# **California Department of Rehabilitation (DOR), Traumatic Brain Injury (TBI) Advisory Board Committees**

# Meeting Minutes

# April 13, 2023

**Opening**

The regular meeting for California Department of Rehabilitation (DOR) Traumatic Brain Injury (TBI) Advisory Board Sub-Committees was called to order at 8:35 a.m. on April 13, 2023 by Matt Berube via virtual meeting.

**DOR Updates provided at all meetings Ana Acton, Tanya Thee and Matt Berube**

**Staffing**

* Megan Sampson is out of the office until 6/1/2023. Regina Cademarti (Staff Services Manager) will be filling in as Chief until her return. Board members can continue to contact Tanya Thee or Matt Berube with questions or concerns.

**Chief News**

* In March, Dr. Katie Shinoda attended the NASHIA SEED Summit in Arlington, VA, and the Brain Injury Awareness Day in Washington D.C. for a congressional briefing with the Administration on Community Living (ACL) followed by a coordinated meeting with California’s congressional representatives to discuss TBI in California. She will be giving a presentation on the information at the TBI Board meeting on April 17th.

**Data Analytics Committee**

Meeting was called to order at 8:35 a.m. by Matt Berube, TBI Program Administrator.

**Members Present (Quorum was reached)**

* Dr. Daniel Ignacio, St. Jude Health and TBI Survivor
* Todd Higgins, Disability Rights California and TBI Survivor
* Dr. Charles Degeneffe, San Diego State University

**Members Not Present**

* Robert Medel, TBI Survivor
* Lili Whittaker, Kensington Foundation and Mother of TBI Survivor

**DOR Staff Present**

* Tanya Thee, DOR TBI Program Administrator
* Matthew Berube, DOR TBI Program Administrator

**Public Present**

* Dan Clark, Community Advocate
* Brenda Plechaty, TBI Caregivers Support Group

**Approval of Meeting Minutes**

* The approval of the meeting minutes for March 9, 2023 was motioned by Dr. Chuck Degeneffe and seconded by Todd Higgins. Minutes were approved by members Ignacio, Higgins, and Degeneffe.

**Committee Business**

* Matt reviewed the forms and training that the committee members were required to complete and submit. Committee members updated the DOR staff on their progress.
* The committee members confirmed that the contact information was correct and up-to-date.
* The DAC Mission Statement was read and reviewed.
	+ “The mission of the Data Analytics Committee is to identify, collect, and analyze data on survivors of TBI in California to inform public awareness, policy, and service provision.”
* The committee agreed to extend the TBI Advisory Board meetings by one hour, beginning in July 2023.
* The committee discussed the Needs Assessment data manuscript.
	+ Reviewed the process for approval
	+ The use of data collected by HARC
	+ Editing/Submitting the manuscript to the Journal of Head Trauma Rehabilitation
	+ Adding the manuscript to the calendar invitation for the next DAC meeting

Committee Comments

* Todd Higgins said the Board meeting should be extended, but that some of that time should be used to give more updates to the other committees about ongoing/upcoming projects and to ask for assistance from other committee members when needed.

Public Comments

* Dan Clark asked that DOR give an overview of the resources and funding available to the Board through the ACL grant. Tanya and Matt will meet with Ana Acton to prepare this material.
* Dan Clark asked that DOR staff contact information be added to the contact information document.

**DOR Updates**

* Tanya and Matt provided DOR updates (see above)

Board Comments: None

Public Comments: Dan Clark asked about the progress of California Traumatic Brain Injury (CATBI) sites was progressing. Tanya gave a brief overview of the status.

**Committee Objectives**

* The committee reviewed the goals of the ACL grant.
	+ Objective: Utilize the TBI Needs Assessment and Registry to inform policy, education, and training statewide.
	+ Outcome: Create data informed education and training leading to expanded services and supports for TBI survivors.
	+ Product: Culturally competent and evidence-based policies, education, and training informed by data gathered in the Needs Assessment and Registry (data provided by DAC).

**Logic Model** (defines common goals, objectives, and shared ‘why’)

**Data Analytics Committee Logic Model**

Problem statement 1:

• Conducting only, one data collection effort (e.g., needs assessment, survey) fails to capture the changing and current nature of TBI related needs in CA.

• Insufficient time to conduct data collection efforts makes it more difficult to locate a funding source and conduct a robust needs assessment process to identify a broad and unique set of needs.

Goal:

We will implement a process to conduct a data collection efforts every two years.

External factors--1:

• Number of resources, availability of ACL funding, other funding sources, need to find a vendor, time, lack of data (e.g., medical information, homelessness, justice involvement, activities of daily living) from registry sources, how do we identify the populations we haven’t identified.

