

REPORT TO THE LEGISLATURE

**Washington State Traumatic Brain Injury Council
Comprehensive Statewide Plan
2019-2020**

RCW 74.31.020
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Executive Summary

Traumatic Brain Injury (TBI) is a major public health problem in Washington state. TBI may be caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain¹. Based upon nationwide statistics it is estimated there are over 145,000 individuals living with TBI-related disabilities in Washington². The United States (U.S.) Centers for Disease Control (CDC) estimates there are over 1.4 million new cases of brain injury in the U.S. each year. That is about eight times the number of people newly diagnosed with breast cancer and 34 times the number of new cases of HIV/AIDS. Direct and indirect medical costs of TBI, such as lost productivity, totaled an estimated \$60 billion in the U.S. in 2000. The Comprehensive Statewide Plan included in this report to the Legislature addresses the unique needs of Washington State citizens living with or affected by TBI.

The Washington Traumatic Brain Injury Strategic Partnership Advisory Council (TBI Council) and the Department of Social and Health Services (DSHS) have collaborated to develop the Comprehensive Statewide Plan pursuant to Chapter 74.31 RCW. The Comprehensive Statewide Plan is updated every two years to:

- Address the needs of individuals with traumatic brain injuries;
- Form strategic partnerships;
- Foster the development of services and supports for those impacted by traumatic brain injuries; and
- Report the activities and recommendations of the TBI Council.

Those recommendations are to:

1. Continue with the foundational activities outlined in Chapter 74.31 RCW: Information & Referral, Public Awareness, TBI-related Support Groups, and activities of the Council.
2. Build provider capacity through training and education of the medical community, insurance companies, housing and supportive service providers, schools, and employers.
3. Improve coordination of policies, programs, and services.
4. Establish partnership agreements with the private sector, state agencies,

¹ Centers for Disease Control and Prevention

² Centers for Disease Control and Prevention

schools, tribal governments, the federal government, and others to develop integrated services.

5. Address other areas of focus including systemic reform and self-advocacy.

Background

Chapter 74.31 RCW, also known as the Tommy Manning Act, addresses issues related to Traumatic Brain Injury (TBI). The statute recognizes that current programs and services were not funded or designed to address the diverse needs of individuals with TBI.

The intent of the statute is to bring together public and private experts to address the needs and gaps in services for the community of TBI survivors, caregivers, and their families. This was carried out by creating the Washington Traumatic Brain Injury Strategic Partnership Advisory Council (TBI Council). The Council is composed of 25 members from the public and private sector and includes individuals with TBI, medical professionals serving individuals living with TBI, human service providers, family members of individuals with TBI, caregivers serving individuals with TBI, and state agency representatives.

The legislation also created a TBI account in the state treasury. Revenue for the account is generated through a \$2 fee collected from traffic violations. Based upon predictions, less than \$2.4 million will be deposited into the account during the 2017-19 Biennium. This is a significant drop from previously, when the average was over \$3 million. The account is used to fund the legislatively mandated activities included in the statewide TBI comprehensive plan to provide a public awareness campaign;

- Services relating to TBI support groups;
- Information and referral services; and
- Staff costs to support the TBI Council's activities.

Ten years since the inception of the Tommy Manning act, the need for services continues to grow. Currently the TBI Account is exhausting its balance to continue services at their current level, while TBI advocates work on proposals to increase revenue. Funding of the mandated tasks has helped thousands of Washington State citizens better understand the relatively new concept of TBI, which is still widely misunderstood. In past years, the TBI Council has been able to approve projects intended to explore innovative ways of assisting survivors of TBI

through research, pilot programs, and marketing materials. However, recent revenue trends have forced a fiscally conservative annual budget.

