

## **Traumatic Brain Injury (TBI) in Washington: 2021-2023 Experiences and Trends with Services and Supports Assessment**

From October 2021-April 2022, project staff met monthly with representatives from Washington Department of Social and Health Services and the Traumatic Brain Injury Strategic Partnership Advisory Council of Washington State to write a statewide research survey.

The goal of the survey was to learn:

1. What problems people with TBI have getting the services and supports they need
2. What kind of help is available to people with TBI

This survey was based on two previous brain injury needs assessment surveys (Oregon and [Colorado](#)). Three versions of the survey were created:

- one for those with lived experience of TBI
- one for caregivers of those with TBI
- one for service providers who serve those with TBI

In the Summer of 2022, draft surveys were reviewed with a diverse group of people with lived experience. Surveys were updated based on their feedback.

### **Methods**

#### **Online Survey**

The survey was available online in Spanish and English. People taking the survey could ask for assistance, including live translation. Questions were multiple choice and short answer. A statewide outreach plan included flyers with QR codes, social media, email campaigns, and outreach through personal networks. This resulted in thousands of individual contacts across the state in many areas (e.g., education, safety, health care, behavioral health, housing). There was an additional focus on underserved populations (communities of color, homeless communities, LGBTQ+ communities, Tribal communities, rural communities, survivors of intimate partner violence, and those that have served in the military).

Data was collected from November 2022- November 2023. In total, 765 people took the survey; 437 people with lived experience of TBI, 184 caregivers, and 144 service providers.

[Quantitative results can be found here.](#)

#### **Interviews**

In total, 19 people who took the survey were interviewed. 9 people with lived experience of TBI, 6 caregivers, and 4 service providers. Interview participants were chosen based on two

factors. The first factor was demographics. Participants from traditionally marginalized communities (e.g., non-white, living in rural areas, lower socioeconomic status) were a priority for interviews. We also selected participants with military or first responder service. The second factor was the participants' responses to the survey. Participants who had unique responses and responses that were representative of the data set were chosen for interviews.

## Qualitative Analysis

Narrative data were analyzed using Thematic Analysis. Steps of Thematic Analysis include:

1. Making key decisions
2. Careful reading of data
3. Organizing data into categories
4. Identifying and defining categories into codes
5. Discussing codes and organizing into broader theme

Each step was done by the entire research team (Assistant Research Professor, Research Associate, and Senior Research Assistant).

## Findings

Themes were found based on two main criteria:

1. How often a theme came up
2. How related the theme was to the goal of the survey

Themes were generated from each type of participant.

## Lived Experience of TBI

1. Caregiver relationship is essential. A loss of this relationship can be catastrophic
2. Compassion and patience are important to recovery
3. It is difficult to know what services are available and who is eligible
4. Providers often don't listen to or believe lived experience
5. Providers are often unsure how to serve people with TBI

## Caregivers

1. Caregivers are not prioritized by anyone, leaving their needs unaddressed
2. TBI Caregivers face long term, intense challenges
3. People with lived experience of TBI need support with awareness and acceptance of injury
4. People with lived experience of TBI have difficulty obtaining diagnosis and treatment
5. TBI support groups provide needed community

## Service Providers

1. Advocacy is needed to support persons with TBI
2. Insurance companies refuse coverage of services needed post TBI
3. Providers are unsure how to serve people with TBI and their families
4. Need for TBI training and resources for all stakeholders
5. Partnerships/relationships between professionals and organizations are helpful

## Recommendations

Based on the findings above, the following is recommended:

### Invest in Connections

1. Host regional provider network meetings and workshops
2. Offer TBI provider trainings
3. Host regional and community specific virtual TBI support groups with regular in person events

### Make the Invisible Visible

1. Develop a strategy for screening for lifetime history of TBI; including when to screen, who screens, and action plans for positive TBI screens
2. Increase the communication of information about current programs for people with TBI and caregivers to communities
3. Invest in education, awareness, and advocacy campaigns about TBI

### Support the Supports

1. Meaningfully include the perspective of caregivers in all TBI initiatives, recognizing the critical roles of in-home/family caregivers and their unique needs.
2. Advocate for development of caregiver supports (e.g., respite care, mental health care, financial compensation, targeted education).
3. Support group facilitators should be knowledgeable and paid for their time.

## Limitations

Populations not well represented in this data set are:

- those living in long term care facilities
- current K-12 students
- those living on tribal lands

It is recommended that further resources are invested to continue relationship building with these communities and work towards identifying their specific needs.