California Traumatic Brain Injury Program State Plan

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# Acronyms

ABI Acquired Brain Injury

ACL Administration for Community Living

BI Brain Injury

CA California

CalAIM California Advancing and Innovating Medi-Cal

CDC Center of Disease Control

CIQ Community Integration Questionnaire

CVC California vehicle code

DMH Department of Mental Health

DOR Department of Rehabilitation

EMS Emergency Medical Services

HARC Health Assessment and Research for Communities

HRSA Health Resources and Services Administration

LEMSA Local Emergency Medical Service Agencies

MPAI-4 Mayo-Portland Adaptability Inventory

nTBI Non-Traumatic Brain Injury

PTSD Post-Traumatic Stress Disorder

SB Senate Bill

SD Standard Deviation

TBI Traumatic Brain Injury

VA Veterans Affairs

# Executive Summary

The California Traumatic Brain Injury (TBI) Program State Plan, required as part of the Administration of Community Living (ACL) Grant, is a living document that provides an actionable, measurable blueprint to leverage partnerships and funding, to meet the needs of all Californians affected by TBI.

The Program is part of the California Department of Rehabilitation’s (DOR) TBI Program which acts as the umbrella entity to the TBI Advisory Board, the State Plan Committee, the Registry Committee, the Needs Assessment Committee, the Sustainable Funding Committee, the Survivor Committee, and six State-funded TBI sites.

This Plan lays out a brief history of the TBI Program, and the work of the committees to develop a blueprint to guide the program to achieve its goals. Guided by the State Plan Committee, the State Plan will be revised at least annually to ensure it remains relevant and is working towards programmatic goals.

The goals of the California State Plan are:

* Establish a TBI Advisory Board with collective knowledge to work with DOR to identify policies, practices, and an applicable and stable funding source which could include a private public partnership.
  + Improve resource facilitation and coordination for people with TBI and their caregivers by creating a statewide TBI needs assessment survey that provides data on gaps in services and supports.
  + Identify one or more funding mechanisms to support locally based services and outline ideas for funding mechanisms for expansion of services and usable resources for longer-term funding.
  + Create a statewide TBI registry through the work of a committee to design and develop a statewide TBI registry with appropriate interagency agreements between state departments.
  + Create a Survivor Committee, comprised of survivors of all brain injuries, to establish and promote plain language materials, education, and training about TBI for survivors and the and public, medical, rehabilitation, and community support professionals about the needs of TBI survivors and their families.
  + Provide culturally competent resources to entities that intersect with homeless and domestic violence populations to expand systems to support early identification, interventions, resource facilitation, and coordination for people with TBI.
  + Utilize data to inform policy, education, and training leading to expanded services and supports through a statewide network for TBI Survivors.

This report lays out the work to date of the various TBI committees to reach these goals and plan a path forward to a unified, fully funded TBI network that meets the needs of all Californians with TBI.

# California’s TBI Program

## Background

The California Department of Rehabilitation works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living, and equality for individuals with disabilities.

California’s TBI Program is located within the Independent Living and Community Access Division. This Division and its sections and programs are dedicated to transforming the lives of people with disabilities through education, advocacy, and partnerships to help build a world without barriers for people with disabilities.

## Funding history

In 1998, after three unsuccessful attempts, the California Legislature passed Senate Bill (SB) 2232. The legislative intent was to establish a coordinated service model to address existing gaps and assist individuals with TBI in leading productive, independent lives. SB 2232 authorized the initial funding of $500,000 to fund four TBI pilot project service sites to be administered by the Department of Mental Health (DMH). Under SB 2232 - Seymour, Chapter 1292, the TBI Program was funded by Section 1464 of the Penal Code, through a 0.66 percent allocation of the Seat Belt Penalty Fund. The original intent of the funding was to establish demonstration projects for community based post-acute TBI services with the goal of creating a new model of service delivery that would address existing gaps in services to TBI survivors.

When the DMH was disbanded in 2009, SB 398 – Monning, Chapter 439 moved the TBI Program from DMH to DOR. Since the transfer, the TBI Program has faced declining funds; as seat belt usage has normalized, revenue from the Seat Belt Penalty fund decreased until it could no longer be a viable source of funding for the program. In compliance with one of the mandates of SB 398, DOR pursued federal grants, 1915(c) waivers, Budget Change Proposals, and a vocational rehabilitation funded service delivery model to establish sustainable statewide funding for the Program. Currently, the Program is being funded through the California General Fund as a result of legislative and Governor support; however, the funding is not guaranteed.

## Eligible Individuals

Another important aspect of California’s TBI Program is that under SB 2232 and California Welfare and Institution (WIC) Code 4354, et seq., California’s TBI Program focuses on serving individuals over the age of 18. According to 42 United States Code 15002 (8), if an individual acquires a TBI before the age of 22 and manifests developmental problems, that individual is classified as “developmentally disabled” and is qualified to receive services and benefits under that diagnosis. However, if an individual acquires a TBI on their 22nd birthday or later and it results in a disability, they will not be diagnosed with a developmental disability, and cannot qualify for those same services. This designation both limits the availability of affordable services to TBI survivors as TBI is excluded by name in many waivers for mental health services, but also makes it difficult to accurately quantify, diagnose, and treat TBI when individuals are provided with an alternative diagnosis in childhood.

## TBI Program Design

The DOR provides leadership and direction to promote employment, independence, and equality for people with TBI. DOR’s cross-disability, independent living philosophy, and experience and expertise in administering vocational rehabilitation and independent living services provide a supportive environment to meet the growing needs of Californians with TBI.

California’s TBI Program is dually funded; the state-funded program, described above, provides grants to non-profit organizations that directly serve individuals living with TBI, and a federally funded program, through which this State Plan has been created, to strengthen the system of services and supports to maximize the independence, well-being, and health of people with brain injuries, their caregivers, and families.

### State-Funded Program

For more than 20 years, the TBI Program sites have provided unique pre-vocational and community reintegration services that help bridge the gap for post-acute services needed by individuals with TBI who are not eligible for nursing facilities, in-patient care programs, or DOR’s Vocational Rehabilitation program. In addition, the TBI sites provide leadership to establish new services and partnerships for TBI survivors in their communities.

Under WIC code, these TBI Program sites must offer a core set of services to be eligible TBI survivors: supported living, community reintegration, vocational support, information and referral, service coordination, and public and professional education. The sites are situated in a variety of organizational settings, including an outpatient hospital clinic, a community services organization affiliated with a hospital, and an independent living center. A 2005 evaluative report by Berkeley Policy Associates (Independent Evaluation of the Traumatic Brain Injury Services of California – Addendum to Legislative Report 2005) showed that most individuals receiving services from these sites benefited from the core services provided, along with the additional services that each site offers. As each site is unique, services may be based on different models of care, such as medical, person-centered, or independent living, and therefore the additional services provided to consumers vary from site to site.