A Long-Term Vision of a Comprehensive Statewide TBI System

DSHS and the TBI Council recognize that a multi-year strategy is necessary to achieve the long-term vision for individuals in Washington state living with a TBI. The recommendations to the Legislature in this report address immediate and urgent needs for prevention, public awareness activities, and necessary services. The Council and TBI community envision a system that is characterized by:

- Public and private efforts to assure broad public awareness of TBI;
- Effective prevention programs for all age groups;
- Cultural competence in TBI services and programs;
- Outreach to underserved populations;
- Education for first responders and law enforcement;
- Effective screening and early intervention for children and youth to include a statewide post-concussion return to learn program;
- Effective screening and early intervention for adults to include a statewide post-concussion return to work program;
- Specialized services in public and private programs;
- Coordination of care and services across all systems;
- Transitional supports for individuals with TBI and their family members; and
- Full community integration and participation for those living with TBI.

Council Accomplishments in 2017-2018

DSHS and the TBI Council worked diligently over the past two years to accomplish foundational activities that supported a multi-year strategy to achieve the long-term vision for persons impacted by TBI. The following are examples of those foundational activities in 2017-2018:

- Funded the Brain Energy Support Group, which provided 1,200 people access to attend brain injury support groups across Washington State every month. Groups engaged in a variety of activities from discussions, to sharing resources, to participating in community activities. Goals were established and met to offer education, coaching, and technical support. These efforts assisted participants to have safe spaces to come together and support one another. In addition, they provided opportunities to test new skills, learn new behaviors, and explore ideas in real world situations;
- Received over 11,000 Brain Injury Alliance of Washington (BIAWA) TBI Resource Center calls;
- Served 200 new clients through the BIAWA TBI Resource Management Program, including 50 pediatric enrollments;
- Successfully sponsored TBI conferences in 2017 and 2018 with over 800 attendees, and funded over 150 attendance scholarships each year. The conferences provide education and resources to TBI survivors, family members and healthcare professionals;
- Supported two Inland Northwest Brain Injury Symposiums at the Eastern Washington University Spokane Campus;
- Participated on the Department of Corrections (DOC) TBI Task Force with the University of Washington School of Rehabilitation that utilized grant funding to develop a TBI-specific training. The training was presented to all staff at DOC and continuing efforts will include a pilot project targeted towards incarcerated people with TBI. This pilot will focus to provide support, education and re-entry services as they enter work release and/or are supervised in the community;
- Partnered with the Washington State Unit on Aging to successfully apply for a Lifespan Respite Program grant with a focus on TBI survivors, their family members, and caregivers;
- Maintained the TBI Council website to provide education, advocacy, research, and support to TBI survivors, caregivers, and providers <https://www.dshs.wa.gov/altsa/traumatic-brain-injury/traumatic-brain-injury-advisory-council>;
- Participated on the University of Washington TBI Model Systems Advisory Board;

- Partnered with the Inland Northwest Health Services for TBI awareness and prevention conference in Eastern Washington;
- Increased public awareness of TBI through outreach efforts;
- Increased TBI Council membership with more representation from outside the greater Puget Sound Metropolitan area. Membership participation is at an all-time high in the TBI Council's ten year history;
- Coordinated with the BIAWA to provide statewide Continuing Education training to long-term services and supports providers on TBI;
- Coordinated with BIAWA to provide statewide training to Home and Community Services (HCS) staff on TBI;
- Partnered with the Aging and Long-Term Support Administration Training Unit to develop an eight hour TBI specialty training curriculum for use by community trainers and long-term services and supports providers, including Adult Family Home providers;
- Identified residential providers to specialize in serving HCS clients with TBI and supporting them with training, and Expanded Community Services/Specialized Behavioral Support contracts;
- Funded Seattle BrainWorks Program which provided:
 - 10,000 hours of direct service to program members
 - 1,403 free classes and 2,801 hours of volunteer services to members at Seattle BrainWorks
 - Collaborated with Division of Vocational Rehabilitation to support individuals with TBI for employment services
- Partnered with the Washington Department of Veterans Affairs whose TBI programing during the 2016-2018 biennium provided:
 - Statewide direct service and ongoing case management for over 372 veterans and their families
 - Participation in 21 conferences/summits
 - Training for 1,743 service providers that represented 32 counties
 - Attendance to 28 community events connecting with 712 veterans
 - Training and support to 204 justice staff in five different jurisdictions (spanning first responders, police departments, courts, jails, prisons and community corrections)

