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Proposed Recommendations for Organizations Providing
Community Integration Services to Traumatic Brain Injury Survivors

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Public Health

by

Stephanie M. Boumediene

2019

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ABSTRACT OF THE DISSERTATION

Proposed Recommendations for Organizations Providing Community Integration Services to Traumatic Brain Injury Survivors

by

Stephanie M. Boumediene

Doctor of Public Health

University of California, Los Angeles, 2019

Professor Beth Ann Glenn-Mallouk, Chair

Traumatic Brain Injury (TBI) remains a significant health condition that touches all populations and communities, with the current TBI Continuum of Care consisting of medical acute care, rehabilitation and community integration. In the past, TBI was seen as a one-time event, with the TBI survivor expected to re-integrate back into the community after a convalescence period. Now researchers understand that a TBI, whether mild or severe, can be a chronic condition, following a survivor throughout their lifetime. This concept places even more importance on the community integration sector of the TBI Continuum of Care. Unlike the medical and rehabilitation sectors, which have universally-applied standards of care, the community integration (CI) sector does not as yet have common standards by which to measure outcomes. This means organizations providing CI services can be very diverse and can run the gamut for quality of care.

This dissertation focuses on the creation of a list of proposed recommendations for community integration organizations supporting TBI survivors. The research includes interviewing of CI sites throughout California, as well as interviews of individuals throughout the TBI Continuum of Care. This list of proposed recommendation focuses on potential strategies that CI organizations can adopt to improve the quality and availability of services, continuously monitor patient outcome, and enhance organizational sustainability, thereby improving the quality of life for TBI survivors and their families in California.

The dissertation of Stephanie M. Boumediene is approved.

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University of California, Los Angeles

2019

DEDICATION

To my family: my husband, for his unwavering love, faith and his endless support; for my children who continually encouraged me; and the rest of my family who kept me focused on this dream. To Dr. Paul Torrens who opened the door and guided me through. It takes a village.

“Never ever, ever give up” – Prof. Richard P. Feynman

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VITA/BIOGRAPHICAL SKETCH

Stephanie M. Boumediene received her Bachelor in Business Administration (BBA) from Loyola-Marymount (LMU) in Los Angeles, California and her Master in Public Health (MPH) from the University of California at Los Angeles (UCLA).

After graduating from LMU, Stephanie accepted a position at the United Nations in Geneva, Switzerland, where she stayed for several years. From there Stephanie represented the US Department of Agriculture's (USDA) interests in North Africa, working as the senior economist based at the USDA's Foreign Trade Office based in Algiers, Algeria.

Returning to the United States, Stephanie then progressed through senior management positions in both international (Surgical Eye Expeditions International – SEE Intl.) and domestic (American Red Cross, National Multiple Sclerosis Foundation, Sansum Medical Clinic, PathPoint) non-governmental organizations (INGOs and NGOs) dedicated to the provision of promoting healthcare and public health initiatives. As President of SEE International, Stephanie supported the mission of delivering of free sight-restoring surgery to underserved populations around the world. Working with local in-country medical personnel, she expanded the reach of SEE medical teams to new countries, while leading teams to countries in Africa for this effort.

Then, working as an executive for Sanford-Burnham-Prebys Institute (SBP), a world-class NCI-designated Cancer Center research institute, Stephanie assisted in successfully developing a collaborative effort between the Institute and the University of California at Santa Barbara (UCSB) campus, with the building and completion of a Nanomedicine Research Center.

As president of the Board of Directors for a TBI Community Integration organization, she worked with the staff to build the organization's program services and organizational structure, ensuring sustainability for the organization into the future. Currently, Stephanie

consults on issues of health disparities and healthcare access, and how these affect socially and economically disadvantaged populations in the MENA (Middle East and North Africa) region.

CHAPTER 1: INTRODUCTION

Traumatic brain injury (TBI) has been called the ‘silent epidemic’ of the 21st century (Langlois, 2004,) and represents a global public health challenge (Coronado, 2012). Once seen as a singular medical incident, TBI is now understood to be a complex injury that often results in cognitive impairment and psychiatric disorders. It can affect survivors in a variety of ways including changes in mood, behavior and personality (Heiden, 2018). For some individuals, the post-TBI effects may be short-term and negligible, while for others it can be a profound injury with life-long consequences.

After medical stabilization and physical rehabilitation, a TBI survivor is faced with the challenge of reintegrating back into her/his social network and community. Post-injury, TBI survivors may face one or many of the following impairments: disruption in cognitive abilities, alterations in personality, the emergence of psychiatric disorders and psychological distress. This is the in coping with the impact of TBI that community integration becomes essential and necessary. The long-term emotional, psychological and physical impairments experienced by a TBI survivor can adversely affect their self-image, independence in living, and successful community integration (Malec, 2013). As Truelle has noted, bridging the space effectively between the medical/rehabilitation and community integration phases requires a “semiology with a psycho-social perspective rather than the traditional medical-oriented healthcare position” (Truelle, 2010, P.689).

1. Statement of the Problem

As medical care achieves more success in extending long-term TBI survival rates, the need for psychiatric and psychosocial management in TBI patients to cope with the long-term disorders and re-integrate into their community becomes increasingly necessary. While medical

interventions to repair the injury to the brain have increased in their success, as well as treatment protocols for managing resulting psychiatric disorders, far less movement has been accomplished on managing the psychosocial aspects of TBI, specifically that of integrating these individuals into their communities. Until there is such a system in place TBI survivors remain at risk of being underserved and “lost” post-discharge (Lew, 2006). In tandem, community integration programs have struggled to keep up with an ever-increasing demand for their services. The challenge facing the psychosocial sector of care is that currently no common guidelines for traumatic brain injury community integration are available.

TBI is a significant health condition that can touch all populations and communities. Male or female; young or old; Latino or Caucasian; military veteran or sports athlete – all can suffer a TBI with varying degrees of severity during a lifespan. One common thread throughout many TBI survivors’ post-hospitalization/rehabilitation experiences is the sensation of loss or isolation - whether that be a loss of independence, cognitive functioning, social connections, family bonds, employment or a sense of belonging (Malec, 2013). Additionally, as the TBI survivor withdraws from his/her social network, he/she may rely more heavily on family for emotional support and leisure activities, thereby placing further stress on caregivers (Wise, 2010). When TBI survivor attempts to reintegrate back into the fabric of her/his community, dealing with the sense of loss/isolation and maintaining a quality of life can become a dominant focus. This is why community integration services are so important. Age of the survivor can play a role in how each individual responds to services. In the case of a young TBI survivor in their early 20s, they may experience a regression back to primary the family networks of their childhood. Elderly TBI survivors, on the other hand, can feel a deep sense of isolationism and

often retreat into themselves. The research in this dissertation focuses on adult TBI survivors (ages 22 through 65) and not on pediatric survivors or individuals over 65.

Community integration is defined as post-rehabilitation work on daily living skills including social, vocational and recreational services are important factors in the quality of life for TBI survivors as they go about their daily lives (Gerber, 2015). For community integration programs it has been shown that to be successful, these programs should focus on three areas: social and leisure activity, independent living and employment or other work activity (Corrigan, 1994). And while the research and clinical care communities can guide the definition, equally important is what the TBI survivor values. McColl indicated that what TBI survivors value is the importance of meeting new people and building a social network (McColl, 1998). Research suggests that participation in formal community integration day programs have a positive impact on the TBI survivor and caregiver by lessening the feelings of isolation and loss while reducing the caregiving pressure on family (Gerber, 2015). But unlike the medical and rehabilitation components of the TBI continuum of care which have structured models, outcomes and certifying associations, research has identified areas of deficit within the psycho-social model of community integration. For example, two hospitals located geographically distant from each other can have very similar models of TBI clinical care and employ the equivalent outcome measures for medical and rehabilitation care, but the same cannot be said about existing psycho-social community integration organizations. Even those community integration organizations located within close geographic proximity can be vastly different, with the quality of programming, care and outcome measures varying greatly across the community integration spectrum. There is no consensus on a single community integration model within the sector.

A critical component that can affect uniform quality of community integration services is sustainable funding. This is an area of vast inequities for community integration providers in California. Unlike other health conditions (developmentally and intellectually disabled populations) that are maintained by federal waivers supporting long-term services across almost all states, brain injury long-term services are not uniformly sustained by individual states. To provide services, some states apply for and accept federal dollars through Medicaid Home and Community-based Services (HCBS) waiver program. The challenge remains that HCBS programs vary considerably in terms of eligibility and numbers served. California does not accept Medicaid waiver funding for TBI programs, which leaves community integration organizations within California often scrambling for funding from various funding sources to keep psychosocial services going for the TBI individual. This lack of continuity in funding adds to the growing disparity in the quality of services for California TBI community integration programs at a time when these services are needed most.

When faced with the chronic life-long aspects of a TBI injury, the absence of care continuity poses a problem for not only the TBI survivor and caregiver, but to the community of TBI survivors as well. As the US population ages there are concerns that TBI will become a more common diagnosis due to increased risk of injury, with poorer outcomes (Flanagan, 2008). A consistent standard of community integration that can be applied across the sector could become an answer for the equivalency of care quality, for Community integration organizational financial sustainability, for improved quality of live for a TBI survivor, and ultimately for society as a whole.

2. Purpose of this Study

Currently in the State of California, there are almost as many types of community integration organizations as there are causes of TBI. While this may sound a bit exaggerated, the truth is community integration programs presently exist at (1) formal post-hospitalization rehabilitation outpatient services, (2) independent living centers, (3) clubhouses, and (4) adult day care centers across the State. In providing a community integration program, each of these organizations is attempting to respond to an overwhelming demand for services, but each of these organization's mission for delivering care may be different. What often organically grows in reaction to the need for community integration services looks very different depending where you are in the State. Locally-driven supply and available resources can produce very diverse approaches to community integration. While these varied methods are valuable and do fill a niche, they all would benefit from proposed recommendations to guide their delivery of CI services to TBI survivors and families and to enhance the sustainability of the organizations over time.

Honoring the individuality of organizations, the research in this dissertation focuses on gathering input from executive directors and staff of seven community integration organizations across California that represent the CATBI network, as well as senior professionals working with other organizations within the TBI continuum of care. This input from a diverse group of community integration professionals will then be utilized to inform the development of proposed recommendations for community integration organizations supporting adult TBI survivors. These proposed recommendations would then provide a 'road map' to organizations separated by geography and situated in diverse settings to provide a uniform set of community integration services within California.

CHAPTER 2: BACKGROUND ON TBI

1. Classifications of Brain Injury

The Brain Injury Association of America (BIAA, also known as BIAUSA) has identified two types of brain injury: traumatic and non-traumatic (or acquired) brain injury. BIAA defines traumatic brain injury (TBI) as “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (BIAA, website). A traumatic brain injury can be either mild, moderate or severe, depending on the type of damage the brain has experienced (NIH, 2019). A mild TBI may leave the person fully conscious or experience a brief moment of unconsciousness; the individual could also suffer from headache, dizziness, confusion, blurred vision to name just a few symptoms. Someone who has a moderate to severe TBI may experience those symptoms plus a stronger headache, with nausea, vomiting, convulsions, seizures, pupil dilation, slurred speech, agitation, weakness or numbness in extremities, the inability to remain conscious (NIH, 2019). While this is not the complete list of symptoms it does give an overview of what can happen.

Acquired brain injury (ABI) is defined as “an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth” and is brought on by internal factors, such as a lack of oxygen or pressure from a tumor (BIAA, website). ABI includes stroke, aneurysm, anoxia, hypoxia, tumors, near drowning, electric shock and infections to the brain (BIA, website). Stroke is the most common form of ABI. The two types of stroke are Ischemic stroke, which occurs when an artery is blocked by either a blood clot, plaque build-up or fatty deposits, and Hemorrhagic stroke, where a blood vessel in the brain breaks, causing blood leakage into a specific area of the brain (Shavelle, 2001).

Often there is confusion about the definitions of an acquired brain injury versus a traumatic brain injury. While BIAA notes that “by definition, any traumatic brain injury (e.g., from a motor vehicle accident, or assault) could be considered an acquired brain injury” (BIAA website), the Centers for Disease Control and Prevention (CDC, 2003) defines brain injury under the clinical case definition for craniocerebral trauma, which is inclusive of ABI and TBI: “an occurrence of injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury: observed or self-reported decreased level of consciousness; amnesia; skull fracture; and any objective neurological or neuropsychological abnormality or diagnosed intracranial lesions” (CDC, 2003, P.2). Therefore, for the purposes of this dissertation, TBI will be defined as an impairment of brain functioning that is physically or psychologically demonstrated.

2. Brain Injury as a Public Health and Policy Issue

Traumatic brain injury has been recognized as a diagnosis for years, but unlike intellectual or developmental disability conditions, it was not identified as a disability by US public health policy makers until relatively recently. This is likely due to the fact that each TBI has unique features associated with a wide variation in symptom severity and the resulting limitations in activity. In short, no two TBIs are alike. As one researcher stated: “changing public policy requires the ability to define a situation or a problem” (Rosen, 1994, P.2). This has been the challenge with efforts to standardize TBI definitions, interventions and public health policy. In 1988 the US Congress created the first Federal Interagency Brain Injury Task Force to identify the issues around TBI service delivery, research and training (Reid-Arndt, 2010). This official policy acknowledgement of TBI as a cause of disability was advocated by BIAA leaders, TBI survivors and others in the hopes the US government and the medical establishment would

recognize the prevalence of this condition; the need to address its possible long-term disability effects, the costs to society for this type of disability, and to build an infrastructure to support treatment and research (Reid-Arndt, 2010).

Since 1988 there have been additional public health policy efforts including the 1996 TBI Act, when Congress formally recognized TBI as a disability, and passed a law tasking the CDC with implementing protocol to (1) reduce TBI incidence by creating a uniform TBI reporting system in order to monitor rates; (2) encourage research to identify effective preventive strategies; (3) design public educational programs to broaden public awareness of TBI; (4) provide monetary support through grants to plan and develop programming in order to reduce TBI incidence rates, and (5) present a report to Congress explaining the prevalence and incidence rates of TBI in the United States (Coronado, 2012). Additionally, the Health Resources and Services Administration (HRSA) was tasked to develop state advisory councils, with the National Institutes of Health (NIH) identifying practice guidelines and therapeutic interventions.

Even with all of these endeavors, brain injury remains underappreciated as a public health issue (Coronado, 2012). By 2016 forty-one states utilized CDC recommended definitions and guidelines, but only twenty states ended up being funded by the CDC for TBI surveillance and prevention reporting systems (California not being one of them), which means this continues to be a barrier to the completion of a nation-wide TBI statistical database (CDC, 2011). Because of this gap, current surveillance programs underestimate the national prevalence and incident rates for TBI disability, impairment, functional limitation and death (Leibson, 2010). Researchers are hampered in their efforts to evaluate TBI's influence on quality of life for TBI survivors, social economic costs for interventions, and service provision (NIH, 1999). Additionally, those entities receiving federal funds for TBI epidemiology research depend mainly on International Statistical

Classification of Diseases and Related Health Problems (ICD-10-CM) coded billing information for their research, which was not designed for true surveillance purposes (Leibson, 2011)..

Another shortfall is the fact that the societal burden of TBI is often portrayed either in the media or at government levels in deaths or injuries within a population, with the ongoing/future care quantified in cash amounts (Masel, 2009). Often left undiscussed are the hidden costs of psychological and behavioral consequences that may leave a TBI survivor unemployable, exhibiting aggressive behavior, and suffering from extreme moods (Masel, 2010). These individuals can experience a significant amount of physical, psychosocial, emotional and cognitive disabilities, which in turn affects not only TBI survivors lives but those of family and caretakers. It also poses a huge financial burden to the survivor, the family, the community and beyond (Malec, 2013). This equates to a large global public health burden and huge economic costs, and adversely impacts the ability of public health community, both in the US and globally, to adequately respond to the medical and psychosocial needs of TBI survivors.

3. Epidemiology of Brain Injury

According to the World Health Organization, TBI is a growing health problem and the major cause of injury-related death and disability worldwide, with the annual global TBI incident rate at 64-74 million new cases (Dewan, 2018). For all age groups, TBI is 30-40% of all injury-related deaths and will remain the most important cause of disability from a neurological disease until 2030 (Maas, 2017), with TBI mortality rates roughly 2-3 times higher than those of Alzheimers and cerebrovascular conditions (WHO, 2006). The long-term consequences of a TBI can include a lifetime of secondary conditions which may make it impossible for the TBI survivor to have a quality life. Even a minor TBI has hidden costs to survivor, caretaker and overall society. This includes the inability to find gainful employment or to hold a job for long-

term; uninhibited and uncontrollable behavior by the TBI survivor that may be aggressive in nature; or the presence of altered mood swings (Kim 2007).

Globally, TBI costs economies a total of US\$400 billion a year, and represents roughly 0.5% of the global economic output (World Bank, 2017). Within the 28 countries that comprise the European Union, approximately 37% of all injury-related mortality is either caused by or associated with TBI; in the United States, this number is 30.5% (Maas, 2017). The CDC, which has been collecting TBI data for three decades, has focused on emergency department visits, hospital admissions and deaths (CDC, 2015). The most recent CDC data indicates annually 2 million Americans are treated and released from an ER, with 282,000 hospital admissions, and 56,000 deaths (Taylor, 2017).

In the 21st century the types of TBI cases are shifting, with low-income and middle-income countries (LMICs) reporting a disproportionate amount of the burden of disability caused by traffic accidents in a younger demographic (Maas, 2008). In high-income countries (HICs) such as the United States, the demographic profile is increasingly elderly, with the most common cause of TBIs being a fall (Maas, 2008). Additionally in the US, TBIs are increasingly being reported under sports injuries and fire-arms related injuries. The US, in fact, is only surpassed by a few Central American countries in the rate of fire-arm related deaths (Taylor, 2017).

Twenty percent of all TBIs in the US can be attributed to violence-related incidences, with the highest prevalence of TBI in the age group of 15 to 24 years due to firearm usage. Assault comprises 75% of all pediatric incidences (CDC, 2004). While 3% of TBIs are sports related, over 90% of sports-related TBIs are mild and often go unreported. Alcohol is associated with half of all TBI cases (Maas, 2008).

The incidence of brain injury increases when looking at vulnerable populations, especially in incarcerated populations (Williams 2010), refugees (Doherty, 2016) and homeless populations (Oddy, 2012). Researchers have found evidence that TBI may be a risk factor for criminal behavior, with a criminal lifestyle increasing the risk of a TBI (Williams, 2016). The prevalence of a TBI in an American prison population is roughly 3-8 times higher than in non-prisoner populations, with 60% of the prison population having suffered a TBI (Hughes, 2015). Factors which pre-dispose an individual in this subpopulation to a TBI include risk-taking behavior, socio-economic hardship, and the frequent use of alcohol and substance abuse as well as a cycle of head injuries brought about by altered behavior (McMillan, 2012).

Men are more than three times as likely to experience a TBI as women (Colantonio, 2010), with TBI a leading cause of death in young men. Because of this increased risk, research focus has traditionally been placed on outcomes for men and often overlook the influence of gender (Brown, 2012). But while the incident rate for men is high, the frequency of injury also means there are millions of women who annually sustain a TBI. Subgroups of women are at increased risk of TBI, such as female athletes who are more likely to sustain a concussion than their male counterparts, and to have poorer outcomes (Colantonio, 2010).

Social factors can affect outcomes, with older women who sustain a TBI ending up in long-term care facilities more often than men who tend to recuperate at home (Brown, 2012). Researchers have found that women with TBI, in spite of manifesting physical and mental symptoms similar to those described by male TBI survivors, reported that they forego personal care or rehabilitation in order to fulfill domestic obligations (Alston, 2012).

For military service members, TBI is a significant health issue. Of the 2.5 million veterans who returned from the Iraqi and Afghani combat theaters, over 344,000 individuals sustained a

TBI as a primary or secondary diagnosis (Dismuke, 2016). This equates to roughly 13.7% of the current military population who have suffered TBI and blast-related concussions (Dismuke, 2016). Because of this high incidence rate, TBI has become a major focus of the Veterans' Administration health initiatives.

The incidence of TBI is higher in Hispanic/Latino and African American populations than for white individuals. In comparing minorities with white TBI survivors, people of color receive overall poorer quality treatment, employment, functional outcomes and community integration (Arango-Lasprilla, 2010). Minorities of both civilian and military populations also have been shown to not utilize rehabilitation services as much as whites (Dismuke, 2016). But unfortunately few research studies investigating the role of race/ethnicity on neuropsychological and neurobehavioral functioning and quality of life currently exist (Williams, 2009). With the minority population of the US reaching 45% of the total population by 2050 (Sander, 2018), it becomes increasingly important to understand how culture is perceived in order to have successful TBI community integration outcomes.

4. Brain Injury as Chronic Disease Process

Brain injury can be classified under the World Health Organization (WHO) definition for chronic condition: "it is permanent, caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, and/or may require a long period of observation, supervision, or care." (Masel, 2010, P. 1530). TBI decreases life expectancy and increases the risks of mortality (Masel, 2010). It is linked to an increase in seizures, neurodegenerative diseases, neuroendocrine diseases, psychiatric diseases and non-neurological diseases that can affect an individual and their quality of life (Corrigan, 2013).

Medical researchers are now conceptualizing TBI not as a single event in a patient's life, but rather as the beginning of a disease course. TBI is not a static disease process; it has the potential to affect many of the body's organs and systems over the length of a patient's life.

In evidence-based research supporting the concept of TBI as a chronic disease, the Brain Injury Association of America (BIAA) notes in a 2004 mortality study of 2,178 individuals one-year post-injury with moderate or severe TBI, patients were twice as likely to die as a similar non-brain injured cohort, with a life expectancy reduced by seven years (Harrison-Felix, 2006). Further studies by Harrison-Felix on causes of mortality in this cohort reveal that individuals surviving more than one year with a TBI are 37 times more likely to die from seizures, 12 times more likely to die from septicemia, four times more likely to die from pneumonia, three times more likely to die of suicide, 2.5 times more likely to die from digestive disorders, and three times more likely to die from other respiratory conditions than a cohort matched from the overall population for age, race, and gender. The largest proportion of mortality for individuals with TBI was directly linked to circulatory problems (Harrison-Felix, 2006), with a mortality rate of 29 percent. While this last statistic was not a radically different number from that of the general population, this is a 34 percent increase over the expected number of deaths from circulatory disease.

TBI survivors are three times more likely to die of circulatory disease (Shavelle, 2001). While it makes sense that patients who experience a moderate to severe TBI would have higher rates of mortality than the general population, Brown and colleagues show that there is a small but statistically important decrease in long-term survival of patients with mild TBI compared to the population at large (Brown, 2004). In view of the fact that many more annual cases of mild TBI exist and may go undetected in a population as compared to moderate to severe TBI occur,

the increased mortality of mild TBI patients would result in a substantial number of TBI-related deaths.

TBI is also associated with neurological disorders that can lead to early death. This includes epilepsy, a leading cause of mortality in young adults with TBI (Masel, 2010), as well as sleep apnea, which causes impaired cognition and cardiac arrhythmias during the sleep cycle (Masel, 2010). Neurodegenerative diseases leading to declines in cognitive function after a TBI include traumatic encephalopathy (known as “punch drunk” or *dementia pugilistica*, famously represented by the late boxer Muhammad Ali in his disturbed gait, slurred speech and hand tremors), Alzheimer’s dementia, and Parkinson’s Disease. Age is a factor in decline over the long term, with older patients manifesting larger declines than younger patients (Corrigan, 2013).

Even though many patients may appear to survive a TBI without any long-term effects, often the initial TBI begins a chronic disease path that will be an eventual factor in mortality months to years later in the patient’s life. These chronic conditions include neurological disorders (epilepsy, increased cognitive deficits and sleep disorders), neurodegenerative diseases (chronic traumatic encephalopathy, Alzheimer’s dementia and Parkinson’s disease), neuroendocrine disorders (post traumatic hypopituitarism and thyroid disorders), psychiatric disease (major depression, OCD, aggression, confusion, etc.), as well as non-neurological disorders (sexual dysfunction, urinary incontinence, and musculoskeletal and metabolic dysfunctions). Chronic brain injury affects multiple organ systems that lead to causative and accelerative disease (Masel, 2010).

a) Neurological Disorders

Traumatic brain injury is a leading cause of epilepsy, with 5% of all epilepsy in the general population attributed to brain injury. In young adults TBI is a major cause of seizures (Masel, 2010). Depending on the severity of injury, adult survivors of TBI are 1.5 – 17 times more likely to develop seizures (Annegers, 1998). The time from injury to onset of first post-TBI seizure can be as long as twelve years (Aarabi, 2000).

Cognitive deficits include four groups as they are related to the phases of TBI. The first phase is a loss of consciousness or coma which occurs soon after the initial injury. Phase two is marked by cognitive and behavioral abnormalities (confusion, agitation, and disorientation) during which the TBI survivor has difficulty recalling events, time and learning new information. Phases one and two last from a few days to one-month post-TBI and are a form of post-traumatic delirium. Phase three is a rapid recovery of cognition lasting 6-12 months, followed by phase four, a plateauing of recovery over 12-24 months, during which the TBI individual can encounter difficulties with information-processing, attention deficit issues, problems with executive function, and short- and long-term memory loss. This last phase has been called ‘dementia due to head trauma.’ (Rao, 2000).

Sleep disorders are a common complaint of TBI survivors, with sleep disturbances being reported in 70% of TBI outpatients (Masel, 2010). There is also an increased occurrence of obstructive sleep apnea (OSA), which is linked to decreased cognitive functioning and severe cardiac arrhythmias during sleep, as well as a higher risk of mortality (Masel, 2010). Trauma to the nervous system can have a direct effect on the survivor’s immune system, which can manifest as biological conditions similar to rheumatoid arthritis and lupus (Brown, 2011).

b) *Neurodegenerative Diseases*

The assumption within the medical establishment is that cognitive gains accomplished immediately post-TBI can be preserved and even increased over the long-term. While this is true for many TBI survivors, new research has shown a subset of individuals exists who experience a decline in their cognitive abilities post-TBI (Till, 2008). The best predictor of cognitive decline was found to be the amount of therapy received at 5-months post-injury. Till noted that TBI survivors, regardless of the acuteness of the injury, who received more therapy in the initial months following their injury were less likely to manifest declines over the long-term (Till, 2008). Age is also a dynamic in long-term cognitive outcomes, with older individuals showing a greater decline over the five years following TBI than young adults (Marquez de la Plata, 2008).

Alzheimer's disease, chronic traumatic encephalopathy, and Parkinson's disease all count TBI as a risk factor. In a large study done with World War II veterans, researchers found that any history of TBI more than doubled the risks of developing Alzheimer's and/or non-Alzheimer's dementia in later life (Plassman, 2000). There also exists a direct association between the acuteness of a TBI and a higher risk for Alzheimer's disease. A moderate TBI correlates to a 2.3-fold increase in risk, with severe TBI quadrupling the risk of developing Alzheimer's disease (Schofield, 1997). Even TBI survivors who do not manifest any known cognitive impairments post-TBI have shown an increased risk of an earlier onset of Alzheimer's disease (Schofield, 1997).

Chronic traumatic encephalopathy (CTE – “punch drunk” or *dementia pugilistica*) is produced by repeated blows to the head, causing decreased attention span, difficulty in concentration and memory, culminating in tremors, disrupted gait, and slurred speech (Masel, 2010). Once thought to be an affliction of only retired boxers, CTE is now appearing in autopsies

of retired football players (Omalu, 2006). With repetitive head injuries now evident in various high school and junior high contact sports, CTE may become more prominent than once thought.

Parkinson's disease is categorized as a loss of neurons in the *substantia nigra*, which leads to a selective loss of dopamine and its metabolites (Masel, 2010). And while the pathology of Parkinson's disease is well understood, the mechanisms of how neurons die remain unclear. Symptoms of Parkinson's disease include tremor, rigidity, dementia, slowness of movement and postural instability (Dunnett and Bjorklund, 1999). Studies done on WWII veteran sets of twins show that if both twins are diagnosed with Parkinson's disease and one of the twins also has a TBI, that twin will more likely have earlier onset of Parkinson's disease (Goldman, 2006). Additionally, if only one of the twins is diagnosed with Parkinson's disease, that individual is more likely to have had a TBI. Individuals who have suffered a TBI sustain an increased risk of Parkinson's disease, a risk that is directly linked to the severity of the TBI (Bower, 2003).

Recently, promising new research that grew out of the experience of the Iraq and Afghanistan veterans who incurred multiple IED blast traumas (the 'signature wound' of NATO troops in both war theatres) has shown how proteins, called integrins, send signals that physically disrupt connections among brain cells and contribute to microscale damage that persists over time, directly contributing to neurodegenerative disease. (Hamilton, 2015; Hemphill, 2015).

c) Neuroendocrine Disorders

Neuroendocrine dysfunction is caused by various conditions triggered by an imbalance of hormone production associated with the brain. The two areas of the brain responsible for hormone production are the pituitary gland and the hypothalamus. Injury to the hypothalamus or pituitary gland because of a TBI can result in vascular damage, brain swelling, rupture, vasospasm, and pituitary swelling (Masel, 2010). Depending on the severity, the TBI injury may

adversely affect the production of pituitary hormones and other neuroendocrine brain functions. The resulting complex hormonal responses lead to acute and/or chronic post-traumatic hypopituitarism (PTH). While the underlying reasons for PTH are uncertain, speculation centers on vascular and structural changes to the pituitary, hypothalamus and pituitary stalk (Masel, 2010). In moderate to severe TBIs, Schneider found that 30% suffered from PTH over the first year after injury (Schneider, 2007a). Even survivors who do not immediately manifest PTH immediate post-injury have been found to develop deficits one year later (Aimaretti, 2005). The Institute of Medicine (IOM) recognized the need for monitoring PTH in their 2009 report on returning Gulf War veterans, where they found that “hormonal alterations substantially modify the post-traumatic clinical course and the success of therapy and rehabilitation underscores the need for the identification and timely management of hormone deficiency to optimize patient recovery from head trauma, to improve quality of life...” (IOM, 2009, P#6).

Chronic PTH causes related neuroendocrine disorders, including growth hormone (GH) and gonadotropin deficiencies and hypothyroidism. Roughly 20% of moderate to severe TBIs result in GH deficiency (Agha and Thompson, 2005). Symptoms of GH include increased fatigue, depression, osteoporosis, hair loss, anemia, decreased tolerance for exercise, hypercholesterolemia, atherosclerosis and an important increase in mortality from vascular disease (Rosen, T., Bengtsson, B.A, 1990). Post-TBI, gonadotropin deficiencies are detected in 10-15% of patients (Agha and Thompson, 2005). Symptoms of gonadotropin deficiencies in adult males post-TBI include decreased libido, muscle mass and strength. Agha and Thompson found 5% of all individuals post-TBI suffered from hypothyroidism, with associated symptoms of dyspnea, weight gain, bradycardia and intellectual impairment, depression, hyperlipidemia, hypothermia, intolerance for cold, irregular menses and infertility (Agha and Thompson, 2006).

While hypogonadism, when the body's sex glands produce little or no hormones, is common just following a TBI, it also endures in 10-17% of long-term TBI survivors (Agha and Thompson, 2005).

d) Psychiatric Disease

In 1937, C. P. Symonds remarked that “The response to head injury depends on the kind of head that was injured” (Symonds, 1937). The major risk factors for psychiatric disorders post-TBI injury include age, alcoholism, marital discord, financial instability, poor interpersonal skills, as well as difficulties being and remaining employed. In terms of cost, psychiatric disease is one of the most important healthcare issues facing the US, with estimates putting the price of these disorders at one-third the total amount of the American healthcare budget (Voshol, 2003). For TBI survivors, their families and caregivers, psychiatric disorders are among the most disabling of all outcomes sustained from the TBI injury (Masel, 2010). Often, TBI survivors are left with significant long-term neurobehavioral symptoms. Mood disorders, depression, anxiety, mania, psychosis and apathy are psychiatric ailments that have been connected with brain injury for many years.

In 1904, Adolph Meyer suggested these symptoms were “traumatic insanities” and recommended that there was a direct association between these indicators and brain lesions (Meyer, 1904). TBI is associated with confusion, aggression, and agitation. Both mild and moderate TBI are linked to an increased risk of obsessive-compulsive disorder, anxiety disorders, apathy and major depression (Fleminger, 2008) as well as increased substance abuse (Hibbard, 1998; Holsinger, 2002; Koponen, 2002; Silver, 2006). In chronic brain injury, the prevalence of psychosis is 20%. The incidence of depression is 18-61%; mania 1-22%; post-traumatic stress disorder occurs in 3-59% of TBI survivors, and 20-40% suffer from post-

traumatic aggression (Kim, 2007). TBI is also associated with high rates of suicidal ideation, attempted suicide and completed suicide (Masel, 2010).

Psychiatric disorders continue to afflict TBI survivors long after the initial event. Koponen found in a study of 60 patients, followed up to 30 years post-injury, that 50% developed a serious mental disorder only *after* their TBI injury (Koponen, 2002). Additionally, in a study that tracked TBI survivors at 2- and 5-years post-TBI, a higher occurrence of behavioral, cognitive and emotional changes happened at 5 years rather than at the 2-year mark (Olver, 1996). Thirty-two percent of those employed at the two-year mark post-TBI were unemployed at the five-year period.

e) Non-neurological Disorders

As noted earlier, during the acute phase of a TBI injury, non-neurological disorders can be a direct cause of mortality and morbidity (Corral, 2012). While the pathophysiology of systemic complications of TBI remains unclear, it is known that non-neurological complications can occur directly from either the injury or as a consequence of therapy (Lim, 2007). In long-term TBI survivors, sexual dysfunction, incontinence, metabolic disorders, and musculoskeletal dysfunction are common ailments (Masel, 2010).

Functional and physiological sexuality plays an important role in the quality of life. While sexual dysfunction is a significant topic in the general non-TBI population, it is an equally important issue for many TBI survivors. Sexual disorders are often described as difficulties with sexual desire and with psycho-physiological changes connected to sexual response cycles (Hibbard, 2005). For post-TBI survivors, physiological, physical and body image negatively impact sexual activity and interest, with between 40-60% of the TBI population indicating problems with sexual dysfunction (Zasler, 2007). For male TBI patients, predictors of sexual

dysfunction include age at time of TBI injury, and depression, which is the most sensitive predictor of sexual dysfunction. For female TBI survivors, depression combined with an endocrine disorder is the most sensitive predictor of sexual dysfunction (Hibbard, 2005). Transient hypogonadism, the state where the body's sex glands produce little or no sex hormones, is common following TBI. It also continues on in 10-17% of long-term TBI survivors, manifesting in muscle weakness, osteoporosis, fertility and psychosocial concerns (Agha and Thompson, 2005).

Brain injury can often affect the cerebral structures that control bladder storage and emptying functions, contributing to one of the most distressing outcomes of a TBI injury, bladder and bowel incontinence. Fecal incontinence is a psychologically and socially devastating condition, which can lead to skin breakdown, decubitus ulcers and skin infections. In a study involving 1,000 TBI patients, one-third were incontinent of bowel at hospital admission, 12% remained so at discharge, and 5% at 1-year post-hospitalization (Foxy-Orenstein, 2003). Urinary incontinence is also a social and medical issue. It is linked to recurrent urinary tract infections (UTIs), and decubitus ulcers. Chua found in the records of 84 TBI patients admitted to hospital rehabilitation with six weeks of initial injury, and after the initial acute phase, 62% reported urinary incontinence. While this figure improved to 36% at time of discharge, 18% remained incontinent at the six-month mark (Chua, 2003).

Musculoskeletal dysfunction brought on by a TBI can have a negative impact on the physical, social and mental health of the survivor. A variety of risk factors have been identified for musculoskeletal disorders; many of which can be direct results of a brain injury. Because of this, TBI survivors are a higher risk cohort for developing arthritis and other musculoskeletal disorders. Recent long-term outcome studies reported greater than expected rates of arthritis in

TBI survivors up to 24 years post-injury, with higher self-reporting, especially from the middle-aged population (Brown, 2011).

Contingent upon the type of injury sustained, many TBI survivors can suffer a major body trauma that could cause joint injuries, which contribute to degenerative joint disease (Hibbard, 1998). Physical inactivity due to a prolonged period of unconsciousness could lead to musculoskeletal dysfunction. Often postural instability is reported after a brain injury, as well as disordered gait. Abnormal forces on weight-bearing joints could lead to degenerative changes and ultimately arthritis (Brown, 2011). Extended usage of mobility supports such as wheelchairs or crutches can lead to musculoskeletal disorders. Traumatic stress exposures have been linked to the onset of fibromyalgia (Boscarino, 2004).

Metabolic disorders are common, as TBI seems to affect the way the body absorbs, exploits and converts amino acids (Masel, 2010). Amino acids integrate into functional and structural proteins, playing a significant role in brain function. They are the forerunners of neurotransmitters engaged in cognitive, motor, neuroendocrine and behavioral functions. Abnormalities in the metabolism of amino acids may be a factor in the increase of symptoms such as fatigue, poor learning and decreased memory in TBI survivors.