### Federally Funded Program

In 2018, DOR was awarded a TBI State Partnership Program grant by the U.S. Department of Health and Human Services, Administration for Community Living (ACL). The goal of this project was to establish a statewide network of resources, services, and supports that foster independence and improve the quality of life for persons with traumatic brain injury.

Under the 2018 grant, the TBI Program identified four areas for program expansion and outlined the outcomes and products it intended to create through the term of the grant.

The goals of the grant were:

* Establish a TBI Advisory Board.
* Improve resource facilitation and coordination for people with TBI and their caregivers.
* Identify one or more funding mechanisms to support locally based services.
* Create a statewide TBI registry.

The intended outcomes were:

* The infrastructure to support a TBI Advisory Board and candidates interested in serving on it.
* A statewide TBI needs assessment survey to provide data on gaps in services and supports.
* Usable resources for longer-term funding.
* A plan for creating a statewide TBI registry

The intended products of the grant were:

* Data on service gaps and levels of need per county.
* A revised website with robust data and referral sources.
* A state plan outlining ideas for funding mechanisms and expansion of services.
* A workgroup to design and develop a statewide TBI registry with appropriate interagency agreements between state departments.

In 2021, DOR’s TBI Program was awarded another TBI State Partnership Program grant from ACL to continue and expand the work of the TBI Advisory Board, Committees, and Program staff. For detailed information about the current work under the 2021 TBI State Partnership Program grant, please see [California’s Focus](#_California’s_Focus).

### Contact Information

Website: <https://dor.ca.gov/Home/TraumaticBrainInjury>

Email: [TBI@dor.ca.gov](mailto:TBI@dor.ca.gov)

Voice: (916) 558-5780

# Introduction to Brain Injury

## Definitions of Brain Injury

An acquired brain injury (ABI) is an injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. This type of brain injury is one that has occurred *after* birth and results in a change to the brain’s activity, affecting the physical integrity, metabolic activity, or functional ability of nerve cells in the brain. Brain injuries that occur from birth, or just before or after birth, are called congenital brain injury.

An ABI is the umbrella term for brain injuries after birth. There are two types of ABI: traumatic and non-traumatic.

Traumatic Brain Injury (TBI) is defined as an alteration in brain function, or other evidence of brain pathology caused by an external force such as a jolt, blow, or penetration to the head. Most non-fatal TBIs are caused by falls, motor vehicle accidents, or being struck by a person or an object, such as in sports.

Non-Traumatic Brain Injury (nTBI) is defined as an injury to the brain that is caused by internal factors, such as lack of oxygen, exposure to toxins, pressure from a tumor, etc.

TBI can be classified as mild (concussion), moderate, or severe based on the individual’s clinical presentation, and the effects of TBI can be temporary or permanent. TBI affect different areas of the brain in diverse ways, meaning that no two TBI are alike.According to hospital discharge records in California for 2018 and 2019, more than 50 percent of moderate to severe TBI patients did not go directly home. Thus, it is necessary and vital to have a wide range of services to meet individual and community needs and ensure that people have access to these services.

## Common Causes of TBI

* Falls, trips, and slips lead to half of TBI hospitalizations, with the risk increasing for older adults[[1]](#footnote-2).
* Assault, community altercations, firearm violence , elder abuse, intimate partner violence, and child abuse, which can affect brain development in children and is often missed by professionals.
* Motor vehicle accidents, which are a leading cause of death in the United States.
* Sports concussions.

## Common Causes of nTBI

* Lack of oxygen to the brain (called anoxic brain injury), can occur in cases of near drowning, intimate partner violence, electrocution, or choking.
* Blood infections, or septicemia, due to untreated infections in the lungs, skin, urinary tract, abdomen, sinuses, or teeth, Meningitis, endocarditis, and myelitis.
* Degenerative brain conditions such as Parkinson's disease, Alzheimer's disease, or some other form of dementia.
* Alcohol and drug use.
* Tumors, seizures, and surgery to remove tumors or stop seizures.
* Stroke, either through a blocked artery (80 percent of strokes) or bleeding due to an aneurysm, which is when an artery may have a damaged or weak spot from birth.

## TBI in California and the Silent Epidemic

Each year, thousands of emergency visits, hospitalizations, and deaths occur in California due to TBI. TBI disables six times more people each year than spinal cord injuries, multiple sclerosis, HIV/AIDS, and breast cancer combined. While brain injury can cause physical challenges, the cognitive, emotional, behavioral, and social challenges caused by brain injury are often the most disabling and they are also exceedingly difficult for the public to understand. This is one of the primary reasons brain injuries are referred to as the “Silent Epidemic.”

In addition to injury-related challenges, individuals and families experience difficulties and stresses associated with navigating, accessing, receiving, and paying for services. Adjustment to disability after brain injury is extremely difficult. Without appropriate care management, rehabilitation and long-term services and supports, survivors and family members frequently experience unemployment, social isolation, re-occurring hospitalizations, institutionalization, and homelessness.

TBI is a growing public health concern. Along with spinal cord injury, TBI is the greatest contributor to death and disability globally, among all trauma-related injuries.[[2]](#footnote-3) According to the World Health Organization (WHO), in 2020 TBI became the main cause of death and disability in the world and affects over 10 million people annually.[[3]](#footnote-4) Within the United States, the CDC estimated that TBI accounted for 2.87 million emergency department visits, hospitalizations, and deaths in 2014,[[4]](#footnote-5) and 5.3 million Americans live with disabilities as a result of TBI.2,4 In 2014, the CDC also estimated that TBI took the lives of an average of 155 people each day in the U.S.5

Of those that survive a TBI, over 50 percent are moderately to severely disabled at five years post-injury,[[5]](#footnote-6) and over 85 percent experienced a psychiatric disorder within the first-year post-injury.[[6]](#footnote-7) 2,4

Many people with a TBI have long lasting effects, that can result in lifelong disabilities and impairments that can include 2,4 [[7]](#footnote-8):

* Trouble communicating and learning skills
* Difficulty understanding and thinking clearly
* Difficulty speaking and word loss
* Depression
* Personality Changes
* Impulsiveness
* Problems with balance and coordination
* Weakness in arms, legs, and hands
* Problems with hearing and vision
* Memory loss or difficulty retaining information
* Inability to control emotions
* Increased nervousness or anxiety
* Headaches
* Fatigue
* Sleep Disturbance

JULIE’S STORY- AN UNDIAGNOSED TBI

“Julie” was 24 when she sustained a TBI and other bodily injuries. She was uninsured at the time of her accident and received minimal healthcare after leaving the hospital. Her life was saved, but she didn’t understand why she couldn’t keep track of things like she did before. She did not receive much education about TBI and was struggling. Without services and supports, Julie struggled through daily life, with little hope of employment and independence.

