: none"> <li>• Limited funds</li> <li>• Limited coordinated leadership support of TBI services at the State level</li> <li>• Absence of a coordinated statewide structure of TBI services, beginning in the Emergency Department and continuing post-acute care in all areas, including rural communities</li> <li>• No centralized clearinghouse of information for TBI, restricting access to services</li> <li>• State challenges with implementing Olmstead</li> <li>• Limited preventive information and public awareness-education about TBI</li> <li>• Inadequate TBI epidemiology and surveillance</li> <li>• Little coordination between TBI services and funding at the County level</li> <li>• Limited communication with TBI stakeholders in all communities, especially underserved and underrepresented communities</li> <li>• Lack of adequate TBI case management services</li> <li>• Insurance challenges – Medi-Cal, Medicare, and private insurance (limited coverage for TBI services and few Medi-Cal providers serving TBI survivors)</li> </ul>

<sup>46</sup> An Environmental Scan is an analysis and evaluation of internal conditions and external data and factors that affect the capacity of the organization’s initiative to meet its mission.

## APPENDIX F

### SWOT ANALYSIS

#### **Traumatic Brain Injury (TBI) Environmental Scan: SWOT Analysis<sup>47</sup> Based on Feedback from TBI Advisory Board and Other Stakeholders (August 2009)**

#### External Factors

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Engage with Veterans and other underserved groups</li> <li>• Develop statewide TBI infrastructure and education campaign</li> <li>• Work cohesively with the Independent Living Centers and other disability groups</li> <li>• Move seven TBI sites to the Department of Rehabilitation</li> <li>• Study and assess other State TBI waiver efforts</li> <li>• Develop long-term supportive housing options including groups homes and other least restricted options</li> <li>• Work more constructively with University of CA's research system and clinical scientists studying TBI</li> <li>• DOR's RFA promotes collaboration between veterans and Independent Living Centers on behalf of TBI survivors</li> <li>• Promote local level involvement in Health Care Reform</li> <li>• Partner with the aging network to address Fall Prevention – TBI among seniors</li> <li>• Coordinate/partner with various State initiatives addressing the long-term support needs of persons with disabilities, e.g., Real Choice Systems Change (RCSC) Grants</li> <li>• Partner with local and statewide foundations to enhance services and understanding of TBI</li> <li>• Coordinate with current Information and Assistance Programs including the Independent Living Centers' Systems Change Advocates</li> <li>• Engage TBI service providers in the Ticket to Work</li> </ul>	<ul style="list-style-type: none"> <li>• Waiver may inadvertently be perceived as the sole solution to all TBI needs, preventing development of a more comprehensive approach by the State to address TBI needs</li> <li>• Changes in state administration leadership during the next election may alter current focus on TBI</li> <li>• Landscape of TBI services and insurance reimbursement is producing significant and substantive changes in treating and supporting TBI survivors</li> <li>• Need to assess costs associated with a waiver/ SPA, including cost neutrality</li> <li>• High levels of unemployment (including reduced capacity to employ student workers)</li> <li>• Disconnect between medical assessment of TBI survivor and survivors' functional abilities</li> <li>• Funding reductions in California's Home and Community-Based Services System, including the In-Home Supportive Services Program</li> <li>• Increase in TBI incidence and prevalence in California</li> </ul>

<sup>47</sup> An Environmental Scan is an analysis and evaluation of internal conditions and external data and factors that affect the capacity of the organization's initiative to meet its mission.

Copies of *Advancing California's Traumatic Brain Injury Service System: Next Steps* are available for download from the California Department of Mental Health website at [www.dmh.ca.gov](http://www.dmh.ca.gov) or from the California Department of Rehabilitation website at [www.dor.ca.gov](http://www.dor.ca.gov). Hard copies can be requested by contacting the State Level Programs Branch via postal mail, email, telephone, or by contacting the Traumatic Brain Injury Specialist at the California Department of Rehabilitation.

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