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

CDC Center of Disease Control

CIL Centers for Independent Living

DMH Department of Mental Health

DOR Department of Rehabilitation

HRSA Health Resources and Services Administration

nTBI Non-Traumatic Brain Injury

PTSD Post-Traumatic Stress Disorder

SB Senate Bill

SD Standard Deviation

TBI Traumatic Brain Injury

# Executive Summary

The California Department of Rehabilitation’s (DOR) Traumatic Brain Injury (TBI) Program serves 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.

To develop the State Plan, the TBI Program created a TBI Advisory Board and the State Plan Committee to guide the work.

## State Plan Committee Mission Statement

Explore, identify, and facilitate sustainable funding for TBI programs and initiatives in the state of California.

## Purpose of a State Plan

The State Plan provides an actionable, measurable blueprint to leverage partnerships and funding, to meet the needs of all Californians affected by TBI.

Goals and Objectives

* + - * Establish a TBI Advisory Board

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

Create 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

Outline ideas for funding mechanisms for expansion of services and usable resources for longer-term funding.

* + - * Create a statewide TBI registry

Create a workgroup to design and develop a statewide TBI registry with appropriate interagency agreements between state departments.

# California’s TBI Program

## History of TBI in California

Members of the California Rehabilitation Association, consisting primarily of hospitals, were frustrated by the number of individuals with TBI who could not afford post-acute services. They legislatively advocated for a trust fund. After three attempts, the California Legislature passed Senate Bill (SB) 2232 in 1988; the 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), which was eventually transferred to the Department of Rehabilitation (DOR) who currently oversees the funding. The first four competitively bid contracts were awarded in 1990. The intent of the law was to demonstrate the effectiveness of a coordinated service approach that furthers the goal of assisting individuals with TBI to live productive, independent lives that may include paid employment.

## About the TBI Program

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 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 twenty 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.

TBI disables six times more people each year than spinal cord injuries, multiple sclerosis, HIV/AIDS, and breast cancer combined. California’s TBI resources empower individuals with brain injuries to be participating citizens essential to our community’s social and economic success.

These TBI service sites must offer a core set of services to 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 almost all individuals receiving services from these sites benefited.

The funding for these TBI sites initially came from the California TBI Fund, established by Section 1464 of the Penal Code. The legislation stated that 0.66 percent of the state penalty funds would be contributed to the TBI Fund. This fund was known as the “seat belt penalty fund.” Initially, this funding was sufficient for the TBI sites; but over time, the seat belt penalty revenue shrank, as more drivers and passengers complied with the seat belt laws. From 2015-2018, the revenue decreased to even lower funding levels per site, as low as $120,000 per year.

In January 2019, the Governor’s proposed budget switched the funding source to the State General Fund, including $1.2 million from the General Fund for TBI. By switching from the state penalty fund to the General Fund (a more sustainable funding source), the DOR was able to provide $150,000 per TBI site for services for consumers in 2019-2020.

However:

* + - * The covid pandemic and other economic stresses on the General Fund do not guarantee stable, long-term funding, nor funding increases, to expand the program.
			* The TBI service sites serve only 16 of 58 counties in California, and the TBI program, as described in California Welfare and Institutions Code 4354, recognizes that this limited geographic scope is insufficient to address statewide needs.
			* 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.

### 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.

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.

This State Plan is a living document that outlines the progress made from the initial grant period from 2018 through 2021 and will act as a blueprint that will guide the work and progress made thereafter.

## 2018 through 2021 TBI State Partnership Program

### Goals:

* + - * 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.

### Outcomes:

* + - * 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

### Products:

* + - * 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.

### Contact Information

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

Email: 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. An ABI is the umbrella term for all brain injuries.

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.

Brain injuries that occur from birth, or just before or after birth, are called congenital brain injury.

Under Senate Bill 2232 and California Welfare and Institution Code 4354, et seq., California’s Trauma Brain Injury Program focuses on TBI in individuals over the age of 18.