TBI has far-reaching implications, with studies demonstrating its close ties with homelessness,[[8]](#footnote-9) incarceration,[[9]](#footnote-10) substance abuse,[[10]](#footnote-11) mental health concerns, domestic violence, and US military service.3 For example, a systematic review of homelessness and TBI revealed that the lifetime prevalence of TBI in the homeless population was over 53 percent, with between 51 percent and 92 percent sustaining their head injury prior to the onset of homelessness.7 These consequences of a TBI negatively impact families, communities, and the economy; and they create a significant public health burden across the country, including California.

# California’s TBI Advisory Board

Mission Statement

The California Traumatic Brain Injury (TBI) Advisory Board advises state leadership on policies, programs, and services impacting people with TBI, their families, and support systems.

## History

California’s initial Traumatic Brain Injury Advisory Board (Advisory Board) was created in 1999, as an advisory board to the California Department of Mental Health (DMH). The Advisory Board received two Health Resources and Services Administration (HRSA) Grants. The first grant, in 2002, was a one-year planning grant. The second grant, in 2006, was a three-year TBI Implementation Grant. DMH obtained a fourth year, no-cost extension to allow the Advisory Board to complete the *Advancing California’s Traumatic Brain Injury Service System: Next Steps* report and to participate in a critical strategic planning session in June 2010 to plan for the future of the Advisory Board.

In 2009, SB 398 transferred the California TBI Program from DMH to the California Department of Rehabilitation. However, the state instituted significant government spending cutbacks in 2010 due to the Great Recession, and the Advisory Board was disbanded. Therefore, no funding existed for an Advisory Board between July 2010 and September 2018.

In 2018, DOR’s TBI Program received a grant from ACL and created an Advisory Board to guide the development of the state plan. DOR’s Directorate appointed members to the Advisory Board who were residents of California and reflected the diversity of the state with respect to race, ethnicity, gender, geography, types of disabilities across the age span, and users of types of services that an individual with a disability may receive. At least 51 percent of the Board members (including committee members) must consist of TBI survivors, ensuring a majority representation for the purpose of ensuring that all TBI Advisory Board actions and projects are aligned with the person-centered approach and maintain a focus on individuals with TBI, their families, and their caregivers.

The California TBI Advisory Board is led by its chair and vice chair and currently has five active subcommittees:

* Registry
* Needs Assessment
* State Plan
* Sustainable Funding
* Survivor

The Board meets quarterly, while the committees meet monthly. All meetings are publicly noticed and encourage public stakeholder engagement.

Each committee has worked collaboratively with the Advisory Board and the TBI Program to meet the goals and objectives outlined in the State Plan.

# Registry Committee

## Mission Statement

The California TBI registry gathers demographic and clinical data on TBI to guide public policy and improve the quality of life of all Californians affected by TBI.

## Goals and Objectives

* Develop a plan for creating a statewide TBI registry, all of which will assist in improvements to California’s TBI Program.
* Create a workgroup to design and develop a statewide TBI registry with appropriate interagency agreements between state departments.
* Collaborate with TBI State Partnership Program mentor states to explore steps and develop resources to establish a statewide TBI registry to better support California’s population with TBI.

## Purpose

In the Children’s Health Act of 2000, Congress authorized the CDC to develop a “National Program of TBI Registries” to collect data about TBI. TBI registries require the following primary functions: data collection; identification (maintaining personal identifiers and contact information); and linking people to services (helping them get information about available services).

California does not yet have a TBI registry or data system in place; however, it has a variety of data that collected through diverse sources based on specific metrics from the needs assessment, trauma registry, California Health and Human Services Agency, and a survey through California’s Center for Data Insights and Innovation. California Health and Human Services Agency collects data from a variety of State departments including the California Department of Aging, California Department of Public Health, Department of Health Care Services, Department of Managed Health Care, and the Department of State Hospitals.

California’s TBI Registry is being developed to connect individuals to services by identifying the key policies, resources, and education required to remove the barriers and gaps in services currently in place. A registry itself is a collection of data, or information, about a particular group of individuals who share a common characteristic, which in this case are twofold: 1) they are California residents and 2) they obtained a traumatic brain injury. The ways in which this data is compiled and utilized determines the purpose of the registry; some can be as simple as compiling a list of individuals, while others can be complex systems that provide case coordination.

### Characteristics and Functions of California’s TBI Registry

California is developing its registry using a combination of data collection, and identification to create linkage to services.

#### Data Collection

* California’s 28 Independent Living Centers who serve individuals with disabilities statewide. Information collected include services received, disability type, age, location, and other data elements.
* California’s Assistive Technology Program: data includes qualitative and quantitative information about the types of assistive technology requested and received by individuals with disabilities throughout California
* California Department of Rehabilitation: Vocational Rehabilitation Program data includes services received, disability type, age, location, and other data elements.
* The Registry Committee partnered with California’s six sites to collect outcomes data, through quarterly collection of the Community Integration Questionnaire (CIQ) and Mayo-Portland Adaptability Inventory (MPAI-4).
* Local healthcare organizations – The Committee is collaborating with local healthcare organizations to obtain data from their electronic medical records.
* California Emergency Medical Services Authority. The California Trauma Registry accumulates data from the 81 statewide Level 1 Trauma Centers. The Registry Committee worked with the California Trauma Registry to extract TBI-related data for people who presented to those designated Trauma Centers. This data is skewed toward more moderate and severe TBI and does not capture mild TBI survivors who may present to alternate healthcare resources – whereas the vast majority of TBIs are mild to moderate.