5. Traumatic Brain Injury Continuum of Care

Every brain injury is variable in nature, and no two injuries are alike. The same is true for recovery, care, level of disability, community integration and outcomes (Doig, 2001). With the ultimate goal of the traumatic brain injury continuum of care being a decrease in mortality/morbidity rates, health risks and suffering (Caro, 2010), each stage of the system supports a different aspect of whole person care. Positive cognitive, functional/physical outcomes and community integration are all components of this system. Trauma care and initial

hospitalization, rehabilitation hospitals (including inpatient), post-acute rehabilitation and finally community integration services all combine to further the TBI survivor along to a successful conclusion.

Care can cross functional lines and organizational structures to create the integrated system, with seven performance care layers: field screening and interventions (done by paramedics in the field); logistical management and transit care; emergency TBI hospital care; neuro-trauma care at trauma units; comprehensive TBI rehabilitative care; psychiatric care; community reintegration (Caro, 2010). As patient numbers increase, case management surges and chronic conditions begin to manifest, with effectiveness and sustainability becoming a population health issue (Caro, 2011). The challenge of the TBI continuum of care is such that as more care resources are enabled, the systematic sustainability of these layers can become compromised from the holistic perspective. Sustaining quality care requires re-engineering to mitigate risk. Systemic strategies that support the seven layers of performance are guided by strategic drivers for performance sustainability: emergency medical leadership; innovative virtualization; TBI collaborative networks; value paradigm shifts; intelligence system architecture (Caro, 2010).

Acute hospitalization and trauma care are the initial phase, with the survivor remaining in the acute care setting until stabilized and the injury severity is diagnosed. The length of this phase is governed by variables that include brain injury severity, surgery needs, any signs (and duration) of coma, plus any presentation of complications. Medical interventions can include medications and surgery. Willer has described the medical model as a 'life-risk' situation, where the ultimate goal is preserving life, with the TBI survivor highly dependent upon others, especially the physician (Willer, 1993).

Upon discharge from the acute care setting, the TBI survivor then moves on to the rehabilitation hospital stage, either acute or inpatient. The rehabilitation process is highly structured and incorporates physical therapy, speech therapy, occupational therapy, cognitive rehabilitation, psychological support and education. Rehabilitation interventions build upon the medical model, and include the use of mobility devices, the learning of new skills and adaptations to the survivor's home environment in response to the level of impairment. According to Willer, the main goal of rehabilitation is maximizing functioning through the reduction of disabilities rather than a decrease in handicaps (Willer, 1993). As with the medical model, the solutions proposed in the rehabilitation model rest on the intervention of allied health professionals.

Once an individual has been discharged from rehabilitation and goes back into their community, they can face a variety of cognitive, physical, behavioral and emotional challenges. The life roles an individual played pre-injury may have been taken on by others while the TBI survivor was hospitalized and in rehabilitation (Gerber, 2015). The longer the period of hospitalization and rehabilitation, the harder it is for a TBI survivor to successfully reintegrate back into familial and societal roles.

Social reintegration strategies are critical to the success of the TBI survivor's assimilation back into society, but much of the research focusing on this area assumes that the survivor's family, work and social units are already healthy, integrated and functioning as one unit. This is often not the case, and the TBI survivor may be faced with a fragmented support system. (Wheeler, 2007). This is where TBI community integration organizations can play a key role.

CHAPTER 3 – FRAMEWORK OF COMMUNITY INTEGRATION

1. Community Integration

What is community integration? Simply described, it means a TBI survivor is able to successfully assimilate back into the social fabric of that individual's community to such a degree that quality of life is markedly improved post-TBI (Parvaneh, 2015). The level of successful assimilation is unique to each individual; one TBI survivor may be able to go back to work fulltime, while another may only be able to volunteer on a limited basis, but both are deemed successful in their integration. Historically, community integration has been characterized by three major fields: productive activity (which includes paid/volunteer employment), social networking with family, friends and community; and independent living (Malec, 2013). The research challenge has been that these three topics haven't always been given equal importance. Crucial disparities in resources remain that impede improvement in community integration for TBI survivors (Sullivan-Bolyai, 2005). Looking at the literature, studies do exist assessing the efficacy of community integration. However, the lack of a consistent definition of community integration remains an issue, as descriptions cover everything from outpatient rehabilitation to day services (Evans, 2008). The environments for these programs also vary and are not uniform with the definition of community integration being accomplished within the TBI survivor's social and physical environments. These can include telephone counseling only, behavioral management in a natural setting (community-based), mentor/peer support groups, interdisciplinary rehabilitation in an outpatient setting, educational training programs, outdoor experiential education, and return to work programs.

Community integration can be defined as “rehabilitation that takes place within the client's physical and social environment, for example, in their home or other community facility”

as well as support the role of the caregiver (Sakellariou, 2006). The ultimate goal of community integration is to increase a TBI survivor's quality of life and functional independence within the context of that person's life role and routine (Sakellariou, 2006). Due to the need to reduce healthcare costs, TBI survivors are being discharged sooner from the hospital and the time spent in rehabilitation has been diminished, resulting in poorer long-term outcomes and greater caregiver burdens (Mass, 2017). Because of this, current community integration programs are designed to help to meet the chronic psychosocial needs of the TBI survivor and caregiver, and include services focusing on quality of life, functional independence, cognitive abilities and community participation (Trudel, 2007). Outcomes measuring the changes over these areas would include the quality of life, functional independence, physical, psychological and social functioning, community participation levels of the TBI survivor, along with caregiver support.

The need for returning a TBI survivor back to full participation in the community has been documented since World War I, when the military first utilized occupational therapy units to help veterans return back to society after a TBI (Sander, 2010). But as surgical and medical advances have improved the survival rates of TBI, the concept of community integration has become more important. This is especially true when it comes to the increase in post-acute brain injury rehabilitation programs across the country and the globe focusing on improving participation.

For the specific research included in this dissertation, community integration is defined as psycho-social rehabilitation taking place within a community setting, with the aim of increasing the TBI survivor's quality of life and functional independence as well as minimizing the psychological impact of caregiving on the TBI survivor's principle caregiver. The demographic is adult survivors only, with both TBI and ABI diagnoses. Interventions include programs

focusing on increasing quality of life, cognitive improvement, strengthening functional independence, expanding community participation for both TBI survivors and caregivers.

1. History of Community Integration

The concept of community integration first appeared in the 1970s in the mental health sector as a response to the deinstitutionalization of patients with mental illnesses. Known as “The Clubhouse Model,” successful community integration was described as the capacity to productively engage in an assortment of unstructured community activities (Jacobs, 1994). Willer and colleagues promoted the measurement of community integration, defining it as “effective role performance in community settings” with three areas of integration: home, where the TBI survivor is an active participant in the management of the home; social in that the survivor successfully joins in activities in the community and participates in social relationships; and productive activities, where the TBI survivor is engaged in either volunteer, employment or education pursuits (Willer 1993). Building off of the independent living concepts of normalization (returning to a normal state) and social valorization (adding positive change to an individual’s status in society) (Condeluci, 1987) as well as the medical/rehabilitation models, Willer and associates then created a community integration non-medical model, entitled “Whatever It Takes” (WIT) (Willer, 1993). A practical approach to community integration, Whatever It Takes promotes self-determination as the chosen objective for TBI survivors while incorporating behavioral and cognitive goals utilizing the process of informed choice. As Willer notes, “Complete self-determination may not be possible, but maximum self-determination is.” (Willer, 1993). Simple but innovative, the ten principles of Whatever It Takes are the following:

- No two individuals with a TBI are the same

- Independent living skills are more likely to generalize and be successful when learned in the environments where they will be used
- Environments are easier to modify than people are
- Community integration must be holistic in nature
- Life is a ‘place-and-train’ undertaking
- Natural social supports will outlast professional supports
- Interventions must never do more harm than good
- The brain injury continuum of care can inadvertently produce barriers to community integration
- Respect for the TBI survivor is an overriding principle
- The needs of a TBI survivor last a lifetime; so should resources

McColl took this one step further by expanding the definition of community integration as “having something to do, somewhere to live, someone to love” (McColl, 1998). In later literature, McColl identified four elements of community integration: assimilation, or the ability to socially ‘fit in’; social support, in being a part of a network of family and friends; occupation, having meaningful and fun activities in one’s life; and independent living, where the TBI survivor has the capacity to make everyday choices and decisions (McColl, 2001). Additionally, McColl and others agreed that community integration can be broken into objective and subjective domains. The objective components of community integration focus on what a TBI survivor does, while the subjective domains concentrate on how a TBI survivor feels about what they do, along with any limitations (McColl, 2001).

TBI survivors are significantly less assimilated into their communities than the general population, with this isolation manifesting negative and long-term effects on participation in

daily life roles (Willer, 1993). When it came to successfully measuring community integration, researchers noted that the traditional medical model was limited in its scope because clinical symptom evaluation did not capture the level or satisfaction of a survivor's integration (Willer, 1994). More recently, Cicerone determined that both social participation and quality of life “comprise the most meaningful outcome of [TBI] rehabilitation”, but that these have historically not been the focus of program effectiveness (Cicerone, 2004).

During the first-year post-injury, survivors report diverse health needs, even after rehabilitation is complete (Corrigan, 2004). TBI community integration concentrates on programs designed around social, psycho-social, cognitive, vocational and community environments for the TBI survivor (Cicerone, 2004). Unlike the medical component of the TBI continuum of care, community integration-expanded programs, known as comprehensive day programs (or CDT) can address long-term chronic physical, mental health and socialization outcomes of the TBI survivor. The Clubhouse Model bases much of its day programming on this method of comprehensive day programming. According to Malec, the comprehensive day programs approach has six specific characteristics: an emphasis on interpersonal, psycho-social and cognitive areas; an approach that is interdisciplinary; cognizance of social skill issues; support and involvement of caregiver; significance of vocational concerns; and importance of outcome measures (Malec, 2001). Comprehensive day programs are structured with some aspects mirroring the medical model, with TBI survivors interacting in mostly group settings, with individual one-on-one meeting as required.

The challenge faced by many community integration organizations is that few provide comprehensive programs such as the comprehensive day program (CDT) to support the long-term chronic needs of the TBI survivor, and little is known about those organizations that attempt

to deliver an increased continuum of care (Cicerone, 2004). Often in the context of society, a disabled individual who manifests physical and mental illnesses is viewed as different and can go up against perceived cultural norms. Research indicates that between 26%–45% of TBI survivors are poorly assimilated into their communities (Doig 2001). These individuals may have their positions within the community limited due to the barrier of social stigma attached to their condition, thereby creating a sense of isolationism within the survivor and a long-term negative impact on life roles such as family member, friend, worker, or student (Wheeler, 2007).

Even without significant physical and cognitive impairment, survivors of TBI are often faced with poor community integration outcomes that include diminished social integration, reduced social participation and decreased quality of life (Cicerone, 2004). Research has shown a direct correlation between poor psychosocial outcomes with increased depression, anxiety, coping and self-esteem (Anson, 2006). In terms of quality of life, both negative and positive affective states are essential in gauging the long-term objective and subjective outcomes post-TBI. Affective states can be described as emotional responses to experiences (Juengst, 2014). Negative effects include fear, distress, guilt, lethargy and irritability, which may be expressed as anxiety and depression. Positive affects consist of energy, joy, interest, and enthusiasm, with poor positive affects exhibiting as low self-esteem, depression, or weak coping skills. Overall poor (high negative, low positive) affect is a factor in depression, with research indicating it may continue even after the depression has been successfully treated. High negative affect (guilt, fear, nervousness, etc.) can exist after a TBI, even if no clinical symptoms of depression are present (Juengst, 2014). Low positive affect can also signify early symptoms of depression. Because it may in fact overlap with depression, poor affect may be considered an independent factor contributing to the quality of community integration post-TBI (Cicerone, 2007). Poor affective

state is a health outcome that should be monitored for improvement within a community integration model system. As the goals of the TBI system of care shift towards chronic care of TBI in community-based and person-centered services, a focus on community integration from both an objective and subjective perspective has value. Traditionally, community integration success has been measured through objective outcomes such as return to work (Sander, 2010). Recent research proposes the subjective assessment of satisfaction with participation in community, family, and household activities is a better measurement of a TBI survivor's perspective of community integration to be accomplished. Through the dual evaluation of objective (frequency) and subjective (life satisfaction), a more inclusive perspective is gained of the relationships between community integration post-TBI and affective states (Djikers, 2006).

Psychosocial deficits post-TBI can come from internal impairment and external sources (Togher, 2012). Internal impairment centers on the survivor's pre-existing features and the level of injury severity. These sources include pre-TBI elements (e.g. personality), impairment brought about by the TBI, limitations on activity linked to skill loss, and indirect effects of psychiatric disorders (such as depression and anxiety). External factors involve opportunities for social participation, which is the framework for remediation to improve the impairment of damaged neural, cognitive, and emotional processes of the TBI survivor (Ylvisaker, 2003). Increasing participation improves the efficacy of remediation of impairment and skills (Togher, 2012).

A challenge for psycho-social rehabilitation is that the different long-term injuries faced by a TBI survivor can hinder recovery throughout a survivor's life span. Impairments of fatigue, emotional control and perception can inhibit during the early phases of recovery. Self-awareness can impede successful community integration, and limitations in social skills and communication

can deter a TBI survivor from effectively transitioning to work, school or social environments. Depression and anxiety can also affect the level of social integration, with approximately 60% of all TBI survivors reporting poorer psychosocial outcomes (Whelan-Goodinson, 2008). Additionally, affective states, unlike psychiatric diagnosis, can vary widely across the life of the TBI survivor.

In viewing TBI as a chronic condition, challenges exist in addressing TBI psychosocial deficits. Social consequences of TBI are both complex and profound, requiring a multi-faceted approach for success (Togher, 2012). There are many post-acute programs including outpatient community integration, residential community integration, day treatments, and neurobehavioral programs (Malec, 2001). Studies have shown a decrease in psychosocial issues, increase in work participation and better community integration for day-programs versus both residential programs and neurobehavioral interventions (Geurtsen, 2010).

Even after improvements in physical functioning, psychosocial problems can remain, including depression, loneliness, and decreased social networks (Gerber, 2015). A one-year post-injury study of mild-to-severe TBI survivors showed decreased participation in leisure activities, but an increase in playing computer/video games and watching television. A 3-to-5-year post-injury study of mild-to-severe TBI survivors showed 60% of the population experienced difficulties joining in leisure activities (Wise, 2010). And veterans living in the community one-year post injury experienced decreased social interactions and productivity in comparison to individuals without disabilities (Williams 2014).

A TBI survivor's social isolation can cause an undue burden on the caregiver. This in turn can heighten the caregiver's own depression and anxiety, decrease his/her own social independence and overall quality of life. Other disease-centered day programs (such as those for

dementia and Alzheimer's) have well documented histories of success, but research on day programs for TBI is fragmented and may not lend itself to building across a multi-disciplinary field (Cicerone, 2011).

Many TBI survivors, once rehabilitation is complete, return home and end up leading a life that is isolated, restricted, and less satisfying than the life led pre-injury. The Clubhouse model of drop-in day programming can offer psychosocial support to meet social, emotional and cognitive needs in an informal setting (Fraas, 2007). Using the Community Integration Questionnaire (CIQ) a 2012 study compared social participation in one-year post-TBI survivors attending a drop-in day program with a group that did not frequent a program. Results reflected higher social participation scores for those participants in the Clubhouse day program than those who were not enrolled in any programs (McLean, 2012). Often, however, behavioral challenges of a TBI survivor may be too disruptive to benefit from the informal, un-structured atmosphere of a Clubhouse or drop-in program, leading to further isolation.

2. Outcomes Research – Assessing Community Integration

The literature evaluating the effectiveness of community integration programs is relatively limited in both scope and quality. Reistetter (2005) conducted a systematic review and was only able to identify a handful of articles that examine the effect of community integration programs on quality of life or similar outcomes in TBI survivors. Although this review was published 14 year ago, we were unable to identify a more recent systematic review except those focused narrowly on specific populations such as pediatric populations (Agnihotri, 2010); older adults (Richie, 2014); or others specific groups such as survivors of assault (Kim, 2013). Some additional evaluation studies have been published since 2005, but most of these studies have

been uncontrolled and small in scope, although they provide some support for the potential effectiveness of CI programs (e.g., Wheeler, 2012).

Perhaps the lack of a robust evidence base in this area is due in part to the substantial variation in opinions about what represents CI and how CI should be measured. The World Health Organization's (WHO) International Classification of Functioning Disability and Health (ICF) presents an illness and disability structure defining the effects of disease, promoting a greater understanding of health issues, their description and how they may be improved (Wade, 2003). The ICF describes internal and external consequences of health from which outcomes can be derived. The internal outcomes of illness within an individual focus on body functions (pathology) and structures (impairment within the body). The external effects of illness center on activities (performance of tasks) and participation in a life (social environment) (WHO, 2001). In terms of activities for TBI survivors, there has been growth in the CI realm to adopt inclusive service delivery practices in an effort to expand and improve recreational and therapeutic services (Miller, 2014).

Interwoven with the model of community integration is the notion of what should be assessed in terms of TBI impact on participation. Traditional measures have focused on the objective characteristics of community integration, like frequency of social pursuits or productive activities. Historically the tools most widely used for these types of objective concepts are the Community Integration Questionnaire (CIQ); the Mayo-Portland Adaptability Inventory-4 (MPAI-4) or the Craig Handicap Assessment and Reporting Technique (CHART) (Sander, 2010). The CIQ, created in 1993 to measure the degree with which a TBI survivor can function within the home and community, is a 15-item tool assessing three domains of community participation: home integration, social integration and productivity. High scores

represent greater independence and integration in the TBI survivor. While the CIQ utilizes behavioral indicators of integration, it does not focus on feelings or emotional status (Dijkers 1997; Willer 1994). The MPAI-4 evaluates disability in three areas: abilities, adjustment, and participation, and was designed to reflect the WHO's distinction between impairment, activities and participation (Malec, 2012). Using 29 items rated on a 5-point impairment scale, the MPAI-4 includes a range of physical, cognitive, behavioral, emotional and functional impairments. The CHART was originally created for assessing spinal cord injuries, objectively measuring the degree to which a disability ultimately results in a handicap. It is also used in TBI injuries. It mirrors the WHO's ICF and focuses on physical independence, mobility, occupation, social integration, and economic self-sufficiency (Sander, 2010). Its limitations are that it does not include subjective appraisals and personal preferences of the participants.

Researchers have examined factors which predict levels of success for community integration after a TBI (Winkler, 2006). In an Australian study, measures of functional status, disability, memory and cognition were coupled with demographic and clinical characteristics, with predictor variables being cognition, functional disability, fine motor skills, memory, and activities of daily living (Winkler, 2006). Outcome variables of community integration and vocational endeavors were measured by the Community Integration Questionnaire (CIQ) and employment status (Winkler, 2006).

A shortcoming of some of the tools is the lack of a process to assess individual differences within priorities, with Dijkers arguing that the preferences a TBI survivor places on the diverse community integration activities should also be considered when looking at TBI outcomes (Dijkers, 2010). Researchers have shown a disconnection between community participation and life satisfaction (Cicerone, 2004). An example of this would be return to

employment. For society as a whole, a return to work may be perceived as the most valuable measurable outcome for a TBI survivor (Ownsworth, 2004). And even though the research and medical communities may acknowledge the importance of relationships for a TBI survivor, most rehabilitation and clinical research remains focused on independent living and employment measures. For the individual TBI survivor, however, a return to work may not be what they see as their primary goal and may not contribute to what they perceive as a good quality of life.

Measures focusing on the subjective aspects of community integration have been created to include qualities excluded in the more objective measures. These tools include the Community Integration Measure (CIM) and the Quality of Life After Brain Injury (QOLIBRI). The CIM incorporates topics such as how comfortable a TBI survivor feels within their community; their sense of belonging to that community and whether they feel useful (McColl, 2001). The CIM is distinct from the CIQ, and objectively measures participation (Sander, 2010). The QOLIBRI is the first measurement tool created to assess health-related quality of life (HQoL) post-TBI and covers the six dimensions of HQoL: Cognition; Self; Daily Life and Autonomy; Social Relationships; Emotions; and Physical Problems (Truelle, 2008).

Community integration approaches have shifted from the use of repetitive exercises in order to re-train cognitive functions, to interventions that now take into account a ‘whole person’ philosophy of support, which focuses on the TBI survivor’s individual and ecological context (Ylvisaker, 2003). This includes the assessment and efforts to ameliorate challenging behaviors, which are linked to poor community integration outcomes (Sloan, 2004). Emphasis has moved beyond just the results of the injury-impairment and into the interaction of the TBI survivor with his/her environment, including family dynamics, social support, government policies, and accessibility issues (Whiteneck, 2009).

2. Potential Model Programs to Guide TBI Community Integration

Several models already in existence possess a potential adaptability to support key elements of a TBI community integration standard. Some of these come from the non-TBI psychosocial domain, others are from within the TBI continuum of care. None, however, specifically just address the needs of TBI community integration. The models discussed here include (1) Program for Assertive Community Treatment (PACT); (2) the Clubhouse day model; (3) behavioral health models; (4) disability regional center system; (5) independent living center model, and the (6) chronic care model. While there are many models to choose from, the ones listed above were selected because of their quality as evidenced-based programming (EBP); their longevity and success within their specific sectors; the potential adaptability into standards for TBI community integration; and the clear process and outcome measurements used.

1. Program for Assertive Community Treatment (PACT)

Originally created over 40 years ago at the Mendota Mental Health Institute (MMHI) in Wisconsin to assist the severe mentally ill (SMI) reintegrate back into the community, Program for Assertive Community Treatment (PACT) is now recognized as an effective psychosocial model by civilian and military programs alike (Stein, 1980). It has been incorporated into the Department of Veterans Affairs psychiatric modules of care (VA, 2000). The program has been successfully implemented in 35 states, as well as in Canada, Sweden and Australia (Phillips, 2001).

In the late 1970s, health professionals saw severely mentally ill patients being discharged into a stable community setting, only to find them back in the psychiatric hospital just a few

weeks later. In an effort to help patients reintegrate and remain in the community after discharge, the group at MMHI assessed the delivery process of psychiatric services and what the severest needs of the individual patients were. PACT is used whenever there are patients who manifest the most intractable symptoms of mental illness coupled with severe functional impairment issues. These individuals unsurprisingly have some of the highest inpatient recidivism and the poorest quality of life outcomes (Phillips, et.al. 2001).

PACT is built upon eight philosophical goals: a team approach to service; community-based; person-centered; assertive outreach; flexible service delivery; 24/7 crisis availability; include natural support; and recovery as the goal (SAMHSA, 2016). A care team of professionals are responsible for providing the services to the patient. Services under PACT are available 24 hours, 7 days a week. The provision of services is not done in a generalized atmosphere, but ‘in vivo’ – in real life settings where support is needed and the context of problems can be realistically dealt with on a real time basis (Bond, 2015).

Organizations using PACT are in urban and rural locations, and have adapted to specific populations, such as those with SMI and are homeless or veterans with mental illness (Phillips, et.al. 2001). Individual programs can be tailored to specific outcome goals, such as dual-diagnosis treatment or employment. PACT can emphasize personal growth or basic survival. Some of these programs can include caregivers and family as members of a treatment team, but this is not a universal requirement.

a. Process and Outcome Measures of PACT

PACT is measured through a series of formal process assessments and outcome measures found on the Substance Abuse and Mental Health Services Administration (SAMHSA) website. These assessments are done every six months during the first two years of a new program, and

thereafter on a yearly basis. The primary goals of PACT are to help consumers with SMI live independent lives in their own communities; to lower hospitalization rates; to decrease homelessness; and to diminish the level of incarceration. Assessing the programmatic structure (or process) includes a Readiness Assessment to gauge the human resources and logistics (Phillips, 2001). This includes staffing, facility/equipment, medication administration, consumer records, program budget, clinical process administration and monitoring. Two evidence-based tools have been developed to measure how PACT services are provided to clients: the Assertive Community Treatment (ACT) Fidelity Scale and the General Organizational Index (GOI). The ACT Fidelity Scale has 28 program specific areas with each item valued on a 5-point scale from 1 (not implemented) to 5 (fully implemented). The scale monitors three categories: human resources, organization, and nature of services. The second set of process measures is the GOI, which is not a fidelity scale, but is specific to each evidence-based practice. The GOI can measure organization-wide operating procedures that are used to support EBP.

To measure the success of PACT, there is no one formal outcome measurement tool but rather a core set of suggested outcomes to be evaluated that will form the basis of a quality assurance system: psychiatric/substance abuse hospitalizations; incarceration; housing stability; independent living; competitive employment; educational involvement; and the stage of substance abuse treatment an individual is currently in. These are suggested because they reflect the primary goals of PACT and are straightforward quantitative data that can be measured. Most research on the efficiencies of PACT have focused on the aggregation of program elements. The SAMHSA website does offer a diverse list of pre-established outcome measurements for each evidence-based program in PACT. Outcome measures are suggested to be monitored on a 3-month basis to enhance reliability in results.

b. Strengths and Weaknesses of PACT

As a tool to assist the severely mentally ill, research indicates that assertive community treatments are no more expensive than other types of community-based care and are more satisfying to patients and their caregivers (Phillips, 2001). It has also been shown that PACT results in a lower rate of psychiatric hospitalizations and a higher stability rate in housing. No difference was found between consumers in PACTs attaining employment versus clients enrolled in the Clubhouse model (McKay, 2016).

PACT services are provided by a diverse group of professionals which allows interventions to be quickly adjusted if need be. And while there remains a list of core services provided individually to clients these are not limited to a predetermined set of interventions. This means that the team is the service delivery vehicle within the PACT model and can make adjustments to services if need be. If a PACT exists in a community where mental health access is limited, it may result in better access and therefore more effective treatment. Additionally, hospital care is more expensive than community care, so for the consumer who has a history of high services use, PACT may actually be more cost effective.

The issues with PACT focus on structural components, such as a lack of a time limit on a service; the whole team approach and cross-training; funding; the ability for mental health professionals within states to modify the program in terms of scope eligibility and program services so much that it no longer serves the populations it was meant to serve (Phillips, et.al. 2001). The relationship between the PACT staff and the larger hospital system of care is important and can suffer from a level of detachment between the two, which then leads to difficulty in creating communication channels between PACT members and the larger

continuum of care system. All of these issues would present as big challenges to a TBI CI organization trying to implement a similar model.

Several national organizations (non-TBI) have gone ahead to try to standardize PACT, but each attempt by an organization did not necessarily reflect similar efforts for standardization across other psycho-social organizations. An example would be the Veteran's Administration and its specifications that a veteran can be shifted from intensive care to a less intensive care if the requirements for readiness are met after one year of PACT treatment. The concept of a necessary staff-to-patient ratio is a discussed among researchers but remains very different among organizations. There exists now within mental health community experts those who believe patients are better served by being placed in less intensive services than in a "for-life" assertive community treatment. Additionally, staffing a PACT for 24-hour care is now seen as a potentially prohibitive cost, with many mental health providers opting to send patients after-hours and weekends to existing evening crisis centers. This breaks the continuity of care the individual may have been receiving at the PACT. These discussions and decisions have made for potential financial concerns for the future of PACT, the challenge being there currently are no formal guidelines for structural changes many decisions program planners will need in order to promote cost efficiencies. Researchers have found that the most successful characteristics supporting implementation of the PACT model were the team approach, *in vivo* services, assertive engagement, small caseloads, and the defined admission criteria. And while all of these suggest the importance of including these components, researchers note that only programs who held closely to the model were used and therefore did not have enough variability to determine different effects of any one specific component on outcomes (Phillips, 2001).

2. Clubhouse Day Model

Fountainhead House in Hell's Kitchen, Manhattan, the first Clubhouse in existence, opened in 1948. The Clubhouse was expressly created as a non-clinical integrated therapeutic working community of adults with severe mental illness (SMI) who, upon returning to their communities from psychiatric hospitals, found they had no place to live, work or socialize. Without productive and fulfilling lives, these patients quickly destabilized back into mental illness. The philosophy of Clubhouse model is to see each individual participant as an active 'member' of the group, with each member possessing individual strengths that assist in recovery of severe mental illness, to the point where the individual can lead a satisfying life. Each day members are responsible for overall program operations, whether they be answering phones, cooking, cleaning or program planning. All activities are organized into what is termed a "work-ordered day" (Jacobs, 1994). This parallels the hours of a typical business day of the community where a Clubhouse is located. The daily tasks of life are the activities, and unlike other programs that simulate work, the Clubhouse philosophy sees these tasks as essential to the program's success. Members decide on which tasks they want to do according to their own personal goals; the theory being through these tasks individuals will learn new work skills and gain social connections. Employment is considered a "restorative" function, and a key component of the Clubhouse program, with options being either traditional employment (TE) where a client is placed in a subsidized job with the ultimate intent of finding a non-subsidized position as soon as possible, supported employment (SE) which is a competitive job placement in an integrated setting that includes supports such as job coach, etc., and independent employment (IE) where the individual is hired into a competitive employment and does no longer needs disability supports (IE) (Adkins, 2004). Each of these stages of employment meet the Federal definition of

“competitive employment,” with open positions mainstreamed in society beginning at minimum wage.

Clubhouse staff work alongside members and are not separated from them during the day. There is no delineation between members and staff based upon the disability, nor is there a time limit for membership – a member can be a part of a Clubhouse for a lifetime, if need be. Four important messages are at the core of the Clubhouse philosophy: (1) the Clubhouse belongs to those who participate and those who work to make it a success. Teamwork is the key, and membership is an inclusive concept, providing individuals a sense of belonging within a community’s social fabric; (2) the structure is built upon the understanding that members are expected to show up on a daily basis; (3) creating and maintaining a climate of inclusiveness is intentional – a pronounced difference to traditional mental health day program services where participants join not because they were wanted by the program, but because they needed services delivered by the program (McKay, 2016).

Clubhouse International is a non-profit member organization for clubhouses that works towards decreasing social and economic isolation for individuals with mental health issues. Clubhouse International is the accrediting entity for clubhouses worldwide and has a set of evidence-based quality standards that all member clubhouses must adhere to if they are to remain a member. The International Standards for Clubhouse Programs™ (see Appendix C) defines the Clubhouse Model of rehabilitation and acts as both a ‘Bill of Rights’; a code of ethics for members, staff, and administrators; and informs accreditation (Clubhouse International, 2015, February). There is an official accreditation process by CI to ensure that the Clubhouse complies with the International Standards for Clubhouse Programs™. Similar to other accreditation programs, accreditation includes a self-study, a site visit, a findings report, and recommendation

for accreditation or for deference. Accreditation is awarded for one year or three years. While all Clubhouses that are affiliated with CI make the effort to become accredited (accreditation started in 1992), roughly half of those have achieved Clubhouse accreditation.

a. Process and Outcome Measures of the Clubhouse Model

In the 70 years since the first Clubhouse opened its doors, over 326 Clubhouses have been built in 33 countries and 36 US states. There are many other organizations who claim to follow the Clubhouse model but are not affiliated with CI and do not have fidelity to the standards.

A literature search shows there are currently two process measures for clubhouse fidelity: the Clubhouse Fidelity Index (CFI) (Lucca, 2000) and the Clubhouse Research and Evaluation Screening Survey (CRESS) (Macias et.al. 2001). The CFI is a short tool that assesses program implementation of Clubhouse components and differentiates services at three levels of Clubhouse fidelity. The CRESS is designed to measure operational fidelity and assess a Clubhouse's readiness for accreditation and performance in model outcomes (Macias, et.al., 2001). CRESS has criterion-oriented validity for measuring Clubhouse model-related performance along with a "demonstrated ease in administration to a national sample of mental health programs" (McKay, 2016).

The most commonly measured quantitative outcomes reflect the core goals of the Clubhouse model and center on (1) employment, which includes transitional employment (TE), supported employment (SE) and independent employment (IE); (2) hospitalization and recidivism; (3) health-related quality of life; (4) social relationships; (5) education and (6) health promotion (McKay, 2016).

1. Employment: research measuring the Clubhouse model against the PACT in a randomized control trial (RCT) found that the PACT program retained a higher number of active clients (79 vs. 58) after two years (Macias, 2006). And while there was no difference between the number of participants who attained competitive work, Clubhouse members remained employed for a longer number of days (264 vs. 173) (Macias, 2006).
2. Hospitalization/recidivism: evidence as compiled by McKay (2016) shows that Clubhouse members in comparison with control groups have a lower rate of hospitalization and re-hospitalization, and that people in Clubhouse models experienced a longer time in the community before rehospitalization. (McKay, 2016).
3. Health-related Quality of Life: the Clubhouse was compared to the PATH model in an RCT which focused on supported employment and whether this improved overall quality of life (Gold, 2016). Clubhouse members were found to have a greater global quality of life improvement than those in the PATH model, especially when it came to their social and financial aspects (Gold, 2016).
4. Social Relationships: using eight quasi-experimental studies and two observational studies, (McKay, 2016) compared Clubhouse participants with non-Clubhouse clients in the same geographic areas. Matching individuals in both groups for gender, age, mental health history and diagnosis, the scores for Clubhouse members were much higher for overall well-being, financial, legal and safety health. The Clubhouse shows it has a positive impact on the lives of its members, especially when used as a tool for social integration in the community (McKay, 2016).

5. Education: a comparison trial between a mental health center (MHC)-supported education program, a Clubhouse and a transition to college program suggested that educational supports at the Clubhouse level can be beneficial (McKay, 2016).
6. Health Promotion: wellness is a relatively new area within the Clubhouse model. While only a few studies have been devoted to the benefits of health promotional activities in the Clubhouse environment, those studies (mixed methods study and observational studies – McKay and Pelletier, 2007) have shown promise. Those Clubhouses offering health education, nutrition, exercise, weight loss programs, and other activities found improvements in emotional health and aerobic activity.

b. Strengths and Weaknesses of the Clubhouse Model

Even though the Clubhouse model has been recognized by SAMHSA as an evidence-based practice and is documented as one of the oldest psychosocial models in use, few studies have centered on the effectiveness of services. The reviews that have been done have focused narrowly on employment outcomes and not on the other services offered by the Clubhouse. Methodological limitations exist, as very little research using random controlled trials, quasi-experimental studies and observational studies have been accomplished (McKay, 2016). What analysis that has been done with observational studies report only findings comparing Clubhouse members with one another and did not include pre- and post-comparisons, thereby making it difficult to ascertain whether it was Clubhouse membership in itself that produced any benefits.

From the mid-1980s onward, Clubhouses dedicated to brain injury were established. But Clubhouses that were extensively modified or those that combine psychiatric disability with brain injury survivors have not for the most part been successful. For Clubhouses dedicated to brain injury, all members are encouraged to contribute regardless of the severity of their injury.

As with the mental health Clubhouses, brain injury Clubhouses are built upon the same International Standards for the Clubhouse Model of Rehabilitation. These standards also represent a Bill of Rights and a code of ethics. The concept revolves around designing a quality of life that is personally satisfying. Participants create their own life, no matter how long it may take to achieve. The program components include the work-ordered day module, along with transitional employment and independent employment programs; evening, weekend and holiday social activities; community support; residential; and governance.

Initial findings show within Clubhouse brain injured populations, 20% to 40% of members have returned to employment; 50% to 60% live independently in their communities; and almost 85% are able to be independent in their daily activities (Jacobs, 1994).

Many TBI survivors, once rehabilitation is complete, return home and end up leading a life that is isolated, restricted, and less satisfying than the life led pre-injury. The Clubhouse model of drop-in day programming can offer psychosocial support to meet social emotional and cognitive needs in an informal setting (Fraas, 2007). Using the Community Integration Questionnaire (CIQ) a 2012 study compared social participation in 1-year post-TBI survivors attending a drop-in day program with a group that did not frequent a program. Results reflected higher social participation scores for those participants in the Clubhouse day program than those who were not enrolled in any programs (McLean, 2012). Often, however, behavioral challenges of a TBI survivor may be too disruptive to benefit from the informal, un-structured atmosphere of a Clubhouse or drop-in program, leading to further isolation.

3. Behavioral Health Model – Positive Behavior Support

a. Process and Outcome Measures of Positive Behavior Support

Positive Behavior Support (PBS) is one of several behavioral health models currently used successfully with disabled populations. Positive Behavior Support was chosen for this discussion because, much like the PACT and the clubhouse models, PBS focuses on using evidence-based programs to guide an individual's behavior away from negative emotions such as aggression, anxiety, lack of motivation or depression towards achieving positive behaviors, thereby increasing a person's quality of life (Carr, 2002). The main pillars of this model are quality of life issues, diverse stakeholder participation, and systems change where needed (Scheuermann, 2015).

Positive Behavior Support is based upon three sources: applied behavior analysis (ABA), normalization, and person-centered values (Carr, 2002). Applied behavior analysis contributions to PBS are evidence-based strategies and techniques built within a framework focused on behavioral change, as well as assessment and intervention tools (Bambara, 1998). Normalization is the concept that disabled individuals should have the ability to reside in the same communities and have the same opportunities as anyone else (Condeluci, 1987). Person-centered values include the person-centered planning of an individual's goals and empowering the individual towards self-determination and away from problem behavior, thereby improving quality of life.