• Systems to put in place to process the separate pieces of data (“Frankenstein”) so that the interpretations can be influential to policy/decision makers (e.g., legislators) and service providers (e.g., CBOs, VA, DOR)

Problem statement 2:

• There is a lack of understanding of the needs of specific populations of persons with TBI and data collection efforts should better capture these needs to inform the service system.

Goal:

Identify the specific populations that we currently lack data on to include them in future data collection efforts.

External factors-2:

• Identify partners in various communities, creating trust with underrepresented communities in data collection efforts, creating linkages to community-based organizations (CBOs) to assist in data collection efforts, understanding census data to better understand the populations in CA (e.g., Social Vulnerability Index), need to get support from other states on how to reach rural and difficult to reach communities (e.g., NASHIA).

 • Difficulties dealing with the mild TBI.

• ILC’s dealing with all disabilities, which do not necessarily appreciate the subtle accommodation needed for specific service populations.

• Funding silos (CA homelessness, SB 48 California DDS – in the “5th” category)

• Survivors served by the regional center as a separate category (could this information be available – ask them! If not, how?)

• Regional Center category is an important category

Problem statement 3:

• Due to the limited use of demographics of data collection efforts, this has limited the scope of the data collection process.

Goal:

Data collection efforts will be strengthened by utilizing demographic data (e.g., registry, census).

External factors-3:

• Get support from state and federal entities (e.g., NASHIA, ACL, California Department of Administrative Services; epidemiologists) to get ideas on different ways to use data, select a vendor with expertise to incorporate data collection efforts, address barriers/disparities identified via demographics to inform the data collection process in a format that could be used.

Assumptions

• Assumption for funding (ACL, DOR)

• Combining needs assessment and registry

Identify resources

• Funding Needs Assessment/Registry contractor

• Contractor to analyze and synthesize

• UCLA, CSUN (TBI research) – Dr. Sheets, Dr. Thomas

Project outcomes

• Locate funding sources for data collection efforts by the end of 2023

• Identify and clarify the processes for ongoing needs assessment and registry (October 1st, 2023)

• Create a sustainable plan proposal to the DOR

• Disseminate information to other Silos

• Identify activities

• Seeking organizations to fund research efforts (translation from clinical to public policy, CDC public health surveillance grants)

• Address the number and resources provided to survivors of TBI served by Regional Center

• Publish in the scientific peer-review literature.

Timeline 2023 (to April 2025)

• July – DAC will submit proposal to publish (using proposal)

• August – Submit to Journal of Head Trauma Rehabilitation

• September/December – publishing process

• October 1st – Clarify the processes for ongoing needs assessment and registry

• November 1st –Send the sustainable plan proposal to the DOR (every 2 years)

• December 31st: Locate funding sources

**Approval of DAC Logic Model**

* The approval of the DAC Logic Model in its present form was motioned by Todd Higgins and seconded by Dr. Chuck Degeneffe. The Logic Model was approved by members Ignacio, Higgins, and Degeneffe.
	+ Committee comments
		- None
	+ Public comments
		- Dan asked if the logic model could be amended; Matt said it could be, and additions/alterations would need committee’s approval.

**Future Meeting Dates**

* TBI Board Meeting – April 17, 2023
* TBI Board Committees – May 11, 2023
	+ Committee comments
		- Chuck asked if the committee would be combining data from Needs Assessment and HARC project.
		- Todd asked for details of contract with HARC; Tanya provided details.
	+ Public comments
		- Dan asked to be sent a copy of the chat from the meeting.

**Adjournment**

The motion to adjourn was made by Todd Higgins and seconded by Charles Degeneffe. The meeting adjournment was at 10:13 a.m.

**Education and Public Outreach Committee**

Meeting was called to order at 11:07 a.m. by Matt Berube, TBI Program Administrator

**Committee Business – Randy Dinning**

**Members Present (Quorum not met)**

* Randy Dinning, Regional Ombudsman
* Vincent Martinez, TBI Survivor
* Heidi Frye, Independent Living Center of Kern County and TBI Survivor

**Members Not Present**

* Theresa Woo, DOR
* Dr. Henry Huie, Santa Clara Valley Medical Chief of Brain Rehabilitation
* Dr. Steven Chan, Physical Medicine and Rehabilitation at Kaiser Permanente

**DOR Staff Present**

* Matthew Berube, DOR TBI Program Administrator
* Tanya Thee, DOR TBI Program Administrator

**Public Present**

* Dan Clark, Community Advocate
* Brenda Plechaty, TBI Caregivers Support Group

**Approval of Meeting Minutes**

* The approval of the meeting minutes for March 9, 2023 could not be voted upon because of a lack of quorum.