#### Identification

* + From July 1, 2019, to June 30, 2020, the (then) seven State-funded TBI sites provided direct ongoing services to 1,128 unduplicated TBI survivors, and community reintegration, supported living, vocational, information and referral, public and professional education, and other services to 23,357 individuals, including TBI survivors and their loved ones.
  + From July 1, 2020, to June 30, 2021, the six State-funded sites provided direct ongoing services to 794 individual consumers and provided 31,591 services including, but not limited to, information, referral, and education services to TBI survivors and their loved ones.
  + These sites provide services to 23 counties throughout California including: Yuba, Sutter, Nevada, Colusa, Butte, Shasta, Sacramento, Yolo, Placer, El Dorado, Los Angeles, Kern, Santa Barbara, Venture, San Luis Obispo, Solano, San Mateo, Sonoma, Monterey, Santa Cruz, San Benito, Santa Clara, Alameda, Contra Costa, Orange, San Bernardino, Riverside, and Kern
  + California Trauma Registry Data thus far includes:

|  |  |  |
| --- | --- | --- |
| DATA | 2018 | 2019 |
| # of TBI cases | 11,389 | 8,472 |
| % male cases | 69% | 69% |
| % female cases | 31% | 31% |
| Alcohol involved | 70.2% | 72.3% |
| Hospitalized cases discharged to home/self-care | 38% | 37.1% |

#### Linkage to services

Progress and learnings to date include:

* Determining outcomes data for post-acute services – California has six statewide TBI grant sites that provide services for TBI survivors and their families. These six sites include outpatient rehabilitation centers, community-based services, and community living centers.
* Recommendation to the TBI Program to change reporting metrics from Community Integration Questionnaire (CIQ) to a more comprehensive Mayo-Portland Adaptability Inventory (MPAI-4).
* Creation of the Survivor Committee to provide insight into specific initiatives related to findings.
* Utilizing the data collected to date, in addition to population data surrounding access to transportation, median income levels, and access to healthcare, it became apparent that there is a tremendous need for TBI services in Central California. Stanislaus, Merced, Madera, Fresno, Kings, Tulare, and Kern County ranked among the bottom 25 percent in all these categories when compared to the rest of California, with no access to State-funded sites and minimal access to other TBI Programs through other funding sources. As a result, the TBI Program will be targeting organizations in this area to serve these counties utilizing funding through its Home and Community-Based Services opportunity with the intention of funding up to three sites to directly serve TBI survivors.

#### Follow-up data collection

* The Registry Committee is in the process of conducting a statewide survey with CalSpeaks, an organization based at Sacramento State University, which conducts large state-wide surveys to gather qualitative and quantitative data. The survey will include TBI survivors, caregivers, and medical professionals.

## Future Areas of Focus

* Report on and publish findings on the impact of TBI in California.
* Advocate for state legislation and funding to establish and maintain a central ongoing registry for TBI data.
* Use registry data to increase access to support resources and services.
* Use registry data to guide public policy regarding TBI and services.

# Needs Assessment Committee

Mission Statement

The Needs Assessment Committee is committed to identifying a needs assessment tool to provide a voice for individuals with TBI, their families and professionals in California to identify their needs for services.

## Goals and Objectives

* To create a person-centered needs assessment tool that will identify the appropriate services needed by the individual to achieve their stated goals.

Summary of Tasks Completed

The Needs Assessment Committee has:

* Reviewed the needs assessment reports from partner states to determine domains focused on, which included: Public Education, awareness, prevention, and research; case management and neuropsychological evaluation; rehabilitation services including, physical, occupational, speech, and cognition; psychological services for survivors and family members; supported, assisted, and future employment.
* Interviewed colleagues from the following states on best practice approaches in conducting needs assessments: Vermont, Idaho, Alaska, North Carolina, Virginia, Minnesota, Nebraska, Tennessee, and Massachusetts.
* Produced a summary report on best practice approaches in needs assessments in Alaska, Idaho, Maryland, and Massachusetts with distribution, outreach to underrepresented communities, survey design, survey funding, and what they would do the next time they conducted a needs assessment.
* Created a draft California Needs Assessment survey tool.
* Created a draft request for proposal document to seek vendors to conduct the California Needs Assessment.
* Reviewed and discussed the proposal with prospective vendors.
* HARC began individual Needs Assessment interviews with individuals living with TBI, their caregivers, and their practitioners in February 2022. The written Needs Assessment Survey will be released by April 1, 2022.

California’s TBI Needs Assessment

The Health Assessment and Research for Communities (HARC) was chosen to facilitate California’s TBI Needs Assessment survey and key informant interviews. HARC is a nonprofit organization based in Riverside County, California, that provides research and evaluation services related to health, wellness, and quality of life.

The first stage of the California TBI Needs Assessment involved key informant interviews targeting three groups of subject matter experts: people with TBI, caregivers of people with TBI, and healthcare professionals/service providers for people with TBI. The interviews were conducted in English and Spanish and were qualitatively analyzed using MAXQDA software to identify recurring themes among participant responses. This qualitative data was used to design the California TBI Needs Assessment survey, as well as to provide findings in the participants’ own words for the final report, where the qualitative findings supplement and help interpret the quantitative survey data.

“Explaining what it is like to have a TBI is nearly impossible; especially when I don’t understand it myself. Experiencing daily life of living with my TBI is a very lonely existence. I lost everything: my fortune, my marriage, my home, I can’t drive, I live in pain, and struggle every day. Yet, I wouldn’t change what happened to me as it has made me a much better person for having survived it.” – Jason Levy

The second stage involved utilizing the knowledge gained from the background research and the qualitative key informant interviews to guide the development of three surveys for the three target audiences listed above. The surveys were provided in multiple languages through the online platform, SoGo, and disseminated through DOR’s network of partners, stakeholders, and networks, in addition to outside agencies to reach individuals across California.

All qualitative data from the open-ended questions on the surveys were analyzed using Statistical Package for the Social Sciences (SPSS) to examine not only descriptive statistics on each of the variables, but also potential disparities based on demographics (e.g., age, gender, immigration status, socioeconomic status, race, ethnicity) to lift any issues of inequity that emerged.

HARC will provide DOR with a report containing an executive summary, introduction, methodology, results for each key informant, and conclusion. The narrative will be supplemented by tables, charts, maps, and/or other visual aids to enhance understanding. The quantitative data from the survey will be supplemented with anonymized quotes from the key informant interviews to illustrate the themes in participants’ own words and lift their voices.

DOR and HARC identified key informants to serve as subject matter experts for the key informant interviews. Specifically, the interviews targeted three groups of subject matter experts:

* People living with TBI
* Caregivers of people with TBI
* Healthcare professionals/service providers for people with TBI

The key informant interview subject matter experts were recruited through California’s 28 Independent Living Centers, California’s six state-funded TBI sites, DOR’s 14 Districts, the California State Independent Living Council, the California Foundation for Independent Living Centers, the Northern California Traumatic Brain Injury Model System, UCLA Health (Mednet), Centre for Neuro Skills, San Joaquin Valley Rehabilitation Hospital, Schurig Center for Brain Injury Recovery, the Brain Injury Network, Brain Injury Association of America, Casa Colina Hospital & Centers for Healthcare, Kaiser Permanente’s Traumatic Brain Injury Caregiver Support Group, and the Family Caregiver Alliance.

The TBI Program strove to ensure that participants reflected diverse perspectives (e.g., people from rural and urban areas; people from across California; and people of different races/ethnicities, genders, ages, socioeconomic classes, etc.).