## Common Causes of TBI

* + - * Falls, trips, and slips lead to half of TBI hospitalizations, with the risk increasing for older adults[[1]](#footnote-1).
			* Assault, including child abuse, elder abuse, and intimate partner violence, can affect brain development in children and is often missed by professionals. Community altercations and firearm violence are also large contributors to TBI.
			* Motor vehicle accidents are the leading cause of death in the United States and a high contributor to TBIs.
			* Sports concussions and head impacts are one of the leading causes of TBI in youth, with [a new CDC study](https://www.cdc.gov/traumaticbraininjury/pubs/youth_football_head_impacts.html) reporting youth tackle football athletes ages 6 to 14 sustaining 15 times more head impacts than flag football athletes during a practice or game and 23 times more hard head impacts.

## 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 can also lead to nTBI.
			* 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

Each year, thousands of TBI emergency visits, hospitalizations and deaths occur in California. 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 very 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 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. TBIs affect different areas of the brain in different ways, meaning that no two TBIs are alike.According to hospital discharge records in California for 2018 and 2019, more than 50 percent of severe—moderate 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.

TBI is a growing public health concern. Within the United States, The Centers for Disease Control (CDC) [[2]](#footnote-2) estimated that TBIs accounted for 2.87 million emergency department visits, hospitalizations, and deaths in 2014; and 5.3 million Americans live with disabilities because of TBI.In 2014, the CDC also estimated that TBI took the lives of an average of 155 people each day in the U.S.[[3]](#footnote-3)

Of those that survive a TBI, over 50 percent are moderately to severely disabled at five years post-injury,and over 85 percent experienced a psychiatric disorder within the first-year post-injury.Common areas of impairment include headaches, fatigue, sleep disturbances, vision changes, depression, impaired attention, poor executive function, poor memory, speech difficulties, comprehension issues, and impulsivity. These impairments affect a person’s cognitive, emotional, behavioral, and physical well-being, as well the person’s families, friends, workplaces, and communities.

“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, 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.

TBI has far-reaching implications, with studies demonstrating its close ties with homelessness,incarceration, substance abuse,mental health concerns, domestic violence**,** and US military service[[4]](#footnote-4).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 to 92 percent sustaining their head injury prior to the onset of homelessness[[5]](#footnote-5).

Many people with a TBI have long lasting effects, that can result in lifelong disabilities and impairments that can include[[6]](#footnote-6):

* + - * 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

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, Assembly Bill (AB) 398 transferred the California TBI Program from DMH to the California Department of Rehabilitation (DOR). 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 has five active subcommittees:

1. Registry
2. Needs Assessment
3. State Plan
4. Sustainable Funding
5. 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.”

## Purpose

California needs better statewide data to paint a comprehensive picture of the depth and breadth of TBI incidents. A TBI registry and state-level partnership with the agencies and organizations that collect data on TBI incidents will provide a better system of tracking incidents and the need for longer-term services and supports across the state. The TBI registry will support individuals with TBI, their families, caregivers, and service providers to be better informed of TBI services within their area and across the state. As the TBI state registry continues to expand with the addition of new and existing partnerships, possible linkages with mentor states would support individuals with TBI, their families and caregivers connect to relevant resources through the TBI state registries. California will work with mentor states to develop best practices to ensure individual privacy and confidentiality.

## 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 our population with TBI

## Key Findings and Work

State demographics and clinical characteristics of TBI would allow for a more adequate response to the public health issue. Which was identified as an area of need by the Advisory Board and TBI Program. The Registry Committee was formed to address the necessity and develop a plan to create a statewide registry, to gather data, guide public policy, and connect TBI survivors with needed services. This involves looking at incidence, prevalence, and outcomes data.

Progress and learnings to date include:

