**Traumatic Brain Injury Needs Assessment for California**

Scope of Work and Cost Proposal

January 18th 2024

# Background

Traumatic brain injury (TBI) is the leading contributor to death and disability rates worldwide across all trauma-related injuries. According to the Center’s for Disease Control, there were 2.5 million TBI-related emergency department visits in the United States, which does not reflect the much higher number of individuals who experienced a head trauma and brain injury that do not present to medical centers (CDC, 2019). TBI is an injury to the head, may result in structural or functional disruptions of typical brain integrity. TBI is a type of acquired brain injury (ABI) and is distinct from non-traumatic etiologies of ABI, such as strokes or infections. In 2020, there were approximately 69,000 deaths attributable to TBI in the United States (US), with the highest rates reported among adults aged 75 and older and males (Centers for Disease Control and Prevention, 2023). TBI is accompanied by a range of post-injury symptoms, such as fatigue, forgetfulness, dizziness, and light sensitivity. Some evidence suggests that survivors of TBI recover from post-concussive symptoms within 3 to 12 months. On the contrary, a scoping review reported that over 50% of survivors of just one “mild” TBI go on to experience chronic cognitive impairment (McInnes et al., 2017).

In addition to cognitive impairments, psychiatric disorders post-TBI are also commonly reported, namely post-traumatic stress, depression, and anxiety (Dilley, 2011; Bryant et al., 2010; Riggio, 2011; Scholten et al., 2016). A systematic review found that across 34 studies, the prevalence of mood disorders was as high as 21% post-TBI (Scholten et al., 2016). Scholten and colleagues (2014) also found the prevalence rates of anxiety and mood disorders increased over time and participants with a psychiatric history and without employment had an increased risk of onset. Also, psychological distress post-TBI relates to poorer well-being across 18 months post-baseline (Donnelly & Donnelly, 2021). Furthermore, a case-control study of long-term cognitive and emotional sequelae from TBI found that after approximately six years, participants with TBI had poorer global cognitive performance and this observation was not explained by perceived deficits or depressive symptoms, suggesting that other factors account for sustained long-term impairment (Konrad et al., 2011). Factors may include psychological aspects including stress appraisal, which is correlated with well-being post-TBI and scholars advocate for early psychological intervention to mitigate adverse rehabilitation outcomes (Kendall & Terry, 2009).

Scholars have conceptualized TBI as a disease process whose outcome is determined by a complex interaction between preinjury factors, injury characteristics, comorbid disorders (e.g., depression, anxiety, stress; Polinder et al., 2015). Polinder and colleagues advocated for future interventions to examine mechanisms of change in post-concussive symptoms and interactions between social and psychological factors. Indeed, existing interventions for post-injury deficits from ABI often do not include mental health symptoms as an outcome (Hauger et al., 2022). Given the high prevalence of cognitive and emotional sequelae post-TBI, multi-modal interventions that reduce post-concussive symptoms and psychological distress are important to reduce health disparities among this population.

Rates of traumatic brain injury (TBI) have traditionally relied on medical incidences to estimate prevalence. However, issues related to reporting and accessing medical care (e.g., unaware, uninsured, undocumented; Rao et al., 2020), charting medical encounters (e.g., unspecified head injury S09; Peterson et al., 2020), and diagnosis/definition (Patricios et al., 2023; Silverberg et al., 2023), have raised questions regarding the true prevalence of TBI in the community. Moreover, there have been organized efforts to move away from simple tripartite classification of TBI as mild, moderate, or severe to incorporating other severity indicators.

The California Department of Rehabilitation (DOR) provides many services for people with TBI, including supported living services, vocational supportive services, community reintegration services, and public and professional education services. In order to better understand the needs of survivors with TBI and how to meet those needs, DOR wishes to conduct a TBI-specific needs assessment for adults in California.