Interventions are similar to those of the PACT and Clubhouse model, with emphasis on personal satisfaction, improved social networks, employment, recreation and leisure activities, and community integration. Outcome success is qualitative in nature and focuses less on problematic behaviors and more on enhancement of family life, inclusion within the community, independent supported living, building of social relationships and personal satisfaction, which should lead then lead to a better quality of life (Carr, 2002).

b. Strengths and Weaknesses of Positive Behavior Support

PBS has been used effectively with young, school-aged developmentally disabled individuals. Because it is traditionally utilized in a grade school/high school setting (Korensky, 2015), it is geared towards a more rewards-based system - with tokens for good behavior and time-outs for bad behavior - than might be workable for adult TBI survivors. Any outcomes currently in use would need to be adapted to an adult cohort. Because of this diverse age group of stakeholders, traditional functional analysis used in the school-space may stress the assessment validity and is therefore no longer workable. While it is just beginning to be used with TBI populations which is a step forward, it is currently specifically used with children and adolescents, and any outcome measurements currently in use would have to be adapted to the adult population (Ylvisaker, 1998).

4. California Regional Center Model

The California Regional Center (CRC) model was initially created in the late 1960s in response to the needs of developmentally disabled individuals who were institutionalized by the State. CRCs are non-profit organizations that contract with the California Department of Developmental Services (DDS) to provide/coordinate support services for Californians with developmental disabilities. Spurred on by the Lanterman Mental Retardation Act (1969), a profound shift occurred in how the developmentally and intellectually disabled were treated. The Lanterman Act states that people with disabilities have the right to services and supports which empower them to live a more independent and fulfilling life. At the time, many disabled individuals were being released from State institutions and being placed in integrated community settings. CRCs took an increasing role in assisting them to find supports. Participants at CRCs must have a disability that was acquired before the person's 18th birthday; a disability that is

expected to continue on indefinitely and present a substantial disability as it is defined by Section 4512 of the California Welfare and Institutions Code. This also includes intellectual disability, autism, cerebral palsy, and epilepsy. CRCs also include conditions that are closely related to intellectual disability or require a similar treatment but does not include other disabilities that are solely physical in nature. They have 21 offices throughout California to provide a local resource to help find and access the many services available to individuals and their families, with participant eligibility established through diagnosis and assessment performed by regional centers.

As directed by the Lanterman Act, California established a dual system in support of people with developmental disabilities: developmental centers and community support systems. Developmental centers provide training services with the intent of increasing the individual's functioning skills, level of independence and ability to live within the community. The second system, the community system of supports and services, is a network of agencies contracted by the State to provide services to individuals and their families. While both systems may share a common mission of increasing the opportunities and potentials of each individual to live and participate in the community, they are separate in their methods.

a. Process and Outcome Measures of California Regional Center model

The California Department of Developmental Services (DDS) monitors all CRCs in the State, using the NCI (National Core Indicators) and the National Quality Forum (NQF) fidelity assessment guidelines. The NCI is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). A voluntary program, the NCI was created to gather a standard set of performance and outcome measures across a wide variety of items in order to build a national

benchmark. It has become an important piece in each state's quality management systems in assessing regional centers and other disability providers. The tools include an Adult Consumer Survey, Family Survey and Staff Stability Survey. Taken all together they measure the following indicators: 1) Individual Outcomes which concentrate on how well the system supports adults with disabilities to find employment, to socialize in their communities, build meaningful relationships, and increase self-determination; 2) Health, Welfare and Rights that address safety and personal security, health and wellness, and the protection of individual rights; 3) System Performance, including indicators that focus on a) service coordination, consumer and family involvement in provider decisions, the use of services and supports, b) integration of cultural competencies, and c) consumer access to services and supports; 4) Staff Stability which assess provider staff stability/turnover and staff competencies; and 5) Family Indicators which focuses on how successful the system is in supporting the adult consumer and their families in fulfilling the individual outcomes of independence, socialization, employment and self-determination.

Additionally, CRCs also utilize the National Quality Forum's (NQF) performance measures. The NQF is a national organization committed to improving the quality of healthcare. It has created 45 evidence-based practices for monitoring culturally appropriate and patient-centered care and focuses on seven key domains that include leadership; integration of cultural competencies into all management and operational systems; patient/provider communications; delivery of care and supports; staff diversity and training; engagement of community; and data collection and public accountability.

b. Strengths and Weaknesses of the Regional Center Model

Regional centers are dependent upon federal allocations for funding channeled through the Department of Developmental Services. The regional centers manage as point of service

(POS) providers, and they have little to no control over their budgets as dictated by federal constraints. Because funding levels have not increased proportionately along with the economy, the DDS is forced to juggle funding across centers in order to make the system whole. While California has shown a surplus of funding at the top budgetary level, little has trickled down to the DDS and even less has been reflected in the regional center budgets. Hiring and keeping good staff is a challenge. Consequently, the basic mission of CRCs to provide service coordination, support to individuals and their families, and monitor quality assurance has been negatively affected by economy-driven staff turnover rates. This in turn compromises the ability to support individuals in the community. Because of this, quality assurance programs are endangered and regional centers are unable to develop medical, dental, psychiatric, crisis, day and residential programming. Community Service Providers, the tandem system to regional centers, are also struggling. The strong economy has made it difficult for providers to recruit and retain qualified staff. This high turnover and low staff experience hobbles the ability to provide effective services and quality assurance.

5. Independent Living Center Model

Independent Living Center model (ILC) has a long history in California. The ILC model is closely tied to other social movements of the late 1960s and 70s, beginning with the deinstitutionalization movement by parents and caregivers to move their developmentally disabled loved ones out of institutions and back into their homes and communities. A movement away from the medical model's definition of disability – that of viewing the disability as an impairment within an individual - occurred, with advocates pushing for a more social inequality definition – a distinct difference between seeing a disability as an impairment versus as an experience of social oppression (Berghs, 2016). As with the PACT, Clubhouse and behavioral

models listed above, the ILC model was originally built on the idea of “normalization” where individuals with developmental disabilities should be living in as normal a home setting as possible (Wolfenberger, 1972). This also included young people who had been warehoused by the state in nursing homes for lack of better alternatives. In 1973 at the federal level Congress over-rode a veto by President Nixon, and the Rehabilitation Act of 1973 was passed. Under this groundbreaking law, handicapped individuals could no longer be discriminated against or denied benefits from a federal program (Shaikh, 2018)

In 1982, the California Foundation for Independent Living Centers (CFILC) was formed, more as a “trade” organization for supporting the efforts of executive directors of ILCs throughout California. As it progressed, the CFILC worked to have certification and standardization of programs put in place. In order for an ILC to receive state and federal funding, certification standards were designed, with ILC certification being conducted by the California Department of Rehabilitation (DoR). Currently there are 28 ILCs throughout California, with 22 officially certified by the DoR. Part of the certification process includes that each ILC incorporate the consumer control philosophy throughout all processes. This empowers disabled individuals (or “consumers” as ILCs term their members) to have the right to make decisions that may affect what an ILC provides.

a. Process and Outcome Measures of the Independent Living Center model

As with the Clubhouse model, an ILC must provide core services, with the goal of these services promoting independent living for the consumer. These services include peer support, information and referral, individual and systems advocacy, independent living skills training, and transition services. These core services promote self-determination, empowerment and community inclusion for individuals with disabilities.

The two main categories for measuring the success of ILCs are organizational operations and consumer services. Each of these areas are then divided into access measures, process measures and outcome measures. Access measures would include accessibility to an ILC via public transportation, convenience for the consumer of program scheduling, accessibility of the ILC to underserved populations. Process measures monitor how services are delivered by ILC staff and how advocacy is provided within the community. These measures encompass system change efforts within the ILC, the types of consumers served, the efforts to promote consumer empowerment and control at an ILC, what specific services are provided, and the relationships between staff and consumers. Finally, outcome measures focus on measuring the changes that hopefully occur within a consumer's life while at an ILC, and any community changes that result from an ILC's activities.

b. Strengths and Weaknesses of the Independent Living Center Model

The ILC philosophy views disability more as a social construct and less like the medical model's impairment definition, which empowers the individual to see themselves as more than just a medical condition. Because ILCs see their mission as supporting consumers to attain a better quality of life, there are components of this model that lend to the TBI community integration model. Additionally, ILCs have a long history of federal funding, so they have been used to using evidence-based measures and the standardization of outcomes. All of these can be seen as strengths. The only weakness would be there isn't much of psychosocial component which would be of use to the TBI community integration model. Often in ILCs, TBI survivors are not seen as a different population from the developmentally disabled and suffer for the lack of neuropsychosocial components.

6. Chronic Care Model

The Chronic Care Model (CCM) is a structured program for managing a life-long condition. Acting as the proactive interface between all areas of a health system and community resources, a CCM's sustained effort is to support an individual with a chronic disease throughout their life (Coleman, 2009). The first application of CCM was to diabetes management in 1998 (McCulloch et.al., 1998). The objective of CCM is to build a relationship between an informed patient and a proactive healthcare provider in order to improve that person's lifelong care and quality of life.

a. Process and Outcome Measures of the Chronic Care Model

CCM focuses on six main elements, with outcome measures for each. These are:

1. Health Systems – working to build and improve a health organization at all levels in order to provide high quality services.
2. Design of Delivery System – this includes clearly describing all staff roles and tasks, using evidence-based care and case management while being culturally competent in meeting the needs of patients as the organization is delivering cost-efficient clinical care and self-management support for individuals.
3. Self-Management Support (SMS) – empowering the patient to take a proactive role in the management of their disease by providing both organization and community resources.
4. Decision Support – making sure evidence-based guidelines are utilized throughout the organization, from the creation of clinical care to the management of staff to sharing information with all patients.

5. Information Systems – creating a database system to include patient and population-level data that facilitates efficient care and increases coordination between the clinical care team members as well as with patients for their individualized care.
6. Community – externally of the organization, work to establish and involve community entities to promote and enhance clinical interventions for the services needed and to advocate for patient care beyond the clinical care.

b. Strengths and Weaknesses of the Chronic Care Model

CMM was originally created for long-term management of a chronic medical condition such as diabetes, asthma, heart disease, obesity, and osteoarthritis. It is the most widely-accepted model for life-long care management (Heiden, 2017). The creation of a CCM for TBI would be valuable, as demand exists for a program covering the complexities of TBI treatment and long-term care, but currently no CCM model addressing cognitive deficiencies exists. And while a Chronic Care Model for Neurological Conditions (CCM-NC) has been developed to tackle the challenges of caring for a person with Parkinson’s Disease, Multiple Sclerosis, etc., it remains to be validated (Heiden, 2017). “Invisible” diseases such as TBI or PTSD have yet to be properly addressed in a CCM format; it remains unclear as to which components of TBI chronic care should be included in a CCM, or in which order of importance (Malec, 2010).

7. Outcomes

Even without significant physical and cognitive impairment, survivors of TBI are often faced with poor community integration outcomes that include diminished social integration, reduced social participation and decreased quality of life (Cicerone, 2004). Research has shown a direct correlation between poor psychosocial outcomes with increased depression, anxiety, coping and self-esteem (Anson, 2006). In terms of quality of life, both negative and positive

affective states are essential in gauging the long-term objective and subjective outcomes post-TBI. As the goals of this pillar of the TBI system of care shift towards chronic care of TBI in community-based and person-centered services, a focus on community integration from both an objective and subjective perspective has value. Traditionally, community integration success has been measured through objective outcomes such as return to work (Sander, 2010). Recent research proposes that through the subjective assessment of satisfaction with participation in community, family, household activities a better measurement of an TBI survivor's perspective of community integration can be accomplished. Through the dual evaluation of objective (frequency) and subjective (life satisfaction), a more inclusive perspective is gained of the relationships between community integration post-TBI and affective states (Djikers, 2006).

Affective states can be described as emotional responses to experiences (Juengst, 2014). Negative affects include fear, distress, guilt and irritability, which may be expressed as anxiety and depression. Positive affects consist of energy, interest, pride, with poor positive affects exhibiting as low self-esteem, depression, or weak coping skills. Overall poor (high negative, low positive) affect is a factor in depression, with research indicating it may continue even after the depression has been successfully treated. High negative affect (guilt, fear, nervousness, etc.) can exist after a TBI, even if no clinical symptoms of depression are present (Juengst, 2014). Low positive affect can also signify early symptoms of depression. Because it may in fact overlap with depression, poor affect may be considered an independent factor contributing to successful community integration post-TBI (Cicerone, 2007).

Psychosocial deficits post-TBI can come from internal impairment and external sources (Togher, 2012). Internal impairment centers on the survivor's pre-existing features and the level of injury severity. These sources include pre-TBI elements (e.g. personality), impairment

brought about by the TBI, limitations on activity linked to skill loss, and indirect effects of psychiatric disorders (such as depression and anxiety). External factors involve opportunities for social participation, which is the framework for remediation to improve the impairment of damaged neural, cognitive, and emotional processes of the TBI survivor (Ylvisaker, 2003). Increasing participation improves the efficacy of remediation of impairment and skills (Togher, 2012).

3. Funding Models for TBI CI Services Across the U.S.

The provision of TBI CI services is funded differently across the United States. During the 1980s states started to make concerted efforts to respond to the needs of families with TBI survivors. The development of TBI CI programs was different for each state, and individual states built infrastructures and capacities to support the unique needs of TBI survivors. To fund these efforts, states responded in various ways: some used state revenues; other used dedicated funds (which were usually derived from traffic fines, license plates, or boating registrations and were called a “trust fund”); vocational rehabilitation; Title V Special Health Care Needs; and Medicaid Waivers (Vaughn, 2015). The TBI Act of 1996 approved the use of Federal funds in assisting states to expand capacity for rehabilitation and services. In 1997 the US Department of Health and Human Services’ (HHS) Health Resources and Services Administration (HRSA) agency began offering time-limited grants in order to fund the expansion of service capacity to include underserved and unserved populations such as returning military, veterans, domestic abuse survivors, and children (Vaughn, 2015). Table 1 below shows the types of funding for TBI services by state.

1. Trust Fund Programs

Currently 23 states have legislated funding for various types of programs and services for TBI survivors and their caregivers. The funds are identified as trust funds, and come from traffic fines, vehicle registration, motor vehicle licenses, and boat registration. This revenue is collected across a state through county clerks and forwarded to a state treasurer to be held in a non-reverting account. The state legislature designates a state agency to dispense the funds. States can use this funding for education, service coordination, rehabilitation, or community integration services. For California, its TBI funding comes from the trust fund which derives its funding from the California Penalty Assessment Fund, with the Department of Rehabilitation is the state agency administering the funds through a multi-year grant.

2. HCBS Medicaid Waivers

Section 1915(c) of the Social Security act gives states the ability to support home and community-based services (HCBS) in addition to Medicaid State Plan services for individuals eligible for Medicaid and may be seen as at risk of being placed in institutional or nursing facilities (Vaughn, 2015). States provide HCBS waiver services to TBI survivors through additional waiver programs for people with disabilities through the 1115 Demonstration waivers that deliver managed care for long-term services and supports (LTSS). These services include case management, in-home supports, durable medical equipment, therapies, and in-home/vehicle modifications (Vaughn, 2015). California has target populations under HCBS waivers covering Seniors; Seniors and Adults with Physical Difficulties; Medically Fragile Dependent Children; and HIV/AIDs. It does not currently have funds through any HCBS program for TBI support.

3. Federal HRSA TBI Grants

The Federal TBI State Grant Program, started in 1997, was created to support states’ efforts to increase and enhance services to underserved and unserved populations, including veterans and returning military, victims of domestic abuse, children, and people with co-occurring health conditions. These grants have helped states build systems for early referral from hospital to community integration services; vocational training; information and referral services; and service co-ordination for TBI survivors.

Table 1. State TBI Programs by Funding Source

State TBI Programs – Funding	States
BOTH Trust Fund/Dedicated Funding AND Medicaid HCBS/1115 Demonstration Waivers	UT, NM, CO, MN, MS, FL, KY, PA, MD, NJ, CT, MA
Medicaid CBS Waiver Program OR 1115 Demonstration Site ONLY	WY, NE, KS, IA, IL, IN, SC, WV, NY, VT, NH, ME
Trust Fund Program/Dedicated Funds ONLY	HI, CA, WA, MT, AZ, TX, LA, MO, TN, AL, GA, VA
Receives State Revenue to Support Only Specific TBI Services	AK, OH, ND
Receiving Funding in Support of TBI Services Under Other HCBS Waiver Programs, Other Federal Programs, Disability Programs	OR, ID, OR, NV, SD, OK, AR, WI, MI, NC, RI

CHAPTER 4: CALIFORNIA TBI SERVICES

1. TBI Services as Funded by CA Department of Rehabilitation Grant Process

State-level funding support of community integration programs in California initially began over thirty years ago with the creation of a demonstration project. Funding for these CI services has traditionally been associated with a recurring grant process awarded to only a finite number of organizations every four to five years.

In 1988, California passed Senate Bill (SB) 2232 (Chapter 1292, Statutes of 1988), authorizing initial funding for the first pilot project specifically designed to prove the effectiveness of a coordinated community integration service model within the TBI continuum of

care. Housed under the California Department of Mental Health (DMH), preliminary funding of \$500,000 was equally allocated to four sites chosen to be in the demonstration project. This roughly equated to \$125,000 for each of the four sites, which ranged from independent living resource centers to hospital programs to small non-profits.

In 1999, the state legislature voted to add additional number of demonstration sites, thereby increasing to seven locations beginning in 2000. All sites were independent of one another, with again several being Independent Living Resource Centers of care. None focused solely on brain injury, but incorporated brain injury care into their programming alongside developmentally and intellectually disabled adults. TBI community integration services offered at the seven sites under the state grant included information and referral, supportive living services, community re-integration, and public-professional education at some level, but not consistent across the sites. Several (but not all) sites also provided outreach and prevention education. The sites reported their outcomes independently of each other to DMH.. Funding was through the “Seat Belt” State Penalty Assessment Fund, which included income derived from seat belt violations.

By 2004, the organizations collectively realized in order to successfully strengthen a statewide system of TBI services, it would be advantageous to create an association of the seven TBI sites. Establishing a loose coalition, the new group was called The Traumatic Brain Injury Services of California (TBISCA). The mission of TBISCA was to “provide a unified voice for TBI survivors, their families, and the community through collaborative partnerships, legislative advocacy, and TBI education.” Independent of DMH, no standard of generalized care guideline was included in this association, and none was requested by the DMH at the time.

In 2005, TBISCA was awarded a two-year capacity building grant from The California Endowment. TBISCA used the grant to develop and implement an effective sustainability and growth plan through the use of a survey tool that collected the views of TBI survivors, caregivers, and key stakeholders in each service area. At the conclusion of the grant period in the spring of 2008, TBISCA had established viable strategic and operational plans; launched a statewide TBI coalition; hosted a statewide conference on TBI; revised the TBISCA brochure; developed bi-lingual TBI Fact Sheets; submitted budget augmentation requests and became involved in state-level public policy efforts. Recommendations for common program services was not included in this initiative, and all sites continued to provide CI support as would appropriately fit within each of their organizational missions. Unfortunately, because there was no specific sustaining funding to keep tools updated and current, by 2016 the coalition had fallen apart, with TBISCA sites siloing into their own respective work environments. Most of the collaborative information was no longer in use. A website designed for the group fell by the wayside and the hopes of an annual statewide conference were sidelined.

In 2006 DMH was awarded a three-year TBI State Implementation Grant from the Health Resources and Services Administration (HRSA), US Department of Health and Human Services (DHHS). The primary purpose of this award was to establish a TBI Advisory Board to advance awareness and understanding of TBI in California through public policy and education, along with strengthening TBI state partnerships. Prior to the TBI CI grant's completion, DMH provided a one-year extension at no cost to conduct various stakeholder meetings and develop a project report that would assist with the development of a Medicaid (Medi-Cal) waiver and/or State Plan Amendment to improve TBI services. In May 2010 a final report, entitled "Advancing California's Traumatic Brain Injury Service System: Next Steps" (CA Dept. of Mental Health,

2009) was published. The report (informally titled “The Green Book” due to the cover color) included a summary of all stakeholder meetings; an overview of Medicaid waiver options and State Plan Amendments for possible collaborations; and a final summary of key findings in moving forward. The findings involved providing long-term support and insurance coverage for a host of community reintegration services and activities; establishing accessible and affordable supported living options; coordination of TBI services at the state and local level; and improvement of TBI data collection and reporting to enhance TBI program effectiveness and system accountability. What was noted as a need but not formally addressed was recommendations for service provision, with corresponding outcome measurements.

In 2010, Administrative oversight of the State’s brain injury pilot program transitioned from the California Department of Mental Health to the California Department of Rehabilitation (DoR) through the passage of Assembly Bill (AB) 398. This move was initiated as the prevailing consensus was that the DoR would have more recourses to address the disability needs of TBI survivors. This legislation also put into effect a competitive bidding process and an investigative procedure to verify whether the use of a specified Medi-Cal waiver would be beneficial to the TBI survivors in California in a quest for sustainable funding.

A Request for Application (RFA) was released in March of 2014 to all California organizations potentially interested in applying. This was subsequently pulled because of a realization that a Medi-Cal waiver was not as straight forward a process to obtain as previously thought, especially for the non-medical applicants. The DoR then granted a 1-year extension until more research was done by the Department on the viability of a Medi-Cal waiver. Another competitive bid RFA was re-released on March 6, 2015 with a submission deadline of March 27, 2015. The new structured requirements from the DoR for the multi-year funding (2016-2019)

included a quarterly reporting of outcomes based upon the Community Integration Questionnaire (CIQ) and demographic information on clients over the life of the grant. Out of 12 statewide CI organizations bidding, seven sites were chosen, four of which were new sites. While some of these organizations remained from the original 1980s pilot project participants, others had never previously participated.

From 1988 through the 2015 of the grant program, the funds per site remained static at an annual sum of \$150,000. If adjusted for inflation, this number would be \$320,000 in 2019 dollars. The \$150,000 provided for mandated core services, with a minimum match of 20% on the CI organization's part in order to receive the funds. Historically the majority of sites have provided a match greater than the 20% requirement. This State funding has remained the same throughout the years since its original authorization, and actually had a 20% decrease in 2015 to \$120,000 per site (Table 1). This year (2018-2019) due to the shortfalls in the State Penalty Fund, the budget amount was decreased by 23% or \$115,000 per site. The funding which the sites receive equates to roughly 0.066 of one percent of the State Penalty Fund. But the Seat Belt State Penalty Assessment Fund is steadily declining, as fewer and fewer drivers are being ticketed for not using seat belts. Because of this, the fund can no longer be seen as a recurring revenue source sufficient enough to meet the \$1.5 million annual projected budget for the TBI CI program. Additional State monies drawn from other funds now temporarily make up the deficit, but this is just a temporary fix. With limited monies available through the State program, sites must augment and leverage revenue streams through a variety of public and private funding sources where available to assure mandated core services are provided. But because not all the sites have the time or staff for fundraising, some services are being cut back. Additionally, the legislation which supports the TBI CI program "sunset" every few years. This means it must be

re-introduced in the legislature for approval. Originally scheduled to sunset in 2019, this has now been pushed to 2020. All of this is added on to the daily work of the seven sites.

Table 1. DoR Annual Grant Budget for TBI Program

Budget Year	Amount
FY 10-11	\$ 1,172,000
FY 11-12	\$ 1,176,000
FY 12-13	\$ 1,168,000
FY 13-14	\$ 1,002,000
FY 14-15	\$ 1,002,000
FY 15-16	\$ 1,002,000
FY 16-17	\$ 1,200,000
FY 17-18	\$ 1,114,000
FY 18-19	\$ 892,000

From DoR mail correspondence, April 2019.

2. California Association for Brain Injury (CATBI)

Throughout the past decade, TBISCA remained a loose association, with little unifying role in support of TBI community integration advocacy issues at the State level. This changed in late 2016, when members understood the reality that if they were to continue as a group and expand services, (A) they would need to search for additional new revenue streams beyond the DoR grant, and (B) their collective power would be much stronger as a base of advocacy for unmet TBI needs across the State. In November 2016, TBISCA renamed itself the California Association for Traumatic Brain Injury (CATBI), with the express intent to unify support behind TBI/community integration issues, expand funding initiatives, and further public education throughout California. CATBI’s mission is now “Partnering to restore identity and independence after brain injury,” with a vision statement reflecting “A future where individuals with brain injury reach their full potential.”

CATBI’s seven organizations currently support only a fraction of community members in 18 of California’s 58 counties (Table 2). Sensitive to the reality that unmet needs vastly

overwhelm current resources, CATBI is in the process of devising a business strategy to expand organizational membership. This includes the formal acknowledgment of a need for common community integration recommendations (hence this dissertation) for use in both a certification process for CATBI membership and for future funding opportunities. In addition to the DoR-mandated Community Integration Questionnaire (CIQ), the group is in discussion to implement across the coalition both the Quality of Life After Brain Injury (QOLIBRI) for consumer data collection and the Mayo-Portland Assessment Inventory-4 (MPAI-4) to capture caregiver data.

The DoR for its part is very aware of the challenges faced by these seven sites and all TBI CI organizations across the state and has been working to assist the CI sites beyond its current grant process. To this end, the Department recently applied for and received a grant from the Administration for Community Living (ACL) to create a statewide TBI Advisory Board. Meeting on a quarterly basis the Advisory Board is to address the topical issues such as data collection and service delivery challenges of California's CI programs.

3. Demographics of Brain Injury Across California

The state of California consists of 58 counties (Figure 1). Overall, the State has a TBI rate of 3% of its total population (Lagbas, 2013) as compared to the National rate for TBI is 2% (Lagbas, 2013). Counties vary in TBI incidence rates, from 1% in Alpine County up to 6% in Imperial County (Lagbas, 2013). Within the 58 counties, however, there are major gaps in community integration programs, with the demand for services often far outstripping supply. Not all counties have providers of TBI community integration services. Many counties are rural in nature and do not have access to resources that would assist in the establishment of organizations supporting community integration for TBI survivors. These counties often are forced to send TBI survivors to neighboring counties for care. The most recent year for collected statewide data

shows 32,838 patients hospitalized in California under a TBI diagnosis, with MediCal and MediCare billed for costs in 65 per cent of all hospitalizations (California DPH, 2014).

4. The regions and population(s) served by CATBI

Of the seven CATBI sites, three are independent living centers (ILC) which have programming for intellectually and developmentally disabled individuals. Brain injury survivors are a separate population recently included in their programming. A fourth CATBI site historically supported brain injured adults only but has recently accepted developmentally disabled adults into their employment component in order to gain State employment funding. Two other sites are programs run through the auspices of large medical systems. Finally, one site solely supports traumatic and acquired brain injury survivors as its population. Four of the sites are located in Northern California, with three located in Southern California. CATBI members all serve a diverse ethnic, rural and urban population of TBI survivors. According to CATBI members, more than 75% of TBI survivors assisted by all seven sites are low income.

Table 2. CATBI Individuals Served By County 2010-2014

California Traumatic Brain Injury (CATBI) Organizational Site	County Served	County Population 2013	Total Brain Injury Cases 2010-2014	Brain Injury Incident Rate 2010-2014	Actual Consumers Served By CATBI in FY 14-15
Independent Living Center, Northern California	Monterey	428,826	11,269	3%	50
	Santa Cruz	269,419	6,729	2%	25
	San Benito	57,600	1,799	3%	1
Independent Living Center, Northern California	Butte	222,090	8,382	4%	28
	Shasta	178,980	6,368	4%	16
	Sutter	95,350	1,896	2%	4
	Nevada	98,200	4,303	4%	28
	Yuba	73,340	1,883	3%	2
Hospital, Northern California	Sacramento	1,462,000	55,052	4%	51
	Placer	367,309	13,657	4%	19
	El Dorado	181,737	8,673	5%	3
Brain Injury Support Center, Northern California	Santa Clara	1,862,000	60,842	3%	191
	San Mateo	747,373	21,668	3%	36
Brain Injury Support Center, Southern California	Santa Barbara	435,697	13,555	3%	113
	San Luis Obispo	276,443	7,650	3%	8
	Ventura	839,620	32,873	4%	58
Hospital, Southern California	Orange	3,114,000	97,110	3%	73
Independent Living Center, Southern California	Los Angeles	9,974,023	323,751	3%	212
			<i>677,460</i>	<i>Total Served by CATBI</i>	<i>918</i>

Source: California Department of Public Health EPICENTER, California Injury Data Online.
<http://epicenter.cdph.ca.gov/ReportMenus/TraumaticBrainInjury.aspx>

The DoR began collecting data from the sites in FY2010 – 2011. And while the DoR has been diligent in requiring information from all grant recipients, prior to FY2013 - 2014, data was either not completely collected or had been lost at the individual TBI provider level.

Additionally, the composition of organizations changed in 2016, with three new first-time sites.

Table 3 provides an overview of the data collected from FY 2010-2011 through FY 2016 – 2017.

The numbers listed in the columns representing services may signify a TBI survivor attending more than one of the same service. The final column provides the physical total headcount of individuals supported by all services and is not a duplicative count.

Table 3: Total Individuals Served By Service as Noted Under DoR Grant Requirements

Fiscal Year	Community Integration	Supported Living	Vocational Rehabilitation	Other Case Coordination	Information and Referral	Public & Professional Information	Total Consumers Served
2010-2011	656	273	182		5525	6200	Data not collected or lost
2011-2012	835	575	444		4429	11125	Data not collected or lost
2012-2013	1088	635	490		3829	13259	Data not collected or lost
2013-2014	820	570	379		3618	16489	2412
2014-2015	378	215	243	429	6440	5300	918
2015-2016	446	247	229	454	7851	4693	893
2016-2017	409	327	278	436	8875	7083	965

5. Specialty of TBI Services

The current core services for CATBI sites include community integration; supportive living services; vocational supportive services; information and referral; and public-professional education. The challenge exists that while all CATBI sites provide those services, the complexity and frequency of these services differ from organization to organization. Ideally, community integration organizations supporting brain injury should have staff that specialize in serving this specific population. Individuals who have suffered a TBI can often have cognitive, behavioral, and mental health disabilities that require more comprehensive service coordination or on-going case management services in order for the individual to live independently and find and maintain employment. Individuals with TBI are often not served well by existing funding streams and service models or are not eligible for the type of services that they could benefit from.

6. Unmet TBI needs across California

While case management, supportive living, community integration, and vocational supportive type of services are available through other programs and funding sources, individuals with TBI are often unserved or underserved. Unmet needs for California TBI survivors include both the delivery of these services and the geographic existence of provider organizations. The current trend across the country is to group TBI survivors in with special needs population for community integration services. California is no different in this effort. The

most critical TBI services that CATBI strives to provide (and where gaps exist) include case management, supportive living, community integration, and vocational supportive services.

While these may seem similar to those services offered to other special needs populations, TBI survivors do not face the same cognitive, emotional and physical challenges as intellectually and developmentally disabled populations and should be viewed as independent from other populations. The services for TBI survivors include:

- a. Case Management Services** has become the core of a TBI CI program. While replicating successful case management processes found in other disability sectors is the key, often TBI CI programs either do not see case management as essential to service delivery or are too short staffed to make an impact.
- b. Community Integration Services** help to broaden an individual's independent functioning with the goal of living in the community and participating in community life. These services include providing or arranging for access to housing; transportation; medical care; rehabilitative therapies; day programs; chemical dependency recovery programs; personal assistance; and, education. For many types of disabilities, community reintegration services are provided immediately after injury and individuals learn new skills and get connected to resources to assist them with managing their lives and navigating the world with a disability. For individuals with TBI, community reintegration services may need to be repeated multiple times throughout the year or over the span of their lives. This is especially true if life circumstances change and they need more comprehensive supports to live successfully in the community.

- c. Supported Living Services** includes a range of training, support, and appropriate supervision to maximize independence where the participant lives. These services include support with maintaining housing; the ability to pay bills or to be independent while shopping; coordination of personal care, medical, and transportation services; and the capacity to connect to community resources. Depending on the extent of the TBI, some individuals may need monthly, weekly, or even daily supported living services and case management to remain living independently in their residence.
- d. Vocational Supportive Services** offer prevocational and educational services to individuals who are unserved or underserved by existing vocational rehabilitation services. In order to find and maintain employment, individuals with TBI often require extensive and on-going training, supervision and support services; advocacy for workplace equality; support to negotiate worksite flexibility and support mechanisms which permits the TBI CI participant to function competitively in the work place. On-going job coach service are critical to successfully finding and maintaining employment.

7. Other Disability Programs and TBI Service Gaps

TBI community integration organizations should be able to provide these services to individuals with TBI regardless of age, residential living arrangements, and in appropriate community-based settings. Critical TBI-specific services are often not available through other programs and funding sources in a way that meet the unique needs of individuals with TBI in California. Special-needs programing supported by federal funding include the following:

- a. **Developmentally Disabled (DD)** waiver services may contain all of the TBI community's preferred services, but this waiver has eligibility restrictions such as formal diagnosis of development disability prior to age 18.
 - i) **TBI Service Gaps:** Many individuals with TBI who have significant cognitive disabilities would benefit from some of the services provided under the DD waiver such as case management, supported living, community integration, and vocational support but are not eligible due to acquiring the TBI after the age of 18.

- b. **Assisted Living Waiver (ALW)** has a tier in place for some individuals with TBI, but this waiver contains a housing restriction (i.e., either Residential Facilities for the Elderly or public subsidized housing). Participants must be over 21 years old.
 - i) **TBI Service Gaps:** The ALW is limited in California with many communities, especially rural communities, not having access to the waiver. ALW is a more restrictive environment than living in an apartment or house with the needed supports. Often ALW residents are older, and younger individuals with TBI may want to live in more age appropriate settings.

- c. **Nursing Facility/Acute Hospital (NF-A) waiver** has no age limit and represents the best existing-waiver option for adding or expanding services for the TBI population. Many desired services are already included in the waiver, with the exception of vocational supportive services.
 - i) **TBI Service Gaps:** This waiver is only available to individuals with TBI who are at the NF-A level of care, meaning a more severe case of TBI. There are many individuals with TBI that need case management, supported living, community

- reintegration, and vocational support to live independently and maintain employment but are not eligible because they do not meet the NF-A level of care designation.
- d. **Multipurpose Senior Services Program (MSSP)** has an age restriction of 65 years or older but contains many of the preferred services for TBI survivors.
 - i) **TBI Service Gaps:** The MSSP waiver is only for individuals over the age of 65 years. MSSP service provider locations are geographically limited and there are often wait lists. The MSSP does not have any vocational supportive services.
 - e. **Community Based Adult Services (CBAS)** has an age restriction of 18 years and above and contains services for individuals with cognitive disorders and brain injuries. Providers are adult day health care centers and work mostly with Medi-Cal managed care plans, although exemptions exist.
 - i) **TBI Service Gaps:** While the CBAS waiver is available for individuals over the age of 18, it is often not an appropriate setting for younger individuals. CBAS service provider locations are geographically limited, especially in rural areas, and there are often wait lists. Care is more in the medical model format, and CBAS does not have any vocational supportive services.
 - f. **Behavioral Health Services** offers community mental health services and alcohol and drug treatment services.
 - i) **TBI Service Gaps:** Behavioral components of TBI often resemble psychiatric disabilities and can be difficult to diagnose. Individuals with TBI have higher than average substance abuse issues. Behavioral health services are often unequipped to serve individuals with TBI due to lack of specialized services and capacity. There is often a misunderstanding about TBI and mental health or lack of access

to service due to diagnosis. County behavioral health will not serve TBI because it is out of their scope through the implementation of managed care.

- g. Vocational Rehabilitation (VR) Services** provides services to job seekers with physical and mental disabilities.

 - i) TBI Service Gaps:** The VR system only services individuals with TBI who are work-ready. Many individuals with TBI need pre-employment and job-readiness services. Individuals with TBI have historically been underserved by the VR system due to the need for on-going supported employment type services to find and maintain employment for individuals with TBI. Job coach-to-number-of-consumer ratios must be reduced for the job coach to have the time needed for successful employment outcomes. Job coaches who specialize in serving people with TBI who have employment goals are in demand.
- h. Independent Living Centers (ILCs)** serve people of any age and with any type of disability and provide some of the needed TBI services, such as information and referral and community reintegration services.

 - i) TBI Service Gaps:** Many of the ILCs do not have the capacity to provide on-going service coordination and case management, supported living, and vocational supportive services to meet the needs of individuals with TBI that need higher levels of on-going service. Many of the ILCs do not have staffing with the specific specialization to TBI.

8. Next Steps

Both the organizations comprising CATBI and the DoR staff are very mindful of the acute unmet community integration unmet needs the California TBI population faces and have

been cognizant of these since the beginning of the pilot TBI grant program. These providers are concerned as to what next steps should be to expand services, measure these programs, and obtain new streams of financial support in an ever-diminishing pool of funding. CATBI members and State officials are interested in seeing what suggested recommendations for common service provision might look like, as they believe this an important tool for many of the challenges they currently face. In order to create this standard, this dissertation suggests a qualitative approach as is explained in the next chapter.