- Creation and implementation of “Max Impact” in July 2017. “Max” is a smartphone app created to assist Washington State veterans to manage their symptoms, learn more about TBI, and connect with one another and local resources. The app has been hugely successful reaching:
 - 1,665 downloads;
 - 1,644 referrals to local agencies;
 - 237 links to crisis centers;
 - Consistent users in 18 Washington state counties, across the country and in other parts of the world.

Foundations for Recommendations

In making recommendations for the 2019-2020 Comprehensive Statewide Plan, DSHS and the TBI Council acknowledged and considered the following underlying foundation:

TBI can impact anyone, at any time, in any geographical area of the state. TBI planning, coordination, and service delivery must address broad needs across the life span. TBI impacts all age groups, cultures, races and socioeconomic classes. There is a distinct lack of statistical analysis on the number of survivors of brain injury in Washington State. It is important to note more research should be conducted within Washington to determine the number of individuals who have a TBI in order to support ongoing services and supports to meet their needs. In 2015 the Washington Department of Health found hospitals reported 6,263 people with TBI, and an unknown number of individuals sustained injuries that were treated in other settings or went untreated.

Planning, coordination, and service delivery must emphasize cultural competency, ethnic and cultural diversity, and outreach to underserved populations.

Some population groups are disproportionately impacted by TBI:

- Nationally, there is a higher incidence of TBI in Native American and Alaskan Native communities than in the general population and African Americans have the highest death rate from TBI³;
- In 2013, among children aged 14 and younger, TBI contributed to nearly 640,000 emergency room visits and 18,000 hospital stays nationwide⁴;

³ Center for Disease Control

⁴ Center for Disease Control

- As of March 2018, 383,947 service members have been newly diagnosed with TBI since 2000⁵; and
- In Washington the highest number of TBI-related deaths are among persons ages 85 years and older. Among those with TBI-related hospitalizations persons ages 75 to 84 were most affected⁶;
- Washington State ranks 7th in the nation for veterans reporting TBI and veterans in Washington state incur TBI three times the rate of their civilian counterparts, increasing the veteran's risk of homelessness, incarceration and suicide.⁷

Most TBIs are preventable and early intervention increases long-term success for individuals, their families and community supports. TBI planning must address prevention and early intervention. According to the Center for Disease Control:

- 47% of all TBI-related emergency department visits, hospitalizations, and deaths are fall related;
- 70% of concussions among high school athletes result from colliding with another athlete; and
- Motor vehicle crashes are the leading cause of death for U.S. teens. Six teens aged 16 to 19 die every day from motor vehicle injuries.

Potentially, any of these causes of TBI can in some measure be prevented. Long-term disability related to any of these causes of TBI can be greatly reduced by early and appropriate intervention. TBI planning must expand public awareness, information and referral, timely intervention and service activities.

TBI impacts Washington's citizens across many public and private systems. Passage of RCW 74.31.030 provided ongoing public funding in the state with a specific role to address the needs of this unique community. TBI affects schools at all levels and there hasn't been development of a statewide plan for return to learn after a concussion or more severe levels of brain injury. All sectors of the judicial systems from Juvenile Rehabilitation to adult prison and parole systems are all effected by brain injury. Veterans may require assistance to bridge federal and state services to meet their needs.