# Proposed Work

The Data Analytics Committee (DAC) is proposing to conduct a follow-up needs assessment as informed by the data collection efforts conducted in 2022. DOR proposes to collect data for this needs assessment via key informant interviews and multimodal survey methodology, as illustrated in the summary table below. **This process is subject to revision and improvement for each cycle, which is proposed to occur once every three (3) years.**

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| --- | --- | --- |
| Phase | Timing | Cost |
| Project Management | Ongoing (starts in July 2024) | $18,021 |
| Key Informant Interviews | July 2024 – January 2025 | $40,040 |
| Pre-Survey Data Collection | July 2024 – September 2024 | $8,060 |
| Survey Data Collection | October 2024 – April 2025 | $15,010 |
| Data Management | July 2024 – October 2024 | $12,010 |
| Data Analysis and Report Writing | April 2025 – June 2025 | $45,000 |
| Total | 12 months | $138,141 |

# Detailed Work Description

## Project Management

The project will begin in July 2024, after State TBI contracts have been enacted, with a kick-off meeting between project staff and DOR staff. Roles for the duration of the project will be established, including the following: Who should be responsible? Who should be accountable? Who should be consulted? Who should be informed? Accountability facilitates on-time project completion. Each week, project staff assigned will have an internal meeting to coordinate all the moving parts and ensure that work is consistently completed on schedule and any issues are quickly addressed. After each internal meeting, DOR staff will be updated via email on the current status of the project; phone calls or video calls to connect are available within one business day’s request. Project Staff will submit invoices on a monthly basis for the hours worked/costs incurred (e.g., transcription services, translation services, etc.).

## Key Informant Interviews

To begin the process of the needs assessment, the Project team will begin by conducting background research on the needs of people with TBI, the services available to support people with TBI, best practices for conducting research with people with TBI, and other topics.

After this preparation, the Project Team will both identify strategies to recruit and sample from a wide range of demographics and geographic locations as well as work with the DOR to identify key informants who can serve as subject matter experts for the key informant interviews. Specifically, the interviews will target three groups:

1. People with TBI
2. Caregivers of people with TBI
3. Healthcare professionals/service providers for people with TBI

The Project Team and DOR will target a finished sample size of 40 individuals per group, for a total of 120 interviews. The Project Team and DOR will strive to ensure that the subject matter experts reflect 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.).

The group of healthcare professionals/service providers for people with TBI will include not only those professionals who work directly in TBI-specific programs but also those who serve populations that often experience TBI but are less likely to be treated (e.g., persons experiencing homelessness, survivors of domestic violence, persons formerly incarcerated, etc.).

The Project Team will create draft interview guides for each of the three groups of subject matter experts; DOR will have the opportunity to review and request revisions before the interview guides are finalized. The interview guides will be designed to elicit open-ended responses from subject matter experts, which will allow them to describe their experiences and their needs in their own words. There will be no more than 10 questions on the interview guide, supplemented by prompts to assist interviewers in guiding the interview.

Interviews will be conducted by Project Staff in English and Spanish via phone call or video call. Interviews will be audio-recorded and transcribed for analysis purposes. For those conducted in Spanish transcripts will be translated into English.

The interviews will be qualitatively analyzed using Dedoose software to identify recurring themes among participant responses. This qualitative data will be used to design the survey as well as to provide findings in the participants’ own words for the final report, where the qualitative findings will supplement and help interpret the quantitative survey data. The research design will be a mixed methods exploratory design that will iteratively inform subsequent efforts.

## Survey Data Collection

The Project Team will utilize 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:

1. People with TBI
2. Caregivers of people with TBI
3. Healthcare professionals/service providers for people with TBI

Because the topics of the surveys will depend on the themes/knowledge that will emerge from the earlier steps of the project, the exact content of the survey cannot be detailed here. However, the surveys will include broad topics from the bulleted list below. Note that these topics will be thoroughly reviewed and discussed at the kick-off meeting and subsequent discussions to determine the ideal form of question wording for each of the surveys. Survey topics will likely include the following:

* Demographics
* Participation in TBI-related services (e.g., post-acute rehabilitation, skills training, case management, day programs, residential services, etc.)
* Unmet needs/barriers to the above services (e.g., transportation, distance to services, cost, lack of caregivers, etc.)
* Needs for caregivers of people with TBI (e.g., respite care)
* The impact of TBI on individuals and their support systems
* Behavioral health status, including unmet needs
* Physical health status, including unmet needs
* Medical concerns, including unmet needs
* Substance use disorders
* Housing stability
* Social engagement
* …among others

Each of the three surveys will be limited to 40 close-ended questions (e.g., yes/no, rating scales, agree/disagree scales, etc.) and 5 open-ended questions that allow participants to elaborate on the themes in their own words. This question limit is meant to minimize the time burden on participants as they complete the survey and to provide focus for the final report.