**Committee Business (Randy Dinning)**

* Could not be conducted because of a lack of quorum.
* No committee business could be conducted; Attendees engaged in general conversation of relevant topics.

Committee comment

* None

Public comment

* None

**DOR Updates**

* Matt and Tanya provided DOR updates (see above)

**TBI Resource List**

* Randy showed a rough draft of a potential timeline for creating a resource document for use by TBI Survivors, their families, and caregivers.

**Logic Model**

Problem statements:

1. There is a lack of awareness of education materials available for survivors and organizations that currently or may intersect with the TBI Community
2. The existing educational resources are challenging to disseminate to the appropriate stakeholders.
3. Resources are not linguistically or culturally accessible.
4. There is a need for accessible materials and literature for TBI survivors and stakeholders.
5. There are significant gaps among resources and in delivery to TBI survivors.
6. There is a lack of awareness of symptoms/diagnosis of TBI

Action items:

* TBI EPOC members start accumulating resources that are used for TBI survivors, caregivers?
* https://msktc.org/TBI
* Central, comprehensive directory / repository for these resources?
* Living document, shared drive?

Goal statement:

To design, disseminate and maintain an active directory of accessible and appropriate resources for TBI survivors, caregivers, organizations, and the public.

External factors:

* Input from clients re unusable web sites or value of resource
* Lack of funding, personnel/admin changes
* Process for updating/review, DOR procedures
* Extent/Breadth of language and cultural considerations

Assumptions:

* There is insufficient availability of concise and complete data.
* Not everyone has access to the internet.

Identify resources:1. CATBI -12 TBI Sites (for Data and advocacy)

2. DOR leadership3. TBI Advisory Board4. HCAI- Data5. Trauma Registry Data6. IL Network7. DHCS8. TBI Survivors and lived experience9. NASHIA10. BIA Cal11. Other state advisory boards13. Legislative champions14. Other state Departments (DHCS, DDS, DMH)15. National Concussion Legislation to follow nationally - Conley (Virginia)16. Healthcare and Health Insurance Plan Teams

17. Private Philanthropic Organizations

Project outcomes:

Broader dissemination of resources

Improve quality, relevance and usefulness of resources through user feedback

Activities:

* Continue to qualify resources
* Identify and qualify outreach opportunities
* Survey survivors – join groups, find out what the problems are
* Add more categories to the Resources directory (e.g., symptoms management, new research, care centers, peer counseling/survivors groups)
	+ VA
	+ SSA
	+ Therapy
	+ Peer counseling
	+ DOR
	+ AARP
* The committee discussed the next steps to complete the Logic Model, including:
* Determine problem statement - updated
	+ There is a lack of awareness of education materials available for survivors and organizations that currently or may intersect with the TBI Community
	+ The existing educational resources are challenging to disseminate to the appropriate stakeholders.
	+ Resources are not linguistically or culturally accessible.
* Randy Dinning reviewed Goal Statement and led the group in the following:
	+ Developing a goal statement
	+ Identifying external factors
	+ Listing assumptions
	+ Identifying resources
	+ Listing Project outcomes
	+ Identifying activities
* Randy will send the updated document to Matt Berube

Committee comments

* None

Public comments

* None

**Future Meeting Dates**

* TBI Board Meeting – April 17, 2023
* TBI Board Committees – May 11, 2023

**Adjournment**

Motion for adjournment was made by Vincent Martinez. Meeting ended at 12:05 pm.

**Public Policy and Funding Committee**

Meeting was called to order at 2:13 p.m. by Matt Berube, TBI Program Administrator

**Committee Business – Kristie Warren**

**Members Present (Quorum was met)**

* Kristie Warren, TBI Survivor
* Dr. Katie Shinoda, Mercy General Hospital
* Erin Johnson, TBI Survivor

**Members Not Present**

* Eric Williams, TBI Survivor
* Michael Roscoe, TBI Survivor

**DOR Staff Present**

* Matthew Berube, DOR TBI Program Administrator

**Public Present**

* Dan Clark, Community Advocate
* Nicole Turpin, Resources for Independence, Central Valley
* Gabby Chambers, Jodi House
* Dr. Daniel Ignacio, St. Jude Health and TBI Survivor

**Approval of Meeting Minutes**

* No meeting was held for March 9, 2023 because of a lack of quorum.

**Committee Business**

* The committee members agreed to extending the quarterly Traumatic Brain Injury Advisory Board meetings by one hour, beginning in July 2023.
* Committee would like specific information regarding funds and resources available to it for its projects and activities.
* The PPFC will ask the full TBI Advisory at it quarterly meeting on April 17, 2023 for funding to continue the operations of the current California Traumatic Brain Injury (CATBI) sites.
	+ The committee discussed various funding proposals.