⁵ Defense and Veterans Brain Injury Center

⁶ Washington Department of Health

⁷ U.S. Department of Veterans Affairs, in response to a CRS request

TBI planning must address services and interventions that are specific to the needs of those living with TBI and their families. Currently, people living with TBI are served in a variety of human service programs designed to meet the needs of a broader population, including mental health, alcohol and substance use disorders, developmental disabilities and long-term care. Targeted, specialized treatment, services and intervention can provide a more efficient use of resources and improve community integration of individuals who live with severe impacts from TBI.

Process Used to Develop the Recommendations

Under the direction of the legislature, the TBI Council and DSHS followed a collaborative process to develop recommendations that will build a comprehensive system of care to help meet the needs of individuals living with TBI in Washington State.

The TBI Council created Technical Advisory Committees (TAC). Each committee focused on specialty areas identified by the council to ensure the recommendations presented reflect the expertise of those living with TBI, family members, providers, caregivers, the private sector and Chapter 74.31 RCW designated state agencies. TAC's focus areas were:

- Building provider capacity and provider training;
- Improving the coordination of policies, programs and services;
- Establishing partnership agreements with the private sector, state agencies, Tribal governments, federal government, and others to develop services that integrate TBI services; and
- Addressing other areas of focus, such as systematic reform and self-advocacy.

Each TAC produced recommendations which were presented to the entire council. The council came to consensus on the final recommendations as the foundation for immediate system development and long-range planning.

Final Recommendations

To address the long-term vision for a comprehensive statewide TBI system, DSHS and the TBI Council have identified the following recommendations to the Legislature:

1. **Foundational Activities:** Continue with the foundational activities outlined in Chapter 74.31 RCW: Information & Referral, Public Awareness, TBI-related Support Groups and activities of the Council.
2. **Revenue Sustainability:** Ensure revenue for the TBI account is maintained and sustainable. Unless revenue trends change, long-term sustainability will require legislative change to fully fund and support Chapter 74.31 RCW.
3. **Before TBI Occurs – Prevention and Awareness:**

A. Prevention

- i. Develop a statewide TBI registry, with the ability to provide data from each of the 39 counties;
- ii. Disseminate reviewed TBI research data;
- iii. Partner with public and private agencies that are equipped to engage in TBI prevention pre-injury through injury onset, rehabilitation, re-integration and long-term management;
- iv. Collaborate on TBI prevention in adult long-term services and supports residential facilities and “Safe Kids” prevention campaigns;
- v. Develop partnerships with organizations to incorporate a TBI focus that includes human resource compliance, disability coordinators and employee assistance programs; and
- vi. Gather and utilize data regarding the dynamics of daily life after a TBI.

B. Awareness

- i. Utilize existing research findings to facilitate education and training materials for:
 - Medical and behavioral health providers;
 - Emergency responders and law enforcement;
 - K-12 public and private school students;
 - Washington State colleges and universities;
 - Scholastic athletic departments;
 - Veterans’ organizations;
 - Homeless and domestic violence organizations;
 - Jails and correctional facilities;
 - DSHS employed and contracted case managers;
- ii. Promote educational partnerships across organizational and cultural boundaries;
- iii. Target outreach to higher risk minority populations;
- iv. Support community-based TBI awareness events and campaigns across the state with an emphasis on rural regions; and

- v. Partner with organizations serving individuals with abuse onset head injuries, including domestic violence and child abuse organizations.

4. **During the TBI – Proper Diagnosis, Access to Care, and Coordination of Care:**

A. Screening and Diagnosis

- i. Develop TBI continuing education and uniform screening protocols for medical providers to ensure early recognition of TBI among:
 - Criminal justice personnel (e.g. law enforcement, corrections, etc.);
 - Hospital, urgent care, and general clinic staff;
 - Homeless and domestic violence shelter staff;
 - Nursing homes, adult family homes, and related facilities;
 - Behavioral health providers and organizations;
 - K-12 and post-secondary schools faculty and staff;
 - DSHS employed and contracted case managers.