The Project Team will design the survey to maintain an 8th-grade reading level so that the surveys are accessible to those with low literacy. The surveys will be programmed into an online survey platform, and formatted for maximum mobile capabilities so that they can be accessed on a computer, tablet, or smart phone. The surveys should also be in a format to be mailed in physical hard copy for those who require or prefer this alternate format.

The Project Team will provide the three draft surveys to DOR for review and will then revise accordingly. Once finalized, Project Team staff will translate the surveys into Spanish. Project Team will also coordinate with outside translators to translate the survey into other languages, if necessary. Based on data from the U.S. Census Bureau, the top five languages needed to reach Californians are, in order, Spanish, Chinese, Vietnamese, Tagalog, and Korean.[[1]](#footnote-1) Thus, the survey will be provided in five total languages. Review of the survey instruments in these additional four languages (Spanish, Chinese, Vietnamese, and Korean) by DOR staff/consultants would be greatly appreciated.

Project Team and DOR will pilot test the surveys to ensure any relevant skip logic functions as planned, including the non-English versions of the surveys. After approval, the surveys will go live online. The Project Team will rely heavily on gathered intel and research to appropriately and effectively access diverse subpopulations. DOR will send the survey invitations to each of the twelve state-funded TBI sites, California’s 28 Independent Living Centers in California, as well as through DOR’s vocational rehabilitation program. Project Team will also partner with outside agencies to disseminate the survey and recruit stakeholders, such as caregiver resource centers; senior centers; and organizations that serve people of color, people who are homeless, people who are undocumented, people who are survivors of domestic violence, people who are justice involved, Medi-Cal long term services and supports, etc.

Statistical power is the power to detect real differences (assuming that real differences exist in the population as a whole). In general, a sample size of approximately 400 is enough statistical power for basic comparisons between groups. As such, the Project Team will target a completed sample size of 400 for each of the three target groups (thus, 1,200 overall). A larger sample size is highly desirable and will hopefully be attained; 400 in each group is the minimum. To encourage additional participation, there may be additional financial needs to incorporate incentives for participation.

**Data Management**

A data management system will be created to collect, transfer, code, and store the data. Historically, the data collection system across the CATBI sites has been generally limited in standardization and uniform reporting in a way that facilitates a fundable program. This proposal includes a cohesive system developed to facilitate communication and data transfer. The data management system will include a hub for each TBI site, which will feed into a master data center. This system will automate data collection and scoring survey assessments, storing the data for the project team’s availability. The data management system will automatically code data collected directly from clients, clean the dataset, and store it securely for real-time analysis to inform policy recommendations. Therefore, it is recommended that the governing body of this efficient transfer system and data analysis be the TBI Advisory Board, directly, at least quarterly.

## Data Analysis and Report Writing

When the survey closes, the Project Team will code hardcopy data, download the survey data, and clean the dataset (e.g., remove ineligible participants, create variables, etc.). All qualitative data from the open-ended questions on the surveys will be translated into English for analysis. The data will be analyzed using SPSS (Statistical Package for the Social Sciences) 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 up any issues of inequity that emerge. Quantitative data acquired from surveys and consumer packets as well as past available data (e.g., past reporting years for CATBI) will be integrated.

The report will be written with the DOR staff as the target audience; as such, the language will be more elevated than it would be for a lay person but will not require technical or statistical knowledge to understand results. 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.