Figure 1: California Counties



Table 4. TBI Incident Rate by California County

County	Non-fatal ER Visits ¹	Non-fatal Hospitalization ¹	Total Visits 2010 -2014	Total Population ²	TBI Incident Rate
Alameda	45,025	5,629	50,654	1,647,704	3%
Alpine	14	1	15	1,071	1%
Amador	1,189	210	1,399	37,383	4%
Butte	7,149	1,233	8,382	226,864	4%
Calaveras	1,209	212	1,421	45,171	3%
Colusa	348	94	442	21,588	2%
Contra Costa	37,192	3,740	40,932	1,135,127	4%
Del Norte	1,193	94	1,287	27,540	5%
El Dorado	951	7,722	8,673	185,625	5%
Fresno	21,668	2,900	24,568	979,915	3%
Glenn	860	126	986	28,085	4%
Humboldt	4,672	436	5,108	136,646	4%
Imperial	9,525	751	10,276	180,883	6%
Inyo	718	36	754	18,144	4%
Kern	17,975	3,463	21,438	884,788	2%
Kings	4,713	414	5,127	149,785	3%
Lake	2,484	314	2,798	64,116	4%
Lassen	965	45	1,010	30,870	3%
Los Angeles	283,913	39,838	323,751	10,137,915	3%
Madera	3,817	450	4,267	154,697	3%
Marin	8,325	1,129	9,454	260,651	4%
Mariposa	469	83	552	17,410	3%
Mendocino	3,096	356	3,452	87,628	4%
Merced	10,489	832	11,321	268,672	4%
Modoc	259	28	287	8,795	3%
Mono	516	13	529	13,981	4%
Monterey	9,960	1,309	11,269	435,232	3%
Napa	4,638	534	5,172	142,166	4%
Nevada	3,870	433	4,303	99,107	4%
Orange	83,230	13,880	97,110	3,172,532	3%
Placer	12,064	1,593	13,657	380,531	4%
Plumas	624	58	682	18,627	4%
Riverside	70,115	8,383	78,498	2,387,741	3%
Sacramento	47,118	7,934	55,052	1,514,460	4%
San Benito	1,602	197	1,799	59,414	3%
San Bernadino	68,667	7,456	76,123	2,140,096	4%
San Diego	100,918	20,466	121,384	3,317,749	4%
San Francisco	26,792	3,949	30,741	870,887	4%
San Joaquin	22,552	2,339	24,891	733,709	3%
San Luis Obispo	6,979	671	7,650	282,887	3%
San Mateo	19,488	2,180	21,668	764,797	3%
Santa Barbara	11,949	1,606	13,555	446,170	3%
Santa Clara	55,153	5,689	60,842	1,919,402	3%
Santa Cruz	5,852	877	6,729	274,673	2%
Shasta	5,414	954	6,368	179,631	4%
Sierra	77	10	87	2,947	3%
Siskiyou	1,406	144	1,550	43,603	4%
Solano	15,062	1,623	16,685	440,207	4%
Sonoma	16,136	1,925	18,061	503,070	4%
Stanislaus	16,444	2,092	18,536	541,560	3%
Sutter	1,492	404	1,896	96,651	2%
Tehama	2,103	229	2,332	63,276	4%
Trinity	382	69	451	12,782	4%
Tulare	13,315	1,237	14,552	460,437	3%
Tuolumne	2,431	310	2,741	53,804	5%
Ventura	29,474	3,399	32,873	849,738	4%
Yolo	5,800	838	6,638	215,802	3%
Yuba	1,541	342	1,883	75,275	3%
State Total	1,131,382	163,279	1,294,661	39,250,017	3%

NOTE: U.S. National brain injury incident rate is 2%.

¹Source: California Department of Public Health EPICENTER, California Injury Data Online. <http://epicenter.cdph.ca.gov/ReportMenus/TraumaticBrainInjury.aspx>

²United States Census Bureau / American FactFinder. "Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2016". 2016 Population Estimates Program. Web. March 2017. <http://factfinder2.census.gov>.

CHAPTER 5 - METHODS

1. Research Approach

This project represents a single case study of one network, that of CATBI. Modest in size and budget, CATBI organizations have been trying to make a difference in their communities and in the lives of TBI survivors and their caregivers through the delivery of quality CI services. A case study approach was selected because a single case allows the researcher to better study and understand the issues and any underlying factors in a natural context and reveals subjective experience and meanings this experience may have for individuals and organizations within the context of focus (Starman, 2013). As Yin (2003) notes, a case study is “an empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when boundaries between phenomenon and context are not clearly evident (Yin, 2003, P#13). With the case study, researchers can observe complex issues in “real-life” settings (Crowe, 2011). Data for this case study were collected through interviews with representatives of CATBI organizations and additional stakeholders working with the TBI community and a focus group with CATBI representatives.

Qualitative description (QD) was selected as the analysis approach to solicit, identify and evaluate information for incorporation into TBI community integration recommendations for common service provision. This methodological approach was chosen for several reasons, chief among them being it is a meaningful way to analyze, develop and refine interventions addressing health disparities in vulnerable populations (Sandelowski, 2009). Qualitative description varies in structure from other traditional qualitative approaches in that “... it does not have as its goal a “thick description” as required in ethnography, or theory development as in grounded theory, or searching for the interpretive meaning of an experience as in phenomenology.” (Sullivan-Bolyai,

2005, P. 128). It is a naturalistic method of inquiry that observes and interprets individuals and groups within their social and cultural contexts. QD is considered a “categorical approach that offers a comprehensive summary of an event from the participant’s point of view using everyday language.” (Sandelowski, 2000, P.79). This idea that QD does not require “reading between the lines” by individuals and is easily understood by both lay and medical professionals is what made this approach appealing.

QD can also provide in-depth information to health-related concerns and challenges through the use of a focus group and in terms of public health research, with QD having the ability to directly translate a current health issue and advance information about methods to enhance care in everyday language (Sandelowski, 2009). This is valuable when trying to improve health care disparities for vulnerable populations who are also disenfranchised or neglected, as it gives a cohort the opportunity to address decision-making within a group. It is a method that can be used to create new or refine existing interventions in an effort to further program development. To be a success, an instrument should be in simple language (as with the interview guide created for this research), that is easily understood by both the cohorts involved and the community at large (Sullivan-Bolyai, 2005).

The qualitative description method offers the researcher an approach that can interpret data and ascertain a path for creating new health interventions and enhancing program development. QD gives the researcher the ability to observe and understand a complex set of data from multiple sources reflecting human context (Sullivan-Bolyai, 2005). Ultimately the goal of qualitative description is to successfully interpret facts in everyday language that is both accurate and easily understood by people (Sandelowski, 2009). With this in mind, data for this research topic was gathered through several QD phases: selection of target sample, instrument

development (see Table 1), data collection, and data management and analysis (see Table 1 below). In Phase 1 the stakeholder sample was identified. In Phase 2 instruments for obtaining data were devised. Phase 3 pertained to the collection of data, including the gathering of both quantitative and qualitative information. Finally in Phase 4, information collected through the various activities were pulled together in preparation for analysis.

Table 1: List of Collection Tools Created

Collection Tool		# of Participants
(A)	Interview Guide for Internal CATBI stakeholders	9
(B)	Interview Guide for External stakeholders	14
(C)	Focus Group Initial Questionnaire	7
(D)	Program Services by Type and Site Survey	9
(E)	Organizational Structure by Site Survey	9

2. PHASE I: SELECTION OF THE TARGET STUDY SAMPLE

TBI community integration has many stakeholders who approach the topic from various perspectives. These include internal stakeholders (those who work from within community integration organizations) and external stakeholders (including government, non-profit, research and academic who affect change through policy, research, and advocacy). In order to obtain as many perspectives as possible, both internal and external individuals were targeted as the sample for this research. Specifically, “internal stakeholders” were defined as representatives of CATBI network sites (see Table 2 below) and “external stakeholders” were defined as national leaders within the TBI continuum of care. The names of CATBI respondents and their organizations have been scrubbed from the data to keep them both anonymous.

TABLE 2: List of Internal Stakeholders, CATBI

Location of Organization	# of Participants
Independent Living Center, Northern California	1
Independent Living Center, Northern California	1
Brain Injury Support Cnter, Northern California	2
Hospital, Southern California	1
Hospital, Northern California	1
Independent Living Center, Southern California	1
Brain Injury Support Center, Southern California	2
Total CATBI Individual Interviewees	9

Table 2 lists the first group to be interviewed, which are the CATBI internal stakeholders (n=9). This list is comprised of executive directors and senior staff of CATBI sites. These individuals were chosen because they directly deliver community integration services to adult TBI survivors and are deeply familiar with the daily challenges of providing services.

The second group of stakeholders is found in Table 3 and is comprised of external stakeholders: state and national executive leaders in academic, government or non-profit arenas within the field of TBI community integration (n=14). These individuals were interviewed in order to learn their thoughts about community integration and to find out whether their views mirrored, complemented or disagreed with those of the internal stakeholders. It should be noted that given the target sample, this dissertation focused primarily on understanding CI services delivered in California, outside of the Veteran’s Administration health system.

Table 3: List of External Stakeholders

Name of Organization	# of Participants
Independent Living Resource Center	1
California Department of Rehabilitation	1
Rehabilitation Institute/Neuroscience Institute	1
Hospital - Acute Rehabilitation	1
Department of Rehabilitation Medicine, School of Medicine	1
Department of Physical Medicine and Rehabilitation, School of Medicine	1
Community Action Partnership (CAP)	1
California Association for Adult Day Care Services (CAADS)	1
Brain Injury Rehabilitation Organization	1
Community-Based Adult Services Section (CBAS), California Department of Health Care Services	2
California Department of Health Care Services	1
Brain Injury Association, California Chapter (BIACAL)	1
Community Integration Organization	1
Total Individual External Interviewees	14

Finally, a subset of the CATBI group physically met for a focus group and meeting. The seven executive directors were invited and six attended, bringing additional staff with them for the two-day focus group and meeting (n=15). Of the staff who attended, 8 of the 9 had not been included in the Interview Phase. The executive directors (n=7), however, were already represented in the original count for Version A interviewees, with their participating organizations listed in Table 4, below:

Table 4: List of Organizations Participating in Focus Group Interview

Location of Organization	# of Participants
Independent Living Center, Northern California	1
California Department of Rehabilitation	1
Independent Living Center, Northern California	3
Independent Living Center, Southern California	2
Hospital, Northern California	2
Brain Injury Support Center, Northern California	2
Brain Injury Support Center, Southern California	3
Hospital, Southern California	1
Total Focus Group/ Interview Participants	15

3. PHASE 2: INSTRUMENTS

1. Development of Study Instruments

a. Interview Guide

The question of what common community integration recommendations should include led to the design of an initial interview guide. This was done by first informally speaking with staff at the seven CATBI sites over several months to see what their concerns and needs would be now and in the future. While this group is core to the research, there are other experts outside of the CATBI CI organizational model whose opinions and knowledge would add a compelling perspective. The decision to include a cross-section of the TBI sector's many stakeholders necessitated the design of two interview guides, Versions A and B. Version A respondents include CATBI staff (Table 2, above). This group is the recipient of DoR state funding and strive to take their organizations (and their members) to the next level of services and sustainability. Version B respondents include TBI sector professionals located on the West Coast, Central US and the East Coast, and represented not just community integration but other aspects of the TBI continuum of care including medical, rehabilitation, non-profit and academic research (Table 3, above). Both versions cover nine (9) questions that are similar in content but devised for a

specific stakeholder cohort. The content of Interview Guide Version A for CATBI members (Table 5) focuses on all aspects of what defines community integration for someone working within the CATBI group: from the types of services that should be available in a CI environment, to educational resources for the survivor and care giver, to who are the identified partners within the community, to performance measures, to the definition of community integration, to barriers/opportunities to CI success, to thoughts about sustainability, to finally the future of the CI model. Version B for External Stakeholders (Table 6) asks the similar questions but to a different group of respondents. In creating this instrument, the hope was this would eventually lead to a foundation for proposed recommendations strengthening TBI psycho-social organizations' collaborative efforts to deliver comparable levels of services and quality of care, wherever they may be located.

b. Focus Group Interview Guide

The Focus Group Interview Guide was designed after the completed interviews. Based on the conversations between the researcher and CATBI respondents during the individual interviews, the CATBI members were interested in collaborating to compare each site's services and structure. They agreed to the researcher's suggestion of physically bringing the CATBI members together in one geographic location to discuss and compare what basic services are available to all sites, what their programs consist of and how organizations might be similar in their organizational structure. The Focus Group Guide (Table 7) was designed by this researcher with this in mind, in order to facilitate an inaugural face-to-face discussion between CATBI members to see how they could work more collaboratively in the provision of community integration care across the State. The guide included questions on both services and organizational structure. Once the two-day meeting was scheduled, the Focus Group Guide was emailed out to all

participants roughly two weeks prior to the meeting to give CATBI members the opportunity of coming to the meeting with prepared responses.

This instrument contains 10 questions focusing on program services and organizational management of the seven CATBI sites. Both the meeting and the Focus Group Guide were limited to CATBI group participation (Table 4) because it asks specific questions about what constitutes CATBI services on program and organizational levels. Once the meeting convened, however, this researcher understood that a more quantitative approach be added in order to capture the most complete information as possible. This is why the Program Services Survey was changed from a questionnaire-type instrument into a fill-in worksheet and the Organizational Structure Survey was created to capture some of the quantitative data not previously incorporated elsewhere.

c. Program Services Survey

It became clear once responses to the Focus Group guide were returned that the information should be presented into two different surveys; one for program services and one for organizational structure. The Program Services Survey (Table 8) focuses on the content of community integration services each site was providing, .

d. Organizational Structure Survey

As with the Program Services Guide, a template for an Organizational Structure Survey Guide (Table 9) was drafted by this researcher in order to be completed during the meeting. The Organizational Structure Survey was the final instrument to be developed. It grew organically as a complement to the Program Services Survey. During the meeting process this researcher understood that the Program Services Survey did not address all the topics the CATBI members

wanted to discuss. With input from the attendees, this survey template was created at the end of the first day of the meeting and completed on the second day of the meeting.

4. PHASE 3: DATA COLLECTION METHODS

The data collection tools used for this research were thematic in nature and focused around community integration. Assessing broadly the same topics with slightly different framing given the two respondent groups, the principle investigator for this research (Stephanie M. Boumediene) was responsible for all interviewing and collection of data.

a. Interviews

Phone interviews and face-to-face interviews (wherever possible) were set up to be completed over several months. Interviews, whether by phone or in person averaged 90 minutes in length. All interviews were recorded with the iPhone app TapeACall Pro, with the consent of all interviewees. Notes were also taken to capture any perceptions or additional thoughts on the part of the researcher. Once a call was complete, the information was then manually transcribed into Word documents.

b. Focus Group Meeting and the Focus Group Guide

From the beginning, the executive directors saw the importance of this and ultimately agreed to convene a focus group for accomplishing this task. Working collaboratively with the executive directors on logistics, a two-day meeting (September 13-14 2017) was arranged, which centered on the creation of a spreadsheet identifying all services and structures across the member organizations. All seven sites were physically represented at the meeting. All executive directors attended the meeting in Santa Barbara, as did other senior level CATBI staff (n=15). With this researcher as the facilitator, the objectives were to formulate and categorize program development and organizational structure of CATBI in the hopes of expanding both. Santa

Barbara was chosen as the site for the meeting because it was roughly the same distance from the Southern California sites to Santa Barbara as it was from Northern California to Santa Barbara. Prior to this meeting, this level of structured collaborative analysis had not been done by these providers.

The Focus Group Guide was sent via email by this researcher to all of the CATBI members two weeks in advance of the two-day meeting. Participants were requested to complete as much as possible and be prepared to share additional input during the meeting. Roughly 60% (n=9) of the Guides were completed and returned to the researcher prior to the meeting. This information was then used to begin building the Program Services Survey. The remaining 40% (n=6) of responses were collected at the meeting. Notes during the two-day meeting were taken by both this researcher and a CATBI site staff member. This researcher then took both sets of notes, combined them and incorporated the information into the Program Services Survey worksheet and the Organizational Structure Survey.

c. Program Services Survey

The Programs Services Survey was based on the responses from the Focus Group Guide as well as in-depth discussions that occurred during the meeting. Partially completed and passed out to the meeting attendees the first day of the meetings, the remaining respondents furnished their input. Additional conversations were had about the Survey during the two-day meetings, with edits added to the Survey document.

d. Organizational Structure Survey

During the two-day meeting, participants were encouraged to expand the discussion to compare and contrast their own organization within the group. A second spreadsheet focusing on organizational structure was completed during the last meeting day. This compared and

contrasted items such as geographic locations, staff benefits, funding sources, and contingency plans for emergency funding, etc., adding another dimension to analyzing community integration models. By the end of the two day-meeting, both spreadsheets were completed, but CATBI staff were given additional time to process these takeaways. Any new edits were incorporated by this researcher and then sent back to all participants for final approval. This occurred over roughly the two weeks post-meeting.

5. PHASE 4: DATA MANAGEMENT AND ANALYSIS

Using all the instruments, the information was compiled from respondents using qualitative descriptive strategies. These strategies include coding from interviews, observations and notes; recording the researcher's insights on discussions; sorting data by categorizing similar trends, themes and familiar phrases; examining commonalities and/or differences and pulling these for further analysis; identifying generalizations which hold true for the data; comparing these with current knowledge in the field in an effort to understand any latent (or hidden) variables (Sullivan-Bolyai, 2005).

Originally starting with the interview responses, the compilation of notes and observations from each interview were then assessed and added. All interviews, notes, observations and research insights were coded into NVivo qualitative data analysis software. Nodes were created within the software to begin researching specific themes. Child nodes are classified within the hierarchy under parent node. Table 10 lists both parent and child nodes created in this research. These parent nodes were more deductive in nature to begin with and the topics were generalized in nature. But as the analysis progressed through the identification of child nodes, the interview and observational layers were peeled away, and inclusive new

knowledge about community integration services came through the data. These findings and data are discussed at length in Chapter 6.

TABLE 5: INTERVIEW GUIDE FOR CATBI STAKEHOLDERS

1. What population do you serve?
2. Types of services that should be available in a TBI CI organization: What community integration services does your organization offer? What should be available that you don't currently do?
 - a. Case management/psychosocial screening
 - b. Transitional/reintegration therapies
 - i. OT
 - ii. PT
 - iii. ST
 - iv. Behavioral Health
 - c. Caregiver respite and counseling
 - d. Education and referrals
 - e. Advocacy services
 - f. Vocational services
 - g. Independent living services
 - h. Veterans services
 - i. Residential services
 - j. Assistive technology
 - k. Day program services
3. Types of educational resources for TBI survivors and caregivers: What educational resources do you provide?
 - a. Participants
 - b. Caregivers
4. Community Stakeholders for TBI CI organizations: Who are your partner-organizations within your community supporting TBI community integration?
 - a. Hospital
 - b. Rehabilitation hospital
 - c. Behavioral wellness
 - d. Primary care physicians (patient centered medical home, PCMH)
 - e. Ambulatory care clinics
 - f. Adult day health care (ADHC)
 - g. Community based adult services (CBAS)
 - h. Independent living centers (ILC)
5. Performance outcome measures: How do you assess outcomes?
 - a. What do you measure?
 - i. For the TBI survivor

- ii. For the caregiver
 - b. What tools do you use for mobility? Cognitive function? How did you decide on which tools to use?
 - c. What are your sources? (QOLIBRI, CIQ, Mayo-Portland, etc.)
 - d. Frequency of measurement – baseline, 6-month, 12-month, etc.
6. Community Integration: How do you define community integration? What would be the key elements for a successful TBI CI program?
7. Barriers and opportunities for CI success: What are the barriers to a successful TBI CI program? Opportunities?
8. Sustainability: What are your ideas about sustainability into the future?
9. The future of community integration: What future developments do you see for the TBI community integration sector?

TABLE 6: INTERVIEW GUIDE FOR EXTERNAL COMMUNITY INTEGRATION STAKEHOLDERS

1. What is your background?
2. What community integration services do you think should be available in a CI organization?
 - a. Case management/psychosocial screening
 - b. Transitional/reintegration therapies
 - i. OT
 - ii. PT
 - iii. ST
 - iv. Behavioral Health
 - c. Caregiver respite and counseling
 - d. Education and referrals
 - e. Advocacy services
 - f. Vocational services
 - g. Independent living services
 - h. Veterans services
 - i. Residential services
 - j. Assistive technology
 - k. Day program services
3. What educational resources should be provided to participants and caregivers?
4. Who do you think should be partnering in support of TBI community integration?
 - a. Hospital
 - b. Rehabilitation hospital
 - c. Behavioral wellness
 - d. Primary care physicians (patient centered medical home, PCMH)
 - e. Ambulatory care clinics
 - f. Adult day health care (ADHC)
 - g. Community based adult services (CBAS)
 - h. Independent living centers (ILC)
5. What outcomes would you like to see be assessed?
 - a. For TBI survivor? For caregiver?
 - b. How would you decide on which tools to use?
 - c. Possible sources? (QOLIBRI, CIQ, Mayo-Portland, etc.)
 - d. Frequency of measurement – baseline, 6-month, 12-month, etc.
6. In your opinion, what would be the key elements of a successful TBI CI program?
7. What are the barriers to a successful TBI CI program? Opportunities?
8. What are your ideas about sustainability into the future?
9. What future developments do you see for the TBI community integration sector?

TABLE 7: CATBI FOCUS GROUP INTERVIEW GUIDE

1. Please describe the host agency for your TBI program; for example, a non-profit hospital, a free standing private non-profit community-based agency, etc.
2. How many staff persons in your organization are involved in providing direct services to clients under the TBI grant? This is a physical count; therefore, if a person is only providing service, part of the time, they would still be counted as 1 (whole number).
3. What level of direct service staffing does the TBI grant pay for? This is a partial count based on full time equivalent (FTE) staff; therefore if funding pays only half of a person's full-time salary, then that person counts as .5 FTE. Please total up the number of FTE's providing direct service through the grant and provide that number.
4. What is the minimum degree required for the staff that provide direct service to TBI clients? For example, does the current staff have to have at least a bachelor's degree or an advanced degree? If multiple staff with different degrees work through the grant, please note that and report them whether or not they are fully funded under the grant.
5. Would you agree that your program is serving the maximum number of clients possible (unduplicated) with the current staff? Yes or No?
6. Is there a "discharge" process for clients in your program; this includes "closing" cases? If so, please describe the criteria for when work with a client is officially considered completed and you no longer maintain a case file or provide services.
7. Is there a waiting list for service at your organization?
8. What is the best estimate of the time and effort spent by your agency in providing the four categories of service under the grant? Please prioritize so the four categories total to 100%.
9. Please provide an example(s) (brief narrative) of a successful service intervention outcome(s) for a client/clients and which service areas were addressed.
10. Please provide a brief narrative of how your program provides services/interventions for your clients.

TABLE 8: PROGRAM SERVICES BY TYPE AND BY CATBI SITE (TEMPLATE)

ITEM NUMBER	SERVICES	ORGANIZATION						
		ILC - NorCal	ILC - NorCal	ILC - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NoCal	Hospital - SoCal
1	Initial intake/assessment (non-medical psychosocial screening included)							
2	CIQ (upon intake)							
3	Medical/clinical psycho-social services							
4	Transition from hospital, SNF, etc.							
5	Community-reintegration services							
6	Transitional therapy services:							
	6a. Occupational Therapy (OT)							
	6b. Physical Therapy (PT)							
	6c. Speech Therapy (ST)							
	6d. Behavioral Health Therapy							
7	Formal/licensed counseling (reimbursable)							
8	Informal Counseling (evidence-based); peer counseling; person-centered; WRAP (Wellness Recovery Action Program)							
9	Substance Abuse							
10	Support Group							
11	Caregiver Respite							
12	Caregiver Counseling (licensed)							
13	Caregiver Support Group							
14	Education							
15	Systems Change Advocacy (legislative & insuring policy, procedures, systems are responsive to needs of TBI individuals)							
16	Individual Advocacy Services (assistance/information on rights & services toward individual housing, benefits, etc)							
17	Vocational Services (to help individual attain/maintain employment - not DoR)							
18	DoR Certified Vendor							
19	Independent Living Services - individual or group?							
20	Independent Living Services Curriculum							
21	Veterans Assistance							
22	Contracted with Veterans Administration							
23	Residential Services (Home Visits)							
24	Assistive Technology - device lending library; technology training; equipment reuse							
25	Housing Assistance for homeless & at-risk							
26	Benefits Assistance							
27	Day Program focusing on cognitive, physical & social							
28	Pre-vocational (Day) Program							
29	Goal-based							
30	Bilingual Services							

TABLE 9: ORGANIZATIONAL STRUCTURE BY CATBI SITE (TEMPLATE)

SURVEY QUESTIONS	ORGANIZATION						
	ILC - NorCal	ILC - NorCal	ILC - SoCal	TBI Support Center - SoCal	Hospital - NoCal	TBI Support Center - NoCal	Hospital - SoCal
1. Please describe the host agency for your TBI program; for example, a non-							
2. How many staff persons in your organization are involved in providing							
3. What level of direct service staffing does the DoR TBI grant pay for? This							
4. Definition of FTE							
5. Does your organization provide benefits?							
6. What is the minimum degree required for the staff that provide							
7. Would you agree that your program is serving the maximum number of							
8. Are you able to meet the needs in the community with the							
9. Is there a "discharge" process for clients in your program; this includes							
10. Is there a waiting list for service at your organization?							
11. What is the best estimate of the time and effort spent by your agency							
(a) Community Integration							
(b) Supportive Living Services							
(c) Vocational Supportive Services							
(d) Other Case Coordination							
(e) Public and Professional Education							
12. Please provide a brief narrative of how your program provides							
13. What happens if DOR funding goes away?							
14. Does your organization have different geographic satellite locations?							
15. Satellite locations by city							
16. Funding Sources							
17. Contingency Plan if no future DOR grant							

TABLE 10: NODES AND CHILDNODE CATEGORIES FROM NVIVO ANALYSIS

#	Node Name	ChildNode	Sources - Nodes	Sources- ChildNodes	References - Nodes	References - ChildNodes
1	Barriers		3		61	
2	Community Integration		4		22	
		Definition		2		9
		Person Driven Content		2		5
3	Community Stakeholders		4		53	
		Adult Day Care		1		1
		Ambulatory Care		1		1
		Behavioral Wellness		1		5
		CBAS		1		3
		Educational		1		3
		Homeless Shelters		1		1
		Hospitals		1		8
		Independent Living Centers		1		5
		Outpatient Programs		1		2
		Primary Care		1		3
		Regional Centers		2		7
		Rehabilitation Hospitals		1		3
		VA		1		1
4	Opportunities		1		16	
5	Other Prospective Models		4		21	
		Chronic Care		2		2
		Clubhouse Model		2		2
		Independent Living Centers		3		5
		Medical Model		2		8
		Neurobehavioral		1		1
		Outpatient Rehabilitation		1		0
		PACT		1		0
		Regional Centers		2		4
6	Performance Outcome Measures		2		37	
		CIQ		1		4
		Measurement Frequency		1		2
		MAYO-Portland Inventory		2		7
		Other Measures		1		9
		QOLIBRI		1		7
7	Program Components		6		10	
		Advocacy Services		1		5
		Assistive Technology		1		4
		Behavioral Health/Substance Abuse		4		6
		Caregiver Respite		2		6
		Case Management		3		17
		Educational Referrals		2		19
		Independent Living Services		2		8
		Residential Services		2		6
		Transitional Reintegration Therapies		2		10
		Veterans Services		1		8
		Vocational Services		2		12
8	Sustainability		5		58	
9	TBI Continuum of Care		3		12	
		Medical		2		7
		Psychological		1		1
		Rehabilitation		1		1
10	The Future of CI		3		26	

CHAPTER 6 – RESULTS

Part 1: California Association of Traumatic Brain Injury Organizations (CATBI) Interview Guide Results

A. CATBI Representatives Interviews

Community integration staff comprise the interviewee population for internal stakeholder interviews. Executive Directors and program staff from the seven CATBI sites were questioned for their perspective on the community integration services model and what they see would make it stronger and sustainable. Approximately 60% of staff and executive directors interviewed had first-hand experience with either a traumatic brain injured (TBI), acquired brain injured (ABI), developmentally disabled (DD), or intellectually disabled (ID) person in their family. This experience led them into the psycho-social sector. Approximately 75% of all the executive directors interviewed (n=7) have made this sector their life-long career, with an average of 15 years of employment within this field. The seven current CATBI member sites are listed in Table 1 below.

Table 1. California Association of Traumatic Brain Injury Organizations (CATBI)

Location of Organization	# of Participants
Independent Living Center, Northern California	1
Independent Living Center, Northern California	1
Brain Injury Support Cnter, Northern California	2
Hospital, Southern California	1
Hospital, Northern California	1
Independent Living Center, Southern California	1
Brain Injury Support Center, Southern California	2
Total CATBI Individual Interviewees	9

1. Population Served by CATBI Organizations

Overall, the sites support adult survivors of TBI. The three independent living centers, however, did accept pediatric TBI survivors whenever they presented. Four of the sites ran their major programming for Developmentally Disabled (DD) and Intellectually Disabled (ID)

populations, with TBI a newer population brought in through the DoR grant. One Northern California organization had historically been a TBI-only program, but recently incorporated DD and ID populations to take advantage of DoR funding for employment services. Two organizations support the TBI survivor within the context of their cognitive rehabilitation programs that are offered to TBI, stroke and spinal cord injury patients. Finally, one Southern California organization is dedicated to TBI and ABI survivors and does not accept other disease conditions (unless these are secondary diagnoses to a brain injury). All seven organizations have been in place for over 25+ years, with almost all created around the mid-1980s when disability awareness was increasing among social service providers.

2. Definition of Community Integration

Respondents' definitions of community integration suggest a multi-dimensional concept. Many acknowledged that it can mean *“different things to different people which makes it kind of vague.”* Most interviewees initially responded with *“helping survivors attain a better quality of life”*. When pressed to define further what that meant, definitions included everything from learning personal hygiene to expanding social relationships to living independently. One definition was *“supportive services that help people to live the lives that they want to live.”* This includes skills training, living independently, employment. Another definition was *“supporting the individual in reaching their highest level of functioning, post-injury; to have the highest quality of life and getting that person to a point to where they feel they are a contributing member of the community.”*

A clear delineation was made between the medical model of care and the psycho-social model of care, and where community integration fits within the psycho-social model as compared to the medical and rehabilitation models. As one interviewee explained: *“...the*

medical model will save you – keep you alive initially – but we know what is needed to be able to live in the community long term and what affects the quality of life.” Several interviewees stressed the idea that there should be less of a medical model emphasis for consumers, due to the idea that the TBI survivor is no longer a trauma patient, but someone who is rebuilding themselves as a person. There was an acknowledgement that a successful community integration program is *“a little rehab, a little cognitive, a little social – all of these components need to be in place to make it work. Plus, outcomes and measurements. A successful TBI CI program also needs to have an end date for treatment.”*

3. Services Provided by CATBI Organizations

Interviewees from the CATBI organizations were provided with a hard copy list of possible services that could be available to TBI survivors and were asked to indicate which (if any) of these services were currently being offered at their respective sites (Table 2).

Table 2: List of Services

Item	Service
A	Case Management/Psychosocial Screening
B	Transitional/Reintegration Therapies
i	OT
ii	PT
iii	ST
iv	Behavioral Health and Substance Abuse
C	Caregiver Respite and Counseling
D	Education and Referrals
E	Advocacy Services
F	Vocational Services
g	Independent Living Services
H	Veteran Services
I	Residential Services
J	Assistive Technology
K	Day Program Services

The results highlighting which services are provided by CATBI site are presented in Table 7 in Chapter 5 (CATBI Programs Services Survey). Although all CATBI members provided multiple services, no one site offered all listed services. All of the seven CATBI organizations saw this list as a ‘wish list’ for what they hoped would one day be included in their programming. Many felt that not any one item on the list was more important than others, with the common refrain being they were all “equally important” and “should be seen as stepping stones” to complete care. As one interviewee stated, “you can’t deliver everything, so you try and collaborate and partner and support and raise up the organization.”

a. Case Management and Psychosocial Screening

All seven CATBI sites utilize a psychosocial screening tool at the initial intake of a TBI survivor. However, the seven organizations did not use the same tool. The majority of sites use the Community Integration Questionnaire (CIQ), a simple 15-item questionnaire assessing quality of life while others use the four-page Quality of Life After Brain Injury (QOLIBRI) questionnaire. Medical/clinical psychosocial services are provided on-site at only three of the seven organizations, these being the two hospital-based programs and one non-medical site. The other four sites refer out to community partners for this service. Neuropsychological testing is done at only one site, in a hospital program. All CATBI sites expressed interest in having neuropsychological testing available, but since this can only be overseen by a certified neuropsychologist with specialty training, this is not feasible at the non-clinical sites.

In order to comply with DoR grant funding stipulations, case management has been adopted within all CATBI organizations, although respondents reported originally being hesitant to adopt the model because of its origins within the medical model. And while all do use it, there

remains a slight negative bias due to its association with the medical model and not the psychosocial model.

“The medical model is what all the waivers are built on – that language, right? That language seems a completely different language than what we have in the psychosocial model. So, okay, you want us to call it case management, we’ll call it that to adapt to that medical model and not visa-versa. I think we lose an opportunity – I mean, there was a time when I would have said ‘No, we aren’t going to do this case management that’s billable under MediCal.’ But I feel in order to move forward and be seen as a valid partner in healthcare, then we do it.”

Case management was already in use at those sites based in a medical environment, and they easily adapted to the use of this approach. The independent living center sites (ILCs), however, wrestle with the term and meaning of case management. While the three ILC sites acknowledge the value of the concept, under the ILC philosophy a participant is viewed as an individual and not as a “case needed to be managed”. There is also a push back that this concept was transferred directly from the medical model, which is seen as less person-centered and more physician-centered. One interviewee preferred the term “service coordination” to case management because *“you are an individual, you are more than capable of doing what you need to, probably than what most of society has told you you are capable of doing.”*

b. Transitional/Reintegration Therapies and Services

i) Transitional Therapies

Occupational therapy (OT), speech therapy (ST) and physical therapy (PT) are services that the sites recognize as valuable components of the community integration model. All respondents agree these transitional therapies should continue past the traditional rehabilitation phase into the community integration phase. The challenge facing the non-medical organizations is the difficulty in finding funding to support these therapies, as well as the space/privacy requirements for one-on-one appointments. Of the seven CATBI sites, only three offer OT, ST and PT based on insurance eligibility, with two of these three sites embedded within a

hospital/rehabilitation model. One non-medical site offers ST and refers out for OT and PT with the remaining three sites (all ILCs) refer all TBI survivors out for PT, OT, and ST. The two hospital-centered sites that offer these therapies do so because they have licensed therapists on staff, unlike the other four sites. They are also able to bill for these therapies. The non-medical organization offering these therapies directly bill the patients who then seek reimbursement from their insurance company. This non-medical organization has entered into a partnership with a local hospital group's MediCal offshoot for publicly insured patients in need of OT, PT and ST and is has been able to make this a viable funding source for the site.

ii) Behavioral Health and Substance Abuse

One of the challenges for the four non-medical CATBI sites is the accessibility of medical information. When a TBI survivor presents to one of the hospital programs, their medical history and information are accessible through whatever electronic medical record system is in place. The four non-medical organizations, however, are at a disadvantage, as any medical information gathered is by volunteer-basis only. The non-medical CATBI sites may have some awareness of an individual's health issues but only if the TBI survivor is willing to share information. Because this is on a volunteer-only basis, some CATBI sites are better in obtaining information than other sites. Another challenge is obtaining access to any potential shared databases with local hospitals from which to gather this information. This is important when trying to ascertain what health issues an individual might present with, including mental and behavioral health, and can leave the non-medical sites at a distinct disadvantage. As one of the ILCs stated: *"We try to get down to the root issues where people feel safe enough and can talk about that, and then you can connect them to the services."*

To bridge this gap for behavioral health support, the four non-medical sites creatively work with community partners through service coordination in attempts to alleviate this problem. Again, each organization goes about this in a different way as currently no standardized protocol exists. One of the ILCs uses a mental health assistance program in partnership with its county's Behavioral Health Department; another promotes a "friendly-visitor" program of weekly home visits; a third supplies a coping with stress class to members, and the fourth gives a structured weekly behavioral health class.

Substance abuse is a risk factor for TBI (Taylor, 2003), with 36%-73% of TBI survivors being intoxicated at the time of the TBI injury (Beaulieu-Bonneau, 2018). Moreover, 31%-79% of TBI survivors have a pre-TBI history of alcohol abuse, 21%-44% have a history of drug abuse, and 8%-13% drug abuse (Ponsford, 2008). There is a higher prevalence of current substance abuse among survivors who have incurred a mild TBI versus individuals with a severe TBI. This is probably due to the fact that someone with a milder TBI is more likely to continue using substances than a survivor with a severe TBI (Graham, 2008). Many survivors of mild TBIs self-medicate to escape from the effects of TBI; it is this cohort that has a larger percentage of people who do not receive community integration services and are therefore unlikely to have access to substance abuse programs (Beaulieu-Bonneau, 2018). Provision of substance abuse modules can be seen as a core service for successful community integration, however none of the CATBI organizations have in-house substance abuse services; they all refer out to their respective community partners.

c. Caregiver Respite and Counseling

Within the community integration organizations interviewed for this research, caregiver respite is defined as a service offered to caregivers of TBI survivors in an effort to support the

needs of these individuals as they adapt to caring for their family member. Even though all CATBI sites acknowledge the importance of such programs, six of the seven CATBI members do not offer caregiver respite services and instead refer caregivers out to other community agencies for support. However, one site obtained funding to offer support groups for caregivers, with measuring the outcome on caregiver quality of life and how it related to the quality of life in survivors. When the other organizations learned of this during a monthly CATBI phone call, they expressed some interest to include these services, if funding is available. One director commented: *“There’s no formal tracking of caregiver quality of life because it’s just been hard. It’s like herding cats. We would never get enough data for it to be meaningful.”*

Licensed clinical counseling for both caregivers and TBI survivors is done with a neuropsychologist or Marriage Family Therapist (MFT) at the two hospital locations and one of the non-medical organizations. The other four refer out to the community. The reverse is true for informal peer counseling services, where the ILCs and the other CI organizations provide full peer counseling, but the two hospital-based programs do not.

d. Education and Referrals

CATBI members, when asked about provision of health education, define three target audiences for educational efforts: community stakeholders at large, TBI survivors and caregivers. Each of the sites carries out educational activities for community partners, such as annual workshops for law enforcement, concussion clinics for high school sports teams, and community presentations at public events. And while all sites agree there is value to these efforts, many have had to activities due to budget cuts. One ILC Director noted *“I have to weigh direct services, case management, or go out and do this education. And to us it’s more important*

to do the direct services, so that's not done." As with many other items on the programs list, there is no one standard procedure for community outreach, with each site doing what they can.