* Creating the above mission statement, to guide the actions and decisions of the Committee
* Partnering with mentor states and meeting with subject matter experts that have implemented state registries (including Alabama, Nebraska, Idaho, Virginia) to learn from their experiences.
* California Trauma Registry data – Establishing a relationship with the preexisting California Trauma Registry, which is maintained by the California Emergency Medical Services Authority, to obtain TBI related data. The California Trauma Registry accumulates data from the 81 statewide 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. California Trauma Registry Data thus far includes:
	+ In 2018, CA trauma centers recorded 11389 cases of TBI with 69 percent occurring in males and 31 percent in females
	+ In 2019, CA trauma centers recorded 8472 cases of TBI with 69 percent occurring in males and 31 percent in females
	+ Alcohol was involved in 8003 (70.2 percent) of the cases in 2018 and 6123 (72.3 percent) in 2019.
	+ In 2018, only 4335 (38 percent) of HOSPITALIZED cases were discharged to home or self-care (routine discharge) and 3145(37.1 percent) in 2019.
* Determining outcomes data for post-acute services – California has six statewide TBI grant sites that supply services for TBI survivors and their families. These six sites include outpatient rehabilitation centers, community-based services, and community living centers.
* 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).
* 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 data. The survey will include TBI survivors, caregivers, and medical professionals.
* Local healthcare organizations – The Committee is collaborating with local healthcare organizations to obtain data from their electronic medical records.

## 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.

Summary of Tasks Completed

* + - * Review of needs assessments from other states:
* The Needs Assessment Committee reviewed 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.
* Needs Assessment Committee members 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.
* The Needs Assessments Committee 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.
* Creation of a draft California Needs Assessment survey tool.
* Creation of a draft request for proposal document to seek vendors to conduct the California Needs Assessment.
* Review and discussion with prospective vendors to conduct the California Needs Assessment.
* Dr. Darla Hagge from California State University-Sacramento Department of Communication Sciences and Disorders;
* Drs. Fred McFarlane, Mary Baker- Ericzén, and Charles Compton from the San Diego State University Interwork Institute;
* Mr. Chris Morin, Health Assessment and Research for Communities Health Assessment Research for Communities.
* On October 18, 2021, the TBI Advisory Board approved the proposal submitted by Health Assessment and Research for Communities (HARC) for California’s Needs Assessment.
* 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.

Future Goals

* + - * The Needs Assessment Committee will select a vendor to conduct the California Needs Assessment.
			* The Needs Assessment Committee and California Department of Rehabilitation TBI Advisory Board staff members will guide, assist, and supervise the work of the vendor in conducting the needs assessment.
			* The California Needs Assessment will be completed by May 31, 2022.

# Sustainable Funding Committee

## Mission Statement

“Explore Identify and facilitate sustainable funding for TBI programs and initiatives in the State of California.”

## Purpose

In California, there are more than 200,000 incidents each year of non-fatal TBI injuries, effecting populations that are culturally and linguistically diverse and those that live in both rural and urban communities.[[7]](#footnote-7) 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, with a standard deviation (SD) of $41,071, primarily from inpatient ($4,675, SD of $29,982) and non-emergency department outpatient/physician office visits ($4,207, SD of $12,697).[[8]](#footnote-8) A systematic review and quality assessment of in-hospital costs after severe TBI reported costs within the US between $258,790 to $401,808.[[9]](#footnote-9) In short, culturally and linguistically diverse populations throughout California, both in rural and urban communities, are impacted by TBI, and while some have access to services, the cost of care is a barrier for many, highlighting a crucial gap in the availability of post-acute care services and supports for many Californians living with TBI.

The California TBI Program consists of state funding for six nonprofit organizations that use three different system models – independent living, medical, and social-behavioral – to provide services in 27 of the 58 counties in California. Historically, the Department has had seven TBI sites with each TBI site receiving $150,000 annually to provide five mandated services: community reintegration, supported living services, vocational supportive services, information and referral, and public and professional education. Although there were seven TBI sites, in 2020 one site closed, causing the Department to redistribute grant funding across the remaining six TBI sites. The Department is in the process of re-competing the grants and, due to limited funding, has decided to maintain the number of sites at six.

The TBI program had been funded through a 0.66 percent allocation of California’s Seatbelt Penalty Fund (SPF). The SPF experienced a steady decline of more than $50 million from state fiscal year 2006-07 to the present, resulting in a loss of over $300,000 per year for the TBI Fund that supports the TBI sites. California’s Governor and Legislature have augmented the funding source through the State General Fund to maintain services at the existing TBI sites, but stakeholders report that even if the services can be maintained, more TBI sites and services are needed, especially in rural areas of 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.[[10]](#footnote-10)

In summation, Californians with TBI need more services and the funding and infrastructure does 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 in effective, high-quality, equitable, evidence-based services and supports for all individuals with TBI, their families, and their support networks that results 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 and to ensure all people with TBI, including those from diverse and underserved populations, and other stakeholders are provided ample opportunity to contribute meaningfully to needs assessments and state plans that will drive improvement of TBI services and supports.