Each key informant category had a designated script introducing the purpose of the interview, the length of the survey, and ensuring confidentiality of participant personal information. Each survey was designed to be 12 questions structed in a conversational manner to elicit information for reporting and expanding the scope of the written survey.

The survey Questions can be found in [Appendix I](#_Appendix_I).

Future Goals

* Use the data and experience from the Needs Assessment to identify additional areas of research.
* Use the data to identify specific educational information that can be created to better serve individuals with TBI, caregivers, and practitioners.

# Sustainable Funding Committee

## Mission Statement

Explore, identify, and facilitate sustainable funding for TBI Programs and initiatives in the State of California.

## Goals and Objectives

* To sustain funding for the TBI Program.
* Increase funding to our 6 sites and grow the program to include more sites in unserved and underserved areas.
* To provide adequate funding to the TBI Advisory Board to compensate for the end of the TBI State Partnership Program grant funding.
* Provide education materials to survivors, caregivers, and families of survivors and future initiatives.

## Purpose

In California, there are more than 200,000 incidents each year of non-fatal TBI injuries, affecting populations that are culturally and linguistically diverse and live in both rural and urban communities.[[11]](#footnote-12) In 2015, the most recent year of statewide data collected; there were 32,627 non-fatal hospitalizations and 210,910 non-fatal emergency department visits in California with a diagnosis of TBI. According to a 2019 retrospective analysis on healthcare resource utilization and costs within the first year following a mild TBI, the mean follow-up healthcare costs were $13,564.[[12]](#footnote-13) A systematic review and quality assessment of in-hospital costs after severe TBI reported costs within the US between $258,790 to $401,808.[[13]](#footnote-14)

Through SB 398, California’s Governor and Legislature have augmented the funding source through the State General Fund to maintain services at the existing TBI sites through June 2024, but stakeholders report that even if the services can be maintained, more TBI sites and services are needed, especially in rural areas of California. With the current amount of funding, in 2021 the six state-funded sites provide direct ongoing services to 794 individual consumers and 31,591 services covering only 23 of the 58 counties in California. Due to socioeconomic and distance barriers to regional medical centers, in addition to decreased access to neuroimaging and consultants, and an increased risk of vehicular injuries, California needs funding to expand its services to reach all populations within the state.[[14]](#footnote-15)

In summation, Californians with TBI need more services and community integration resources. The funding and infrastructure do not currently support the maintenance or expansion of the program to also include the unserved counties in California. The TBI Program has relied on federal grants for funding to provide California much-needed tools, such as the TBI Advisory Board’s collective knowledge to work with the Department to identify the systems to create a better coordinated public investment. The systems should be effective, high-quality, equitable, evidence-based services and supports for all individuals with TBI, their families, and their support networks and result in fewer people with TBI encountering barriers to needed services and supports. These grants have also been used to provide usable resources to propose sustainable funding for the TBI Program to increase collaboration and coordination of state level activities across systems and supports. Lastly, these grants have also ensured all people with TBI, including those from diverse and underserved populations, and other stakeholders are provided many opportunities to contribute meaningfully to needs assessments and state plans that will drive improvement of TBI services and supports.

Moreover, the following need to be taken into consideration:

* The COVID-19 pandemic and other economic stresses on the General Fund do not guarantee stable, long-term funding, nor funding increases, to expand the program.
* Many existing healthcare and service delivery systems have gaps, including unavailable or insufficient post-acute therapies (physical, occupational, speech), vocational rehabilitation, neuropsychological support, mental health therapy, and peer-based counseling and support groups.
* As California’s population continues to grow, so will the need to generate increased revenue to sustain funding for state-funded sites, the TBI Advisory Board, and the TBI Program. The DOR continues to pursue other funding sources to ensure that the California TBI service sites can continue to provide critical post-acute care to TBI survivors.

## Areas of Interest

* Funds allocated for homelessness, veterans, and inmates (specifically for direct education for inmates, job readiness, education of correctional staff at all levels, TBI site in prison)
* Additional federal funding
* SAMSA
* Additional ACL State Partnership Program grants
* California Advancing and Innovating Medi-Cal (CalAIM)
* Elder and Disability Justice Coordinating Council

## Future Areas to Explore:

* Trust Funds
* TBI Waiver Programs
* Medicare/Medi-Cal waivers
* Registration fees for motorcycles
* Personalized license plates (TBI theme)
* State legislative appropriations
* Expand Registry to include a housing component to match people with housing with moderate fee-for-service for renters
* Alcohol Tax
* Bonds surrounding arrests for assault

# Survivor Committee

## Mission Statement

Ensure the State of California creates person-centered, culturally competent programs that are for TBI survivors, with input from TBI survivors, to meet the needs of TBI survivors, their families, and caregivers.

## Goals and Objectives

* The Survivor Committee’s first initiative is to create Peer Support Specialist TBI curriculum that would allow TBI survivors to become certified TBI Peer Support Specialists. The curriculum would meet the requirements of the US Substance Abuse and Mental Health Services Administration core competencies for "Peer Workers," allowing for services to be reimbursed by Medi-Cal/Medi-Care, so survivors can be paid to support fellow survivors in rehabilitation facilities and other community settings.
* Develop and promote plain language materials and definitions about TBI regarding signs, symptoms, recovery, and self-advocacy to construct educational materials for the public and TBI survivors.
* Identify the needs of people living with TBI, their families, and their support networks. For example: create a pamphlet of information for new survivors to help them to navigate to a single repository of information that will guide them on their recovery.
* Ensure work produced by the TBI Advisory Board and the Department’s TBI Program is person-centered, culturally competent, and responsive to the needs of individuals with TBI and their support systems.
* Provide personal insight into experiences accessing healthcare, including essential resources and information, and the barriers to services and supports a survivor could encounter. For example: identifying free services available, how to navigate the medical system, who to turn to for help with mental health, and identifying the services needed.
* Create culturally competent resources, education, and outreach to organizations that intersect with populations that have a higher prevalence of TBI, such as people experiencing domestic violence or homelessness.
* Work collaboratively with the Department to expand existing systems that support early identification, intervention, resource facilitation, and coordination for people with TBI

## Purpose

The Survivor Committee was established under the 2021 ACL State Partnership Program Grant as one of the goals and objectives to ensure the survivor’s perspective and contribution to the State’s TBI Program.

The Survivor Committee is comprised of brain injury survivors (both acquired and traumatic) who work in collaboration with the TBI Advisory Board to maintain a focus on individuals, their families, support networks, and their caregivers. The Survivor Committee works to establish and promote plain language materials surrounding TBI to improve education and awareness about TBI, expectations for new survivors, and assist in closing gaps in services, supports, and information surrounding TBI. The Survivor Committee reminds the TBI Advisory Board that all work of the Board, Committees, and Program must be person-centered, not provider-centered, and focused on the needs of the survivor, their families, and their support networks.