**Logic Model** (defines common goals, objectives, and shared ‘why’)

Problems for the PPFC to address:

**Public Policy & Funding Committee Logic Model**

Problems

1. Expansion to 12 TBI sites is currently limited by HCBS federal funding (fully funds 6 TBI contracts and augments the 6 TBI Grants funded by the state) end-date of 1/31/24. TBI Grants (state funding) are scheduled to end June 30 2024, with a possible one- or two-year extension.
2. What are sustainable funding sources and how do we connect the data to funding?
3. What is the amount of funding needed to run an effective TBI Program?
4. How to build a statewide TBI program model guided by data to optimize services, continuity, and consistency throughout the state?

Goals: Utilizing the data from Registry/Needs Assessment

1. Identify funding sources to create a funding proposal model so there is no lapse in funding for the current 12 TBI sites.
2. Identify sustainable funding sources connecting the services and data from registry and needs assessment.
3. Provide DOR with a specific recommendation for the amount of TBI site funding.
4. Develop a conceptual model guided by data for TBI Site structure and services.
	1. including: staff training, service provision requirements, certification, cultural and language barriers, consider waiver type services, ADHC, residential programs, behavioral management, population of TBI survivors, etc.
5. DOR leadership, TBI Programs, TBI Advisory Board

External Factors (things DOR does not have control over)

1. Funds available from the state
2. Competing legislative priorities
3. Number of TBI survivors seeking services and supports
4. Accessibility of services (location, rural, cultural/language)
5. Communication between CATBI and the committee for proper documentation of funding
6. Budget Change Proposal anticipated in Spring (to increase funding to TBI Sites and make TBI Program permanent).

Internal Factors

1. Freshman Committee
2. Five Committee Members vs. amount of work needed is a challenge

Assumptions

1. If we have identified a logical sustainable funding source and advocate for the TBI Program, California will dedicate ongoing funds to providing needed services to survivors of TBI.
2. We can find organizations that are able to provide the recommended services.
3. Any recommendation made by the TBI Advisory Board will be accepted by DOR and the state legislature.
4. Any model we create is a forward-thinking model. We can anticipate the needs of TBI survivors in CA.

**Identify our Resources**

1. CATBI -12 TBI Sites (Data and advocacy)
2. DOR leadership
3. TBI Advisory Board
4. HCAI (Healthcare Access and Information) for data
5. Trauma Registry Data
6. IL Network
7. DHCS
8. TBI Survivors and lived experience
9. NASHIA
10. BIA Cal
11. Other state advisory boards
12. Authors of SB 870- Portantino/ Welk (extends age of disability from 18 to 22)
13. Legislative champions
14. Other state Departments (DHCS, DDS, DMH)
15. National Concussion Legislation to follow nationally - Conley (Virginia)
16. Healthcare and Health Insurance Plan Teams
17. Private Philanthropic Organizations
18. Economist or an Actuary

**Project Outcomes**

1. Fewer TBI survivors in the criminal justice system.
2. Improve TBI survivors’ access to resources.

PPFC and BISC

* BCP proposal will need a data guided rationale and a sustainable funding source.
* BCP would need public support at hearings, etc.

Objective: Identify options for long term funding and Utilize the TBI Needs Assessment and Registry to inform policy, education, and training statewide.

Outcome: Expands systems to support early identification, intervention, resource facilitation, and coordination for people with TBI and Identify sustainable funding mechanisms to support locally based TBI services.

Product: A funding model proposal for TBI survivors to receive locally based services through the Department’s TBI sites and culturally competent and evidence-based policies, education, and training informed by data gathered in the Needs Assessment and Registry.

**Approval of PPFC Logic Model**

* The approval of the PPFC Logic Model in its present form was motioned by Dr. Katie Shinoda and seconded by Erin Johnson. The Logic Model was approved by members Shinoda, Johnson, and Warren.
	+ Committee comments
		- None
	+ Public comments
		- Dan Clark said that finding a legislative champion, and gathering community support was important for the successful completion of the committee’s work.

**Future Meeting Dates**

* TBI Board Meeting – April 17, 2023
* TBI Board Committees – May 11, 2023
	+ Committee comments
		- Dr. Katie Shinoda asked member of the public Brenda Plechaty to describe the work of her support group.
	+ Public comments
		- None

**Adjournment**

Motion for adjournment was made by Dr. Katie Shinoda and seconded by Erin Johnson. The meeting ended at 3:38pm.