For TBI survivors, educational services can include health information on TBI, independent living skills, mental health, transportation, housing, mental health and legal services. Social service benefits are a common topic, such as Social Security, MediCal, healthcare or income-related benefits. CATBI organizations have varied platforms for education, including websites, printed material, and psychoeducational groups providing information about cognitive, physical and social issues. But several of the sites only send individuals to well-known websites for information as they do not have the means to develop their own resources.

Education resources for caregivers are much more limited, with most of the sites referring caregivers to community partners that already provide this service. All CATBI members recognize that there is an unmet need for caregivers within the context of CATBI programming, but lack of funding makes this less of a priority, *"For caregivers, I mean there really is a lack of services, to be honest with you. I know it's funny, because we have a weekly TBI support group, but the parents and caregivers have to hang out on their own."*

e. Advocacy Services

Advocacy was identified by all organizations as two-tiered, comprised of individual advocacy services and a broader systems-change advocacy component. For the ILCs, advocacy is a core service in their mission. Case management is the main vehicle for advocacy services, with the independent living program structure including tools for self-advocacy.

All CATBI sites have been involved in political advocacy at the local level, but it has only been within the last two years that CATBI has begun to coalesce as one voice for representing TBI survivors overall. While each organization has in place formal advocacy

supports for rights and services of their members, it has been more challenging for CATBI as a group to promote systems-change. As one manager for an Independent Living Center stated: *“this is incredibly important because without this, the sector may not get State funding; the public does not know about the TBI population, and the TBI survivor and caregiver feels alienated and alone.”* The CATBI member organizations realize that systems-change is needed at the legislative level in California and are currently seeking a formal path to make its voice heard.

f. Vocational Supportive Services

Vocational Supportive Services (VSS) are to assist a TBI survivor with reintegration back into the workforce. Through fulltime or part-time employment or volunteer positions the goal is to support a TBI survivor’s efforts in gaining and keeping some position outside of the home. VSS are offered by each CATBI site, although the range of services varies. Some organizations do pre-employment education (helping the TBI survivor re-learn about the work environment), referrals (referring out the TBI survivor to a potential employer) and vocational assessments (testing of the survivor to see the level of competency in an everyday work environment), while other sites utilize DoR immersion and employment services (a structured program that immerses the TBI survivor in a work environment with the goal of successful employment). Only one site (hospital) does an in-depth pre-employment assessment which includes PT, OT, ST, and neuropsychology assessments. Three of the seven organizations are certified as DoR vendors, meaning they have successfully passed a certification program that allows them to charge DoR for some of their employment services. Some of these sites expressed frustration with the current system as managed by the DoR, with one of the executives at one of the three DoR certified vendor sites commenting that while *“DoR employment staff are nice, they don’t know how to*

work with brain injury survivors. It isn't for lack of training or information on the part of DoR counselors; I just think they don't want to provide services."

g. Independent Living Services (ILS)

Skills taught in the ILS curriculum range from cooking and baking, to personal hygiene and finance, to transportation and social activities. All seven sites provide ILS, with five of the organizations offering both individual and group programming. The remaining two organizations provide these services through an individual-only format. These two sites expressed interest in having group services but are limited in funding. It is clear that all sites see value in this service. As one executive director stated: "Independent living services – there is an on-going need. This is a community integration skill set that is so important for success." Even as they value this type of curriculum, only two of the sites have a formal independent living curriculum, so there is no standardization as to what is being taught throughout CATBI.

h. Veterans' Services

All CATBI sites reported they offer assistance to veterans, but this does not mean a specific veterans' program. A TBI survivor who presents to a CI organization for assistance may be a veteran but because of the at-will disclosure policy of psycho-social services, that person may not disclose his/her veteran status. Two organizations have formal contracts with local Veterans' Administrations for case management of veterans who present with TBI. These two CATBI sites believe they add value to these veteran TBI survivors, but they also shared challenges in recruiting and keeping veterans in the programs. Veteran outreach is seen as an underserved demographic; as one director who has one of the case management programs for veterans noted: "*It's a challenging population – kind of like police or firefighters, they tend to stay within their own population. Very hard.*"

i. Residential Services

None of the CATBI respondents have onsite residential housing, but they all assist clients with finding and keeping housing through case management services. Housing is one of the most challenging areas for TBI survivors and is one of the major concerns for CATBI organizations. One director shared: *“Our homeless population has grown, for sure. It’s difficult to house people; if they are fortunate to have housing, how do we keep them in that housing? Often, people who have housing, do not have safe housing. They are in garages; they are in closets. I am not kidding. It’s really, really bad.”*

Several CATBI members expressed interest in having a transitional housing complex to ease TBI survivors back into the community if funding could be found, *“A place for transitional housing would be really important because we have seen the challenges of social skills, acceptance of the disability and identifying with the disability. You know there is a lot of shame tied to any disability, whether its TBI or what have you; its critical to be able to really transition back into the community successfully.”*

j. Assistive Technology

Assistive technology (AT) includes devices, hardware, software and systems that aid a disabled individual in improving functional capabilities. Five of the seven CATBI sites provide assistive technology services. It is so highly valued by the ILCs that each ILC has an Assistive Technology Coordinator. A director from one of the ILC sites stated: *“AT and the ability for us to lend devices to people who cannot afford them is, like magic for their integration and for their ability to gain independence that they are striving for; to get their lives back.”* The two CATBI organizations that do not provide assistive technology are the two hospital sites. They refer patients out to community organizations.

k. Day Programming

Day services with formalized programming focused on cognitive, physical and social skills has been shown to improve the quality of life of TBI survivors (McKay, 2016). The DoR grant funding of \$150,000/year to each of the seven CATBI sites has allowed organizations who did not serve TBI survivors with day programming in the past to begin supporting this population at their sites. It has also allowed organizations already serving TBI individuals in this capacity to expand their services. How this TBI funding is used varies greatly by organization. But of the seven sites, only three organizations offer a full, 5-day Day program: all of these organizations are non-medical. The other four sites (which include the two hospitals and two independent living centers) refer consumers out into the community. These four sites do not have the funds to support a 5-day program.

4. Community Stakeholders Collaborating with CATBI Organizations

In an effort to provide the most complete support for a TBI survivor, TBI community integration organizations continually work to build partnerships with community stakeholders. As a part of the interview process for this research, the following list of prospective collaborators was presented to CATBI stakeholders who were then solicited for their opinion (Table 3):

Table 3: Community Stakeholders

Community Stakeholders
Hospital
Rehabilitation Hospital
Trauma Hospital
Behavioral Wellness
Primary Care (PCMH)
Ambulatory Care Clinics
Adult Day Health Care (ADHC)
Community-based Adult Services (CBAS)
Independent Living Centers (ILC)

The CATBI sites are located across California in both rural and urban areas and may not have the same access to resources. Not all of the stakeholders listed are in each CATBI site catchment area. For example, one of the CATBI members is in a region of Northern California where there is no trauma hospital. As a result, TBI patients are usually flown to Sacramento, the nearest trauma hospital location. This specific site makes the effort to reach out to TBI survivors when they are transitioning home after hospital and rehabilitation stays. But this approach is not systematic can be hit and miss, and not all TBI survivors find their way to a CATBI organization post-injury. Respondents indicated that there is no one correct approach for identifying new TBI survivors. There is no automatic hand-over between hospital and community integration organization. Often the CATBI site must proactively use many methods to ensure that community stakeholders and the public are aware of their existence. These methods include advertising in media, outreach to local physicians, and word-of-mouth.

While CATBI members felt the list of stakeholders above did reflect many of their current community partners, they saw it as incomplete. Other stakeholders they suggested for inclusion are academic institutions, DoR vocational rehabilitation counselors, inpatient residential, homeless agencies, prison associations, regional centers and the Veterans Administration, however, several sites expressed frustration with the inability to build a relationship with the local VA offices. As one CATBI director said: *“In a perfect world, everyone in the community should be partnering. We are housed in the hospital, but we will work closely with many community organizations that support independent living for our consumers.”*

5. Assessment of Client Outcomes

Prior to the DoR grant, CATBI sites existed independently of one another. Agencies who received DoR funding were required to implement the Community Integration Questionnaire

(CIQ). The CIQ is a standardized measurement tool designed to show a client's level of independence in 3 categories (home integration, community integration, productive activity). The 3 categories loosely correspond to 3 of the core services required by the grant (supported living, community integration, and vocational services). Under the stipulations of the DoR grant, participants were rated on the CIQ at intake, 6 months, 12 months, and 18 months, and then annually if they are still active in services. The CIQ is easy to administer, measures items specific to the TBI grant, but is not the most sensitive assessment tool, as CATBI members have found the CIQ results make it seem like clients plateau when they actually are making compensatory and/or qualitative improvements in their lives.

In addition to the CIQ, four of the CATBI sites opted to administer a quality of life assessment tool, the Quality of Life after Brain Injury (QOLIBRI), which measures client satisfaction with different areas of brain and body function. This tool was specifically designed for TBI and assesses a person's satisfaction with certain abilities, broken down into the following categories: thinking abilities, emotions, independence, social relationships, feelings, and physical problems. To be consistent with the CIQ schedule, sites typically reported administering the QOLIBRI at intake for benchmarking, 6 months, 12 months, 18 months, and then annually if the consumer remains in the program. Along with the QOLIBRI, a few sites also incorporated the Mayo-Portland Adaptability Inventory 4 (MPAI-4), which assesses any potential obstacles to community integration. MPAI-4 has three subscales that focus on ability index, adjustment index, and participation index.

As mandated, all seven sites have been using the CIQ for three years, with annually reporting to the DoR of outcomes. Because of the perceived shortcomings of the CIQ tool, CATBI members reported collectively making the decision to use the QOLIBRI, whose data is

not given to the DoR but kept within the CATBI group for analysis and trending purposes. Three of the sites (all non-hospital) also use the MPAI-4 as an additional outcome assessment.

One of the sites also uses the tool Functional Communication Measures (FCM), which is a series of disorder-specific seven-point rating scales used to describe a patient's functional communication. One of the hospital sites uses functional measurements such as Activity of Daily Living (ADL), medication management and formal therapy assessments for walking, balance and fine motor control.

Only two sites administer any caregiver assessments. One site administers the MPAI-4 to caregivers on the same baseline schedule as for TBI survivors in order to see how the caregiver perceives the improvement or non-improvement of the TBI survivor. The other site uses the Patient Health Questionnaire-9 (PHQ9) depression scale to see how the caregiver is fairing with regard to depressive symptoms given the demands of caregiving. The outcomes of these assessments are then used at the specific CATBI site for in-house decision-making on the specific caregiver programs.

With the exception of the CIQ, the lack of consistency across CATBI sites in using validated tools hampers the ability of individual sites and CATBI overall to accurately measure outcomes for TBI survivors and caregivers.

6. Barriers and Opportunities for CI Success

Interviewees provided diverse ideas as to what they individually identified as barriers to success for TBI community integration programming. Without giving them specific examples, responses seemed to organically group under four titles: organizational structure, program structure, program services, and macro-level topics (i.e. Department of Rehabilitation, state and federal government, society, and local communities).

A. Barriers

a) Barriers: Organizational Structure

i) Organizational Structure – Overall Funding

Funding support was overwhelmingly the biggest barrier respondents identified for keeping their respective organizations healthy, followed closely by the barrier of staffing. All CATBI directors expressed an awareness of the challenges faced by their organizations when funding is not sufficient. And while funding included support from the Department of Rehabilitation, all respondents perceived that most funders do not fully understand the importance of community integration. As one Executive Director explained: *“We haven’t had sufficient money; we haven’t had a funder, a home that really understands our work.”* Fundraising ends up being a good portion of the executive director’s efforts at each site, as most of the CATBI organizations do not have a professional fundraiser on staff. One CATBI executive noted: *“It’s constantly fundraising. Oh gosh; it’s such an uphill challenge, I can never get over it.”* A long-time executive director whose organization is one of the early pilot program adapters and remains in the program to this day shared that *“it’s an absolute joke that there are only 7 sites for this state. And it’s an absolute joke that we have to fight for funding every few years, at the same unchanged level of funding since 1988!”*

Frustration with government stakeholders who provide the state funding was a discussion point during interviews for most of the directors. After being housed under the Department of Mental Health for years and then transferred over to the Department of Rehabilitation (DoR) for the TBI program, there remains a barrier of credibility with state government officials that the CATBI sites believe exists. This is illustrated by the fact that for over 25 years, the level of funding has never changed, nor has the length of funding. Organizations receive funding for only

four years. At the end of this time the grant is re-issued and all sites must re-compete. There is a level of frustration on the part of all CATBI sites in their effort to be seen as a legitimate program by government entities. One director commented

“After everybody being within budget since 1989 – after all these years and still our work hasn’t been valued. Wow. Talk about deflating. What I hope is that the DoR can bring us together soon – sooner rather than later. And I would like to see that as one of our main outcome of our discussion. Because right now we are not one in the eyes of the DoR – we are united in the sense that we respect one another and all that, but as TBI services in California? We still look like pilot projects.”

ii) Organizational Structure – Insurance Reimbursement

While a few of the sites do receive insurance reimbursement (because they have clinical personnel on-staff), most of the sites do not. These organizations see being ineligible to apply for insurance reimbursements as a large barrier. They also believe if CATBI as a group could “get in front” of insurance companies to plead their case, CATBI might be able to win their support. As one staff member noted:

“You know, if insurance would just pay a nominal fee, we would all be in business. We’d be able to stop this nonsense of trying to squeeze money out of the State and all that. I mean, these programs would proliferate if there was insurance funding for them. And then costs would go down, not up! So, you know, they just don’t get it.”

Just how CATBI could become eligible for insurance support is something that until now has eluded the collective.

iii) Organizational Structure – MediCal Eligibility

Another barrier for the majority of CATBI sites is MediCal ineligibility. MediCal eligibility remains very restrictive and does not include the physical, cognitive and emotional TBI-related diagnoses. With the exception of one CATBI hospital and one other non-hospital site, none of the CATBI organizations can identify as either a Managed Care Organization (MCO), a Primary Care Case Management (PCCM), a Prepaid Inpatient Health Plan (PIHP), or a

Prepaid Ambulatory Health Plan (PAHP), which are the types of organizations that can apply to be a MediCal provider.

In 2010, the Department of Mental Health and the Department of Rehabilitation worked closely with the California Traumatic Brain Injury Advisory Board (created at the time by the California Department of Mental Health and comprised of various TBI stakeholders from the State, regional, and private sectors) to publish “Next Steps,” a document for statewide TBI services in California. The impetus behind this paper was the hope that its recommendations would enable the TBI community to expand the infrastructure for community integration care throughout the State. An evaluation of options for TBI community integration organizations to become eligible to receive Medicaid funding (either in a waiver or state plan amendment) was on the table as a potential stream of new funding. This waiver program has proven successful for other states seeking Medicaid reimbursement for services for TBI survivors, and there was expectation that California could also benefit.

The State had an opportunity to design its own waiver program to tackle 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, but cannot duplicate any current state plan services.

When the Department of Rehabilitation took over management of the TBI program from the Department of Mental Health on January 1, 2010, the DoR began an assessment of MediCal funding for TBI community integration services. The State had three Medicaid options (Vaughan, 2014): a waiver option, a state plan amendment option, and a self-directed state plan amendment.

1. Waiver Option, or “home and community-based services waiver” (HCBS). This permits a state to care for certain Medicaid populations in home or other community-based settings instead of institutional or long-term care facilities (hospitals or nursing homes).
2. State Plan Amendment Option (SPA), a unique type of state plan with parallels to HCBS waivers. Each state has flexibility in its Medicaid program, and can request changes by filing a SPA with the state’s regional Center for Medicare and Medicaid Services (CMS). In most cases, the SPA is seen as an easier course of action than a formal waiver to change a state Medicaid plan.
3. Self-Directed State Plan Amendment, which is an option where states can supply as “medical assistance” the payment for part or all of the cost of self-directed personal assistance services (other than room and board) under the State Plan.

In the end, none of the options were pursued by the State and TBI stakeholders. However, in 2016 the Department of Rehabilitation announced a new requirement for receiving the TBI funding: each organization must become independently MediCal-eligible by the end of two years or lose their State DoR funding. This created a lot of confusion within the CATBI sites that were not already MediCal participants. These CATBI organizations, who were non-medical in nature, spent substantive time and money researching the options of how to become eligible. Many of them expressed frustration in the process of attempting to get clear answers in how to become eligible. The Department of Rehabilitation ultimately rescinded this requirement for funding.

CATBI interviewees expressed a visible frustration about their failed attempts to become Medicaid eligible providers. One of the long-term executive directors commented that

“We tried for the Medi-Cal waiver which is used in other states to fund TBI and that failed. Even the amount we get now from the DoR will be sunseting in 2019. It’s a joke. We have to find a different source of funding. There is not enough funding and it needs to be statewide.”

iv) Organizational Structure - Staffing

Staff turnover and finding quality candidates are barriers due to lack of funding. Often, difficult decisions often are made:

“I have lost staff because I can’t retain them. Our admin costs; we were trying to build – we needed a new data management system for the organization and it has cost me close to \$100,000 because there is nothing on the shelf that can give me what I need. It has to be tailored to what I need. And it was either that or staff.”

Identifying and retaining staff was one thing, but an additional barrier was the challenge of finding skilled staff specifically trained in understanding the brain, TBI, and the chronic effects of the condition. Coupled with the task of finding trained staff is the issue of keeping this trained staff content with salaries that are below current market rates. Once trained, these employees are often headhunted away by hospital or rehabilitation organizations.

Another challenge is ensuring that staff of TBI community integration organizations have access to professional development resources. While all the executive directors supported and valued professional development as important to their organization, they are faced with a very real issue of constrained budgets. Several of the CATBI sites mentioned that the medical community may be more open to working with CATBI sites if these organizations pursue recognizable certification programs for staff. One such certification is the Certified Brain Injury Specialist (CBIS). This is a program that covers TBI and diagnostic imaging as well as medical, physical, cognitive, neurobehavioral, and psychosocial consequences of a traumatic brain injury. CBIS certification includes studying TBI in pediatrics and adolescents, as well as living/aging with a brain injury. The CBIS credential course is taught online, done at a student’s own pace. Usually it takes 9-12 months to complete. A high school diploma is required to be eligible to

apply. It is seen as an important credential for TBI staff to obtain, whether the employee be directly in program services or a non-program function. Currently only two of the CATBI organizations have CBIS-credentialed staff, mostly because of budget constraints (CBIS is roughly \$300/applicant). Those that do have CBIS-trained employees highly value what these staff members bring to the table. As one executive director of an Independent Living Center commented:

“This past year I put a lot of money in to getting my staff up to speed – because I really do believe in professional development – I have only two staff that work in my TBI program, but I paid for 7 staff to get trained to be CBIS. When my board asked me why I trained 7 when I only had 2 working on TBI, I said that I don’t know who is going to stay – I need backup. And it’s expensive - \$300 per person – but I think it is a good investment. I have said that to other sites – I think in order to market ourselves well, this is one of the important steps.”

Finding professional licensed staff such as counselors or nurses is difficult for CATBI members because these individuals are most likely trained in the medical and not the psychosocial model of care, and they may not be open to being in a non-medical community-based setting. One CATBI member commented:

“They get all willy-nilly on you when you bring them in to something like what we do. It’s the vocabulary, but it’s also because they view our model as perhaps not as structured as the medical environment. I would say we are as particular about our services, but the medical establishment does not take the time to see this, so often we suffer in finding these medically-trained health professionals.”

v) *Organizational Structure – Community Integration vs. Medical Model*

The medical model’s perception of traumatic brain injury community integration looms large over the community integration sector. Community integration leaders perceive that their work may not be viewed as valuable as what is accomplished within the medical model. This sentiment of not being valued by the medical sector is a common theme among the CATBI members who are not hospital-based. These CATBI’s directors expressed a prevailing sentiment that to be accepted and respected by the medical community, TBI community integration

organizations must look like the medical model. Frustration is tangible when it comes to this perception of how the medical sector views the TBI post-acute community integration model. CATBI directors expressed the idea that the medical model has a narrow scope when it comes to providing physicians with tools to assist TBI survivors post-injury. Physicians would benefit from more TBI education, specifically TBI community integration. Post-rehab, physicians may only see a TBI survivor for 15 minutes twice a year, and then it's to write prescriptions. And when physicians are encouraged to refer a TBI consumer out into the community integration sphere, they resist.

“Doctors have their own issues with brain injury. So, they just medicate a TBI patient, give them seizure medication and send them home, remote, removed. We don't want that! At the very least, we want to keep people from regressing. That's the educational component the medical model and the medical field needs to embrace, because truthfully, they don't. They don't know what's possible and therefore they don't put it into their outcomes.”

Resistance to adopting the medical model is also seen as somewhat of a deterrent to the community integration sector's ability to successfully capture long-term, major funding:

“The whole conversation about the MediCal waiver would have meant that all of us would have had to become MediCal vendorized. And that would mean much more of a medical model environment – vocabulary, services, the need for licensed personnel - all of that. And I was like, we aren't ready for that – I don't have the infrastructure for that kind of system. So, it's almost like, we are still a demonstration site for the California legislature. We're stuck as still being a pilot project, 25 years on.”

b) Barriers: Program Services

i) Program Services – Community Integration vs. Supported Living

The definition of community integration versus that of supported living services is another perceived barrier to providing successful community integration. The executive directors of the three independent living centers all made references to delineating the difference between these two concepts, and the need to make sure staff is properly trained in both. While this

differentiation was not made by the non-independent living center CATBI sites, the ILCs were vocal in their opinion. One ILC respondent commented that:

“Somebody doing community reintegration is similar but different than someone who is doing supported living. To me, those are different positions that are inter-related but not the same – you know, you need dedicated staff with those skill sets for specific core services.”

c) Barriers: Program Structure

i) Program Structure – Model and System of Care

All seven CATBI sites are very cognizant of the fact that without a structured and standardized model of care, they are hampered in their efforts to grow TBI community integration across the State. One interviewee said:

“You know, we are still operating like different models: your model is different than our model, and our model is different than the hospital model. And I think that is one thing that is holding us back. But this is endemic in the psychosocial sector. We all may do good work, but we all come at it very differently. And that’s the issue. That’s what holds us back.”

Working as one unit while remaining independent organizations is seen as challenging. An executive director commented: *“...the thing we need to understand is, before we decide to come together or blend or come to an agreement, we need to understand how we are doing our work independently of one another. I don’t really know what others are doing.”*

Because of their different business structures (medical, rehabilitation, and psychosocial), the sites grapple with what a common model might look like. They all agree, however, that this is a critical and time-sensitive issue. CATBI members realize that while they don’t have to all be identical in their services, they will need to have a standard practice in place. The challenge is to develop and deliver a defined model of care that can be replicated throughout the State. One executive director responded:

“It shouldn’t be based on what tool you have – understood, you have an assessment, okay, and then understood you have an intervention model – and then all those can actually have variability as long as they are deemed to be appropriate for the TBI population. So, then we

don't get caught up too much in worrying about are we all doing it all the same, but is what we are doing accepted standard practice?"

ii) Program Structure – Outcome Metrics and Data System

While all sites concur metrics have become an important component to both program and funding success, not all CATBI members agree in applying the same measurement tools. This is most likely due to the issues of: qualified staffing needed to apply the tools; the varying types of program structures among the sites; and a perception that some of the measurement tools may be too 'lengthy' for repeated use. Several of the CATBI sites openly agree that standardization of measurements ultimately leads to more meaningful data, and some express frustration at the lack of consistency. When asked about what the other sites are doing in order to close the gap on metrics and data, one director remarked about these other CATBI members: *"Nothing has changed – they still don't get it that to be able to go for funding successfully; to be able to see progress in outcome measurement, we have to have one common standard for community integration. I just can't take it anymore."*

CATBI members expressed the lack consistent measurement of outcomes, they have missed out as a group in the past on potential federal funding. The executive director of one of the independent living centers CATBI member said:

"There are opportunities at the federal level that we haven't tapped. This State money we get – the DoR, everyone has good intentions, but it is really limited in scope. We are now a bigger group than when the State first funded us in 1989, but we still don't have what it takes to demonstrate our outcomes in order to get the attention of the ACL or federal funding. We don't have the data; we don't have one uniform model. We do have stories, but that doesn't cut it."

Another point stated was the lack of consistent data collection at the state government level was also a concern. One staff member of an independent living center noted that lack of data collection

“...at the state level and not necessarily at the Department of Rehabilitation level, but just a lack of data collection on behalf of all the state’s TBI service providers is a huge barrier, because without cohesive data, you can’t tell a story and you can’t prove why your services are making a difference, and you can’t prove how your clients are benefitting from your services and how, you know, hospitals and ERs are benefitting from lack of repeat visits. Yes, the lack of standardized data collection is a huge barrier.”

The challenge of having all sites agree to standardized metrics was illustrated with the group’s shared experience with BrainLink. Established by one of the CATBI sites, BrainLink was to be used as a place to gather data from all CATBI sites in order to assess trends and identify opportunities. The database was built and financially supported by 6 of the 7 CATBI sites, only to fall into disuse when sites felt it was too difficult to input data and pull reports.

Barriers: Statewide Issues

i) Overall TBI Awareness

All interviewees mentioned the challenge of addressing the lack of TBI awareness on the part of the public. They saw ‘public’ defined as both members of the lay population and the medical profession. As one of the executive directors of a non-medical facility noted, the lack of

“overall public and private awareness and education about TBI and ABI (acquired brain injury) is a huge barrier. That goes for people in the medical and behavioral health/social work fields as well. If people don’t understand what TBI is, if they don’t understand that it is a chronic disease, if you don’t understand TBI for the social, psychological, behavioral issues that can arise, then there’s just an overall lack of awareness and lack of appropriate care for a TBI community integration program. It’s sad, but people just don’t know what’s out there or what to ask for.”

One executive director of a psychosocial CATBI site stated that when she meets with medical personnel in her attempts to educate the sector:

“I say ‘if this were a heart attack, you automatically get a year of rehabilitation. What is this parsing between organs of the body? Literally, you are covered from the neck down!’ But you know, I get it – brain science is where cardiac science was 50 years ago, so people don’t know that there’s not a pat answer for how you solve this problem that no two brain injuries are the same, no two brains are the same. I think more that the problem is you can’t say what is going to work for you versus what’s going to work for me, the way you can with a heart attack – a certain group of people with a certain kind of heart attack, certain kind of valve problems are going to need X, Y and Z, and they get a year’s rehab if the heart attack is severe enough, with no

questions, no hassle. But the brain is considered – which baffles me – it’s most important organ of the body if you ask me – less than the heart for complexities.”

Another director suggested that making the concept of TBI relatable to the public would help the sector in both TBI awareness and funding success, believing that any financial barriers come from the fact that “... *people still do not understand the prevalence of TBI, and until they need our services, we in effect do not exist. They don’t value our services, but when they need our services, we become their best friend.*” This concept of valued credibility was mentioned numerous times, with one staff respondent noting that:

“We need to get education and awareness of TBI out into the whole community. Our relatability is what makes funding an obstacle, because people don’t value or don’t realize just how widespread TBI is. Other disease-related non-profits have it easier because they have easy concepts the public relates to. Kids and art – we get it; disabled children in wheelchairs, we see that this makes sense. It’s that branding awareness our sector needs to focus on and do the right way.”

ii) Community Support

All CATBI sites noted community support is key but acknowledged it can be challenging to engage the community. And while all the CATBI organizations agreed successful community support would come only through a unified presentation of the services available at CATBI member sites, the marketing concept of branding CATBI was only mentioned by one of the organizations as a key to that potential success.

iii) Advocacy

Advocacy for TBI community integration is a barrier at all levels – local, county, and State. Lack of funding, political contacts and marketing supplies was evident among all CATBI members to varying degrees. CATBI currently does not pay for lobbyists at the State level, and this is a topic of concern for the group. One staff member commented:

“We are good at programming, but the politics, not so much. Because, you know, none of us have a legislative type analyst that could be tracking or researching – I mean, just putting a list

together of local representatives, that's going to take somebody some time to do that, so although I have a community organizer, I can give some of this to them, but they work on local community efforts and initiatives not at the State level."

The CATBI sites, both individually and collectively, believe that to further their cause, they need to become unified and find "a face" of TBI to promote their work. As one director noted:

"We need a highly visible advocate! The reason why Texas has such better coverage and does rehabilitation better than we do is because they had a State senator whose daughter had a brain injury, and he went to bat and said it was unconscionable and that the state had to fix it. So Texas put together rehabilitation programs. Same with the states of Pennsylvania and New Jersey – they both have great programs. It all depends on who is fighting for you, you know?"

All members are cognizant of the barrier a lack of advocacy places on their work. As one non-medical CATBI director shared: *"This is what is hurting us. We are not strong in this – we need to shore that up, or we will continue to have these conversations every year."*

B. Opportunities

The staff of the CATBI sites perceived the above noted barriers as potential opportunities. All were hopeful that State stakeholders would work to overcome the barriers they had listed and enable the TBI community to come together and be supported for community integration services.

a) Opportunities: Organizational Structure

i) Organizational Structure - Overall Funding

Funding remains the top issue for all of the sites. Many see the possibility of working with a managed care organization as a way to alleviate the funding shortages all CATBI members face. One non-medical site director shared: *"I think an opportunity does lie in managed care. As much as that might be a barrier, it could be an opportunity for us if we were to play it right."* Another respondent noted the opportunity to partner with HMO organizations:

“I would love to see us – each of us – be partners with an HMO of some kind, like a Kaiser. This is a no brainer for Kaiser, because by helping to rehabilitate people you keep them from overusing services. Because they will come through our door when they’ve got nothing else to do all day. I see that happen with the person I take care of in my own life... I think if insurance companies are not going to pick up the slack, the HMOs could see this as a very reasonable solution to getting membership better to some degree.”

ii) Organizational Structure – MediCal Eligibility

While this remains a long shot for CATBI, members expressed support in an effort to gain funding through a MediCal waiver, similar to what other states have successfully used to fund their own TBI community integration programs. As one interviewee said,

“We have an opportunity with the California legislature saying this Department of Rehabilitation funding is a short-term fix that there is a strong need to fix this situation. This is an ongoing issue, I mean, as much as that can be a barrier it could be an opportunity as well. I think there is a mega-waiver concept that the Department of Health Care Services (DHCS) have been working on that would cover people with TBI. What if those same services that are available under the Developmental Disability (DD) waiver could be available for those with TBI?”

iii) Organizational Structure – Staffing

Staff training is another area where CATBI directors see an opportunity. One staff director, the only one to have her employees obtain the Certified Brain Injury Specialist (CBIS) certification noted

“For CBIS training, I tell my staff that when they pass the test – and it’s an 80% passing grade; I have had several staff members not pass the first time around – it’s hard – a lot of medical terms! But when they do pass, I make sure they all have CBIS on their email signatures and on their business cards. Because when you go online and you see how many CBIS are in California, they are for the most part all in hospitals. They are not in TBI community integration organizations. I think all seven sites of CATBI under the Department of Rehabilitation grant should all make CBIS certifications a requirement. And you have to renew it, so it’s ongoing professional development, which is excellent.”

iv) Organizational Structure – Community Integration vs. Medical Model

The idea that all CATBI members should agree to one common community integration model was also high on the list of opportunities, as they understand this could lead to better funding and expansion of services. They also expressed the desire with this model to keep

themselves as distinct from the medical model as they possibly could. They felt that by using evidence-based programming, CATBI would be able to come to an agreement on a model that would support the community integration sector while keeping themselves independent from the medical model. One director said:

“I think the group needs to have a collective conversation about how by having different models we’ve cornered ourselves to continue to look like demonstration projects and that’s why we are never going to have institutional funding, because organizations are still demonstrating what they can do and people are still unsure about it. That’s due to a number of factors: we all still do our services differently, and so we really need to have that conversation about agreeing to have this as a model – whatever those pieces may be but we are all going to be doing it the same way – and then what I have noticed is, what gets attention on programs is when it’s evidence-based. That’s where the TBI sites need to be – we need to have that kind of recognition and acceptance. I know for some sites evidence-based programming may be down the road, but I think we all need it now and not later.”

There is an understanding that the success of community integration services rests with those who are working in the sector. One director observed *“The opportunity is we have all of this to develop ourselves. We are the experts.”*

b) Opportunities: Program Services

i) Program Services – Supported Housing and Behavioral Health

One of the areas that is recognized as an unmet need for all sites is supported housing. Currently CATBI members either assist through case management or work with a community partner in finding housing for TBI survivors. But all CATBI members acknowledge that not enough is being done for survivors in this area. As one director said:

“One of the needs none of us are really addressing as much as we could is supported housing/supervised housing. This is something the disability sector does and it would be something where I think our consumers would do well. But it is further down on our lists because so many other issues need our attention and funding.”

Behavioral Health services are an item of great discussion for all CATBI sites and is seen as valuable. The same director who commented on supported housing also remarked

“I think there is a good segment of the population that would benefit so much from behavioral management-type services. You know, those who are a little bit more impaired that start becoming agitated or verbally abusive or physically acting out that benefit from a more comprehensive behavioral health program. This could potentially alleviate a lot of possible emotional wear and tear for our consumers.”

c) Opportunities: Statewide Issues

i) Statewide Issues - Community Support

Community support is seen as an opportunity, especially the cooperation of agencies together in assisting TBI survivors to successfully reintegrate back into their lives. While CATBI members work with community partners within their specific geographic locations to support TBI survivors, many sites expressed the idea that more could be done in collaborative outreach. This includes working with other organizations by the sharing of data:

“It would really be important to be able to talk with the hospital and have access to the same records for one of our members that the hospital has – that way, we can keep tabs on someone who may present at the emergency room. We can help decrease hospital usage of our consumers if we have shared data. But because we are not a medical facility, we aren’t allowed to see medical records. A lot of rehospitalization could be stopped if organizations shared common data. TBI can go in a million different directions in what someone ends up dealing with. The reverse – not facilitating cross overs – makes no sense.”

ii) Statewide Issues - Advocacy

The TBI community integration sector traditionally had an unmet need for statewide advocacy. Most of CATBI’s members may converse with their local electeds, but there is not as yet a concerted effort for lobbying at the State or national level for California’s community integration sector. Directors at CATBI are aware of this opportunity and hope to coalesce around this issue by collectively reaching out to the Governor’s office during the new legislative session. Many of the CATBI members see the changing of the Governor as an opportunity to get in front of the new administration and advocate for funds and awareness.

7. CATBI Sustainability for the Future

The question of what would constitute sustainability brought a myriad of replies from CATBI executive directors and staff. The responses centered on six areas: funding, CATBI, assessments, other models, population health and continuum of TBI care.

Sustainability is a constant topic of conversation for all CATBI members. Foremost on the minds of leadership is a sustainable standard funding model which would allow all sites to expand. Many of the respondents spoke of funding fatigue with the State entities, with so much time and effort repeating itself every four years for the State granting application. As one director stated, *“We go off the cliff every four years.”* Sustainable funding options include HMO, a reimbursable model, new state and federal funding sources.

The idea of merging CATBI’s services within an HMO was a topic several directors supported: *“Well, smaller HMOs would be the sustainable path for us. I don’t believe State funding and relying on it is wise. It’s like ‘Oh wow, this is a found gift,’ but it’s not something we should expect. I just don’t see that that’s going to be our saving grace – it’s always subject to being cut.”* A reimbursable model was also discussed. Even though healthcare is moving away from a fee-for-service model, one CATBI respondent still saw this as an avenue for funding:

“Sustainability to me is there has to be a transaction fee-based organization that believes that brain injury rehabilitation/community integration for the long term is beneficial and cost-effective. And it has to be on a transactional basis. That’s the only sustainable way – they come through the door and that day we get paid by an insurance company for day programming, or we get paid for the licensed services, or whatever they may need.”

Looking for new government funding is another focus for sustainability. Several of the directors of the independent living centers (ILCs) with TBI programs suggested a structure similar to that of the ILCs might open CATBI up to more government funding. As one ILC director replied:

“We get federal and we get State, but it really begins at the federal level. ILCs have two contracts that are directly from the federal, and then the money that the Department of Rehabilitation has for ILCs also comes from federal (Administration for Community Living) but goes through the State down to the ILCs. That’s really our biggest source of funding. CATBI needs to begin cultivating and networking contacts at the federal level like the ILCs. We need to after direct federal funding, and I don’t think we wait for funding at the State level. I think we can make CATBI’s case with the Administration for Community Living.”

