

REPORT TO THE LEGISLATURE

Washington State Traumatic Brain Injury Council Comprehensive Statewide Plan 2017-2018

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Executive Summary

A Traumatic Brain Injury (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. Conservative estimates indicate there are nearly 145,000 individuals living with TBI-related disabilities in Washington. 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 have collaborated to develop the TBI Comprehensive Statewide Plan in pursuant of Chapter 74.31 RCW. The 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:

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

¹ Centers for Disease Control and Prevention

The intent of the statute is to bring together expertise from the public and private sector to address the needs and gaps in services for this community. 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 the TBI account in the state treasury. In the 2013-15 biennium, approximately \$2.8 million dollars was deposited into the account. Revenue for the account is generated through a \$2 dollar fee collected from traffic violations. The account is used to fund the activities included in the statewide TBI comprehensive plan: to provide a public awareness campaign, services relating to TBI, information and referral services, and staff costs to support the council.

A Long-term Vision of a Comprehensive Statewide TBI System

TBI is a contributing factor to one-third of all unintentional injury-related deaths. The Department and Council recognize that a multi-year strategy is necessary to achieve the long-term vision for persons 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 a set of needed, targeted services. For the long-term, the council envisions 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 groups;
- Education for first responders and targeted early intervention;
- Effective screening and intervention for children and youth;
- Specialized services in public and private programs;
- Coordination of services across human service systems;

- Support for families and caregivers;
- Transitional supports for individuals with TBI and their family members;
- Full community integration and participation for those living with TBI.

Council Accomplishments in 2015-2016

The Department and Council worked diligently over this past two years to accomplish foundational activities that support a multi-year strategy necessary to achieve the long-term vision for persons impacted by TBI. As examples of foundational activities, in 2015-2016, the Department and Council:

- Provided TBI-specific training to 122 support group facilitators in both Eastern and Western Washington;
- Promoted the Brain Injury Alliance and Seattle BrainWorks 5th and 6th Annual Walk, Run, & Roll for Thought with over 350 participants;
- Provided essential funding to the Brain Energy Support Team to increase the number of support groups to 76 (62 fully funded), and expand the geographic distribution across the state;
- Worked with Seattle BrainWorks to grow its membership to 75 active members and be open approximately 225 days per year. Seattle BrainWorks provides employment services such as job development, job-site training, transition services, employment planning and collaborates with the Department of Vocational Rehabilitation;
- Provided assistance and outreach to individuals with TBI and their families who need direct assistance to identify and access services. There have been more than 24,000 individuals and families served in 2015 and 2016;
- Sponsored successful TBI conferences in 2015 and 2016 with over 400 attendees, providing education and resources to TBI survivors, family members and healthcare professionals;
- In 2015, the TBI Council sponsored the first ever Eastern Washington TBI Symposium in Spokane, and in 2016 the TBI Council sponsored the 2nd annual TBI Symposium in Richland;

- Maintained www.tbiwashington.org website to provide education, advocacy, research, and support to TBI survivors, caregivers and providers;
- Participated in the University of Washington Return-to-Learn Summit to discuss a return-to-learn protocol for students returning to academic activities after a TBI;
- Leveraged public and private funding to increase public awareness of TBI;
- Partnered with Department of Veterans Affairs (VA) since 2010. In 2015 and 2016, the following activities were conducted:
 - ✓ 50 Vet Corps sites received training on TBI and are visited at least 3 times each year by the VA outreach coordinator to ensure that appropriate referrals and supports are in place for veterans identified with TBI;
 - ✓ 21 trainings conducted at college campuses, military installations, tribal events, and with community partners throughout the state;
 - ✓ 6 trainings for National Guard/Reserve members, and their families;
 - ✓ Conducted 2 breakout workshops at the 2015 and 2016 Washington State TBI Conference. One workshop addressed veteran TBI employment strategies and the other addressed supporting Washington's veterans with TBI, their families and communities;
 - ✓ Approximately 17,000 people, including veterans, attended trainings and received information on TBI and resources available throughout the state;
 - ✓ Partnered with the Washington State Criminal Justice Training Center to provide the Train-the-Trainer First Responder Training Program for law enforcement and corrections personnel;
- Partnered with the University of Washington and Harborview Medical Center to conduct a needs assessment of TBI in public schools.

Foundations for Recommendations

In making these recommendations for a comprehensive TBI plan, the Department 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 and races. In Washington state it is estimated that at least 30,000 individuals sustain a TBI each year. Conservative estimates indicate that 145,000 people in Washington state live with a long-term disability as a result of TBI.