## Goals and Objectives

From 1988 to 2016, each California TBI site received $150,000 totaling a sum of $1.05 million per year from the SPF. However, the fund has been steadily declining as a sustainable revenue source as fewer drivers have been cited for violations, and in state fiscal year 2018-19 funding was reduced to $115,000 per TBI site. The Governor and legislature have augmented the Department’s budget to offset the declining funds but needs continue to exceed resources. In the past, the Department has explored many paths toward a stable funding source, but none have proven to be viable – cooperative contractual agreements using vocational rehabilitation funds; a TBI-specific home and community-based waiver, which could not meet the Medicaid cost neutrality requirement; and a Health Resources and Services Administration grant, for which California was not selected. Given the growing need and demand for services for people living with TBI and their families, it is critically important to stabilize TBI site funding and to begin expanding services to all Californians, including those living in unserved and underserved counties.

To sustain funding for the TBI Program, the Department, the six TBI sites, and the TBI Advisory Board intend to utilize data from the Needs Assessment and Registry to develop a strategic plan to identify base funding, taking into account population, geography, and service needs to support additional TBI sites to serve all Californians. They will also assist in identifying and accessing funding from multiple state-funded programs (e.g., Homeless, Mental Health, Health Care, Corrections, CalAIM, etc.). The plan will also seek to provide adequate funding to the TBI Advisory Board to compensate for the end of the TBI SSP grant funding.

Julie’s story

Julie is a 32 y/o female who had a motor vehicle accident when she was 24 and 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 then she had to pick up the pieces on her own. She did not receive much education about TBI and was struggling. She was emotional about the experience; she didn’t understand why she couldn’t keep track of things like she did before. Her friends weren’t around as she expected, and she was forced to return home and live with her mother and sister again. She was socially isolated, confused, and had significant anxiety regarding driving and trusting friends.

Julie came to Mercy’s TBI Program so anxious to be in a new place that she was visibly shaking. She learned to trust the TBI case coordinator, then the neuropsychologist who helped her understand how her brain was functioning and helped her understand her emotional reaction to what had happened. She participated in Mercy’s vocational evaluation and received training by the speech therapist in work skills. She participated, with the support of the DOR vocational counseling, in a supervised volunteer work experience for 6 weeks. She later enrolled and completed several courses in basic computer skills. She recently started working full time, and periodically seeks the input of the neuropsychologist for help in managing the new stresses of returning to work after many years of being unable to work.

## Current Funding Opportunities

The TBI Program, Advisory Board, and Sustainable Funding Committee are currently exploring the following one-time funding sources:

* + - * American Rescue Act: Home and Community-Based Services: The TBI Program was awarded $5,000,000.00 in one-time funding to provide additional funding the DOR’s state-funding sites and to provide funding to up to six additional sites.
			* SB855 Mental Health Funding
			* Private foundations that fund health initiatives
			* Same You – Emelia Clark’s Foundation
			* State Developmental Disabilities Council (DD)
			* University Centers for Excellence in Developmental Disabilities (UCEDD)
			* Alcohol and Drug Rehabilitation Programs
			* Dementia and TBI correlation through the Master Plan on Aging
			* Department of Public Health

## 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
			* CalAIM
			* Elder and Disability Justice Coordinating Council

## Future Areas to Explore:

* + - * Trust Funds
			* TBI Waiver Programs
			* Medicare/Medi-Cal waivers (Victor Duron)
			* Registration fees for motorcycles (Phil Subia)
			* Personalized license plates (TBI theme) (Phil Subia)
			* State general funding (Carrie England)
			* State legislative appropriations (Carrie England)
			* Expand Registry to include a housing component to match people with housing (we would receive a fee) (Megan Sampson)
			* Alcohol Tax (Daniel Ignacio)
			* Domestic violence funding
			* Bonds surrounding arrests for assault
			* Develop funding sources related to domestic violence

# Survivor Committee

## Mission

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.