Returning to the concept of pushing a statewide MediCal waiver was also discussed.

Several directors continue to support this option, as they feel the initial effort was not completed and deserves another look:

“It’s going to be something more like a TBI waiver, which has been talked about and was actually in the previous State legislation – that was the long-term plan, anyway – it has not materialized. So I don’t know if the plan is dead, or if we’re looking at some type of new tax or fee assessment that’s more sustainable than what we have right now. I really want to know what other states are doing. There are certainly other states that have more robust brain injury programs than California does. We have hardly anything. How were other states able to grow theirs and California is so far behind?”

8. The Future of Community Integration Sector

Responders all seemed concerned with the options facing the community integration sector of the TBI continuum of care. Finance remained a key issue, with many expressing the hope that viable options could be found in the coming years. *“The finance of it really doesn’t bode well for us.”* Funding and the corresponding expansion of services were high on the list of what interviewees would like to see in the future:

“I would say in five years’ time I hope we will identify a stable funding source; I hope we can expand the continuum of services that we have for more supportive living type services. I hope we can expand the vocational services – the more one-on-one training to work around some of the challenges of brain injury. I think our visibility will be much more – I think that’s coming already. I hope the stigma of brain injury is less, because not a lot of people willingly stand up and say ‘Hey, I have a TBI.’ But I also hope people realize the capabilities that TBI survivors still have after a brain injury. I think we should also have more opportunities for day treatment, whether it be activity-based or independent living skills in a day treatment setting.”

Finding a long-term financial partner that might replace the California Department of Rehabilitation (DoR) as a primary funder was a central topic for the future of community

integration. This concept of finding a long-term stable partner seems to circle back to the challenge of finding a method of making CATBI organizations into a model recognized and funded under a Federal program such as MediCare or MediCal. Barring that, one opportunity for Federal funding that several CATBI members expressed interest in was the Administration for Community Living (ACL). A part of the US Department of Health and Human Services, the ACL supports programs enabling older adults and the disabled to live independent lives within the communities of their choosing. As one CATBI executive explained:

“We are State funded, but we need to get in front of the ACL because we need federal money. This State money, everybody has good intentions, but it’s really limited in scope. The ACL is a bigger externality we don’t have what it takes to demonstrate in order to fight for that ACL federal funding. We don’t have the data, we don’t have a uniform model; we have stories, but that doesn’t cut it.”

Another concern for community integration providers is the very real issue of State funders deciding to lump TBI services in with other disabilities for funding, thereby increasing the grantees but lessening the amount of funding to go around. Because of this, many respondents continued to return to the idea of insurance.

“I can see legislators trying to do this – they decide to lump our services in with Dementia and Alzheimers to try to cover more – but I would be worried we will get less. I would worry that they don’t understand brain injury well enough, and they think it’s one in the same with Alzheimers and/or Dementia. We need to maintain our independence because it’s a very unique thing that we do, and unfortunately, we can’t just be combined with other things, or our mission will be lost. If they start grouping us together, we’re hosed. That’s a big threat to the sustainability and the future. We really need to be mindful of this and not let that happen.”

For the community integration sector overall and CATBI specifically, the need for a standard model of care services was paramount. All CATBI directors understand the importance of this but have yet to find a model all agree on. One executive director stated:

“I think the group needs to have a collective conversation about models. Without a model, we’ve cornered ourselves to be relegated to remain as demonstration projects, and that’s why we are never going to have institutional funding, because organizations are still demonstrating what they can do, and people are still unsure about us.”

The need for a more cohesive TBI continuum of care was also noted by many of the CATBI interviewees, with a focus on the use of ‘whole person care’ at the core of the continuum. Several directors pointed to the core concepts of population health and the overall public health model as possible frameworks to build upon for a more consistent delivery of services. For these directors, this doesn’t just mean focusing on care provided in the emergency room to rehabilitation to post-rehab, but also the actual social, physical and emotional structure that needs to be built for patients to thrive.

Finally, all the internal stakeholder responses shared during the interviews indicate that every member of CATBI is on the same page when it comes to considering some sort of model for TBI community integration care. These discussions also helped underscore the value of a collaborative perspective in order to expand their services in support of the TBI community throughout California.

PART 2: External Stakeholders Interview Results

A. External Stakeholders in the TBI Continuum of Care

The interviewees in this section were comprised of external stakeholders who represented organizations outside of CATBI that address aspects of the TBI continuum of care, encompassing medical, rehabilitation, non-profit and governmental sectors. These stakeholders were chosen in order to bring a broader world view to the discussion.

1. Stakeholder Background

Included were leaders of non-profits at either the State or National levels, academics credited with the creation of well-known evidence-based outcome measures used in the sector and beyond, government officials from State and local offices, behavioral wellness expert, medical

personnel that included physiatrists and neurologists, and advocates who work at State and National levels in the furthering of community integration.

While many of the responses of these individuals mirrored those of the CATBI respondents, the external interviewees were able to bring a perspective from a level those in CATBI group could not, just by virtue of where they were in the continuum of care.

2. Definition of Community Integration

This question elicited a lot of discussion among external stakeholders, specifically around whether one common definition could exist. This reflected the same experience within the CATBI group when asked to define community integration. One brain injury medical specialist commented on the difficulty of a singular definition:

“I sit on the community integration committee for the ACRM (American Congress of Rehabilitative Medicine) and agreeing on a clear CI definition is the million-dollar question! We have done literature searches, all that kind of stuff. To me, community integration is getting somebody back into the community so they have a meaningful medical, a vocational IADL experience (Instrumental Activities of Daily Living), you know, so they can be as close to home as possible, and their family be part of their lives or they have a circle of friends. But that just never happens.”

Definitions provided by external stakeholders ranged from community integration being viewed as the final stage of rehabilitation to a broader classification that every opportunity within a TBI survivor’s life in the community is meant for integration. For some external stakeholders, a better definition hinged on the belief that TBI should be formally recognized as a chronic life condition, thus encouraging community integration organizations to work in tandem with the medical sector to enhance quality of life for the TBI survivor. These respondents saw community integration as a facilitator of the medical components by providing opportunities for ongoing exercise, nutritional counseling, management of sleep disturbances, support of any chronic medical problems until the TBI survivor reaches a maximal medical improvement stage.

Focusing on the whole person concept and the belief that TBI services emphasis should be less on an individual's impairment and more on the daily outcomes of their life and the autonomy these bring came across from several respondents currently working in the psycho-social field. For these respondents, the presence of case management is a key component of the definition of community integration. Finally, while respondents are aware of the problem of duplicative services provided across the TBI continuum of care, no specific solution for ameliorating this situation could be provided by any of the interviewees.

3. Community Partners in Care

External respondents viewed this question as an opportunity to expand on the idea of a holistic system of brain injury care to include more direct partners in non-healthcare fields, pushing for an active major role for government agencies in supporting this sector. This would include both state and federal agencies and focused on the issue of successful funding through these entities. External stakeholders were vocal about the need for a stronger relationship between the medical component of TBI care with the community integration sector. They stressed that this should be paramount to CATBI in their efforts of treating TBI as a chronic illness. Many of the respondents also shared the belief that HMOs should be first-line partners with TBI community integration organizations. Because HMOs would be the MediCal providers, having community integration organizations deliver a part of the care and be reimbursed financially for this care by the HMOs was considered innovative and a possible new way of sustainability. This direct collaboration with HMOs would also be an opportunity to educate primary care physicians in the realities of TBI chronic care management.

**Table 4: Community Stakeholders
(External Stakeholder List)**

Community Stakeholder
Hospital
Rehabilitation Hospital
Trauma Hospital
Behavioral Wellness
Primary Care (PCMH)
Ambulatory Care Clinics
Adult Day Health Care (ADHC)
Community-based Adult Services (CBAS)
Independent Living Centers (ILC)

As with the CATBI members, many of the external group’s answers focused directly on the role government should be playing in supporting the community integration sphere. These external respondents had the perception that government (whether at the state or federal level) was not participating enough in making sure community integration was a success. This was especially true of disability support, employment and the concept of self-sufficiency of the TBI survivor. Several of the interviewees expressed a concern that often government agencies, in their efforts to find employment for TBI survivors, often place underestimate their capacity for development, and that these agencies may have their best intentions, but would benefit from a more in-depth understanding of the TBI condition. One stakeholder directly suggested as much:

“We all see that self-sufficient thing differently; in the independent living world it’s you making your own decisions, it’s being as independent as you can be; it’s not ‘I live all by myself, I have a fulltime job, I cook my own meals.’ You know, you may be making your own decisions, but it’s these government organizations that really underestimate individuals with TBI, with developmental disabilities, with learning disabilities. From what I have seen, these government organizations place these individuals in jobs that are way under what they could do. So, I don’t like that, and I like the idea of having them be on this list because it not only benefits the consumer most importantly, but it would also benefit on the educational level those government organizations and prove them wrong.”

Others saw the acute care and rehabilitation hospital stakeholders as key players in the community integration efforts for improving the quality of life. Many did not share the same concerns as those of CATBI members in terms of how the medical sector viewed the efforts of those in the community integration sector. These stakeholders saw the role of the hospitals in terms of bringing awareness to the community integration model and strengthening its legitimacy. They also see the acute and rehabilitation hospitals and their physicians as critical to the wellness model and to the chronic illness management model for quality of life issues.

Both the CATBI members and the external stakeholders agreed that a holistic system of TBI care would be optimal for all parties. One of the external respondents commented that while all the partners listed were important, many of these partners are focused just on their own narrow area of service, and do not look at the whole continuum of care:

“... not all seem to understand that it takes a holistic system of care to successfully treat TBI. For the managed-care plans/HMOs, who would be the MediCal provider to deliver care? They should look into their State mandates and see where this resides. This is an innovation that needs to happen; it is a systemic change issue that needs to be addressed. Transitional services must meet ADA requirements in the least restrictive environment. How do we tap into this? Independent Living Centers (ILCs) are now trying to tap into HMOs. We shouldn't recreate the wheel in the TBI space, as ILCs can help. Again, this is a systemic change which needs to happen.”

Interestingly, only one stakeholder from either group mentioned the importance of including physiatrists in the continuum of TBI care. The lack of mention from other stakeholders regarding the role physiatrists play in supporting TBI survivors may be due to scarcity of this type of physician in geographic locations in California:

“I would add as a stakeholder a physiatrist rather than a primary care physician or neurologist. Because neither primary care nor a neurologist know about brain injury, but a physiatrist is a specialized physician who does know brain injury. They are really rehabilitation physicians. And they tend to be a rare animal.”

While the concept of community outreach is valued by this group of external stakeholders as much as that of the CATBI members, this group of respondents took the concept a bit further, encompassing not only the medical and allied health community collaborators, but also building business alliances. Stakeholders encouraged community integration organizations to promote a more structured outreach to the local community to engage employers, social workers, and leisure resources to support TBI survivors. As one interviewee noted: *“It needs to be all of the community, not just some of the community.”* Other external stakeholders built upon this idea of total community support by suggesting the stronger use of marketing and the creation of a CATBI ‘brand’ as a means to enhance success. Finally, these respondents encouraged CATBI members to go beyond seeking local support and explore options for broader support:

“I would suggest if you were to take a 30,000-foot perspective, you would also need to add statewide legislative awareness a support and governmental awareness and support. The legislative side and the more bureaucratic side, if you will. Because we have to look at where the dollars flow from, and #1 that’s going to be government, as I just mentioned. The other players would need to be the insurance companies, because that’s another source of big dollars.”

4. Educational Resources

The external community stakeholders were in support of a structured educational resources component within community integration services focusing on participants and caregivers. Noting that caregivers were a group that can get easily overwhelmed and frustrated with the new responsibilities of TBI care, External stakeholders pushed for more services around this population.

In addition, this group of external stakeholders was very vocal about delivering more community education as a means of increasing awareness of TBI survivors. The thought behind this being the more community acceptance of TBI, the less the survivor relies on the community integration organization. When that happens, true community integration can occur.

External stakeholders were also concerned about sustainability. Many of these respondents had experienced the challenges of sustaining a TBI program of some type. One community stakeholder from a large academic medical environment mentioned a failed attempt at an academic institution he had managed:

“One of the things we did and I have run now for several years – although we’ve stopped it now because of the issue of sustainability – is a program we call the ‘Collaborative Experience Project’ and it was modeled in some ways along the line of an adult education center. The problem that we ran into there is that we were kind of donating therapist resources – we had a special educator create that program and several therapists donated their time to that, but it became difficult with traditional productivity demands. And then the problem you are finding – getting external funding for that. We tried going through our foundation; that was difficult to get foundation money; we tried putting it on a low-cost, pay-as-you-go model, which obviously has its own difficulties. But that’s where we ended up, trying to figure out how do you sustain it. Even in terms of getting a development grant, then you still have to face the issues of sustainability.”

5. Outcome Assessments

The external community stakeholders were very vocal about the necessity of having both standardized qualitative and quantitative assessment measures in place, with examples of qualitative measures being the QOLIBRI or MPAI-4, and quantitative measures including tools such as neuropsychological testing. One leader of a national brain injury non-profit underlined this importance of having both assessments available for survivors and caregivers:

“I believe that there is a symbiotic relationship between quantitative and qualitative outcomes. Both need to be assessed in order to have the complete picture of recovery. Have a consumer take the QOLIBRI and the MPAI-4 and then look at any schisms. These two measures could be a tool to ultimately identify a model. You need to combine both in order to see progressive outcomes for both TBI survivor and caregiver. The frequency of measurement should be baseline, 6-month, 12-month, etc.”

And while several respondents highlighted the need for researching other types of outcome tools (including medical, mental health, psychosocial, functional status, employment, adaptive equipment and housing) in order to obtain a valid data set, no one standard measurement was selected by those interviewed.

Several of the external stakeholders were unfamiliar with the QOLIBRI, but they were very supportive of the use of a tool measuring qualitative results, such as quality of life. Most interviewed were familiar with the MPAI-4 and how it can be used with both TBI survivors and caregivers for measuring improvement. Other external community stakeholders suggested additional tools beyond the MPAI-4, QOLIBRI and CIQ, but admitted some of these instruments may be too clinical in origin to be applicable in the current community integration sphere. One interviewee shared:

“I agree that the MPAI is a really great tool for both post-acute settings and community-based settings as well. Another awesome resource is the COMBI (Center for Outcome Measurement in Brain Injury) and then NINDS (National Institute of Neurological Disorders and Stroke; there are some community-based outcome measures that are recommended through them, and then TRACK-TBI (Transforming Research and Clinical Knowledge in Traumatic Brain Injury) and TED (TBI Endpoints Development Initiative) which are two large research consortiums headed at UCSF. One of the key components is the identification of appropriate outcome measures and endpoint developments of TBI.”

Sticking to a frequency of assessment was seen as important. An allied health professional who is a board member of one of the CATBI sites remarked:

“It’s really essential to have a baseline, then at 6 months, 12 months, 18 months and continue going because many of our assessment tools are not going to be valid for a single individual because the reliability varies – you know, how they are feeling that day – but if you repeat this over a period of time, you do see a pattern...which enables a TBI community integration organization to tailor programming...”

Presented with the three measurements currently in use within CATBI to choose from, external stakeholders had preferences for certain tools. Most ruled out the CIQ as outdated and not a measurement that captured incremental psycho-social improvements within a TBI survivor. One External respondent who heads a national TBI non-profit commented:

“I have a better feeling about the QOLIBRI than the CIQ, which I think is antiquated and really pretty gross and is covered by the Mayo-Portland. I think the QOLIBRI is good – let me put it this way: there is another dimension to health besides what’s covered by the Mayo-Portland, and it has more to do with a person’s satisfaction with their life, and you know, the QOLIBRI may get at that; there are also other measures, shorter measures; for example, there is something called

the Satisfaction With Life Scale that is very brief and may really hit it on the head. It basically asks how satisfied are you with your life. In fact, there is one measurement expert at the Mayo Clinic, a biostatistician who is kind of high on the one-item quality of life scales.”

The challenge of multiple tools being utilized in lieu of one standard assessment across the TBI psycho-social sector is evident within the external respondents themselves. The executive director of a State-level non-profit working with adult day care services noted that quality of life assessments are what they value, but that there seems to be as many tools as there are organizations using them: *“Getting to a point where we could all be using a set of common evidence-based tools would be great.”*

6. Barriers and Opportunities

A. Barriers

Interviewees provided diverse ideas as to what they individually identified as barriers to success for TBI community integration programming. Without giving them specific areas to discuss, responses organically grouped under four titles, similar to those voiced by CATBI interviewees: organizational structure, program structure, program services, and macro-level topics (i.e. Department of Rehabilitation, state and federal government, society, and local communities).

a) Organizational Structure

i) Organizational Structure – Overall Funding

As with the CATBI interviewees, funding was a key concept that the External group focused on extensively. Like those in the CATBI cohort, for these individuals one of the barriers to the success of community integration was “Money, money, and money.” A lot of discussion focused on the value of what community integration offers those individuals with a disability, and how that is perceived by the population at large. One interviewee commented: *“Funding.*

That's a big barrier. All this does require services and personnel, and that requires money – and where is all that coming from? And, you know, I don't think there is enough funding in our society or that our society puts enough value on this or puts the value on it that they should."

External stakeholders who were familiar with past efforts at the State level to fund CATBI were perplexed by the fact so little is known by both CATBI sites and the community as to how funding is provided to the TBI program, even after all these years. As one external respondent commented, this lack of knowledge is a detriment to TBI services overall and has led to confusion when searching out new sources for funding by CATBI sites:

"It always bugged me that people thought the DoR funding came from the seatbelt tax. It comes from the State Penalty Fund, so it is not tied to the seatbelt tax legislation. The seatbelt tax came into being around the same time these projects were formed, so people linked the TBI initiative with seatbelt monies, which it wasn't. It's not like every time someone gets a seatbelt fine that we get a certain percentage of it – this is what happens in Florida, where every time someone registers a boat \$1 goes directly to their TBI fund for every boat or motorcycle that is registered. But for us, it is the State Penalty Fund, and we just get 0.66% of the entire State Penalty Fund – it's not just seatbelt dollars. That may sound like a lot, but the California State Penalty Fund is declining and has been for a while."

Several respondents shared a perspective that while overall policy may have shifted towards community and person-centered initiatives, funding streams are still medically-driven. There is a belief a bias remains towards medical and institutionalized care rather than for community-based programming.

"It just boggles my mind that there isn't more recognition. And while there is strong funding for research into TBI, there is little for the next steps after injury and rehab. It's really a denial on the part of our government. You just can't fund the medical research portion. I mean, research is incredible, but you've got this huge growing number of people who need services and good quality of life now today. This includes participants, families and caregivers. And the impact of not doing anything because of not having funding is huge."

ii) Organizational Structure – MediCal Eligibility

MediCal is an important topic for the internal CATBI respondents and the external interviewees alike, with many of the members of each group cognizant of the challenges existing

in obtaining these funding sources. The difference between the two cohorts seems to be several external stakeholders wondering why CATBI members haven't availed themselves of this funding earlier, and CATBI members having experienced frustration first hand at not being able to obtain MediCal eligibility. The external respondents also commented that psycho-social providers like CATBI are seen "as orphans" and may need to shift to a mental health funding source in order to achieve MediCal success. One External responder, an executive manager of a large hospital system, noted the dearth of continuity for TBI care across the community integration spectrum. This, coupled with a lack of understanding in how MediCal works, hobbles community integration providers and leads to incomplete care. Another external stakeholder from a state independent living center organization agreed with this assessment, focusing on the challenges community integration entities face when trying to educate themselves on the MediCal certification process, thereby opening up MediCal as a viable funding source:

"We need access to transitional/reintegration modalities to help the integration process, but many organizations just don't know how to access the Medi-Medi streams of funding. State and Federal laws may open up a lot of what can be done, but without the funding, what's the use? We don't have the funding to do it! Access is what we need, but I am not sure how to do this. Maybe not necessarily physicians, but allied health professionals should be accessible. Without this component, certification is impossible."

iii) Organizational Structure - Staffing

Finding, keeping and paying qualified clinicians and trained staff within the sphere of community integration is a topic of concern for external stakeholders as much as it is for CATBI members. Lack of funding and the competition with better-paying local healthcare systems for the workforce and possible ensuing turnover are worries that can affect the quality of services:

"Adequate staffing is a barrier. Forgive me for being blunt but what does that come down to? That comes down to money. If you can hire the people who are effective at what they do, whether its people who are running support groups or social workers or whomever it is; if you can get them paid appropriately, then you're going to all of a sudden come up with this team that's incredibly effective and ultimately serving the mission of the organization."

iv) Organizational Structure – Community Integration vs. Medical Model

The external stakeholder cohort is aware of the difficulties faced by the community integration model's efforts to achieve credibility vis-a-vis the medical model, and how this disadvantage right from the beginning negatively affects funding opportunities and long-term sustainability. One solution recommended by the external stakeholders to improve this situation would be to educate the consumer, caregivers and physicians in the distinctions between the different sectors of TBI care. It was felt that this opportunity to use education would narrow the credibility gap between community integration and the medical model.

b) Program Services

i. Program Services – Case Management

The perceived stigma attached to disability (including brain injury) and the stress accompanying this construct was an important topic for External stakeholders. Many respondents directly attributed the level of success of community integration services with the importance of good case management. The continuity and length of support a TBI survivor receives through case management services is seen as a major factor in the ultimate ability for a TBI survivor to successfully participate in the community (whatever that level of integration may be). The concept of viewing TBI as a chronic disease state with the corresponding lifetime case management is viewed by external stakeholders as important. The majority of both external and CATBI interviewees agreed that TBI should be considered chronic for the purposes of continuity in community integration services, and to not do so would be a detriment to all concerned. One executive of a regional hospital system commented: *“I think that one of the key challenging elements is the longevity to it. You cannot go into this population and just sporadically give them services.”*

As with several of the interviewed CATBI executives, external stakeholders shared the idea that TBI survivors should be eligible for case management and the service programming connected with this from the Regional Centers model in California:

“In my mind, TBI survivors should be eligible for regional center programs. TBI is a chronic condition. They need those lifetime supports; they need that supported employment and yet they don’t qualify for supported employment. They lump TBI survivors in with developmental disabilities for some things, but not for this because it’s too expensive. And one of the requirements to be at a regional center is that the disability had to be present at birth. And that shouldn’t be! At first glance, a TBI survivor has a lot of similarities to a person with developmental disabilities as far as them needing support to be able to function. So they should be looked at as chronic, with case management throughout their lives and be eligible for programs through the regional center.”

c) Program Structure

i) Program Structure – Outcome Metrics and Data System

External stakeholders stress the importance of metrics and the opportunity that is the concept of a standardized data system. Many of the External respondents agree a commitment to evidence-based data is and will remain a key component for future success and without this the community integration sites will suffer in their legitimacy, their funding and their ability to support their TBI consumers. From the perspective of respondents evaluating the effectiveness of services for TBI survivors, outcomes will justify funding requests, which is seen as an important step towards ultimate sustainability. The External stakeholders are cognizant of the resistance present in psycho-social organizations to the implementation of evidence-based tools:

“It’s hard for people in the psycho-social arena to be open to adopting evidence-based tools across the board. You would think they would want to compare apples to apples or provide the best level of care possible, but unfortunately, people are very hesitant because they are worried that someone is going to compare them to someone else. So it’s breaking down those barriers so that everyone learns to play in the sandbox.”

d) Statewide Issues

i) Overall TBI Awareness

The reality that brain injury diagnoses are often lumped with other disabilities in the public's perception remains a concern for the external stakeholders as it was for CATBI respondents. External interviewees view this as a barrier because the unique needs of TBI survivors may be lost among all the other disability groups searching for recognition and funding. This is especially true when TBI is viewed as an equivalent to intellectual and developmental disabilities. TBI organizations and external stakeholders expressed respect for how these two larger disability groups are so successful in promoting awareness and finding funding. But there is also a sense that smaller disability groups like TBI might lose out in the struggle for funding. As one external stakeholder shared:

"I feel very bad about the competitive atmosphere among disability groups. And this is true even within a disability sector – for example, we have two national brain injury organizations (Brain Injury Association of America and North American Brain Injury Society) which is ridiculous – I know good people in both of them. They are all decent people - there's nothing wrong with either organization; it's not like there are good guys and bad guys here. But I just wonder how this happened. It waters down the message and the concept of TBI awareness in the overall community."

The fact that many people in the continuum of care and within the public sphere may have not adapted their view of TBI with the changing times is also seen an obstacle to TBI public awareness. Many External responders noted the disconnect between funders and the community integration sector. A hospital executive in the external stakeholder group commented:

"It's this whole system and it's very difficult – it's almost like a totem pole, if you think about it, and organizations like those in CATBI are on the bottom of the totem pole. And then you've got these funders way up at the top and they're looking for 'Oh, I'm going to feel so much better about myself if I give to the most needy, sad, dying person... I think that's a problem – a huge barrier."

B. Opportunities

a) Organizational Structure

i) Organizational Structure – Staffing

For staffing, external stakeholders return to the need for education as an opportunity, this time for the workforce, including actual experiences with those who have TBI in order to learn more about the diagnosis and how a chronic disease is not necessarily a harbinger of isolation and failure to integrate.

ii) Organizational Structure – Community Integration vs. Medical Model

For the external stakeholder group, it is evident that the large important funding so critical to the sustainability of a sector remains within the purview of the medical model. A common vocabulary is seen as the next solid step towards linking the medical sector with the psycho-social providers in order to ultimately legitimize the community integration services:

“It’s more tailoring your language to the audience – so if you are speaking with the medical community, you’re going to have to use their language so they get it. If you’re talking to a community group, they would probably understand ‘standard of care’ – there may be another way to say it, but the funding is still the medical model. Unfortunately, that’s where the big bucks still live... So we just have to figure out a way to tap into that so it makes sense for everybody – we all should be at the table.”

b) Program Services

i) Program Services – Supported Housing and Behavioral Health

In terms of program services, many of the external stakeholders, especially those who are familiar with the specifics of community integration program services, see two areas in need of more focus and funding: an expansion of supported housing, and a more integrated behavioral health component. For this cohort, supported housing would include all of the items important to helping individual TBI survivors successfully find and keep housing, including the availability of

transportation and the collaboration between cities and counties to make this easier to accomplish.

c) *Statewide Issues*

i) *Statewide Issues - Community Support*

Forming community partnerships across the state is a topic both CATBI and external stakeholder cohorts discussed at length. While both groups acknowledge the challenge collaboration poses at local and state levels, the external respondents expressed strong opinions about this as an avenue towards creating sustainability. Finding a way to build relationships in order to produce win-win alliances within the healthcare sector is seen as the biggest opportunity. The effort to obtain available healthcare dollars to create these collaborations as a means to eventually garner larger funding is a common theme expressed by external respondents. But it is also viewed as a challenge, as the idea of sharing resources remains a contentious idea for some within the different TBI sectors, especially community integration services where resources are already spread very thin.

The idea of a “multi-pronged” approach to community support emerged often in external stakeholder interviews. Many of these individuals have been working within their own professional contexts to further this idea. The concept of creating networks that can be expanded beyond the local levels was advocated by stakeholders as an opportunity to educate community and legislators to the needs of the TBI population. The current president of a state-level brain injury advocacy non-profit underscored the importance of network creation:

“From my limited perspective, it’s really about cross-pollination of all the community-based groups with the statewide groups and the national groups and being able to develop not only programs but, in particular, a legislative approach that is going to be able to translate into political muscle. Because ultimately that’s going to be one of the big targets, not only for us, but it’s got to be one of the big targets for anybody working with the brain injured community, because without political strength and political backing, we’re not going to get anywhere. It’s

going to be an even worse uphill battle dealing with insurance companies, dealing with public agencies, so as we develop that cohesion that's going allow us to develop essentially political/legislative backing, I think we're going to in the longer term be able to get more support that we need. Building a network."

d) Continuum of Care

The External interviewees spoke in-depth about the TBI continuum of care, the model conceptualizing TBI as a chronic disease, and what this means to TBI community integration organizations and the consumers supported by these entities. Communication was considered key to keeping the continuum of care viable and to improving the care system, but this group was unsure as to the specific methods which would ensure this would happen. Collaborating with MediCal partners is also seen as an important part of the continued success of the TBI care system, and that all parties should work together to make this happen.

7. OTHER SUGGESTED MODELS

The External stakeholders were interested in sharing other models of care in the hopes that TBI community integration organizations would work towards creating a uniform type of care incorporating many broader aspects of services. No particular model was chosen by the majority of respondents. This response highlights the challenges within this sector as to standardization. One idea is that TBI is a chronic disease, and community integration services should be built to reflect this. All external stakeholders interviewed hold the view that the formal acknowledgement of this would be a critical step forward for all players throughout the continuum of care. Another suggestion was to follow the United Nation's International Classification of Functioning, Disability and Health (ICF) applications, using this as a template for creating service provisions at the individual level, institutional level, and social level. Other External interviewees spoke to the value of the independent living center model, with its acceptance of various disabilities and its strength in collaboration with other organizations to

treat the whole person. As with the CATBI group, the idea of TBI survivors being allowed in the Regional Center model was also an idea that had substantial support among the external stakeholder group.

The concept of a completely integrated TBI continuum of care model was also discussed as the goal to strive for in the sector. Through a public health approach using communication and education, an integrated system would reflect the medical community, primary care, specialists, hospitals, rehab centers, long-term facilities, and community integration all in one, thereby building a community mission statement around the collaborations.

8. Sustainability in the Future

The responses from external stakeholders on what sustainability might look like for community integration organizations reflect ideas similar to those shared by CATBI. From funding to CATBI's structure, to evidence-based assessments to incorporating the precepts of population health to advancing collaborations within the TBI continuum of care, the external respondents' answers often mirrored those of the CATBI interviewees. And as with the CATBI group, this cohort has a definite sense of urgency in finding feasible solutions to the current challenges facing community integration, seeing time as crucial. Whether the answer resides in finding a new funding stream, accessing a current government funding source, or finding a champion, the external group respondents suggested solutions must align with a goal of 2025.

“Sustainability - we need to get there! We need a 2025 vision of what this would look like, and what we will be doing to make it a reality. When we figure that out, then we work backward to get to baseline. But give us a plan!! We are in crisis mode – we don't have a plan for the next three years to get us to a ten-year plan. We have to recognize barriers; we have to get resources to get people to feel they have the time to do it. We need time and resources to build, then time and resources to implement it.”

Again, funding and how this is obtained are seen as key. Several external stakeholder interviewees focused on the idea of a single payer system as the only way a community

integration model could be sustained in the future. Others agree with the 2025 target date as the cut off for finding the answers to sustainability but differ in what they see as the solution to getting there. Many view MediCal support of community integration services as the successful way forward. They also believe the psycho-social sector is already behind in these efforts:

“We need MediCal funding to be able to expand and provide community integration services to TBI survivors. But I feel, if you can understand this, that we are a little like Dr. Seuss – you know, the Grinch and the little dog, trying to climb the steep mountain with just so much baggage in the sleigh. We aren’t going to get there unless MediCal funding is expanded to include psycho-social services like those we provide.”

Working with insurance entities is another possible solution to sustainability, although responders were at a loss at providing a definitive plan during the interviews. One concern with this option is the challenge that typically when a patient reaches maximum “improvement” both worker’s compensation and insurance companies cut off funding. As TBI is considered a chronic condition, it makes it difficult to determine individual maximum improvement, when in fact the trajectory should be a life course.

Several respondents support an educational initiative challenging the public to move away from the charity model (which depicts the disabled as victims of circumstance deserving pity) in order to view the positive value of community integration services as a key to successfully surviving the future. Additionally, borrowing from the business development and marketing arenas, external stakeholders see the value of perceiving community integration services as a return on investment for everyone involved, with marketing and branding taking a more central role in enhancing sustainability. And while CATBI does recognize the value of marketing, budgets are so tight that little is available for marketing.

As with CATBI members, this group of interviewees recognizes and is sensitive to the uphill battle for acceptance and recognition of brain injury within the public sphere as an

important public health issue. The challenge of how brain injury is viewed by the community and survivors alike remains the fundamental issue. External stakeholders also support the idea of an unidentified “champion” or well-known celebrity media influencer who becomes the famous face of TBI as a way to garner attention and public support. But, like the CATBI members, no one name became readily apparent during the discussion.

“We have to find a champion... There are countless people who are brain injured but they will not go out and be the face of TBI. You know, for breast cancer there’s pink everywhere. We need to have green everywhere; people don’t acknowledge that they have a brain injury because they don’t want to be looked at as ‘retarded’ – my least favorite word in the English language...People just don’t believe it’s so prevalent. I used to love that statistic that TBI is more prevalent than breast cancer, MS, heart attack and spinal cord combined. When you say that, people just look at you like you are insane and will argue with you. But it’s CDC information and they don’t make that stuff up.”

In the end, several external stakeholders acknowledged what they see as a difficult reality for CATBI: that the continuum of care should be attached to the medical model through medically-based standards, something CATBI members may have difficulty accepting because of what they perceive as a lack of inclusivity on the part of the medical sector. As one external stakeholder commented: *“...that’s the only way we can get around anti-trust issues with the medical community.”* While there are many suggested solutions by this cohort, the one key rallying point seems to be the understanding that if nothing is done, a crisis looms for this sector.

9. Future of the TBI Community Integration Sector

While the community stakeholders all shared a hope for the future of community integration, many had concerns of where the sector should go from here. All saw the future of community integration could and should move on from the current situation into a more formal, standard model. The External responses focused solutions on a standard model for delivery of care, possible inclusion of Medicaid, data-driven systems, the acceptance that TBI is a chronic

disease, a focus on marketing and branding with a famous celebrity, and an alignment of outcomes for organizations and outcomes for funders.

Several external stakeholders see the path to MediCal/Medicaid as the principle way to a future, but CATBI members could only be successful at this if they included monetizing the risks and costs involved in community integration services; something not all CATBI members have done. Others hope a successful future for TBI CI organizations includes the acceptance of the notion that TBI is a chronic illness, necessitating seamless care throughout a survivor's lifetime as the goal. The wish is that federal funders will eventually view TBI in this manner, and therefore offer programs and funding much like what is currently occurring with other chronic illnesses such as diabetes. And while there are those in the external stakeholders who see this as a possibility, several voiced their skepticism in the sector accomplishing this by 2025 due to the lack of structure and resources.

Other external stakeholders were frank in their assessment that ultimately the only solution to long-term financial sustainability remains within the realm of funding and the community integration community's ability to adapt its language to reflect more of the medical model, including a bigger focus on case management and outcome measures. Finally, one external stakeholder gave a sobering assessment of the future:

"I think things are going to get worse before they get better. Because of the current healthcare landscape, you know I don't see reimbursement going up, and if reimbursement is not going up, it's going to continue to be difficult to get services. I'm talking about just getting the direct services for the brain injured population, so on the community integration level, boy, that's tough. I really don't know. It troubles me."

Part 3: The Focus Group with CATBI Representatives

A. Development of Focus Group

The interviews of CATBI members brought up a recurring theme about the need for more structure to support the umbrella organization of CATBI, but what that meant was not immediately clear to the interviewees. They were interested in how all current sites could work more collaboratively in the provision of community integration care but had not formally convened for this purpose. As a part of this dissertation, the suggestion for having a group meeting to discuss what each individual CATBI site provided as services, and the concept of how all sites could work more collaboratively in providing care to TBI survivors gained traction. A proposal for compiling a master document for this dissertation listing all CATBI member services was supported by the CATBI Executive Directors. An inaugural two-day conference was scheduled where Executive Directors and a few of their staff members from the current CATBI sites were present. Discussions initially centered around creating a document identifying the commonalities of services provided at all sites. This expanded to include services that were unique to a given site, and whether these would be something all sites would eventually strive to include. Additionally, a separate document identifying operational structures for each CATBI site was added to the discussion. As noted in Chapter 5, at the end of the two-day conference, a Summary of CAATBI Program Service Delivery (Table A) was completed. The Organizational Structure table (Appendix B) was also well started, with sites completing by email. This is the first time the current CATBI sites have come together to identify all organizational and programmatic aspects in a formal structured effort to work towards a standardization of services.

B. Program Services Assessment

Summary of CATBI Program Services Delivery (Table 3) is an overview of the 30 possible services provided at each CATBI organization. These topics highlight a common core of structured services which include case management; supported living services; community reintegration services; and vocational supported services. Within these four areas are also metrics and outcomes attached to each, including initial intake assessments. Program services included: community reintegration services (with specific types of therapies); behavioral health (either neuropsychological or mental health counseling); counseling (peer group); substance abuse; TBI survivor support groups; caregiver respite; caregiver counseling; community education; advocacy services (individual and community); vocational services (pre-employment immersion services and employment); independent living services; assistive technology; housing; veterans services; day programs; and pre-vocational services. Appendix A lists all responses in a comparison chart.

C. Organizational Structure Assessment

Composed of seventeen questions, the Summary of Organizational Structure for CATBI Sites (Table 4) comprehensively depicts the responses for: all of the CATBI member sites' geographic locations, types of funding sources, and specific Department of Rehabilitation contracts above and beyond the grant the seven sites hold. This information was shared for the first time between the sites at this meeting and was compiled to better understand the realities each of the members face in their efforts to have a more common delivery of services for TBI individuals. Below are briefly summarized responses to each questions posed to the sites about organizational structure.