The resources and education established will be distributed to agencies centered around homelessness and housing disparities, law enforcement, domestic violence support networks, and medical practitioners, including urgent care and free clinics, to better serve TBI survivors.

### How to Apply

If you have a brain injury and would like to participate in the Survivor Committee, please email [TBI@dor.ca.gov](mailto:TBI@dor.ca.gov) for further information.

# California’s Focus

Under the 2021 ACL TBI State Partnership Program grant, the goal is to improve the delivery and quality of person-centered services available to TBI survivors, their families, and caregivers by fostering partnerships, providing public education about TBI, and informing culturally competent policies statewide.

## 2021 through 2026 TBI State Partnership Program Goals

The TBI Program, in partnership with the Advisory Board and community stakeholders have outlined the following objectives, outcomes, and anticipated products:

### Objectives

* Expand the TBI Advisory Board to include a TBI Survivor Committee.
* Provide culturally competent resources to entities that intersect with homeless and domestic violence populations.
* Identify options for long term funding to continue California’s state and federal programs past SB 398 and the 2021 ACL State Partnership Program grant.
* Utilize the TBI Needs Assessment and Registry data to inform policy, education, and training statewide.

### Anticipated Outcomes

* Establish and promote plain language materials about TBI for public education through the TBI Survivor Committee.
* Expand systems to support early identification, intervention, resource facilitation, and coordination for people with TBI.
* Identify sustainable funding mechanisms to support locally based TBI services.
* Create data informed education and training leading to expanded services and supports for TBI survivors.

### Expected Products

* Education and training materials for medical, rehabilitation, and community support professionals about the needs of TBI survivors and their families.
* A funding model proposal for TBI survivors to receive locally based services through DOR’s TBI sites.
* Culturally competent and evidenced-based policies, education, and training informed by data gathered in the Needs Assessment and Registry.

## Objective 1: Survivor Committee

The TBI Program intends to expand its existing TBI Advisory Board to include a Survivor Committee that will engage as active and meaningful key decision makers with the TBI Program on all grant funded activities. The Survivor Committee will assist in establishing and promoting plain language materials and definitions about TBI regarding signs, symptoms, recovery, and self-advocacy to inform educational materials for the public and TBI survivors. This committee will help the TBI Program to identify the needs of people living with TBI, their families, and their support networks, barriers to services and supports, and needed outreach and education within the community. Additionally, they will ensure that all work produced by the TBI Advisory Board and the TBI Program is person-centered, culturally, and linguistically competent, and responsive to the needs of individuals with TBI, their families, and their support systems. This committee will provide first-person insight into culturally and linguistically diverse survivor experiences with healthcare professionals, availability of information to all survivors regardless of location, and barriers to services and supports. Transcripts from these meetings will be used to assist in developing plain language for public resources and education to describe survivorship, recovery, advocacy, and ways to obtain services and support. While this program is specifically focused on TBI, the Survivor Committee is open to all survivors of acquired brain injury, traumatic or non-traumatic.

## Objective 2: Resources and Education

California intends to provide culturally competent resources, education, and outreach to entities that intersect with populations with higher prevalence of TBI, such as people experiencing domestic violence or homelessness. The TBI Program and its advisory bodies will expand existing systems to support early identification, intervention, resource facilitation, and coordination for people with TBI. In partnership with the Survivor Committee, the Advisory Board will establish and promote plain language surrounding TBI to improve education and awareness about recognition of a TBI, immediate treatment of suspected TBI, recognition of a TBI survivor, and communication strategies in assisting individuals with TBI at various levels of severity. This information will be disseminated to law enforcement, agencies centered around homelessness and housing disparities, agencies and networks centered around domestic violence, and medical practitioners, including urgent care and free clinics, to better serve TBI survivors.

## Objective 3: Sustainable Funding

It is the State’s intention to identify options for long term funding to support locally based services for individuals with TBI in addition to both state and federal sustainable funding for California’s TBI Program. To identify funding mechanisms to support locally based TBI services, the Advisory Board will identify coverage barriers and actively participate in solutions including CalAIM, which provides funding for In Lieu of Services: medically appropriate and cost-effective alternatives to services across Medi-Cal, California’s Medicaid program. While short-term funding options are more readily recognizable, the Advisory Board’s objective will be to identify and make sustainable funding option proposals to DOR for Advisory Board activities, Home and Community-Based Services programs, and the expansion of the State’s TBI sites to further provide no-cost programs to TBI survivors including physical therapy, occupational therapy, speech therapy, neuropsychology services, and other services related to TBI.

## Objective 4: Statewide Impact

The fourth objective is to use the Needs Assessment and Registry generated from the 2018 TBI State Partnership Program grant to inform TBI policy, education, and training statewide. Through thoughtful examination of data, in addition to information gathered through partnerships with sister agencies, Independent Living Centers, Aging and Disability Resource Connections, and the State-funded TBI sites, DOR and the Advisory Board will create data informed education and training to break down barriers and expand services and supports for TBI survivors. Additionally, data gathered will help inform initiatives and drive policy that may lead to sustainable funding options

## Special Target Populations

Based upon the current research, data, and issues facing persons with TBI in California, in addition to the long-standing historical and structural racism that disproportionately impact minority groups, the two underserved populations that this grant will focus on are TBI survivors experiencing domestic violence and homelessness.

### Domestic Violence

In 2019, 161,123 domestic violence-related calls were made in California to law enforcement for assistance. Of those, 8,552 involved strangulation and suffocation.[[15]](#footnote-16) In the absence of death, acquired and traumatic brain injuries are the most long-lasting consequences of intimate partner violence due to strangulation, blows to the head, and other assaults.[[16]](#footnote-17)

In July of 2019, researchers conducted a community-based study and identified a definitive link between domestic violence and TBI. The study found that one in three women in the United States has experienced intimate partner violence; 81 percent of those women who sought help had sustained a head injury and 83 percent had been strangled.[[17]](#footnote-18) Those who experience domestic violence often develop post-traumatic stress disorder (PTSD), and as a result, those with long-term neurological symptoms will often receive treatment for PTSD and other mental health problems without ever receiving diagnosis or treatment for their TBI.[[18]](#footnote-19) This is due, in part, to incomplete assessments as many clinicians fail to understand the repetitive nature of intimate partner abuse.

With the assistance of the TBI Advisory Board, California’s TBI Program will develop a strategy to address education and advocacy for individuals experiencing intimate partner violence. Through collaborative efforts with agencies and organizations centered around the protection and support of individuals who have experienced domestic violence, the TBI Advisory Board will assist in advocating for resources to expand the program to better support outreach, awareness, and services for TBI cases linked to domestic violence across California.