B. Access to Care

- i. Ensure TBI-specific services are covered by all health care plans, including Medicaid and Medicare. Address gaps in coverage and provider network by:
 - Increasing availability of Medicaid/Medicare providers;
 - Providing medically necessary services not covered under current benefit packages.
- ii. Identify current research on cost/benefit ratio of TBI-specific evaluations and services such as neuropsychological evaluation, cognitive and vocational rehabilitation, behavioral therapy strategies, respite and community integration;
- iii. Increase access to care and awareness in rural communities;
- iv. Increase access to telehealth technology;
- v. Reduce health disparities in underserved populations by ensuring adequate network capacity, cultural and linguistic competency, and effective outreach efforts; and
- vi. Increase access to transportation for TBI survivors.

C. Coordination of Care

- i. Provide support for unpaid caregivers assisting survivors of TBI;

- ii. Improve statewide referral systems for care providers with expertise in TBI, to include providers in all regions of Washington;
- iii. Produce a TBI Tool Kit to provide guidance to TBI survivors and their families;
- iv. Develop routine discharge protocols to provide TBI symptom and treatment information for those with suspected or diagnosed TBI;
- v. Increase access to advocacy services in institutional and residential settings; and
- vi. Improve coordination of services among physical and behavioral supports.

5. **After the TBI - Re-integrating Into Community:**

A. Reintegration - Housing

- i. Partner with hospitals and regional rehabilitation centers to create person-centered community re-integration programs for individuals following a TBI;
- ii. Build capacity and access for quality TBI-specific, post-acute community living settings such as:
 - Residential facilities and settings;
 - Adult Family Homes;
 - Skilled Nursing Facilities;
 - Independent housing.
- iii. Provide TBI training for community facilities.
- iv. Identify key housing and service stakeholders and foster partnerships.

B. Reintegration – Return to Work

- i. Partner with the Division of Vocational Rehabilitation, Washington State Department of Veterans Affairs, Labor and Industries, Occupational Health and Safety Administration, and the Governor’s Committee on Disability Issues and Employment to improve reintegration to work;
- ii. Extend Labor & Industries return to work program beyond the 60-day limit for individuals with TBI;
- iii. Continue and expand partnership opportunities with the Division of Vocational Rehabilitation (DVR) for return to work for individuals with TBI; and
- iv. Provide TBI training for school personnel to facilitate TBI survivor reintegration.

C. Reintegration – Return to School

- i. Partner with the University of Washington, Harborview Injury Prevention and Research Center, Division of Vocational Rehabilitation, and the Office of the Superintendent of Public Instruction to create a program to improve school transitions for students with TBI;
- ii. Develop and implement a “Return to Learn” pilot program to build transition services for students with TBI; and
- iii. Train school personnel and education advocates about the needs of children and youth with TBI and best practices to integrate TBI survivors back into school.

6. **Living with a Brain Injury:**

A. Living with a Brain Injury

- i. Create a stakeholder-driven TBI state plan to encompass the following items:
 - Support Groups;
 - Continuing Education;
 - Housing;
 - Socialization;
 - Community Reintegration;
 - Economic Reintegration.
- ii. Educate primary care physicians and other medical providers to recognize ongoing, reappearing, and increasing TBI symptoms.
- iii. Create consistent screening protocols for medical providers with proactive connection to appropriate resources;
- iv. Educate policy makers on benefits of TBI-supported community-based housing settings;
- v. Share successful TBI housing models with housing providers and developers;
- vi. Educate transportation authorities, to recognize an individual living with a TBI;
- vii. Permanently and sustainably fund a statewide Washington Department of Veterans Affairs TBI program; and
- viii. Educate employers on providing accommodations for employees with TBI; and partner with communities across Washington State to foster community events that encourage inclusion of TBI survivors.