Organizational Structure survey - Host Agency

All seven sites are non-profit charities under the 501(C)3 Internal Revenue classification. Of the seven sites, two were self-described as part of non-profit hospitals, and the remaining five sites described themselves as either Independent Living Center, community benefit organization, or free-standing community-based.

b. Staffing Size

This is a physical count of staff, counted in whole numbers only. These figures varied widely across the seven organizations, with the average number of staff supported by the DoR grant being roughly 3 staff members. Only one of the CATBI members is dedicated strictly to serving survivors of TBI, with the other sites supporting other disabilities/conditions in addition to TBI. In traditionally receiving \$150,000 annually from the DoR for TBI support, question 2 highlights just how important the DoR funding is for these community integration providers.

c. Direct Staffing Supported by DoR Grant

This addresses the partial count of staff based on fulltime employee status (FTE). For example, if DoR funding pays for half of an employee's time, this counts as 0.5 FTE. As can be seen in Attachment 4 (Chapter 5) the DoR funding – while extremely important to all sites - pays for just a portion of staff dedicated to TBI services. For example, the clubhouse site dedicates 6 staff to support the DoR programming, but in actuality the DoR grant funds 3.5 FTEs. This makes it important for the sites to search out other streams of funding to cover the additional FTEs.

d. FTE Definition

Each of the sites has a different amount representing an FTE, ranging from 32 hours to 40 hours. This is the amount where traditionally an employee is eligible for any benefits that might

be offered by an organization. Often, organizations try to keep FTE numbers at a minimum, choosing to hire part-time staff in order to save on benefit costs.

e. Employee Benefits

In an effort to recruit and retain a valuable workforce, all of the CATBI sites offer medical, dental, vision, sick/vacation/PTO, and retirement accounts to full-time staff. But these benefits can be costly, and most of the sites have employees co-pay some of the costs through a pre-tax deduction. Additionally, not all of the CATBI members can afford to offer retirement products to their staff. All sites continue to look at other benefits they can offer staff in an effort to decrease turnover. This may be in the form of paying for an employee's yearly education, such as the certified brain injury specialist credentialing (CBIS), or other items.

f. Educational Requirements for Staff

This elicited a diverse number of responses. One CATBI member has as a minimum requirement a high school education, preferring to focus on credentialing rather than a higher degree requirement. Others ask for advanced professional degrees. The minimum educational requirement for five of the sites is a bachelor's degree. The highest educational requirements (graduate degree level) are at one hospital site, and one community-based site; both of these members have clinical staff on board, and are the only sites offering neuropsychological testing to consumers.

g. Maximum Number of Clients Served

All CATBI members responded they were currently at capacity for supporting TBI survivors. All sites would welcome the opportunity to serve more TBI survivors, but economies of scale, staff turnover and scarce sustainable funding sources prohibit any expansion of programming.

h. Meeting the Needs of the TBI Community

This was a resounding ‘no’ from all CATBI sites. Wait lists are common at many sites. All executive directors expressed frustration in the inability to serve more TBI consumers within their respective communities. These managers also voiced a feeling of concern for those California counties outside of the CATBI catchment areas where there are no resources available.

i. Discharge Procedure

The CATBI members vary widely with regard to this issue, from an independent living center site with a simple procedure of closing a case once a member has met their individualized service plan, to structured protocols at one hospital location. Most of the other sites do have a criteria for closing a case based on prescribed set of measures that include meeting all goals; no new goals; no longer want services; moved away; cannot be contacted; death. All sites keep paper records for a duration of time, with electronic records kept longer.

j. Wait List

With the exception of one hospital site and one community-based location, all the other CATBI members have waiting lists for their services. As one executive director shared: “unfortunately, we have job security, if you can call it that.”

k. Estimated Percentage of Services Provided by DoR Funding

The five service areas that the DoR funding requires grantees to provide are: community integration; supportive living services; vocational support services; other case coordination; public and professional education. The bulk of time spent by CATBI staff at their respective locations is on community integration. This ranges from 65% of time at the TBI clubhouse site, to roughly 56-57% at the independent living center locations, with the least amount of time spent

at both hospital member sites with 35%. Supportive living services has the next largest amount, with independent living centers using 30% of their time supporting this service. One hospital site spends 25%; with the clubhouse member, the community-based site and the other hospital only spending from 9%-15% of their time. Vocational support services are in single digits for the independent living centers, one hospital and the clubhouse model, but at 40% for the community-based site. This larger amount reflects this member's broadening of services in collaboration with the DoR to include job coaching, vocational assessments, and pre-vocational training.

The next service category, other case coordination, shows percentages highest at the two hospital sites and smallest at the independent living centers, reflecting a more structured protocol housed within the medical model. Finally, the least amount of time across the seven sites is dedicated to public and professional educational services.

1. Expected Consequence of Loss of DoR Funding

If the DoR pulled funding or chose not to renew the granting process in 2020, all sites would immediately be negatively impacted. One hospital site would have to eliminate community integration services completely. Other sites would have to stop case management, support groups, and social activities. The threat of a possible increase in hospital re-entry rates exists. A decrease in outcome reporting and data collection would occur. The inability to address at-risk populations such as the homeless would be an issue. Behavioral health would not be addressed. Waitlists, already long at most sites, would grow even larger. All CATBI members stated they would try to continue serving the TBI population if the grant ended, but this would be with great difficulty.

m. Service Sites

Five of the CATBI members have multiple locations - four locations for one of the independent living centers; three locations for two of the ILCs, and three for the clubhouse and community-based site respectively. The only two organizations to not have additional sites are the two members who are hospital-based. See Attachment 2 for the listing by city.

n. Funding Sources

All sites appear to have most of the usual funders – federal, state, county, city, individual, and fundraising – but the breakout of this funding was not discussed on a by-site basis. Three of the sites – the two hospitals and one community-based member have access to MediCare or MediCal funding as well, due to the fact these organizations are able to bill for clinical services.

o. Contingency Planning

An alarming reality is that three of CATBI’s members (including the two hospital sites) currently do not have a contingency plan should DoR funding cease. The other sites spoke about increasing fundraising efforts, fee-for-service or vocational services through the DoR, but all acknowledged that this would not be sufficient to cover the revenue lost from the DoR community integration grant. This is one of the greatest concerns for all seven CATBI members.

Part 4: Discussion of Findings

CATBI members and external respondents value what CI brings to the TBI Continuum of Care. And while both CATBI respondents and the external stakeholders are aware of the challenges facing the CI sector, each group has varying approaches to solutions. When comparing and contrasting the interview responses of both stakeholders (Table 5), many of the answers mirror one another in theme. Where a divergence exists is the assessment at the “10,000 foot” level, with the external stakeholders seeming to have a more expansive view of the barriers

and opportunities that may remain into the future. Table 6 illustrates the Summary of Program Services Delivery by CATBI Sites. By comparing sites, one can see which organizations have a more robust community integration services platform. Additionally, Table 7, Summary of Organizational Structures for CATBI Sites, gives a good overview of all organizational resources each CATBI currently possesses.

Table 5. Compare/Contrast of CATBI and External Stakeholder Interviews

Topic	CATBI	External Stakeholders
Medical Sector and Community Integration	Seeking to be equal partners at the table with other TBI Continuum of Care partners	Believe for CI sector to be taken seriously, CI should act more like the medical sector in common taxonomy, use of assessments
	Due to past history, sees medical sector somewhat adversarial	See the hospitals and physicians as critical to the wellness model/chronic illness management for quality of life issues
	Would like two-way open communication with physicians centering on the wellbeing of TBI survivors in their respective care	Supports CATBI's efforts in working with medical and allied health sectors to promote community outreach; also suggests one step further: building business alliances as well
Sustainability and Funding	Funding fatigue	A sense of urgency: fear that the window is closing
	DoR current grant partner, but CATBI senses DoR doesn't always understand CATBI needs or validates their successes	There is a need for a 2025 vision now, accompanied by a plan to make this a reality
	Look to myriad untested (in CI) funding models as a hope for new money, including HMOs, Fee-for-service, MediCal waiver	Also looks at different funding models, including MediCal waiver
TBI Awareness and Advocacy	Programs needed to better educate both the public and physicians as to TBI as a chronic condition	CI sector should be more vocal about community awareness in the community and beyond
	Community education is constant and overwhelming need, but often gets cut because of staff shortages	Cognizant of the fact that TBI is lumped in with other disabilities to the detriment of TBI
	CATBI members aware they are good at delivering programming, but are not well versed in the workings of public policy	These stakeholders see value in CATBI pursuing a path of collaborating with others to promote public policy at the State level (including lobbying)
Staffing	Remains a constant challenge: lack of quality candidates; high turnover	Respondents understand the salary issues at CI organizations and are concerned this shortcoming is a critical detriment to the health of the sector
	Convincing allied health professionals to work for a CI organization can be a challenge when the candidates realize it is not a clinic environment	Sees the hiring of allied health professional a valuable step for expanding CI services
Future of Community Integration Sector	There is concern across the CATBI members, but overall, they have a more positive outlook than the external stakeholders, with the idea that perhaps in five years' time they will be able to identify a longterm stable funding source	Bleaker perspective than that of CATBI members. If nothing done, a crisis looms. These respondents for the most part believe that CI's best hope is to attach itself to the medical model and utilize clinical-type standards and environment

Table 6: Summary of Program Services Delivery for CATBI Sites

ITEM NUMBER	SERVICES	ORGANIZATION						
		Independent Living Center - NorCal	Independent Living Center - NorCal	Independent Living Center - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NorCal	Hospital - SoCal
1	Initial intake/assessment (non-medical psychosocial screening included)	YES	YES	YES	YES	YES	YES	YES
2	CIQ (upon intake)	YES	YES	YES	YES	YES	YES	YES
3	Medical/clinical psycho-social services	Referral Only	Referral Only	Referral Only	Referral Only	YES	YES	YES
4	Transition from hospital, SNF, etc.	YES	YES	YES	YES	Referral Only	YES	YES
5	Community-reintegration services	YES	YES	YES	YES	YES	YES	YES
6	Transitional therapy services:							
	6a. Occupational Therapy (OT)	By referral (and through service coordination)	By referral (and through service coordination)	By referral (and through service coordination)	Group classes facilitated by licensed professionals; and by referral (and through service coordination)	1:1 w/licensed therapist; external referrals available based on insurance coverage	1:1 w/licensed therapist; external referrals available based on insurance coverage	1:1 w/licensed therapist; external referrals available based on insurance coverage
	6b. Physical Therapy (PT)	N/A	By referral (and through service coordination)	By referral (and through service coordination)	No; non-medical movement classes, massage therapy; and by referral (and through service coordination)	1:1 w/licensed therapist; external referrals available based on insurance coverage	1:1 w/licensed therapist and with groups; external referrals available based on insurance coverage	1:1 w/licensed therapist; external referrals available based on insurance coverage
	6c. Speech Therapy (ST)	N/A	By referral (and through service coordination)	By referral (and through service coordination)	Group classes facilitated by licensed professionals; and by referral (and through service coordination)	1:1 w/licensed therapist; external referrals available based on insurance coverage	1:1 w/licensed therapist and with groups; external referrals available based on insurance coverage	1:1 w/licensed therapist; external referrals available based on insurance coverage
	6d. Behavioral Health Therapy	Work Incentive Planning & assistance through behavioral health department (external sources)	Friendly Visitor Program - weekly home visit by volunteer; WRAP	Social adjustment/coping with stress class; social group (community outings)	Classes designed to contribute to overall greater behavioral health; social group (community outings)	1:1 counseling with neuropsychologist; education & adjustment for TBI; internal and external referrals to Mercy behavioral health department	1:1 counseling with neuropsychologist; additional referrals & consultations available	1:1 w/MFT & LCSW; additional referrals & consultations available internally; clinical internship program for plan/goal follow-up (by phone)
7	Formal/licensed counseling (reimbursable)	NO - referrals	NO - referrals	NO - referrals	NO - referrals	1:1 w/licensed neuropsychologist	1:1 w/licensed neuropsychologist	1:1 w/licensed clinician (MFT/LCSW)
8	Informal Counseling (evidence-based); peer counseling; person-centered; WRAP (Wellness Recovery Action Program)	YES: person-centered and peer counseling	YES: peer counseling; person-centered; WRAP	YES: person-centered and peer counseling	YES: person-centered and peer counseling	NO	YES: person-centered and peer counseling	NO
9	Substance Abuse	NO - referrals	By referral (and through service coordination)	NO - referrals	NO - referrals	NO - referrals	NO - referrals	NO - referrals
10	Support Group	YES - biweekly	YES - weekly	YES - weekly	YES - weekly	YES - weekly & biweekly	YES - weekly	YES - weekly

Table 6: Summary of Program Services Delivery for CATBI Sites (cont.)

ITEM NUMBER	SERVICES	ORGANIZATION						
		Independent Living Center - NorCal	Independent Living Center - NorCal	Independent Living Center - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NorCal	Hospital - SoCal
11	Caregiver Respite	Referral Only	Indirectly by way of member attendance through support groups & referrals	Referral Only	Indirectly by way of member attendance through support groups & referrals	Indirectly by way of member attendance through support groups & referrals	Through day program	Through Family Caregiver Support Program grant (FCSP)
12	Caregiver Counseling (licensed)	Referral Only	Referral Only	Referral Only	Referral Only	YES	YES	YES
13	Caregiver Support Group	Referral Only	Referral Only	Referral Only	Bi-weekly	Referral Only	Bi-weekly	Bi-weekly
14	Education	YES - presentations & community events; workshops; training to law enforcement (quarterly); family education	YES - presentations & community events; workshops; training to law enforcement; family education	YES - presentations & community events; workshops; family education	YES - presentations & community events; workshops; training to law enforcement; family education	YES - presentations & community events; workshops; family education; TBI & anxiety class; monthly concussion class	YES - presentations & community events; workshops; training to law enforcement; family education	YES - general education as requested; collaboration with colleges (CSULB, CSUL)
15	Systems Change Advocacy (legislative & insuring policy, procedures, systems are responsive to needs of TBI individuals)	YES	YES	YES	YES	YES	YES	YES
16	Individual Advocacy Services (assistance/information on rights & services toward individual housing, benefits, etc)	YES	YES	YES	YES	YES	YES	YES
17	Vocational Services (to help individual attain/maintain employment - not DoR)	YES - pre-employment, referrals, & collaboration	Employment network plan to become DoR vendor& referral to One Stop	YES - DoR employment & immersion services	YES - DoR immersion services & general vocational	YES - pre-employment screening by PT/OT/ST/neuropsychology assessments as needed	YES - through formal DoR employment & immersion services, in addition to vocational assessments; pre-vocational training (ILST); job coaching	YES - Client initiated assistance through case management and by referral; tech resources available; assign item & guidance
18	DoR Certified Vendor	NO	NO	YES	YES	NO	YES	NO
19	Independent Living Services - individual or group?	Individual	Individual (looking at group)	Individual & group	Individual & group	Individual & group	Individual & group	Individual
20	Independent Living Services Curriculum	NO	NO	YES	NO	NO	YES	NO
21	Veterans Assistance	YES	YES	YES	YES	YES	YES	YES
22	Contracted with Veterans Administration	NO	NO	NO	NO	NO	YES	NO
23	Residential Services (Home Visits)	NO	YES	YES	YES	YES	YES	YES
24	Assistive Technology - device lending library; technology training; equipment reuse	YES	YES	YES	YES	By referral only	YES	By referral only
25	Housing Assistance for homeless & at-risk	YES	YES	YES	YES	By referral only	YES	YES
26	Benefits Assistance	YES	YES	YES	YES	YES	YES	YES
27	Day Program focusing on cognitive, physical & social	NO- referral only	NO - referral only	YES - 4 days/week; 5-6 hrs/day	YES - 5 days/week; 5 hrs/day in SB (weekly in Solvang; week in SLO)	NO - referral only	YES - 5 days/week; 5 hrs/day	NO - referral only
28	Pre-vocational (Day) Program	NO- referral only	NO - referral only	YES - 4 days/week; 5-6 hrs/day	NO - referral only	NO - referral only	YES - 5 days/week; 5 hrs/day	NO - referral only
29	Goal-based	YES	YES	YES	YES	YES	YES	YES
30	Bilingual Services	YES	YES	YES	YES	YES	YES	YES

Table 7: Summary of Organizational Structures for CATBI Sites

SURVEY QUESTIONS	ORGANIZATION						
	Independent Living Center - NorCal	Independent Living Center - NorCal	Independent Living Center - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NorCal	Hospital - SoCal
1. Please describe the host agency for your TBI program; for example, a non-profit hospital, a free standing private non-profit community based agency, etc.	Non-Profit Community Benefit Organization 501(c)3	Non-profit Independent Living Center 501(c)3	Non-profit Independent Living Center 501(c)3	Free standing community-based non-profit 501(c)3	Mercy Outpatient Rehabilitation Center is an outpatient physical therapy, occupational therapy, and speech therapy clinic associated with Mercy General Hospital (which is a nonprofit hospital under the umbrella of Dignity Health). 501(c)3	Free-standing, community-based nonprofit 501(c)3	St. Jude Brain Injury Network is housed in a nonprofit hospital that is part of a large health network made up of hospitals and medical groups (Providence St. Joseph Health). 501(c)3
2. How many staff persons in your organization are involved in providing direct services to clients under the TBI grant? This is a physical count; therefore, if a person is only providing service, part of the time, they would still be counted as 1 (whole number).	2 staff work directly with TBI Consumers. The number of staff involved with one consumer can increase to 6, if the consumers is need of additional services, such as Information Referral and Assistance, Assistive Technology, Homeless Prevention Services or Work Incentives Planning and Assistance. 2 staff are dedicated to TBI, but additional staff available for other services.	4 staff under DOR; However, it should be noted that other staff on occasion serve individuals with TBI in other specific ways not covered under this grant depending on need. For example, nursing home transition, home modifications, assistive technology etc. 4 dedicated - (1) @ .8, (1) @ .5 = collective total of 4 people = 2.53 FTE	Not Provided	6 staff under DOR, 8 total for TBI. Some also serve other individuals with ABI, as well as other needs not covered under the grant.	9 total - multiple staff with flex hours, no single FTE specifically dedicated to TBI program, all employees service other consumer areas. Mgr & assistant primary TBI contacts (assistant - 12/week covered by grant). Some clinicians are billed to DOR but @ much higher rate.	4 staff on DoR grant; 8-10 people generally work with TBI	2 FTE dedicated to TBI; DoR grant pays for 1.8
3. What level of direct service staffing does the DoR TBI grant pay for? This is a partial count based on full time equivalent (FTE) staff; therefore if funding pays only half of a person's full time salary, then that person counts as .5 FTE. Please total up the number of FTE's providing direct service through the grant and provide that number.	2.5 FTE	2.53 FTE	2 FTE	3.5 FTE	1.12 FTE	2 FTE	1.8 FTE
4. Definition of FTE	37.5 hours	40 hours	40 hours	32 hours	40 hours	32 hours	40 hours
5. Does your organization provide benefits?	medical, dental, vision, sick & vacation, 403(b)0 4% match to FTE (min 30 hours)	medical, dental, vision, sick & vacation (no Retirement) to FTE (min 30 hours)	medical, dental, vision, sick & vacation, IRA w/ match to FTE (40 hours)	medical, dental, 403(b) (no match), PTO/ sick & vacation (30+ hours)	medical, dental, vision, 403(b) w/ match, pension 20 hours for eligibility, sick & vacation	medical, dental, vision (SBI covers 80%), 401(1)k no match, sick & vacation, PTO 30 hours +	medical, dental, vision, 403(b) w/ match, sick & vacation, pension contribution prorated on hour/status
6. What is the minimum degree required for the staff that provide direct service to TBI clients? For example, does the current staff have to have at least a bachelor's degree or an advanced degree? If multiple staff with different degrees work through the grant, please note that and report them whether or not they are fully funded under the grant.	CCCIL does not have an advance degree requirement for Case Managers. However both CCCIL Case Managers hold bachelor degrees in Health and Collaborative Services, and Certified Brain Injury Specialist certificates.	We do not require any specific degree. Minimum requirements are High School Diploma and at least three years experience serving individuals with disabilities (preferably with TBI specifically). Value is placed on services, but most employees do have at least Bachelors. Would rather focus on CBIS v. minimum degree requirements.	Minimum Bachelors for TBI coordinator, other staff experience requirements.	Bachelor's degree. Experience with brain injury a plus. Would rather focus on CBIS v. minimum degree requirements.	Educational requirement depends on the job title. Most have advanced professional degrees and have passed state licensing exams to be able to provide physical therapy, occupational therapy, speech therapy, or neuropsychology (Master's to Doctorate level). Other staff include clerical and rehabilitation aide without a formal degree, but with years of clinical rehab experience.	Bachelor's Degree (Intake/Case Coordination); remaining direct service providers – Masters	Bachelors degree in social sciences/social work
7. Would you agree that your program is serving the maximum number of clients possible (unduplicated) with the current staff? Yes or No?	YES	YES	YES	YES	YES	YES	YES
8. Are you able to meet the needs in the community with the staffing/capacity that you have?	NO	NO	NO	NO - waiting list in SLO, unmet needs in SB/Solvang due to lack of staff	NO	NO	NO
9. Is there a "discharge" process for clients in your program; this includes "closing" cases? If so, please describe the criteria for when work with a client is officially considered completed and you no longer maintain a case file or provide services.	Once a consumer has met their goal within their Individualized Service Plan (ISP), they are asked if they would like to set additional goals. If no additional goals are set then their file is closed. Members are always welcome back with new intake process	FREED uses a goal structure to serve individuals. They can exit services in the following ways: (a) Met all goals, no new goals they want to establish (b) They no longer want services for some reason (c) Move away (d) We cannot contact them for a period of more than three months – calls, letters, reach out to emergency contacts, etc. if no response we exit them from services (e) Death. We maintain paper case files for a period of at least 7 years and electronic records longer. People can come back for services any time.	Not Provided	(a) Met all goals, no new goals they want to establish (b) They no longer want services for some reason (c) Move away (d) No contact after one year (e) Death. We maintain paper case files for a period of at least 7 years and electronic records longer. People can come back for services any time.	Cases are closed when clients have met their goals, or are no longer interested in participating in the services offered. The case file is held open for follow up for 18 months from admission date for follow up questionnaires and data collection (CIQ and QOLIBRI).	Not for grant participants because they are moving within services.	There is no formal discharge process. Clients are welcome to come back at any time. There is formal process for active participation, which involves completing the CIQ.

Table 7: Summary of Organizational Structures for CATBI Sites (cont.)

SURVEY QUESTIONS	ORGANIZATION						
	Independent Living Center - NorCal	Independent Living Center - NorCal	Independent Living Center - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NorCal	Hospital - SoCal
10. Is there a waiting list for service at your organization?	YES	YES	Not Provided	YES - San Luis Obispo (SLO) 20+	YES- there is a waiting list for intake appointments/case management services, and 1:1 counseling with neuropsychology. Wait list is currently 2-3 patients long and takes 4-6 weeks.	NO	NO
11. What is the best estimate of the time and effort spent by your agency in providing the five categories of service under the grant? Please prioritize so the five categories total to 100%.		Note: Utilizing data based on number of services provided not time spent on each service, but this is a best guess.					
(a) Community Integration	57%	56%	Not Provided	65%	35%	40%	35%
(b) Supportive Living Services	30%	30%	Not Provided	15%	25%	9%	14%
(c) Vocational Supportive Services	6%	5%	Not Provided	5%	10%	40%	14%
(d) Other Case Coordination	6%	8%	Not Provided	13%	20%	10%	35%
(e) Public and Professional Education	1%	1%	Not Provided	2%	10%	1%	2%
12. Please provide a brief narrative of how your program provides services/interventions for your clients.	CCCIL promotes the independence of people with disabilities by supporting their equal and full participation in life. CCCIL provides advocacy, education, and support to people with disabilities, their families, and the community. In addition to Case Management CCCIL facilitates support groups and provides information about TBI to professionals in the community.	FREED serves its consumers through a person-centered model where the individual is the center of their services deciding what services they want and if they want services at all. Our services are provided in a skills-transfer based model ensuring that we do not do things for people that they can do for themselves, and that our support is structured in a way that it increases the capacity of the individual to do things more independently the next time. Our services are structured around consumer stated goals and collaborative plans developed to meet those goals. Services are individualized based on each individual's wishes, values, and priorities. Our services are provided in a peer-based model meaning most of our service staff are also individuals with disabilities. Services are also provided through weekly peer support groups and education and outreach.	Not Provided	Jodi House serves adults with acquired or traumatic brain injury, their families, caregivers, friends, volunteers and the community at large. Our Jodi House community includes survivors of: accidents, trauma, sports injuries, stroke, brain tumors and aneurisms, and veterans with brain injury. Jodi House is the "go to" place for adults with brain injury throughout their continuum of care. The Resource/Referral Program provides a lifeline of information, referrals, and support to survivors, family, caregivers and friends. Our staff is available to assist by phone, email, or in person. This service is free of charge and open to all in need.	The Mercy Home and Community Reintegration Program for Traumatic Brain Injury provides supportive services to survivors of traumatic brain injury in a medical model through case management, 1:1 counseling and education, support groups, pre-vocational assessments with licensed therapists (PT, OT, ST, Neuropsychology), and public and professional education and advocacy for improved services and support for the population living with a TBI in California.	Services For Brain Injury assists any post-acute, medically-stable person with a brain injury at any stage of recovery through a comprehensive, customizable continuum of individual clinical therapies (Neuropsychological services, PT, SL/P, OT) combined with weekday, group-based rehabilitation programming. Programming begins with most vulnerable clients and includes ADLs, ILS, basic cognitive skills, personal and social adjustment. The continuum progresses to Pre-Vocational and Vocational programming, followed by Employment Services with Job Placement and Retention. SBI also serves those with high-functioning Autism and Asperberger Syndrome, learning disabilities and other cognitive impairments. Clinical services and programming are supported with Home Visits; Assessments (Neuropsychological Evaluations, CVEs, ESAs); individualized caregiver and family support; a non-cost, weekly, professionally-facilitated support group open to anyone touched by brain injury and their loved ones.	The St. Jude Brain Injury Network serves its clients through a social service case management modality, which includes advocacy, supportive coaching, information, education, training, and the provision of support groups and educational events.

Table 7: Summary of Organizational Structures for CATBI Sites (cont.)

SURVEY QUESTIONS	ORGANIZATION						
	Independent Living Center - NorCal	Independent Living Center - NorCal	Independent Living Center - SoCal	TBI Support Center - SoCal	Hospital - NorCal	TBI Support Center - NorCal	Hospital - SoCal
13. What happens if DOR funding goes away	Would not be able to support social activities, case management, waiting list would be longer. No support groups, general case management only. Grant pays for TBI specific employees.	Would definitely need to cut back on services but would continue to try to serve population. Staff burnout would be a concern.	Not Provided	Case manager is paid through this grant, this would heavily affect services and population served. Hugely negative impact on services.	Community reintegration would be eliminated. Outpatient & medial rehab services only. No social program, no community reitegration, no vocational services, no TBI education	Would definitely need to cut back on services but would definitely continue to try to serve population.	Decrease in services and therefore a decrease in population served.
14. Does your organization have different geographic satellite locations?	YES (3)	YES (3)	YES (4)	YES (3)	NO	YES (3)	NO
15. Satellite locations by city	Salinas (HQ); Capitola; King City; Watsonville	Grass Valley (HQ); Marysville; Chico; Redding	Van Nuys (HQ); 2 other Van Nuys sites; Lancaster	Santa Barbara (HQ); Solvang; San Luis Obispo	Sacramento	San Jose (HQ); Sata Cruz; Oakland	Fullerton (HQ)
16. Funding Sources	Federal; state; county; city; individual donors; fundraising	Federal; state; county; city; individual donors; fundraising	Federal; state; county; city; individual donors; fundraising	Federal; state; county; city; individual donors; family and private foundation grant writing; fundraising	Insurance contracts; MediCare/MediCal; workers compensation	Federal; MediCare; workers compensation; social security; veterans administration; city; fundraising	Insurance contracts; MediCare/MediCal; workers compensation; state; family & private foundations
17. Contingency Plan if no future DOR grant	NONE	Fundraising, fee for service, vocational services. Would only be able to service population through IL model.	Not Provided	Fundraising, more grant writing. Services would be severly impacted; reduction in staff would be necessary.	NONE	Fundraising, fee for service, vocational services through DOR provides some income	NONE

CHAPTER 7: PROPOSED RECOMMENDATIONS

1. Introduction

Health-related organizations identify and value healthcare quality management, with its three elements of structure, process and outcomes. Structure relates to administration, personnel, and facilities. Process includes management policies and procedures, record keeping, diagnosis, program planning and delivery. Outcomes are the anticipated positive results from program services planning efforts. Successful social re-integration requires a multi-dimensional process, with a collaborative interdisciplinary team of clinicians, allied health and community integration professionals working in tandem. The challenge is that no common structure, process and outcome framework exists to connect the physician and allied health professionals with the psycho-social community integration sector. Service provision and hand-off to community integration providers can be fragmented. Often community integration organizations push back against the medical model with its medicalization and clinical intervention, with conflict arising between the medical and non-medical philosophies and models of service delivery (Willer, 1993).

The construct of community integration has been successfully incorporated into programs for addressing other health conditions, including mental illness. As with TBI, the philosophy used for CI for addressing mental health is the idea that someone suffering from mental illness wants to be as independent as possible, to be able to manage their illness, and to participate in family life (Bond 2004). Unlike the TBI CI sector, the mental health field has relatively more evidence to draw on and has been able to come to a consensus on identifying practices that can be classified as evidence-based practices (EBP). These include supported employment, assertive community treatment, illness management and recovery, supported housing and supported

education (Bond, 2004). These six topics are very similar to those used in TBI CI services, but unfortunately the TBI CI professionals have yet to meet to critique and test the TBI CI services for validity.

Currently not enough evidence exists to be able to have evidence-based recommendations or informed standards of care for TBI CI, so the goal of this study is to describe recommendations based upon input solicited from informed stakeholders that this researcher hopes can guide CI providers in California. This would be a positive first step and would provide TBI CI service providers with the opportunity to construct strong evidence-based tool for the benefit of TBI survivors, their families and for the organizations themselves as they search for sustainability.

Community integration (CI) for traumatic brain injury has been a part of the brain injury continuum of care since the 1970s. But as noted in the interviews included within Chapter 6 Case Study Results, community integration can translate differently among organizations serving adult TBI survivors. Because of these discrepancies, the CI sector has suffered from perceived lack of legitimacy on the part of other partners within the TBI continuum of care. As such, the concept of proposed common recommendations would benefit TBI community integration services on several levels: first, the possibility for a standard equivalency for quality of care regardless of geographic location; second, through the use of standard outcomes measures and tests which will provide important data to use in strengthening services; third, giving CI organizations the ability to use these measurements to further search for sustainable funding; and finally, strengthening the legitimacy of the psycho-social model of community integration in the eyes of the TBI continuum of care sector.

While standards of care exist for addressing the physiological aspect of traumatic brain injury, my research was unable to verify any psychosocial standards of care for community integration of TBI adult survivors. Finding an example of just one standard for any aspect of medicine was an initial challenge, as there is no one repository from which to draw standards of care. The Commission on Accreditation for Rehabilitation Facilities (CARF), the largest accreditation organization for rehabilitation programs does have a Brain Injury Specialty Program accreditation with standards, but it focuses only on the clinical aspect of rehabilitation and not on articulating expectations for community integration programs. CARF does require, however, that any rehabilitation hospital interested in being accredited must seek an outside partner within the community for collaboration on community integration, but there are no guidelines for what that community integration should be. Therefore it appears there are no existing standards in community integration for TBI survivors.

Given the relative dearth of research evaluating the effectiveness of CI programs for TBI and the substantial variation in practice related to what is included in a CI program, it was decided that it would be premature to suggest standards of care for CI organizations. Instead, it was decided that this research would better inform a list of recommendations for CI providers focused on improving the quality and type of CI services provided and improving the long-term stability and sustainability of these organizations. In order for the proposed recommendations for psycho-social community integration organizations to be of value, it must be reasonable in scope and applicable to even modest-sized, grassroots community integration organizations. The following recommendations were created based on a comprehensive literature review, interviews with CATBI members and external stakeholders, and a review of existing standards of care

developed to guide delivery of services to address other medical, social and behavioral health issues.

2. The Proposed Recommendations

Table 1: The Proposed Recommendations for TBI Community Integration Organizations

<p>PROPOSED RECOMMENDATION #1: <i>Psychosocial health care needs of TBI survivors and caregivers are identified and acknowledged. Decision-making and Community Integration care plans are based upon a respect for the uniqueness of each TBI survivor's situation. Strategies are developed to address these needs</i></p>
<p>PROPOSED RECOMMENDATION #2: <i>Comprehensive Community Integration (CI) TBI services should be based on current evidence-based research (<u>where available</u>) and include the following modalities:</i></p> <ol style="list-style-type: none"> 1) <i>Case management</i> 2) <i>Transitional/reintegration therapies</i> 3) <i>Caregiver respite and counseling</i> 4) <i>Advocacy services</i> 5) <i>Vocational services</i> 6) <i>Independent living services</i>
<p>PROPOSED RECOMMENDATION #3: <i>TBI CI service organizations should adopt the Chronic Care Model (CCM) for brain injury that conceptualizes each individual's condition. In applying this model the following should be addressed:</i></p> <ol style="list-style-type: none"> 1) <i>Self-management tasks</i> 2) <i>Self-management skills</i>
<p>PROPOSED RECOMMENDATION #4: <i>TBI CI service organizations should facilitate communication by helping the TBI survivor to access the following in order to assist the survivor to learn life strategies:</i></p> <ol style="list-style-type: none"> 1) <i>Assistive technology tools and formal strategies to teach communication techniques to TBI survivors, caregivers, and CI services staff</i> 2) <i>Corresponding training and educational resources to ensure the TBI survivor is supported as technologies develop over time</i>
<p>PROPOSED RECOMMENDATION #5: <i>Outcome identification plan: CI service organizations should select validated measures for inclusion in a comprehensive and ongoing protocol for assessing both disease and Health/Quality of Life (HQoL):</i></p> <ol style="list-style-type: none"> 1) <i>Psychosocial screening at intake for both TBI survivor and caregiver</i> 2) <i>Evidence-based tools to be used incorporating wide-ranging health-related and psychosocial problems, including physical symptoms of TBI injury and chronic conditions; emotional distress; material needs; social supports; behavioral health risks</i> 3) <i>Psychosocial quality-of-life outcome measures</i>

<i>These tools should be administered at in-take and at regular intervals informed by the expected timeline for program enrollment and patient goals.</i>
PROPOSED RECOMMENDATION #6: <i>CI service organizations should work towards addressing social determinants of health that are particularly relevant for the TBI populations such as the high rates of homelessness and previous incarceration.</i>
PROPOSED RECOMMENDATION #7: <i>CI services organizations should invest resources to ensure that staff members have specific training and certification to work with TBI survivors.</i>
PROPOSED RECOMMENDATION #8: <i>CI service organizations should work to engage health professionals across multiple disciplines of the TBI Continuum of Care for the holistic delivery of TBI CI care reflecting a chronic care model, with the intent of improving service delivery and increasing the quality of life for TBI survivors by communicating regularly with health care providers to ensure that CI outcomes can be considered within the larger plan of care.</i>
PROPOSED RECOMMENDATION #9: <i>CI service providers should look for opportunities to align their organizations with the medical and rehabilitation sectors in an effort to improve TBI care coordination and enhance patient outcomes. Leveraging these partnerships may enhance the sustainability of CI organizations, specifically through collaboratively participating in advocacy projects with these sectors. Working closely with the medical and rehabilitation sectors may also open up funding opportunities that are currently not available to CI organizations.</i>

A. Proposed Recommendation #1: *Psychosocial health care needs of TBI survivors and caregivers are identified and acknowledged. Decision-making and Community Integration care plans are based upon a respect for the uniqueness of each TBI survivor's situation. Strategies are developed to address these needs.*

Due to the need to reduce healthcare costs on the part of healthcare providers, TBI survivors are being discharged sooner from the hospital with time spent in rehabilitation diminished, resulting in poorer long-term outcomes and greater caregiver burdens (Corrigan, 2013). This decrease and/or shifting of resources with the TBI care system makes the community integration model even more important for the TBI survivor's successful re-introduction back into society. Without this component, the TBI survivor is often faced with poor community

integration outcomes that include diminished social integration, reduced social participation and decreased quality of life (Cicerone, 2004).

Community integration has been defined as “rehabilitation that takes place within the client’s physical and social environment, for example, in their home or other community facility” as well as supporting the role of the caregiver (Sakellariou, 2006, P#7). Unfortunately the Brain Injury Association of America states the discouraging statistic that 95% of all brain injury survivors do not receive the services they need to establish independence and community integration (Adkins, 2004). Research has shown a direct correlation between poor psychosocial outcomes with increased depression, anxiety, and decreasing coping and self-esteem (Anson, 2006).