The report will have the following sections:

* ***Executive Summary:*** A succinct summary of the entire needs assessment, designed for those who do not have the time to read the entire report.
* ***Introduction:*** This section will provide context for the reader, such that the report can stand on its own and be understood by readers who were not a part of the process.
* ***Methods:*** This section will include a description of how data were collected and analyzed for complete transparency and potential future replication.
* ***Results:*** Results of both the qualitative key informant interviews and the survey will be presented in four (4) chapters:
  + People with TBI
  + Caregivers of people with TBI
  + Healthcare professionals/service providers for people with TBI
  + Integration of Current and Past Data Collection Efforts (see appendix)
* ***Conclusion:*** This section will identify and emphasize the greatest needs, any disparities identified, and recommendations for improving support systems for people with TBI (and their caregivers) in California.

The Project Team will provide the report draft to DOR for review. At this point, DOR can request additional analyses, revisions, etc. After making these revisions, the survey will be considered finalized and will be delivered as both a PDF and a Word document. DOR will maintain the intellectual property rights of all products created during this process, including raw data, interview guides, surveys, and the finished report.

APPENDIX

**What’s been collected**

I. Using survey-based methodology and semi-structured individual interviews, a convenient sampling method was used to generate the first needs assessment. Initial efforts identified TBI resources, mental health services, and peer support were universal needs across three stakeholders (i.e., professionals, caregivers, survivors).

II. In collaboration with the California Department of Rehabilitation’s TBI Advisory Board and the California State Survey Panel, a retrospective cohort study as an initial community-based surveillance study was conducted that utilized three probability-based sampling methods for recruitment. Data was weighted to compensate for practical limitations of sample surveys (e.g., under coverage, differential nonresponse) relative to estimated population parameters.

In the total sample (N = 1,052), who were all residents of California, 42% (n = 437) self-endorsed a history of at least one event of any head/neck injury (M = 3.89, SD = 10.07). Twenty-five percent of responding Californian residents who reported at least one incident of head/neck injury also endorsed experiencing an associated period of lost consciousness (n = 154), thereby fitting a strict definition of a positive TBI screen (15% of sample). In this representative and randomized sample, the potential prevalence of TBI was a wide range from 15 to 42%. The TBI sample represented varying levels of urbanicity (48.1% city; 31.6% suburbs; 20.2% rural) with an average California residence of 10+ years. Moreover, an average of three decades (M = 30.4, SD = 16.2) had elapsed since initial head trauma for the present sample, which were then compared on self-endorsements of cognitive, physical, and social dysfunction to the general California subgroup without head injury.

Ordinary least squared models were used to regress endorsements of employment difficulties, justice system involvements, and experiences with marginalized housing on endorsements of persistent depressive symptoms, generalized anxiety symptoms, neurocognitive disturbances, frequency of intoxication, presence of psychosis, and physical difficulties (e.g., ADLs) after controlling for age, gender, years of education, and income. Each model utilized weighted data in a hierarchical fashion and was conducted twice for both head trauma estimates: one with the highest prevalence rate (any head/neck injury; 42%) as a predictor and another with the lowest TBI prevalence rate (associated loss of consciousness; 15%). All models significantly predicted the psychosocial outcome of interest with the head trauma estimates consistently ranking as a top predictor right next to frequency of intoxication for experiences with marginalized housing, presence of psychosis for justice system involvements, and difficulties with independently completing ADLs for employment difficulties; results were maintained only when used as a dummy coded discrete variable but not as a continuous variable. These findings provide initial evidence from a representative and randomized sample that suggests that complications associated with TBI manifest, over decades, as psychosocial dysfunction in a disease-like fashion. This may have a number of direct and indirect explanations, such as a microstructural abnormality in white matter tracts that impact efficient communication across brain hemispheres, lack of needed environmental supports (e.g., HCBS Medicaid) to manage cognitive and affective symptoms that may be ancillary to a brain injury, unfortunate community messaging (e.g., media), or inaccurate education about appropriate expectations and health-risk behaviors to enhance successful community reintegration following TBI.

1. According to the U.S. Census Bureau, there are 4,038,453 Californians over the age of 5 who speak Spanish at home and speak English less than “very well” and thus, are unlikely to be able to take the survey in English. Likewise, for Chinese: 670,510; Vietnamese: 336,865; Tagalog: 249,455; Korean: 195,113. [↑](#footnote-ref-1)