Some population groups are disproportionately impacted by TBI:

- TBI hospitalization rates are highest among African Americans and American Indians/Alaska Natives.
- Children from birth to 4 years and older adolescents aged 15 to 19 years are among those with the highest rates of TBI nationally.
- Veterans are also disproportionately impacted by TBI due to current international conflicts

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

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 CDC, about 40% of all traumatic brain injuries are caused by falls. Motor vehicle collisions account for 14%. Assaults account for 10% of TBI 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, and timely intervention and service activities.

TBI impacts schools at all levels and all sectors of the judicial systems, from juvenile rehabilitation to adult prison and parole systems. Veterans may require assistance to bridge federal and state services to meet their needs. Passage of RCW 74.31.030 provided ongoing public funding in the state whose specific role was to address the needs of this unique community.

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 and intervention can provide a more efficient use of resources and improves 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 the Department followed a collaborative process to develop recommendations that will create 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 specific gaps and specialty areas to ensure the recommendations presented here reflect the expertise of those living with TBI, family members, providers, caregivers, the private sector and the Chapter 74.31 RCW designated state agencies. TAC 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 governments and others to develop services that integrate TBI;
- Addressing other areas of focus, such as systematic reform and self-advocacy.

This comprehensive statewide plan incorporates key statutory activities identified in Chapter 74.31 RCW, including:

- Continuing the foundational activities delineated in Chapter 74.31 RCW of information and referral, public awareness, and support for TBI-related support groups;
- Maintaining an ongoing public awareness campaign responsive to current needs;
- Further developing and implementing curricula for caregivers, first responders, medical professionals, state agencies, and the criminal justice system and school personnel;
- Establishing coordinated links between TBI Information and Referral services and services provided by tribal governments, Urban Indian programs, schools, programs serving veterans and programs serving children and youth.

The TACs each produced recommendations which were presented to the full council. The council came to consensus on the five broad 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, the Department and Council have identified the following recommendations to the Legislature. Full implementation of the recommendations would require a combination of funding from federal, state funding and private partnerships.

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.

Examples of this include, but are not limited to:

A. Awareness Education/Training

1. Train community therapists, providers/educators and discharge personnel at hospitals;
2. Utilize research in building TBI provider education;
3. Early recognition by emergency room doctors and occupational healthcare providers;
4. Train criminal justice personnel (e.g. law enforcement, corrections, etc.).

B. Insurance

1. Educate policy makers about the need for TBI-specific Medicaid services;
2. Educate the policy makers about the need for insurance reform to include coverage for TBI services, (e.g. if the patient is not diagnosed with TBI they will not have access to specific medical or support services).

C. Housing and Supportive Services

1. Educate the housing developers and service providers about the needs of people with TBI;
2. Educate housing providers about other states' successful housing models.

D. School - Work

1. Train school personnel about the needs of children and youth with TBI and best practices to integrate TBI survivors back into school;
2. Train employers to integrate TBI survivors back to jobs;
3. Educate employers on best practices for achieving fair employment for individuals with TBI.

3. Improve coordination of services.

Examples of this include, but are not limited to:

A. Awareness Education/Training

1. Encourage the research and development of coordination protocols and measures to track progress;
2. Create incentives for regional coordination of services through regional partnerships.

B. Insurance

1. Research current insurance coverage (public & private) for TBI-specific services and identify gaps, including:
 - a. Increase Medicaid/Medicare access (lack of providers who accept low reimbursement rates);
 - b. Provide medically necessary services not covered under current benefit packages (e.g. coverage for neuropsychological examinations in Medicaid).
2. Identify current research on cost/benefit ratio of TBI-specific evaluations and services such as neuropsychological evaluation, cognitive rehabilitation, vocational rehabilitation, behavioral therapy strategies, respite and community integration.

C. Housing

1. Facilitate the creation of a strategic plan focused on TBI housing with supports;
2. Involve stakeholders in the creation of the plan;
3. Utilize the experiences of other communities.

D. School – Work

1. Explore continued partnership opportunities with the Division of Vocational Rehabilitation (DVR) for return to work for individuals with TBI;
2. Extend Labor & Industries (L&I) return to work program beyond the 60-day limit for individuals with TBI;
3. Create a system to improve transition from the hospital (or doctor) back to school and work after a TBI;

4. Develop partnerships with the business/employment community to include human resource, compliance, affirmative action, and disability coordinators.

4. Establish agreements with private sector, state agencies, schools, tribal governments, federal government and others to develop services.