The concept of person-centered care goes hand-in-hand with community integration strategies. Person-centered care is a philosophy of care where individuals requiring health, social, and psychosocial services are seen as equal partners with their providers through the planning, developing and coordinating of individual care (McCance, 2011). Person-centered care doesn’t mean the TBI survivor must bend to adequately fit into routines and services deemed important by a provider. Rather, it is the TBI survivor who is the focal point around which services need to be flexible in order to meet the individual survivor’s goals and needs.

Proposed Recommendation #1 focuses all TBI community integration staff, volunteers and others in the TBI continuum of care on the philosophy that community integration interventions exist to support the individual TBI survivor and not the reverse. While this standard does not call out specific strategies or plans on how to accomplish this, there are aspects of person-centered care that can be used to achieve these strategies. It is at the discretion of the

community integration organization to create plans and protocols that best fit each TBI survivor's needs and goals, remembering that each CI organization should:

1. ... respect the TBI survivor's values
2. ... appreciate the individual TBI survivor's needs and preferences
3. ... carefully coordinate and integrate care plans
4. ... collaborate with the TBI survivor, family and caregivers to verify communication is open and positive and education is always available
5. ... validate each TBI survivor's personal concerns and then verify they are physically safe and comfortable within the CI environment
6. ... offer essential emotional support
7. ... include the TBI survivor's family and friends when constructing plans and strategies
8. ... continually confirm that collaboration and continuity remains between and within services
9. ... assist the TBI survivor if needed in accessing care beyond the community integration organization

From the interviews of diverse stakeholders listed in Chapter 6, the ultimate goal of community integration is to increase a TBI survivor's quality of life and functional independence within the context of that person's life role and routine. Proposed Recommendation #1 assists the community organization in making this happen.

B. Proposed Recommendation #2: *Comprehensive Community Integration (CI) TBI services should be based on current evidence-based research (where available) within the following modalities:*

- 7) *Case management*
- 8) *Transitional/reintegration therapies*
- 9) *Caregiver respite and counseling*
- 10) *Advocacy services*
- 11) *Vocational services*
- 12) *Independent living services*

1) Case Management:

Case management (CM) is a complex intervention for many complex chronic medical conditions, including traumatic brain injury (Lukersmith, 2015). To be successful CM requires multi-faceted support services, interventions and programs (Khan, 2003). Case management comes in variations to support the different sectors where it is utilized, such as health, social, psychosocial, vocational, etc., and can be used in medical, rehabilitation, social public and private environments with both high and low resource scenarios (Huber, 2002). It is a protocol to “support the coordination, integration and management of health and social care in many different contexts for different health conditions.” (Lukersmith, 2016, P#2).

Of the tools discussed by the interviewees, both the CATBI members and the external respondents listed case management as one of the critical foundations for future success. Case management can help reduce costs while safeguarding a TBI survivor’s quality of care (Huber, 2004); it has demonstrated to be effective in many aspects of chronic illness care (Freund, 2010) and has been a valuable tool used to monitor which program interventions are most effective (Young-Joo, 2014). In addition to assisting the TBI survivor adjust to the community, CM can also help an organization recognize whether program components continue to remain useful within the context of the TBI survivor’s daily life. Based on everyday programmatic practices, CM can assist TBI CI organizations needs to identify and distinguish problems within programs that produce dissension between the recommended and the actual program (Reamer, 2018).

2) Transitional/reintegration therapies

As noted earlier in this dissertation, these reintegration therapies include occupational, speech and physical therapies, which continue to benefit TBI survivors after release from rehabilitation. This area of care, also known as transitional rehabilitation therapy, is growing due to an aging baby boom population. These types of therapies when added to a CI program, successfully improve outcomes of TBI survivors (Horstein, 2006). Many of the stakeholders interviewed in Chapter 6 agreed these therapies have improved individual outcomes. Whether this equates to having therapists on-staff or collaborating with community partners to provide transitional/reintegration therapies, this should be a part of any CI organization's programs.

3) Caregiver respite and counseling

Someone who steps into the caregiver role for a TBI survivor is often faced with new demanding responsibilities that may suddenly stretch over a lifetime. A caregiver's lifestyle changes rapidly as they often become more isolated and face challenges such as a lack of personal time, a decrease in privacy, increase in stress, and changes in sleep patterns and employment, as well as poorer health outcomes and a generally lower quality of life (Marsh, 2002). The caregiver can also become isolated from other family members thereby negatively affecting overall functioning within the family (Kolakowsky-Hayner, 2001). These caregiver challenges are also connected to lower rehabilitation results in the TBI survivor (Sander, 2013). Positive TBI survivor outcomes are directly connected to the level of a caregiver's commitment to supporting relationships with the TBI survivor and organizational staff (Glenn, 2005). When a caregiver is emotionally, psychologically and socially supported, all persons involved benefit.

The importance for the TBI survivor's overall quality of life is connected to the mental, emotional and social health of her/his caregiver (Sander, 2013). Examining the current type of

caregiver education and support provided within CATBI would assist the organizations to better assist caregivers. Research indicates that the caregivers' most important educational needs included receiving honest information about TBI, finding financial support, and learning about local community resources (Carlozzi, 2015). Additionally, the ability to feel hope, obtain psychological support when needed, and to know someone would be there to talk about feelings were also important to caregivers (Powell, 2017). Carlozzi found that caregivers are most stressed by prospective behavioral and cognitive changes their TBI survivor might face and welcomed the opportunity to share their fears with CI staff (Carlozzi, 2015).

CATBI members and external interviewees in the current emphasized the value of caregiver support and education; however many also noted that higher costs prohibit most CI organizations for providing full caregiver programs. As such, CI organizations are encouraged to create a caregiver module, even if this equates to a monthly support group for caregivers.

4) Advocacy services

The phrase "Advocacy Services" has several meanings for the CI community. The first definition describes a community integration model of service supporting the TBI survivor and caregiver population at the organizational level, with the second explanation pertaining to legislative efforts at a macro level. In this section advocacy services pertains to the first definition and is a part of the CI model of services, with each CI organization working individually with TBI survivors and caregivers to accomplish a myriad of daily tasks under the goal of becoming independent within the survivor's community. This includes assisting the survivor in obtaining housing, social security benefits, understanding their rights within the healthcare sector, learning to navigate transportation challenges, and other important tasks. This

definition was compiled from the interviews done with CATBI members and internal respondents, as this researcher could not find robust literature on this specific model of service.

5) Vocational services

For many TBI survivors, getting back to work is one of the most, if not the most, important goals they want to achieve after a TBI (Johnston, 2005). For those wanting to get back to employment, vocational status is a strong indicator of overall life satisfaction within this group (Hart, 2006). There are three models for vocational services currently available to CI organizations: program-based vocational model which is centered on job skills training and placement assistance; individual placement through the supported employment model; and the case coordination model (Fadyl, 2009). Each model has a different emphasis, with the program-based model concentrating on jobs skills; supported employment model centering on training on-the-job with continuing support at the work site; and case coordination model focusing on the holistic view of overall coordination of rehabilitation services and early interventions (Malec, 2006).

The program-based model is focused on one-on-one work with the TBI survivor within a very structured platform, with outcomes equating to completing work trials and successful placement with transitional job support (Wehman, 2005). Supported employment or the individual placement model was initially modified to be used with brain injury during the 1980s (Wehman, 2000). It entails quick job placement with minimal pre-employment training; individual on-the-job training while supported by a job coach until a specified level of competence is reached; and continued monitoring of the individual's job performance (Wehman, 2005). The differences between the supported employment model and the other two models is that under supported employment the intervention occurs on-the-job, and there is no specified

time or limit required for completion (Fadyl, 2009). Case coordination approaches vocational services as more an integrated part of a holistic system of care rather than a stand-alone service, individualized to suit the TBI survivor (Malec, 1995). A case coordinator assesses each individual's service needs and then often refers the individual out for vocational rehabilitation (Malec, 2006). The key differences between case coordination and the other two vocational models mentioned are that case coordination concentrates on early intervention and overall care as well as a coordination of vocational services along with other post-acute, community integration services (Fadyl, 2009).

All CATBI organizations in the current study have vocational services and many directly work with the DoR on expanded services including job coaches. Additional services and partnering with the DoR on other vocational programs would expand CATBI members' ability to assist even more TBI survivors in vocational training.

6. Independent Living Services

Independent living services are based upon the Independent Living movement, which began in the late 1960s. The definition is reflected in the title – these services are created in order to assist a TBI survivor to overcome the many obstacles they may face as they re-enter their community while working towards attaining their goal of independence, whatever that may mean for them. This includes social, physical and psychological barriers the TBI survivor will need to overcome, depending upon the severity of the TBI. Social barriers can include inaccessibility issues for employment, housing and transportation; language and communication difficulties. Physical impediments would be daily hygiene, teeth brushing, and cleaning of the survivor's personal space. Psychological obstacles include emotional trauma and understanding why life is now so different for the TBI survivor; depression; and learning to deal with perceptions of others

outside of their own support system. Independent living services have been a core component of community integration model since the 1970s. Each of the CATBI organizations interviewed have robust Independent living services model in place.

Proposed Recommendation #2 represents the core services a strong comprehensive community integration. As with Proposed Recommendation #1, this can be used as a guideline when creating an organization's individual program to suit the needs of their own TBI survivor population.

C. PROPOSED RECOMMENDATION #3: *TBI CI service organizations should adopt the integration of a Chronic Care Model (CCM) for brain injury that conceptualizes each individual's condition. In applying this model the following should be addressed:*

1. *Self-management tasks*
 - *Medical management of condition*
 - *Life role management: creating new behaviors*
 - *Emotional management*
2. *Self-management skills*
 - *Problem-solving*
 - *Decision-making*
 - *Resource utilization*
 - *Patient/provider partnership*
 - *Action planning*
 - *Self-tailoring*

While TBI has yet to be officially acknowledged as a chronic condition by policymakers, it is not for lack of interest on the part of the TBI healthcare sector. Those healthcare professionals directly working with TBI survivors see a value for a chronic care model (CCM) specifically adapted for TBI. The Chronic Care Model is the most recognized system for lifelong care management, and has been adopted in many countries (Heiden, 2018). The challenge facing the members of the TBI continuum of care is that support and services for TBI survivors who

face multiple long-term disease states are often fragmented, duplicated or poorly designed. As noted earlier in this dissertation, this hampers the provision of services and outcome efficiencies.

Over the last 15 years, rehabilitation professionals have come together and recommended that TBI should no longer be viewed as a single event, but rather a chronic disease with possible lifelong complications (Malec, 2013). The need for a disease management system tailored for the multi-symptom chronic phase of TBI is recognized as an important next step in supporting the underserved needs of TBI survivors and their families (Lewis, 2006). And while the Institute of Medicine recognizes there is a need to create a disease model of acute-to-chronic TBI (IOM, 2009), the challenge is that more is known about the acute care process for TBI rather than the chronic phase of TBI. Our medical system is built to treat acute illnesses and is poorly equipped to support chronic illness - the exact stage where community integration could make a positive difference (Coleman, 2009). During the 2013 Galveston Brain Injury Conference, conversation focused on the Chronic Care Model (CCM) and how one could be developed for TBI based upon CCMs already in use (Malec, 2013). The adaptation of the CCM for TBI would be an asset to the whole TBI continuum of care community, specifically because a CCM addresses “the long-term management of chronic medical conditions as a dynamic interaction between all levels of health systems and community resources” (Heiden, 2018, P#135). This is where the community integration sector can step up and contribute to a CCM for TBI.

The self-management tasks and self-management skills lists itemized above in this proposed standard reflect literature gathered on the most prominent CCM disease application, diabetes (Nagelkerk, 2005). As a chronic condition, diabetes presents the highest level of self-management burden of any disease CCM (Heiden, 2018); for example, multiple daily testing and monitoring of glycemic levels that need to be shared with physicians. The second chronic

condition with a large self-management burden would be cancer survivorship (Hewitt, 2005). Collectively, TBI does not have as high a level of self-management burden as diabetes, but it can intensify for individual TBI survivors, making the individual range of burden far greater for TBI (Hewitt, 2005). For example, chronic headaches can plague a TBI survivor, leading to a higher rate of depression, thereby intensifying the burden of self-management (Lucas, 2016). And while the CCMs for diabetes and cancer survivorship do provide evidence-based directives that can be applied to TBI for improving the health and overall quality of life, neither of these CCMs provide instruction for cognitive deficits. A recent introduction of a CCM for neurological conditions does incorporate an additional methods for support in caring for patients with neurological conditions such as Parkinson's disease or Multiple Sclerosis, but this CCM has yet to be validated. Currently no CCM for any chronic disease reflects features supporting cognitive deficits (Heiden, 2018).

Since the Chronic Care Model is the most accepted care system throughout the world for chronic disease states (Coleman, 2009), it would make sense this model would be the preferred evidence-based multi-system standard with which to evaluate the intricacies of TBI services (Malec, 2013).

D. PROPOSED RECOMMENDATION #4: *TBI CI service organizations should facilitate communication by helping the TBI survivor to access the following in order to assist the survivor to learn life strategies:*

- 3) *Assistive technology tools and formal strategies to teach communication techniques to TBI survivors, caregivers, and CI services staff*
- 4) *Corresponding training and educational resources to ensure the TBI survivor is supported as technologies develop over time*

Interviewees for both CATBI and the external respondents in this current study expressed the importance of using technical innovations and communication tools in support of ensuring the TBI survivor's adaptive success as they are reintroduced back into the community (see Chapter

6). The advancements attained in technology within the last thirty years have made computers an integral part of life for the overall population. Similar tools have been adapted for TBI survivors in the form of assistive technology, with the overarching objective being the enrichment of daily life for TBI survivors. The use of assistive technology should enable a TBI survivor to reliably perform pertinent tasks and skills, which ultimately lead the TBI survivor to accomplishing independent activity (Bergman, 2002).

Rehabilitation professionals utilize tools in the remediation rehabilitation of a TBI survivor's dysfunctional brain through the use of repetitive processes and include tools such as calculators and watches with alarms (Bergman, 2002). While these devices do perform an important function, they are narrow in scope and don't always address the many needs of the TBI survivor. An integral part of an assistive technology organizational strategy would be to include a cognitive orthotic program focusing on the specific cognitive needs of each TBI survivor. This type of programming is used to assist a TBI survivor in carrying out life activities they can no longer accomplish on their own due to the trauma they face from the brain injury. Based upon principles of neuropsychology and cognitive psychology (Bergman, 2000), a cognitive orthotic design requires a clinical understanding of a TBI survivor's neuropsychological strengths and weaknesses as well as a focus on the iterative process. There are many educational products that can be used in this program, and because technology is literally being updated almost daily, each community integration organization should look to which tools work best from their own needs. Done correctly, cognitive orthotic design can assist a TBI survivor to successfully complete everyday tasks, thereby boosting self-esteem, increasing self-satisfaction and emotional stability. These advantages are mirrored beyond just the TBI survivor to family and caregivers

who encounter decreased anxiety, enhanced relief and satisfaction from watching their loved ones' improved functioning (Bergman, 2002).

E. PROPOSED RECOMMENDATION #5: *Outcome identification plan: CI service organizations should select validated measures for inclusion in a comprehensive and ongoing protocol for assessing both disease and Health/Quality of Life (HQoL):*

- 4) *Psychosocial screening at intake for both TBI survivor and caregiver*
 - 5) *Evidence-based tools to be used incorporating wide-ranging health-related and psychosocial problems, including physical symptoms of TBI injury and chronic conditions; emotional distress; material needs; social supports; behavioral health risks*
 - 6) *Psychosocial quality-of-life outcome measures*
- These tools should be administered at in-take and at regular intervals informed by the expected timeline for program enrollment and patient goals.*

Proposed Recommendation #5 speaks to the importance of screening and outcomes within the community integration services. While there are many types of evidence-based measures to choose from, it is up to the individual community integration organization to decide which best fits their model. Chapter 3 of this dissertation lists suggested outcomes that are evidence-based and used by current CATBI members. Any community organization starting out building their service model should see what it is they want to measure. The important things are that outcomes be evidence-based and current in the field.

The World Health Organization (WHO) has defined quality of life as “the individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” (WHO, 1995, P#1). This definition is driven by the individual’s personal perception of their own ability to function. Because quality of life is broad in its meaning and can be affected by multiple issues, the health-related quality of life model was created (HRQOL). This measure takes into consideration how an individual perceives their illness and how subsequent treatment might affect the social, physical and mental components of their life (Polinder, 2015). HRQOL measures have been used

in medicine for over thirty years but have only been applied to TBI since around 2005 (Petersen, 2005). Prior to that time, many in the medical field incorrectly assumed that a TBI survivor was unable to satisfactorily assess their own quality of life (Polinder, 2015).

F. PROPOSED RECOMMENDATION #6: *CI service organizations should work towards addressing social determinants of health that are particularly relevant for the TBI populations such as the high rates of homelessness and previous incarceration.*

Built into this community integration care recommendation is the underlying foundation of social determinants of health (Commission on Social Determinants of Health, 2016). These determinants are the circumstances in which people live and include the economic, environmental, political and social conditions which are the contributing factors for a healthy life, ability to function in life and the community, with outcomes that reflect risks and quality of life.

As the medical sector increasingly emphasizes the benefits of patient-centered care, community integration mirrors this in its support of the TBI survivor. Reflecting a holistic approach, community integration has assimilated many psychological, social and emotional aspects of care in order to support a TBI survivor through his/her lifetime. Because community integration promotes a better quality of life for a TBI survivor based on improving the determinants of health, it makes sense that proposed community integration recommendations would reflect some of the objectives of Healthy People 2030, the evidence-based, 10-year plan created by the US government in ongoing efforts to improve American health (Open for Comment: Healthy People, Proposed 2030 Objectives. 2018). While the proposed 2030 plan includes chronic health conditions such as diabetes, chronic kidney disease, cancer and dementia, it does not yet recognize TBI as a chronic disease. Nevertheless, there are recommended 2030 objectives that can be incorporated into the proposed recommendation #6 for community integration. These include: access to care; disability and health; educational and community-

based programs; injury and violence prevention; mental health; nutrition; older adults; oral health; opioids; physical activity; substance abuse; and tobacco use (Open for Comment: Healthy People, Proposed 2030 Objectives. 2018). More and more, disability is increasingly seen as an essential component of population health (Polinder, 2015). Each TBI organization can and should take advantage of the evidence-based outcomes being proposed in the 2030 Healthy People objectives in order to improve the quality of life for TBI survivors and caregivers.

Rates of homeless and incarcerated TBI individuals are important statistics for not only community integration organizations, but also for physicians, hospital and other sectors of the continuum of care. These rates affect not only health outcomes of these at-risk populations but also financial, environmental and social outcomes of society as an aggregate. If CI organizations are able to decrease the health disparities of these populations by collaborating with community partners through devising cooperative measures, this will benefit all of society.

G. PROPOSED RECOMMENDATION #7: *CI organizations should invest resources to ensure that staff members have specific training and certification to work with survivors.*

All CATBI members interviewed for the current study are aware of the weak linkages within their local version of the TBI care process. These links are usually the transition points of TBI survivor hand-off to the next subsystem, where accountability for the survivor may not transition along with the patient. Each CATBI member has staff that are seen as TBI Care Coordinators. These staff are multi-disciplinary in their capacities to advocate and support TBI survivors and care givers through not only the community integration services but through efforts at assisting the survivor with clinical visits, chronic care management, counseling and caregiver support. This position is a resource for community integration organizations. Because this staff position has the ability to be a potential focal point for the handover of TBI survivors from the medical

and rehabilitation sectors on to CI services, CI organizations are a resource that could be monetized to the CI organization's advantage.

Community integration staff are dedicated to improving the quality of life for all those affected by TBI. Education for community integration organizational employees empowers the staff to grow and broaden their experiences. To that end, proficiencies should be incorporated into all employee performance measures, with a stated outcome of certifying as many staff as possible to be certified brain injury specialists (CBIS). Building a strong foundation for staff proficiencies will enable community integration organizations to compete for a high caliber workforce which then supports TBI survivors and families.

H. PROPOSED RECOMMENDATION #8: *CI service organizations should work to engage health professionals across multiple disciplines of the TBI Continuum of Care for the holistic delivery of TBI CI care reflecting a chronic care model, with the intent of improving service delivery and increase the quality of life for TBI survivors by communicating regularly with health care providers to ensure that CI outcomes can be considered within a large plan of care.*

Seeking opportunities (with patient permission) to receive feedback and status updates from health care professionals can inform patient progress in both the CI and medical sectors. A good example of CI/physician communication would be the sharing of CI outcome results with a TBI survivor's physician, and then the physician reciprocating with any pertinent health information. If following Proposed Standard #5 above, a CI organization will be able to build a strong outcomes-driven program that can then be shared with other healthcare providers within the TBI continuum of care. This enables all providers to build a holistic vision of what an individual TBI survivor would need to progress.

PROPOSED RECOMMENDATION #9: *CI service providers should look for opportunities to align their organizations with the medical and rehabilitation sectors in an effort to improve TBI care coordination and enhance patient outcomes. In addition, leveraging these partnerships may enhance the sustainability of CI organizations, specifically through collaboratively participating in advocacy projects with these sectors. Working closely with the medical and rehabilitation*

sectors may also open up funding opportunities that are currently not available to CI organizations.

The TBI continuum of care is composed of smaller sub-systems all committed to reducing mortality and morbidity rates of the TBI survivor. These sub-systems work to enhance cognitive, functional, social and therapeutic outcomes for the TBI survivor, in the hopes of initially sustaining life and then moving on to improving quality of life (Caro 2010). The TBI continuum of care combines caregivers and care systems in order to have a positive impact on TBI survivor outcomes. These care systems are "... complex adaptive systems, which are cross-functional, cross-organizational and cross-systemic" (Caro, 2011, P# 21). But these systems are disparate and tend to function within their own silos, with each silo populated by its own various clinical and resource concerns, sustained by disjointed information data systems (Caro, 2011).

In addition to the importance of the medical component of the continuum of care, ancillary services should be seen just as critical to TBI survivor recovery. Gutman (2009) notes that these supplementary services include audiology, behavioral therapy, cognitive rehabilitation, occupational therapy, optometry, physical therapy, pharmacological therapy, psychiatry, improve patient satisfaction and maximize functional recovery (Gutman, 2009). This is the space where community integration has the opportunity to become a viable and respected partner. Looking at Guzman's list of ancillary services it is clear that many (if not all) of these are services could be provided by a community integration organization, either through work done directly at the organization or in the community with collaborative partnerships.

As more providers recognize chronic care is needed for TBI survivor, and as funding and overall resources are positioned to support TBI survivorship over the long-term, it becomes imperative that TBI continuum of care subsystems collaboratively reassess the current sustainability of the whole TBI system of care. Each community integration organization,

whether a CATBI member or non-member, has the ability to connect with their respective community partners within their geographic areas in order to create a matrix that reflects both common goals and specific available resources to achieve those ambitions. Building an overall matrix between each community integration organization and their local TBI healthcare partners would only strengthen the care system for TBI survivors and caregivers, while improving the mutual collaboration between all subsystems of the TBI continuum of care.

One of the collaborative areas that could strengthen CI organizational sustainability is the realm of advocacy. For advocacy to be successful a strategic advocacy plan should be implemented that is adaptable for use across CI organizations. This can be challenging for several reasons: it requires an understanding of relevant complex issues affecting TBI survivors in community integration; there must be a useful mechanism for delivering communication to all audiences involved; there needs to be strategic skill in recognizing and implementing solutions; and resources need to be effectively assembled for use in furthering these identified solutions (Reid-Arndt, 2010). Additionally, the complex array of possible health consequences can make the CI advocate's job problematic.

In the early days of TBI community integration services, there wasn't always an understanding of the link between clinical practice, community integration and advocacy (Goodall, 1994), but as the years continued and a concerned group of professionals formally created the Brain Injury Association of America (BIAA), advocacy coalesced into an important educational tool (Rosen, 1994). One of the first successful efforts of BIAA was to get both medical professionals and government policymakers to recognize that TBI was in fact a disability, and that its uniqueness calls for a specific support system of treatment (Reid-Arndt, 2010). Secondly, BIAA management understood that advocates must assist policy makers in

understanding and acknowledging that the US healthcare system focuses primarily on acute care and does not adequately prepare both the healthcare sector and the TBI survivor for the possibility of a life-long disability (Goodall, 1994).

Initial advocacy efforts produced an effective plan for overall TBI services (from hospitalization to rehabilitation to community integration) which remains relevant for use today in the community integration sphere (Rosen, 1994). First, when addressing all audiences, advocates for TBI community integration services must speak to the distinctive dynamics linked to the initial TBI injury. This includes the possible stigma of “blaming the victim” for the injury coupled with any prospective cognitive and physical infirmities the TBI survivor may encounter. Second and equally important is educating all audiences on the multitude of prospective outcomes and long-term health issues and how these can challenge program services and CI models (Reid-Arndt, 2010).

While advocacy can save both lives and healthcare costs, CI advocates should remember this is often an uphill educational battle to gain acceptance by both public and governmental cohorts. In 1967 mandatory nationwide helmet laws were required for all states by the federal government in order for states to access highway construction funds. By 1975 only three states had not implemented a universal helmet law (Insurance Institute for Highway Safety, 2010). But in the ensuing years, vocal anti-helmet constituents have chipped away at the universal helmet requirement so that in 2009, only 20 states had the universal helmet laws intact, with 27 states having partial use laws (for young riders and specific populations), and 3 states having no helmet laws (Reid-Arndt, 2010). It has been shown that with helmets, motorcycle injuries are less severe and have better outcomes, and if all motorcycle riders wore helmets, the healthcare costs would be reduced by \$32.5 million just on the basis of intensive care unit days (Croce, 2009).

Alignment of CI organizations with the medical and rehabilitation sectors through collaborative advocacy not only pushes TBI survivor needs to a prominent position for all three sectors, it also can improve sustainability for CI organizations. By working collaboratively together there exists a level of visibility on the macro-level that would benefit CI organizations. This alignment of CI with medical and rehabilitation care providers provides a critical opportunity for the other health care sectors to see CI as a partner – something CATBI members voiced as one of their wishes. This collaboration may also eventually lead to more defined partnerships CATBI, opening up new and important funding streams.

Sustainable funding is the most important goal for CATBI members. By working on creating closer, more defined community partnerships, CATBI could open up new funding streams all while becoming an important resource for these community partners. For example, the Centers for Medicaid and Medicare (CMM) has published specific outcomes for hospitals to achieve in order to continue to receive government funding. Not all of these measures can be applied to TBI survivors, but there are several which could benefit both the CI organization and collaborating hospital. The 30-day risk standardized readmission measure is an important metric for any hospital, since this is the timeframe where many patients present for readmission. The CI organization can work with their TBI survivors to decrease this percentage, thereby assisting the partnering hospital in their outcome measures. The same would be true of reducing the reliance of using the emergency room as a primary care provider. CI organizations are on the front line of health care, and these organizations can make a difference in, as one CATBI interviewee stated “the ‘frequent flyer program of using the ER.” With a strong case management component, CI organizations have the ability to assist in finding housing and getting homeless TBI survivors off the street and enrolled with a Patient Centered Medical Home (PCMH). The TBI survivor is no

longer homeless and much less apt to use the ER as a primary care provider, which improves that metric for hospital.

CATBI should consider in the future the concept of becoming a 501(c)3 non-profit entity, with membership to begin with consisting of the current seven sites. With the ability of providing metrics at all levels, these outcomes would consist of: the individual TBI survivor level; the specific CATBI site, and CATBI overall. Being one collaborative voice gives CATBI the collective power to seek out additional types of funding, including California Mental Health Services Authority (CAL-MHSA) and large state health care foundations (such as the California Endowment or the California Wellness Foundation). Finally, the Medicaid Waiver should again be considered. It has shown to be a critical long-term funding stream in the states that have qualified for the program and is too important a type of funding to ignore.

CHAPTER 8 – CONCLUSION

The goal of this research was to inform the development of recommendations to guide community integration organizations in supporting adult traumatic brain injury (TBI) survivors in California. In order to achieve this goal, a study composed of several parts was conducted to briefly review the existing literature on TBI epidemiology and the treatment continuum, including community integration. In addition, given the goal of improving CI care in California, a decision was made to conduct a case study of a network of CI providers, California Association for Traumatic Brain Injury (CATBI). This group is composed of seven non-profits who have been engaged long-term in the delivery of CI services to TBI patients. These grassroots organizations are small in scale and operate with very modest budgets. Aims of the case study were to describe how TBI is conceptualized and treated in California and to solicit feedback from CI service providers and others within the TBI continuum of care on their perceptions of

how to improve CI treatment in California. Ideally, CI programs would deliver services based on outcomes of controlled effectiveness studies. However, given the current dearth of such research, it was decided that soliciting expert opinions via interviews would be a logical next step in informing CI care for California.

Chapter 1 briefly introduced the topic and articulated the purpose of the dissertation. Chapter 2 presented a case for TBI community integration to be seen within the context of a public health and policy issue affecting millions of people. It also described a summary of the epidemiology of TBI and a conceptualization of TBI as a chronic disease, with potential life-long ramifications for a TBI survivor. Chapter 3 gave an overview of community integration and prospective assessments that would be of value to the community integration TBI sector. It also explored the strengths and weaknesses of existing evidence-based model programs from which the TBI community integration sector could possibly adapt sections for proposed recommendations. Chapter 4 introduced the topic of TBI in California and the California Association of TBI providers (CATBI), a statewide network of seven state-wide organizations that currently receive grant funding for community integration services from the California Department of Rehabilitation (DoR). In Chapter 5 methods used in this dissertation were detailed, with qualitative description serving as the approach preparation for analysis. Chapter 6 summarizes key findings from interviews and a focus group, which then informed Chapter 7 and the development of recommendations for organizations providing CI to TBI survivors and their family members.

Results of the literature review, interviews, and focus group confirmed a lack of standardization related to delivery of CI services. While each CATBI organization expressed a high level of commitment to supporting TBI survivors in attaining a better quality of life,

organizations differed with regard to organizational structure and philosophy, the conceptualization of CI, the importance of monitoring treatment outcomes, and the key services to be included in CI programs. As a result, the type and quality of services provided by CATBI organizations varied widely.

Interviews revealed the high level of challenges facing the CI sector, and stakeholders willingly shared their opinions on what they respectively saw as the most critical barriers. For CATBI organizations, they want the opportunity to be seen as an equal partner at the table along with the other players in the provision of care to TBI survivors. But in doing so, the CATBI members worry that if they move towards using a language that is more medical in intent (such as the phrase “case management”) they will lose their distinctive character and be lost in the medical sector. They respect the medical and rehabilitation sectors, but they also believe what CI offers is as important as those two areas and want to remain independent from the other sectors of care. They believe TBI education is important, for medical professionals and the public alike. There is a need for a concerted effort to promote advocacy at all levels, but currently the CATBI sites have neither the staff nor the funding to properly devote to this important effort. CATBI members suffer from “funding fatigue” - always chasing after each dollar. They want to be able to have a major funder who sees what they can do and fund accordingly on a long-term basis. Staffing is a worry for all seven CATBI organizations, with the challenge being the inability to provide proper pay for equivalent experience, especially when faced with tight budgets. And while CATBI members do value outcome assessments, they often feel as if there isn’t enough time to deliver good program services *and* implement assessments. All CATBI sites firmly believe the services they offer clearly benefits their TBI survivor members; they are just unsure

how to demonstrate and measure these improvement so that they can build sustainability.

Finally, CATBI believes that finding a long-term major funder within five years is achievable.

The external stakeholders had opinions about the state of CI care as well, and these views differ qualitatively from that of CATBI representatives in several key areas. They believe that to be taken seriously, the CI sector should not hesitate to incorporate the taxonomy and assessment tools favored by medical and rehabilitation sectors. In fact, this group of respondents believes that in order to provide the highest quality of services to TBI survivors, strong partnerships with the medical field will be necessary, especially since the external stakeholders see physicians and hospital as central to the wellness model. These stakeholders also expressed that these partnerships with the medical community will likely be key to the long-term viability of CI organizations due to the potential for increased, stable funding. This funding could be achieved through either collaborating to be included in the regional center services; re-visiting the Medicaid waiver for TBI; or looking at partnering with local hospitals. The external stakeholders agree with CATBI in the importance of community outreach but would like to see it taken further to include the business community. They were very vocal about the need for educational resources to promote TBI awareness across all populations. These respondents were also very aware that TBI as a disability is often lumped in with other disabilities such as intellectual disabilities and developmental disabilities and are concerned that in this lumping process the unique needs of the TBI population are obscured. External stakeholders also expressed the need for CI organizations to secure necessary funding to pay staff members a competitive salary, and while they understand this can be challenging, it will ultimately be worthwhile for the organizations. They also valued the importance of outcome assessment and expressed much more positive attitudes about the need and value of outcome assessments than did CATBI

representatives. The external stakeholders were very vocal about the importance of both quantitative and qualitative assessment measures. Finally, external respondents had a much bleaker outlook about the long-term viability of CATBI organizations without major changes taking place in the near future. Their responses reflected a clear sense of urgency for identifying solutions to address the challenges facing the organizations.

The Focus Group with representatives of CATBI organizations was helpful in that it allowed a face-to-face meeting between all seven organizations and dedicated time to discuss strategies for moving the group forward. The two documents which emerged from this discussion were a table summarizing services delivered by each CATBI organization and a second table that described the organizational structure of each CATBI site. These tools will allow CATBI members to compare and contrast sites and identify potential areas for modifications or growth. These two documents can be seen as “jumping off points” for the next stage of CATBI’s efforts to improve the quality and consistency of services delivered by CI organizations and the long-term viability of these organizations.

This research revealed that the challenge community integration organizations are facing in remaining fundable and sustainable is the most critical issue for the field at this time in California. Each of the CATBI organizations interviewed expressed frustration with regard to how tight their budgets were and how little is left over after all monthly costs have been addressed. Therefore, the proposed recommendations put forth in this document included a focus on how organizations might work towards the securement of a higher level of funding that is also stable and sustainable.

The original research goal was to produce a set of recommendations which could be applied to any CI organization in the country, but as this dissertation progressed it became clear to this

researcher that, with the harsh realities facing California CI organizations in particular, community integration within this state should be the focus. After interviewing the individuals in both CATBI and the external stakeholder groups and learning what each perceives as important topics for successful TBI CI care, this researcher would hope to see that CATBI organizations be guided to 1) read and review these proposed recommendations; 2) work together to investigate how these recommendations can guide service delivery; 3) apply these recommendations to CATBI; and 4) collectively begin to seek out funding from such organizations as the California Endowment, the California Wellness Foundation, the California Department of Health Care Services' Mental Health Services Act-Department of Mental Health (MHSA-DMH) and other entities which might pave the way for CATBI to secure sustainable funding, permitting an increase in the provision of CI services across California, thereby improving the quality of life for TBI survivors, their families and the communities in which they live.

Appendix A: Copy of IRB Exemption Certification

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<http://ohrpp.research.ucla.edu>
GC-IRB: (310) 825-7122
M-IRB: (310) 825-5344

EXEMPTION CERTIFICATION

DATE:	2/25/2016
TO:	STEPHANIE M. BOUMEDIENE HEALTH POLICY AND MANAGEMENT
FROM:	WENDY BRUNT Principal Analyst
RE:	IRB#16-000313 A Standard of Care for Community Integration Organizations Supporting Traumatic Brain Injured Adults

The UCLA Institutional Review Board (UCLA IRB) has determined that the above-referenced study meets the criteria for an exemption from IRB review. UCLA's Federal wide Assurance (FWA) with Department of Health and Human Services is FWA00004642.

Any modifications to the research procedures must be submitted to the OHRPP for prospective review and certification of exemption prior to implementation. The project must be renewed by the expiration date if work is to continue.

Submission and Review Information:

Certification Date	2/25/2016
Expiration Date	2/24/2021

Regulatory Determinations

-- This research has been certified as exempt from IRB review per 45 CFR 46.101, category 2.

Documents Reviewed included, but were not limited to:

Document Name	Document Version #
16-000313 Email Request for Interview - BOUMEDIENE.pdf.pdf	0.01

General Conditions of Approval

As indicated in the PI Assurances as part of the IRB requirements for approval, the PI has ultimate responsibility for the conduct of the study, the ethical performance of the project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the IRB.

The PI and study team will comply with all UCLA policies and procedures, as well as with all applicable Federal, State, and local laws regarding the protection of human subjects in research, including, but not limited to, the following:

- Ensuring that the personnel performing the project are qualified, appropriately trained, and will adhere to the provisions of the approved protocol,
- Implementing no changes in the approved protocol or consent process or documents without prior IRB approval (except in an emergency, if necessary to safeguard the well-being of human subjects and then notifying the IRB as soon as possible afterwards),
- Obtaining the legally effective informed consent from human subjects of their legally responsible representative, and using only the currently approved consent process and stamped consent documents, as appropriate, with human subjects,
- Reporting serious or unexpected adverse events as well as protocol violations or other incidents related to the protocol to the IRB according to the OHRPP reporting requirements.
- Assuring that adequate resources to protect research participants (i.e., personnel, funding, time, equipment and space) are in place before implementing the research project, and that the research will stop if adequate resources become unavailable.
- Arranging for a co-investigator to assume direct responsibility of the study if the PI will be unavailable to direct this research personally, for example, when on sabbatical leave or vacation or other absences. Either this person is named as co-investigator in this application, or advising IRB via webIRB in advance of such arrangements.

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