## Purpose

The Survivor Committee is established under the 2021 Administration for Community Living (ACL) State Partnership Program Grant as one of the goals and objectives to ensure the survivor’s perspective and contribution to the State’s Traumatic Brain Injury (TBI) Program.

The Survivor Committee will be solely comprised of brain injury survivors (both acquired and traumatic) who will work in collaboration with the TBI Advisory Board to maintain a focus on individuals, their families, support networks, and their caregivers. The Survivor Committee will establish and promote plain language materials surrounding TBI to improve education and awareness about recognition of a TBI. They will guarantee all work produced by the TBI Advisory Board is 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.

Participation in the Survivor Committee is open to anyone who is a brain injury survivor. If you are a brain injury survivor and are interested in participating, please email TBI@dor.ca.gov for further information.

## Goals and Objectives

* + - * 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.
			* 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.
			* 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.

### How to Apply

If you have an acquired brain injury (ABI) or a traumatic brain injury (TBI) and would like to participate in the Survivor Committee, please email Tanya Thee at TBI@dor.ca.gov. In your email, please provide the following information:

* + - * Name
			* Age
			* Location
			* Type of Brain Injury (and other Disabilities, if applicable)
			* Reasonable Accommodation Needs
			* Desired Participation Frequency (e.g., monthly, bimonthly, quarterly)
			* Date of Brain Injury/Injuries
			* Reason for Interest in Survivor Committee
			* Role You Would Like to Play in the Survivor Committee and/or TBI Program

# State Focus

Under the 2021 ACL TBI State Partnership Program grant, the ultimate 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
* 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 to 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 sustainable funding for California’s TBI program, both State and federal. To identify funding mechanisms to support locally based TBI services, the Advisory Board will identify coverage barriers and actively participate in solutions including California Advancing and Innovating Medi-Cal (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 (HCBS) 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.[[11]](#footnote-11) 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.[[12]](#footnote-12)

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.[[13]](#footnote-13) 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.[[14]](#footnote-14) 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.[[15]](#footnote-15) 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.[[16]](#footnote-16) 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.[[17]](#footnote-17) 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.[[18]](#footnote-18) 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.[[19]](#footnote-19)

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.[[20]](#footnote-20) 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.[[21]](#footnote-21)

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.[[22]](#footnote-22)

#### 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.[[23]](#footnote-23) In the state of California, California vehicle code (CVC) 27803 requires that all motorcycle drivers and passenger wear a helmet when on a motorcycle[[24]](#footnote-24), 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.[[25]](#footnote-25) 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[[26]](#footnote-26) states helmets requires that Each football helmet shall be reconditioned and recertified every other year, unless stated otherwise by the manufacturer.[[27]](#footnote-27) 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

# Appendix

## 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.

DOR’s Traumatic Brain Injury Program is grateful to the TBI Advisory Board and Committee members who have been crucial to the development of this plan.

## TBI Advisory Board

|  |  |
| --- | --- |
| **Katie Shinoda, Board Chair**TBI Advisory BoardRegistry CommitteeFunding Committee | **Daniel Ignacio, Vice Chair**TBI Advisory BoardRegistry CommitteeFunding Committee |
| **Charles Degeneffe**TBI Advisory BoardNeeds Assessment CommitteeState Plan Committee | **Steven Chan**TBI Advisory Board Registry CommitteeState Plan Committee |
| **Eric Williams**TBI Advisory BoardNeeds Assessment CommitteeRegistry Committee | **Susan Hansen**TBI Advisory BoardNeeds Assessment CommitteeState Plan Committee |
| **Henry Huie**TBI Advisory BoardRegistry CommitteeState Plan Committee | **Todd Higgins**TBI Advisory BoardFunding CommitteeNeeds Assessment Committee |
| **Lili Whittaker**TBI Advisory BoardFunding CommitteeState Plan Committee |  |

## California Department of Rehabilitation

|  |  |
| --- | --- |
| **Joe Xavier, Director**California Department of RehabilitationEx-Officio Member | **Megan Sampson, Chief**Independent Living and Assistive Technology SectionEx-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

Bennet Omalu

Kim Baker

M. Adamnson

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