Results Washington:

The recommendations and commitment of the TBI Council is in alignment with several Governor Inslee identified Results Washington:

Goal 1: World Class Education – Access & Success - Providing every Washingtonian a world-class education that prepares him or her for a healthy and productive life, including success in a job or career, in the community and as a lifelong learner.

Goal 2: Prosperous Economy – Quality of Life – Washington is a great place to live.

Goal 4: Healthy and Safe Communities - Supported People - Help the most vulnerable people become independent and self-sufficient.

Conclusion

There is an ongoing need to address the unique needs of the TBI community. The Comprehensive Statewide Plan provides an outline of the next steps necessary to address the needs of individuals living with TBI and their families. The report acknowledges the commitment to the work of the Washington State Legislature through ongoing funding of the TBI account to support the continued activities of the TBI Council.

There are no less brain injury survivors today than in 2007 when HB 2055 passed. In fact, as awareness increases, more survivors are screened and identified. While the number of individuals that use TBI services funded through the TBI Trust Fund has increased, the funding provided by the \$2 fee accessed through traffic fines has declined. This plan addresses the need for sustainable funding to ensure the programs established over the last decade can expand to meet the demand.

The Comprehensive Statewide Plan and the recommendations included, represent the commitment and collaboration of TBI experienced volunteers from across the state. TBI continues to alter the lives of individuals in an instant, often with long-term impacts. The volunteers who developed the report were willing to share their expertise toward improving the lives of individuals living with TBI.

Appendix A: Roster of TBI Council Members

| Member | Board Position |
|-----------------------------|---|
| Daniella Clark | Public member with TBI |
| Jeff Hartson | Public member with TBI |
| Heidi Hill | Public member experienced with issues related to the causes of TBI |
| Nick Mehrnoosh | Public member experienced in issues related to the causes of TBI |
| Karen Kaizuka | Family member of individual with TBI |
| Kylie Uriostegui | Family member of individual with TBI |
| Elizabeth York | Rehabilitation Specialist with experience working with persons with TBI |
| Deborah Crawley | Executive Director of the Brain Injury Alliance of Washington |
| Marisa Osorio | Physician with experience working with individuals with TBI |
| Vernon Keven Shipman | Native American Tribe in Washington State |
| Lee Collyer | Social Worker with experience working with persons with TBI |
| Teresa Claycamp | Division of Behavioral Health and Recovery |
| Megan Grundbrecher | Division of Vocational Rehabilitation |
| Will Hitchcock | Department of Health |
| Betsy Jansen | Aging and Long-Term Support Administration |
| Taku Mineshita | Children's Administration |
| Daniel Overton | Washington Department of Veterans Affairs |

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| Karie Rainer | Department of Corrections |
| Ted Ryle | Department of Juvenile Rehabilitation |
| Michael Smith | Disability Rights of Washington |
| Major Adam Hanisch | Washington National Guard |
| Rick Torrance/Mary Baldwin | Department of Commerce |
| Vacant | Individual with expertise working with children with TBI |
| Vacant | Neuropsychologist with experience working with persons with TBI |
| Vacant | Non-Profit organization serving individuals with TBI |

Appendix B: TBI Council Staffing Plan

| Position | Duties |
|---|--|
| TBI Council and Fund Coordinator | <ul style="list-style-type: none"> • Responsible to manage and coordinate the activities of the Washington State Traumatic Brain Injury Council. • Coordinates policy, procedures, and services for individuals with TBI. • Provides available data and information to the council upon request. • Implements, within appropriated funds, the agreed upon recommendations as noted in the Comprehensive Statewide Plan. • Assures information and referral services are provided to individuals with TBI. • Provides procurement, oversight and management of contracts related to the TBI Council activities. |
| TBI Council Assistant | <ul style="list-style-type: none"> • Management and distributing information to the TBI Council. • Provides various administrative support and functions to support the TBI Council with information, meetings, correspondence, materials, scheduling, etc. • Works closely with the TBI Coordinator to set priorities and achieve council goals and objectives. |