Examples of this include, but are not limited to:

A. Awareness Education/Training

1. Perform a literature review of current TBI education and training (example: the US Army TBI management strategy, “educate, train, treat & track”);
2. Develop training materials to promote educational partnerships across organizational and cultural boundaries.

B. Insurance

1. Partner with public and private agencies who do TBI prevention work to connect to incident, rehabilitation and re-entry;
2. Assure TBI-specific services are covered in Medicaid (TBI waiver), Medicare, Affordable Care Act, private insurance, tribal health, military, L&I, and other payment systems. Individuals not diagnosed with TBI may not have access to medical or support services;
3. Analyze Essential Health Benefits and identify gaps for individuals with TBI under the Affordable Care Act.

C. Housing

1. Identify key housing and service stakeholders and create and foster partnerships;
2. Implement a TBI housing plan;
3. Educate policy makers on benefits of community-based TBI homes.

D. School – Work

1. 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;
2. 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.

5. Other Areas of focus

Examples of this include, but are not limited to:

A. Systemic reform

1. Insurance

- a. Develop information on the use of diagnostic codes for access to services, identify barriers and propose solutions.

2. Awareness Education/Training

- a. Utilize systems theory and processes that will sustain the TBI Council in meeting the mandate in Chapter 74.31 RCW;
- b. Complete TBI policy development that creates incentives to encourage organizational partnership and collaboration.

3. School – Work

- a. Create sustained funding for the clubhouse model and create partnerships with existing organizations currently involved in employment development;
- b. Develop and implement a Return to Learn pilot program to build transition services for students with TBI.

B. Self-advocacy

1. Awareness Education and Training

- a. Increase scholarship opportunities for the TBI Conferences;
- b. Provide advocacy training;
- c. Encourage TBI survivors to tell their stories in a culturally competent manner.

2. Insurance

- a. Increase understanding of insurance benefits and rights;
- b. Increase knowledge of Medicaid/Medicare benefits and rights.

3. School - Work

- a. Train individuals on disclosure and requesting accommodations.

Conclusion

There is an ongoing need to address the unique needs of the TBI community. This report provides an outline of the next steps necessary to address the needs of individuals living with TBI and their families. The report also acknowledges the commitment to this work taken by the Washington State Legislature through the ongoing funding of the TBI account.

The comprehensive plan and the recommendations included in this report represent the commitment and collaboration of expert volunteers from across the state. TBI continues to alter the lives of individuals in an instant and often with long-term impacts. The volunteers who developed the report were willing to share their expertise towards improving the lives of individuals living with TBI.

Appendix A: Roster of TBI Council Members

Member	Board Position
Bruce Santy	Member of public experienced with issues related to the causes of TBI
Janet Carbary-One Mind	Non-profit organization serving individuals with TBI
Teresa Claycamp	Division of Behavioral Health and Recovery
Deborah Crawley	Executive Director of a Brain Injury Association of Washington
Sara Bos	Rehabilitation Specialist with experience working with persons with TBI
Vacant	Individual with TBI
Karen Kaizuka	Family member of individual with TBI
Andrea Valdez	Department of Health
Betty Schwieterman	Disability Rights of Washington
Jennifer Schonberger	Public member experienced in issues related to the causes of TBI
Daniel Overton	Washington Department of Veterans Affairs
Vacant	Clinical psychologist with experience working with persons with a TBI
Vacant	Department of Social and Health Services
Nita Ku	Family member of individual with TBI
Pete Stone	Washington National Guard

Sharon Ashman	Individual with expertise working with children with TBI
Karie Rainer	Department of Corrections
Felisa Gonzalez	Member of public experienced with issues related to the causes of TBI
Taku Mineshita	Children's Administration
Katie Mirkovich	Division of Vocational Rehabilitation
Betsy Jansen	Aging and Long-Term Support Administration
Vacant	Native American Tribe in Washington State
Jane Kucera Thompson	Neuropsychologist with experience working with persons with TBI
Maria Osorio	Physician with experience working with individuals with TBI
Peter Tassoni	Department of Commerce

Appendix B: TBI Council Staffing Plan

Position	Duties
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**TBI Council and Fund
Coordinator**

- Responsible to manage and coordinate the activities of the Washington State Traumatic Brain Injury Council.
- Coordinate policy, procedures, and services for individuals with TBIs.
- Provide available data and information to the council upon request.
- Implement, within appropriated funds, the agreed upon recommendations as noted in the Comprehensive Statewide Plan.
- Assure 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

- 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.