#### Homeless Population

As of January 2019, 27 percent of people experiencing homelessness in the entire United States are in California.[[19]](#footnote-20) California also has the highest rate of unsheltered homeless individuals in the nation, with 33,000 individuals experiencing chronic homelessness, and costs to shelter all homeless individuals estimated to be between $2 billion and $3 billion annually.[[20]](#footnote-21) Studies have shown co-occurring conditions between TBI and homelessness, and that homelessness is disproportionately a byproduct of systemic inequality: the lingering effects of racism continue to perpetuate disparities in critical areas that impact rates of homelessness.[[21]](#footnote-22) Approximately 53 percent of homeless individuals and others living in unstable housing have had at least one TBI, and the lifetime prevalence of obtaining either a moderate or severe TBI was 22.5 percent.[[22]](#footnote-23) Comparatively, the Centers for Disease Control estimate the lifetime prevalence of TBI for the general population to be 21.7 percent, with a lifetime prevalence of moderate or severe TBI at 2.6 percent.[[23]](#footnote-24)

The California TBI Program with the support of the TBI Advisory Board will identify and outreach to organizations that provide services to underserved and unserved populations with TBI who experience a higher prevalence of homelessness. Future funding and partnerships would give California the preliminary tools to be able to identify key partnerships and work with entities who intersect with those populations to provide training on behavioral indicators to help identify a person who may have a brain injury. State agencies centered around homelessness and housing disparities could assist with best practices on this training, cross-systems collaboration, and development of confidentiality agreements between collaborating organizations and agencies

## Future Areas of Focus

### TBI and Incarceration

A close relationship exists between TBI and incarceration. A history of TBI is highly prevalent amongst those in the criminal legal system. For example, one study showed that approximately 70 percent of youth in the criminal justice system internationally have reported a history of at least one TBI, and the TBI predated the first incarceration 30-50 percent of the time; most had 2.5 or more TBIs; and many acquired additional TBIs while in the justice system.[[24]](#footnote-25) A two-year study by The Disabilities Trust in England found that, of 173 women screened at a local prison, 64 percent had symptoms consistent with a brain injury, of which 96 percent reported a history indicative of a TBI.[[25]](#footnote-26)

There are many reasons why TBIs and justice involvement are closely linked. After a TBI, a person may experience difficulties with cognition, (attention, memory), communication (difficulty understanding instructions, difficulty expressing thoughts), behavior (anger, disinhibition), and mood (depression, anxiety). Many of these impairments frequently have been identified as “risk factors” within criminological research.[[26]](#footnote-27)

#### Goals:

* Educate those involved in the California judicial system, Department of Corrections, and Probation about TBI and its effects.
* TBI screening for those in the justice system.
* Ensure that TBI rehabilitation programs automatically are considered as part of sentencing and probation in California. One study reported a significant decrease in severe anxiety and depression after implementation of brain injury services at the local prison.
* Encourage future research on possible effects of TBI neurorehabilitation and reduced recidivism.

### Examination of Helmet Laws

Helmets have been proven to be effective protection against severe and lethal intracranial injuries such as penetrating traumatic brain injury (TBI). Various studies on helmet use for motorcyclists and bicyclists have demonstrated reduced frequency of severe TBI in accidents.[[27]](#footnote-28) In the state of California, California Vehicle Code (CVC) 27803 requires that all motorcycle drivers and passenger wear a helmet when on a motorcycle[[28]](#footnote-29), motorized bicycle, or motor-driven cycle. CVC section 21212 states that anyone under the age of 18 must use a helmet when using a bicycle, a nonmotorized scooter, a skateboard, or using roller skates. As of Jan 2019, CVC section 21235 now requires that anyone under the age of 18 must have a properly fitted helmet to operate a motorized scooter. However, there does not exist a statewide all age helmet law addressing bicycles, motorized or non-motorized scooters, skateboards, or roller skates. TBI and closed head injuries in motorized scooter use is commonly associated with lack of helmet use.[[29]](#footnote-30) California also does not have a law requiring helmet use for skiers or snowboarders under the age of 18. Helmet use in skiing and snowboarding have been shown to be effective in preventing fractures of the skull and for risk reduction in TBI.

Literature currently lacks consensus on whether helmets are protective against mild TBI such as concussions. Football helmets have been shown to reduce the risk of skull fracture by 60 to 70 percent and the risk of focal brain contusion by 70 to 80 percent, but concussion was only reduced by 20 percent. California AB1 known as the California Youth Football Act[[30]](#footnote-31) requires that each football helmet shall be reconditioned and recertified every other year, unless stated otherwise by the manufacturer.[[31]](#footnote-32) Helmets are most effective when well maintained, age appropriate, worn consistently and correctly, and appropriately certified.

#### Goals:

* Education about helmet use in prevention of TBI
* Consideration of law requiring helmet use for skier or snowboarders under the age of 18
* All age helmet requirements

### Military Service Members and Veterans with TBI

Over the past 20 years, the United States and its allies have engaged in the “Global War on Terrorism,” with military operations focused on Afghanistan, Iraq, and other areas in the greater Middle East. Between 2001 and 2015, it was estimated about 2.5 million U.S. military personnel served in Iraq and Afghanistan.[[32]](#footnote-33) These conflicts present tremendous human and financial costs to veterans with TBI and their family caregivers.

One of the most insidious weapons of war in the Global War on Terrorism involves the use of improvised explosive devices, which can result in simultaneous injuries to multiple body systems. Among the areas of the body injured, TBI has emerged as the “signature wound of war.” In 2015, Baldassaree and associates estimated 15 percent to 20 percent of all military personnel that served in Iraq and Afghanistan incurred TBI.[[33]](#footnote-34) TBI is not only a risk factor in combat but in all areas of military service, such as TBI caused during training-related accidents. From the year 2000 to the first quarter of 2021, a total of 439,609 incidences of TBI were diagnosed among all U.S. military personnel worldwide, including those deployed and those serving stateside.[[34]](#footnote-35) TBI among military service members is qualitatively different than TBI in the civilian population. An example is the risk that military service members face for incurring TBI, along with PTSD and other polytrauma injuries.[[35]](#footnote-36)

Service members leaving the military with service-connected disabilities face significant challenges when transitioning out of military life. These challenges include difficulties with maintaining relationships, engaging in employment, and responding to negative indicators of mental health such as elevated anxiety, depression, substance abuse, and diminished quality of life.[[36]](#footnote-37) All of these challenges can be especially challenging when being a survivor of TBI. It is estimated that less than half a percent (.005) of the U.S. population serves in the military. The challenges veterans with TBI face are extremely difficult for civilian professionals and members of the public to relate to, given this small number of persons who serve in the military.[[37]](#footnote-38)

Many veterans with TBI returning home rely on the support of family to meet their basic needs, which can range from limited to extensive amounts of care.[[38]](#footnote-39) At times, family care is provided out of necessity. Some veterans with TBI may choose not to utilize the services of the U.S. Department of Veterans Affairs (VA), while others might not qualify for various types of income support, rehabilitation, and education benefits. Those looking for civilian services encounter a fragmented and often insufficiently funded array of public supports.[[39]](#footnote-40) The needs of family caregivers can sometimes go unrecognized, resulting in elevated levels of depression[[40]](#footnote-41) and lower ratings of quality of life.[[41]](#footnote-42)

# Appendix I

## Needs Assessment Survey Questions

#### Guide for People with TBI

* To begin, would you like to share a little about yourself and your injury?

How severe was your injury (mild, moderate, or severe)?

* I’d like to get an idea of where you’re at in your recovery. How long has it been since your traumatic brain injury?
* Where are you currently living?
* [For example, in a nursing home, in a rehabilitation facility, at home alone, at home with a caregiver, etc.]
* Is there anyone in your life who helps take care of you or helps you with life responsibilities?
* [If yes] Who are they and how do they help you?
* [If yes] Thinking about your caregiver, what resources or services do you think would be most helpful to them?
* A common experience for people with TBI is changes in relationships, such as with friends or family. Would you say that your relationships have changed in any significant ways since your injury?
* [If yes] How have your relationships changed?
* It’s very common for people with TBI to experience challenges such as depression, anxiety, PTSD, or difficulty controlling emotions. Have you experienced any such challenges with mental health since your injury?
* [If yes] What have those challenges been like for you?
* Have you experienced any other changes, since your injury, that you haven’t yet mentioned?
* [For example, people with TBI often have different changes such as in perception of time, sensitivity to light, or difficulty remembering.]
* People with TBI have different goals for their recovery process. What would you say are your goals for your recovery?
* [For example, resuming daily activities, living independently, adjusting to a “new normal,” etc.]
* It’s very common for people with TBI to have to stop working or for work to be greatly impacted. Did you work before your injury?
* [If yes] How has your injury impacted work?
* [If stopped working] Some people with TBI have the goal of trying to find a job or return to work. What goals do you have regarding finding a job or working?
* Thinking about your recovery process so far, what resources or services have been most helpful and how have they helped you?
* [For example, physical therapy, counseling, housing assistance, etc.]
* Are there any needs you have that are not being met?
* [For example, help with transportation, good health insurance, social support, finding work, etc.]
* What do you think could be done, or what resources could be provided, to help you meet those needs?
* Do you have any other comments that you would like to share?

#### Guide for Caregivers

* To begin, could you tell me a little about the person you care for and their injury?

How severe was their injury (mild, moderate, or severe)?

* I’d like to get an idea of where the person is in their recovery process. How long has it been since their TBI?
* Where are they currently living?

[For example, in a nursing home, in a rehabilitation facility, at home alone, at home with a caregiver, etc.]

* Could you tell me a little about your role as a caregiver? What relationship do you have with the person with TBI beyond that of caregiving?

[For example, are you a spouse, parent, etc.?]

* What kind of help or support do you provide for them?

[For example, meal preparation, help with medication, emotional support, etc.]

* People with TBI often have different needs. What are some of the greatest unmet needs of your client/friend/family member?

[For example, help with transportation, good health insurance, social support, finding work, etc.]

* What do you think could be done, or what resources could be provided, to help meet those needs?
* Caregivers also have needs. What would you say are some of your greatest unmet needs as a caregiver?

[For example, help finding healthcare providers, help understanding TBI, social support, etc.]

* What resources or services would be most helpful to you as a caregiver?
* It’s common for caregivers to experience challenges such as anxiety, depression, or feeling overwhelmed and stressed. Have you experienced any challenges with mental health because of your role as a caregiver?

[If yes] What have those challenges been like for you?

* Do you have any other comments that you would like to share?

#### Guide for Professionals

* First, could you tell me a bit about your professional background? What types of services do you provide and in what settings?
* What are the services or resources that are most helpful to people with TBI?
* What would you say are some of the major unmet needs of people with TBI?
* What are some of the major barriers to meeting those needs?
* How do you think care for people with TBI could be improved in your specific field?
* People with TBI often rely on family or other caregivers. What do you think are some of the major unmet needs of caregivers for people with TBI?
* What services or resources would help support caregivers of people with TBI?
* What are some of the greatest barriers for you, as a professional, to serving and caring for people with TBI?
* What services or resources would most help you to better serve and care for people with TBI?
* What additional education or training would be useful to help you serve people with TBI?

[For example, workshops, training seminars, etc.]

* Do you have any other comments that you would like to share?

# Appendix II

## Acknowledgements

Thank you to the many individuals, groups, and partners who contributed to the creation and development of California’s State Plan. We look forward to continued collaboration s for years to come. A special thank you to Dan Clark, Community Advocate, who never missed a meeting and provided incredible insight and advice.

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## TBI Advisory Board

|  |  |
| --- | --- |
| **Katie Shinoda, Board Chair** TBI Advisory Board Registry Committee Funding Committee | **Daniel Ignacio, Vice Chair** TBI Advisory Board Registry Committee Funding Committee |
| **Charles Degeneffe** TBI Advisory Board Needs Assessment Committee State Plan Committee | **Steven Chan** TBI Advisory Board  Registry Committee State Plan Committee |
| **Eric Williams** TBI Advisory Board Needs Assessment Committee Registry Committee | **Susan Hansen** TBI Advisory Board Needs Assessment Committee State Plan Committee |
| **Henry Huie** TBI Advisory Board Registry Committee State Plan Committee | **Todd Higgins** TBI Advisory Board Funding Committee Needs Assessment Committee |
| **Lili Whittaker** TBI Advisory Board Funding Committee State Plan Committee |  |

## California Department of Rehabilitation

|  |  |
| --- | --- |
| **Joe Xavier, Director** California Department of Rehabilitation Ex-Officio Member | **Megan Sampson, Chief** Independent Living and Assistive Technology Section Ex-Officio Member, Chief TBI Program |
| **Ana Acton, Deputy Director** Independent Living and Community Access Division | **Tanya Thee, Grant Administrator** DOR’s TBI Program |
| **Brandi Bluel, Grant Analyst** DOR’s TBI Program | **Margaret Balistreri, Office Technician**  CA Committee on Employment of People with Disabilities |

## Former Board Members

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Kim Baker

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